



Bell Let's Talk Conversation Toolkit

# Conversation Guide

Tools to start a one-on-one conversation  
about mental health



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# Core concepts of mental health

## Mental health

The World Health Organization (WHO) defines mental health as a state of well-being in which the individual realizes their own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to their community (WHO, Department of Mental Health and Substance Abuse, Victorian Health Promotion Foundation & University of Melbourne, 2004).

Three ideas are central to this definition of mental health: it is an integral part of health, it is more than the absence of illness and it is intimately connected with overall wellness.

## Mental illness

Mental illnesses include a broad range of problems with different symptoms. However, they are generally characterized by some combination of changes in or disruptions of typical thoughts, emotions, behaviour and relationships with others (WHO, 2011). The American Psychiatric Association (APA) refers to mental illnesses as “disorders.”

## Mental health continuum (dual continua of mental health)

Mental health is not the opposite of mental illness. Mental health means well-being rather than just living without an illness. You can have good mental health while living with a mental illness and poor mental health even though you do not have a mental illness.

## Social determinants of mental health

Mental health challenges are largely influenced by the social, economic and physical environments in which people live (WHO & Calouste Gulbenkian Foundation, 2014). These factors often affect whole communities, which puts groups of people at greater risk of poor mental health. Because they affect the mental and physical health statuses of groups of people, they are called “social determinants of health.” The social determinants of mental health include:

- Employment status
- Housing
- Food security
- Trauma (which may be intergenerational or cyclical due to the cycle of poverty)
- Poverty
- Education
- Access to health care
- Racism

## Stigma

Although one in three Canadians will experience a mental illness at some point in their lives, many don't seek out the treatment or support they need because of fear of stigmatization.

Stigma includes both a negative attitude and the physical act of discrimination that results from the negative bias. Stigma means thinking less of a person because of their condition.

Stigma can make people feel unwanted and ashamed. It is often harder to deal with than the illness itself.

Stigmatization of mental illness may interact with other forms of stigma related to social identities, such as race, gender and sexuality. Stigma is especially difficult for people living with these conditions because it can create barriers to accessing necessary social and structural supports. This can result in further experiences of stigma (Jackson-Best & Edwards, 2018).

## Addressing stigma

These are some ways to talk about mental illness, show your support and help those who are facing mental health challenges seek help:

- Be kind: Small acts of kindness make a big difference
- Educate yourself: Learn about and talk more about the signs of mental illness
- Language matters: Pay attention to the words you use about mental health and illness
- Listen and ask: Sometimes, it's best to just listen
- Talk about it: Start a dialogue and break the silence

## Language use

We are all different, yet we all deserve to be treated with respect. Here are some suggested language choices for discussing mental health issues without being stigmatizing (Media Smarts, n.d.).

Respectful language	Disrespectful language
Person with schizophrenia	Schizophrenic
Person with bipolar disorder	Manic depressive
Person with a disability	Handicapped person

Empowering language	Disempowering language
Person with a mental illness	Mentally ill
Person experiencing mental illness	Victim / Sufferer
Person experiencing mental health symptoms	Crazy / Wacko / Lunatic

Do	Don't
Put the person first	Refer to people by their illness
Become informed about mental illnesses	Be judgmental
Speak up about stigma	Let jokes or misinformation go
Talk openly about mental illnesses	Treat mental illnesses as something to be embarrassed about

Terms to avoid
Challenged
Special
Normal versus not normal
Psycho, psychopath or demented

# What does a mental health problem look like?

We all feel sad, worried, scared, irritated or suspicious at times. But these kinds of feelings may become a problem if they get in the way of our daily lives over a long period. These kinds of problems can affect anyone, regardless of their age, educational background, income level, gender or culture.

Mental health problems can affect our feelings, thoughts, physical well-being and actions. The signs may be visible or invisible. This is what you may observe in someone with a mental health problem:

## Feeling

- Feeling sad or irritable for more than two weeks
- Having excessive worries, fears and anxieties
- Having extreme mood swings—from feeling really high to feeling really low
- Feeling apathetic or disinterested in things
- Feeling hopeless or desperate
- Feeling really angry

## Thinking

- Having distorted or confused thoughts
- Having strange beliefs not based in reality (delusions) or hearing, seeing or smelling things that aren't there (hallucinations)
- Having difficulty remembering things and concentrating, which affects work or studies
- Making poor decisions
- Thinking their situation is hopeless, that they are worthless or that things will never get better

## Doing

- Drinking or using other drugs excessively
- Seeming agitated and restless and appearing dishevelled
- Withdrawing from activities and friends
- Crying a lot
- Having many physical complaints, such as headaches or stomach aches with no clear cause
- Having difficulty sleeping
- Having significant changes in eating
- Having a hard time getting motivated for more than two weeks
- Talking about killing or harming oneself

# Let's talk about mental health

Determining how best to start a conversation about mental health can be challenging. However, you don't need to be a mental health expert to help someone in distress. Start talking! Having a conversation is the best way to start breaking down barriers.

Here are some suggestions on how to reach out and support someone you are concerned about.

## Reach out

Ask how the person is doing. Let them know that you have been thinking about them. Be specific about what is concerning you.

*"I've noticed you've been more withdrawn lately. Is everything okay? Do you want to talk?"*

*"How have you been doing? Do you want to talk about what's been on your mind?"*

*"I've noticed... How are you feeling?"*

*"Has anything happened recently that you want to talk about?"*

*"I'm worried about you."*

Even if the person doesn't want to talk or doesn't think there is a problem, knowing that you care and that they can approach you may open up a conversation and help them feel less alone.

## Listen

Listening to someone and giving them a space to be heard is often one of the best things you can do for someone who is facing a mental health challenge.

*"I'm here for you."*

*"I would like to hear more about what's been going on for you."*

*"When is a good time to talk?"*

It's our tendency to jump to problem solving when we want to help, but slowing down and just being with the person gives them a chance to feel connected and think about what would be most helpful for them.

## Offer support

Be compassionate. If the person's behaviour is out of character, it may mean that a person is experiencing a mental health problem or that they are under some other kind of stress. A comment like "just relax" or "you'll get over it" can come across as judgmental. Instead, show the person that you're there to offer support.

*"That sounds really hard."*

*"What do you need right now?"*

*"Is there anything I can do to help?"*

*"It sounds like you're experiencing a lot of stress right now. What do you think would be helpful?"*

*"Would you like to hang out this week?"*

*"Thank you for sharing this with me."*

Be genuine. If the person feels that you are doing this because you care, and are trying to act in their best interest, it is more likely that you'll be able to offer authentic support.

## Discuss resources and next steps

Support the person in coming up with a plan. They may have been through something like this before and have an idea of what helps them, or this might be the first time they have felt this way. In any case, they may need support locating resources and identifying coping strategies.

*"Have you ever felt this way before? What was helpful in the past?"*

*"Have you talked to anyone else about this?"*

*"Have you reached out to your family doctor?"*

*"Let's talk about what will help you cope right now."*

*"Would it be helpful if I came with you to your next appointment?"*

*"I can help you look up mental health supports that might work for you."*

If they don't believe there's a problem, don't argue with them about it and don't suggest possible solutions. You can keep checking in to see how they're doing or try getting together more often, if that's what they want.

# Getting help

The kind of help people need depends on the type and severity of their problem. Here are some guidelines to help direct you in your interactions with someone who appears to be experiencing mental distress.

Level 1 <b>I'm worried about you</b>	Level 2 <b>You need help now</b>	Level 3 <b>It's an emergency</b>
<b>Observations</b>	<b>Observations</b>	<b>Observations</b>
You notice that the person's mood and/or behaviour has changed without explanation.  They are acting out of character.  They seem to be in greater distress than usual.	Their mood and/or behaviour has gotten worse.  You notice that they have been acting out of character for two or more weeks.	The person describes feeling hopeless and starts talking about killing themselves and ways they would do it.  You notice they are becoming more withdrawn, isolated, physically dishevelled and distracted.
<b>Action</b>	<b>Action</b>	<b>Action</b>
"I'm worried about you. Have you thought of what kinds of support might help right now?"  If the person does suggest that their distress might be mental health-related, you could ask if they have a doctor, a community or spiritual advisor or a counsellor they could speak to.  If they don't believe there's a problem, don't disagree or try to suggest possible solutions. Just keep checking in to see how they are doing.	"I really don't think this issue can wait. Do you have a doctor or someone you can call?"  "Can I help you connect with mental health support?"  If the person doesn't want or feel they need to get help, don't push them. Stay supportive. Offer to go to an appointment with them, or ask if you/someone they feel comfortable with could connect with them in the next few days.	"Will you let me take you to a nearby emergency department or is there someone else close to you who can take you?"  If they refuse help, won't let you or someone else accompany them to an emergency department or other mental health support or are not willing to stay in the company of another person, call 911 to ensure their safety. It is important that they are not left alone.

# Resources

## I need help now

- Visit your local emergency department or call 911
- Call Kids Help Phone at 1 800 668-6868 or text TALK to 686868
- Call or text 9-8-8 if you are thinking about suicide or worried about someone who may be thinking of suicide

## I need support and mental health resources

Contact your health care provider (i.e., family doctor or local health clinic)

### **Black Youth Helpline:** [www.blackyouth.ca](http://www.blackyouth.ca)

Black Youth Helpline serves all youth and specifically responds to the need for a Black youth specific service, positioned and resourced to promote access to professional, culturally appropriate support for youth, families and schools. Their National Helpline for Canadian Youth is available toll-free, 7 days a week by calling 1 833 294-8650.

### **Canadian Mental Health Association (CMHA):** [www.cmha.ca](http://www.cmha.ca)

Over 330 CMHA locations all across Canada provide a wide range of programs, services and supports to step in early to prevent and treat mental health issues in those who are struggling, and to support those with mental illness and their families to live well in the community. These local CMHAs are a good place to start when seeking out services and resources in your community. CMHA offices will refer you to other mental health centres in your area. They also offer many programs and services, ranging from workplace and school programs to counseling, information and support groups, and can help coordinate your care and provide day-to-day support.

### **Centre for Addiction and Mental Health (CAMH) website:** [www.camh.ca](http://www.camh.ca)

CAMH is Canada's largest mental health and addiction teaching hospital, as well as one of the world's leading research centres in the area of addiction and mental health. CAMH combines clinical care, research, education, policy development and health promotion to help transform the lives of people affected by mental health and addiction issues.

### **ConnexOntario:** [www.connexontario.ca](http://www.connexontario.ca)

ConnexOntario operates three helplines: a mental health hotline (1 866 531-2600), an alcohol and other drugs hotline (1 800 565-8603) and a problem gambling helpline (1 888 230-3505). These telephone information lines are confidential, free and available 24/7 for people in Ontario. They provide information about services in your community, basic education and support and strategies to help you reach your goals by phone, email or webchat.

### **Hope for Wellness Help Line:** [www.hopeforwellness.ca](http://www.hopeforwellness.ca)

The Hope for Wellness Help Line offers immediate help to all Indigenous peoples across Canada. It is available 24 hours a day, 7 days a week to offer culturally competent counselling and crisis intervention. Call the toll-free Help Line at 1 855 242-3310 or connect to the online chat at [hopeforwellness.ca](http://hopeforwellness.ca).

### **Kids Help Phone: [www.kidshelpphone.ca](http://www.kidshelpphone.ca)**

Kids Help Phone is Canada's only 24/7, national support service that offers professional counselling; information; referrals and volunteer-led, text-based support in both English and French. Call 1 800 668-6868 or text TALK to 686868.

### **Mood Disorders Society of Canada: [www.mooddisorderscanada.ca](http://www.mooddisorderscanada.ca)**

The Mood Disorders Society of Canada provides a range of educational programs and resources designed to support persons impacted by mental illness, their families and caregivers. MDSC offers a wide array of training for health care providers, essential workers and employers on mental illnesses, particularly about depression, bipolar disorder and PTSD.

### **Relief: [www.relief.ca](http://www.relief.ca)**

Relief supports people living with anxiety, depression or bipolar disorder, as well as their loved ones; to help them learn to live with the ups and downs of their mental health and to regain power over it. Relief's approach has remained the same since 1991: self-management support. Relief offers 10-week themed group workshops in English and French, virtually or in person; support groups to share with others who are experiencing similar situations.

### **Schizophrenia Society of Canada: [www.schizophrenia.ca](http://www.schizophrenia.ca)**

The mission of the Schizophrenia society is: "Build a Canada where people living with early psychosis and schizophrenia achieve their potential." The Society offers education and support programs as well as engages in lobbying to affect public policy and research.

### **Strongest Families Institute: [www.strongestfamilies.com](http://www.strongestfamilies.com)**

Strongest Families Institute (SFI) delivers services to children, youth, adults and families living with mild to moderate mental health and other issues through innovative distance-based coaching. SFI equips people with life skills, providing timely support to people in the comfort and privacy of their own homes, day and night.

### **211's phone number and website: [www.211.ca](http://www.211.ca)**

211 is Canada's main source of information on government and community-based health and social services. Call 211 or visit their website.

### **Wellness Together Canada: [wellnesstogether.ca](http://wellnesstogether.ca)**

Wellness Together Canada is a mental health and substance use website that supports people across Canada as well as Canadians living abroad in both official languages. The online service was launched in response to growing mental health concerns related to the COVID-19 pandemic and provides immediate support and resources at no cost.

## **I want to learn more about mental health and mental illness**

### **Canadian Mental Health Association (CMHA): [www.cmha.ca](http://www.cmha.ca)**

CMHA's national website offers simple, easy-to-understand information about mental illness, mental health and how to take care of it. Visit the website for [Fast Facts about Mental Health and Mental Illness](#) and to learn more about a range of topics, including [Coping with Loneliness](#), [Care for the Caregiver](#) and [Eating Disorders](#).

### **Centre for Addiction and Mental Health (CAMH): [www.camh.ca](http://www.camh.ca)**

CAMH's website provides quick access to the best available online information, tools and resources about mental health, including information for clients and families.

The Mental Health and Addiction 101 series are free, quick and easy-to-use online tutorials, which introduce topics concerning substance use and mental health problems: [www.camh.ca/en/health-info/mental-health-101](http://www.camh.ca/en/health-info/mental-health-101)

Find workshops, interviews and seminars posted as videos, including "Mini-Med School," a series of health sciences lectures offered by CAMH in collaboration with the University of Toronto: <https://www.camh.ca/en/professionals/videos/videos-by-subject>

### **Canadian Public Health Association**

Canadian Public Health Association's "What Are The Social Determinants Of Health?" may be a useful resource for those seeking more information about the social determinants. It can be accessed at: [www.cpha.ca/what-are-social-determinants-health](http://www.cpha.ca/what-are-social-determinants-health)

### **Here to Help (BC): [www.heretohelp.bc.ca](http://www.heretohelp.bc.ca)**

Here to Help is a project of the BC Partners for Mental Health and Addictions Information. Here to Help is a collective of seven mental health and addiction agencies that have been working together since 2003 to help prevent and manage mental health and substance use problems.

### **Jack.org: [www.bethere.org](http://www.bethere.org)**

Jack.org is training and empowering young leaders to revolutionize mental health in every province and territory. Through [Jack Talks](#), [Jack Chapters](#), and [Jack Summits](#), young leaders identify and dismantle barriers to positive mental health in their communities. Jack.org's innovations like [Be There](#) and [Jack Originals](#) give people the mental health resources they need to educate themselves.

### **Multicultural Mental Health Resource Centre (MMHRC): [www.mmhrc.ca](http://www.mmhrc.ca)**

This website offers many helpful resources including fact sheets in multiple languages and policy materials on specific topics. Supported by the Mental Health Commission of Canada, the MMHRC focuses on improving the quality and availability of mental health services for people from diverse cultural and ethnic backgrounds, including immigrants, refugees and members of established ethnocultural communities.

### **National Alliance on Mental Illness (NAMI) (US): [www.nami.org](http://www.nami.org)**

NAMI is the National Alliance on Mental Illness, the largest grassroots mental health organization in the United States. NAMI advocates for access to services, treatment, supports and research.

### **National Empowerment Center (US): [www.power2u.org](http://www.power2u.org)**

This consumer/survivor/ex-patient-run organization carries a message of recovery, empowerment, hope and healing to people with lived experience of mental health issues, trauma and extreme states.

### **National Institute of Mental Health (NIMH) (US): [www.nimh.nih.gov](http://www.nimh.nih.gov)**

This organization offers fact sheets, booklets and brochures on mental health topics.

## How to have conversations around mental health

An important part of the champion's role is having positive conversations about mental health with colleagues, participants and people in the local community.

Starting a conversation is a powerful way to challenge mental health stigma and help people to think about their own perceptions and the perceptions of others. Remember, champions don't need to be mental health experts to talk about mental health and challenge stigma.

Positive conversations may lead to talking to someone about their mental health, so it is important that champions can manage this situation effectively, and that they know how to end these conversations when required. The guidance in this section can help.

### Managing conversations

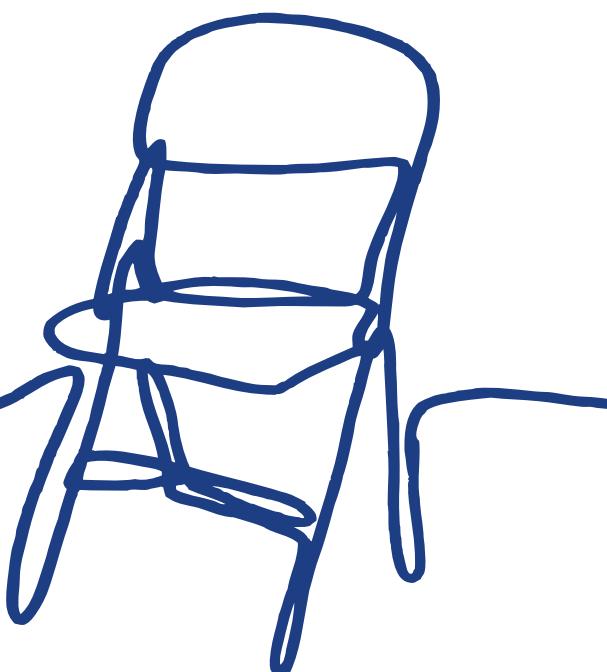
- Find a quiet place with an informal atmosphere, such as a café. A conversation about mental health shouldn't feel like a formal interview.
- Actively listen to the person by giving them your undivided attention. Leave any questions or comments until the person has finished, so you don't interrupt them.
- Once someone knows they're being given the space and time to talk, they're more likely to open up. If someone approaches you wanting to talk, it may not be possible for you to give them the time they need there and then. Instead, show them you recognise that they've taken a positive step by speaking to you, explain why you can't talk now and arrange a better time to have the conversation. If they are in urgent need of help, be sure to signpost them to support.
- Reflecting the words they've used can encourage them to open up more.
- Use empathetic statements such as: "I appreciate this must be difficult for you...".
- Avoid clichés. Comments like "pull yourself together" or "you're just having a bad day" are unhelpful.
- Remind them that mental health problems are more common than people think, and that they can affect anyone at any time.
- Avoid asking too many questions, especially closed questions (which require a 'yes' or 'no' answer) and those that begin with the word 'why.' Ask open questions to invite a more detailed response:
  - Can you describe how you're feeling?
  - How do you look after yourself?
  - What support do you have in place?
- Reassure them that it's positive that they want to talk about their experience, and that they've acknowledged they want support (if this is the case).

## Closing conversations about mental health

Closing conversations effectively helps to reassure the participant that their thoughts and feelings have been listened to, and helps to clarify next steps.

- Sometimes conversations will come to a natural end. If this doesn't happen, provide a gentle indication that the conversation needs to come to an end. You could say something like: "It's been good to talk. We've covered a lot and we will have to wrap up soon because I have another session," or something similar.
- Summarise the conversation and anything you've both agreed to do. For example: "You've told me you're going to speak to your GP about how you're feeling, and I will email you details of your local Mind."
- Ask practical questions such as "Will someone be there when you get home?" or "Is there a friend you can go and see?"
- Offering a listening ear and showing your acceptance, warmth and regard can go a long way to help someone. It may not be possible to get a clear idea of the next steps they'll take as a result of talking to you. Ending the conversation by inviting them to take some time to reflect on what you've discussed, and to consider what they may want to do next could be the best way to bring the conversation to a close, especially if you feel there's nothing more you can say at that time.

If you feel it would be helpful, that it's appropriate within the boundaries of your role, and that you're able to commit to giving more of your time in this way, you may want to arrange another time to meet and talk.



- Ask if they're aware of sources of support, and signpost them to relevant information and help. It may be helpful to ask "What would you like to happen in this situation?" This will help to empower and encourage them to take the course of action that seems right to them. Be clear about what you can do, as well as what you can't,
- The important thing is to listen rather than give advice – the individual needs to be able to act for themselves. Signpost them to sources of support, rather than telling them what you think is best.

### Important note

If someone needs urgent medical attention due to their mental health, direct them to their GP, Accident & Emergency at their nearest hospital, or the Samaritans on 116 123, 24 hours a day, 7 days a week. Alternatively, the yellow box at the top of every page on the Mind website will help direct people appropriately.

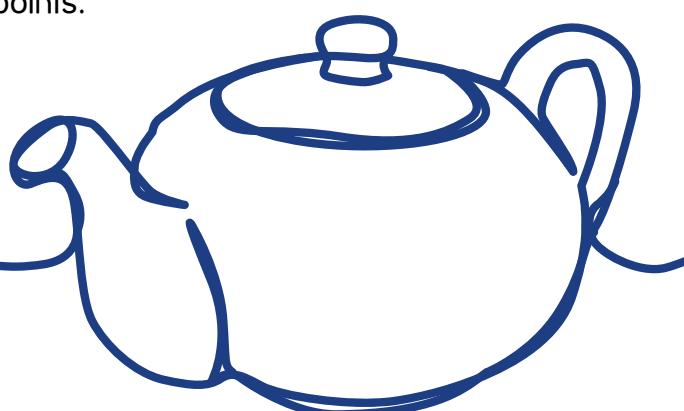
### Starting conversations

Sometimes starting a conversation about mental health is the hardest task, and it's important not to be discouraged by negative experiences.

You may want to practice or role play conversations with a close friend or family member until you become more comfortable. It's important to know your own boundaries and be clear on what personal experiences you're happy to reference in conversation.

Here are some tips to help start conversations:

- Ask someone how they are doing or feeling. Encourage them to engage with an open question focused on them and their wellbeing.
- Use your own personal experiences as a conversation starting point. Be clear on what you're happy to share, before you get started.
- Talk about how you maintain personal wellbeing, relax or de-stress (for example, how you use sport or physical activity as part of your daily or weekly routine).
- Use topical news stories to highlight interesting points.





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camh

# Conversations About Mental Illness:

## What to Say and How to Say It

# What is Mental Illness?

We all feel sad, worried, scared, or suspicious at times — and that's just a part of life. However, when these feelings start to get in the way of our daily lives, over an extended period of time, that's when there might be more going on.

Mental illness can affect anyone regardless of their culture, age, gender, educational background, or financial situation. Even those who you've always known to be cheerful and untroubled, may be fighting a battle that you cannot see.

The state of our mental health can affect our feelings, our thoughts, our physical well-being, and our actions. Although the early signs of mental illness are not always visible, you may observe some changes in those struggling with their mental health.

**1 in 5**

**Canadians experience  
mental illness in any  
given year**

# If It's an Emergency:

If someone is talking about ending their life, perhaps even describing ways they could do it, this may be a medical emergency.

1. Listen to them and take them seriously. Don't judge or minimize their feelings. Be positive and hopeful, and remember that suicide can be prevented.
2. Ask them if they are thinking about suicide or having suicidal thoughts. Don't be afraid that you will put the idea in their head. It may be a relief for them to talk about it.
3. Let them know help is available and that the cause of their suicidal thoughts can be treated.
4. Make a safety plan with them. Who will they call if their feelings get stronger? Who can stay with them to keep them safe? Make a list of phone numbers of people and services they can call if they feel unsafe.

If you are worried that the person you are talking to might be thinking of suicide, you can call 9-8-8: Suicide Crisis Helpline any time for free, confidential support. If the person's life is in danger, please call 9-1-1 or go with them to your nearest emergency department. **Do not leave them alone and try to stay calm until help arrives.**

# I'm Worried About Someone

A conversation is a great start, and an important way to let the person know that they are not alone. However, mental illness can be just as serious as physical illnesses, and getting medical attention or professional help is just as important for both. A family doctor or primary health care provider is often a good place to start.

## **There are many things you can do to help:**

1. Stay supportive. Try to make it as easy as possible for them to get the help they need. Offer to help them find resources in their community, make their appointments, or keep them company if they are nervous about going on their own.
2. Stay in touch and follow up regularly to see how they are doing. Being present can make all the difference.
3. Keep the conversation going. Offer to connect them with counselling services such as Connex Ontario or Kids Help Phone for children and teens.
4. Reflect on the signs in the following pages if you are worried about someone in your life.

# Thoughts and Feelings

Has the person said they are experiencing any of the following thoughts or feelings:

- Angry, irritable, short-tempered or full of rage
- Disconnected, lonely or isolated
- Hopelessness, guilt or shame
- Apathetic, sad or depressed
- Confused, overwhelmed or struggling to concentrate
- Desperate or trapped



# Behaviour

Have you witnessed any of the following behaviour:

- Withdrawing from activities or people they normally enjoy
- Using alcohol or drugs more than usual, or saying that they need them to cope
- Frequent crying, or showing uncontrollable agitation or anger
- Not sleeping well or sleeping a lot
- Giving away possessions or making plans for after their death
- Increased engagement in high risk behaviours such as reckless driving, dangerous sports or activities



# Physical Signs

Have they talked about or showed the following signs:

- Thinking about suicide or wanting to die, even if it seems like they're joking
- Hearing voices, especially voices that tell them to harm themselves or others
- Saying that they don't care about the future or that nothing matters
- Saying goodbye or saying that they'll miss you
- Feeling disconnected from their body or being physically numb
- Feeling like they are not wanted or needed by others



# Talking With a Friend

Start by telling your friend what you have noticed or what is concerning you.

“ I have noticed you don’t seem to be sleeping much, and you’re skipping meals. Is everything okay?

- Suggest going for dinner or a coffee if this is the kind of thing you normally do together. If they are not interested in your usual activities, suggest something new or ask what they would like to do.
- If you struggle or have struggled with your mental health, you could share your experience and create a safe space for your friend to share their experience as well. If they open up to you, listen to their experience and validate their feelings, without inserting your experience into the conversation.
- If your friend confirms that their experience might be mental health related, reassure them that you want to support them through their struggle. Additionally, you can ask if there is a doctor, counsellor, or community/spiritual advisor that they could confide in and seek help from as well.

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# 37%

of Ontario students report experiencing an elevated level of stress or pressure in their lives.\*

## What not to say

-  “Just relax.”
-  “You’ll get over it.”
-  “It’s all in your head.”
-  “Have you tried spending more time outside?”

These comments could come across as judgmental or dismissive, despite your intent. Instead, focus on how you can show your friend that you are someone they can trust.

\*Source: 2024 Ontario Student Drug Use and Health Survey

# Talking With a Colleague

Find an appropriate and private time to approach your colleague. Tell them what you've noticed and why you're concerned.

“ Has something happened recently that you need support with? I'm here to listen if you need to talk.

- Even if your colleague does not think there is a problem, your question will create space to start a conversation.
- If they are open to chatting with you, suggest that you meet outside of work, like at a nearby coffee shop, so there will be no chance of being interrupted or of another colleague listening to your conversation.
- Spend that time listening, without jumping in to problem-solve or diagnose. It is more likely that you will be able to help if your colleague trusts that you are doing this because you care.

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# 52%

of Canadians report feeling burned out because of their jobs in the past year.

## What not to say

-  “I know exactly how you feel.”
-  “Maybe you just need a day off.”
-  “We’ve all got a heavy workload.”

Don’t assume you know what the problem is, or that you experience workplace stress the same way your co-worker does. Out of character behaviour may signify early symptoms of mental illness or other kinds of stress.

\*Source: Ipsos, 2024

# Talking with Your Child

Ask how they are doing casually to create a safe space for conversation. Be specific about what you've noticed and what you're concerned about, without being accusatory or judgmental.

“ You've seemed down a lot lately. Is there anything that's bothering you that you want to talk about?

- Reassure them that no matter what they are going through, you will always love them and care for them unconditionally.
- If they're ready to talk to you, be compassionate and don't assume you know what they're feeling or thinking. Instead, ask if they'd like you to help or take any action on what they've shared.
- Support doesn't always mean talking, it can also be about making time for them and establishing a bond that will hopefully create trust for when it's time to have hard conversations.
- Families can visit the CAMH Family Resource Centre to find support, education and information about mental illness and addictions.

---

**70%** of mental health problems begin during childhood or adolescence.

## What not to say

-  “Snap out of it.”
-  “You don’t even know what real stress is, you’ll see when you’re older.”
-  “I went through the same thing when I was your age, you just have to get over it.”

Statements like this may make them feel judged for feeling the way they do, or for not being able to make themselves feel better. They may not be well-received by a child or teen who is trying to establish their own identity, and may begin to foster feelings of resentment or mistrust towards you.

\*Source: CAMH

# Mental Health

## Mental Health - Having Courageous Conversations

### On this page

[How can I support someone with mental health issues?](#)

[How can workplaces support their workers?](#)

[How do I have “that” conversation with a worker?](#)

[What are some tips for effective verbal communication?](#)

[What are tips for effective non-verbal behaviour and communication?](#)

[What employers can do for mental well-being in the workplace?](#)

[What can workers do to address their mental well-being?](#)

### How can I support someone with mental health issues?

Often we are hesitant to reach out to help a friend or co-worker who is struggling for fear of saying the wrong thing, offending the other person, or worrying that you are not qualified to ask about their health.

However, asking someone a simple “Are you okay?” is a great place to start when it comes to supporting individuals who may be facing mental health challenges. Remember, you don’t need to be a therapist to show compassion and empathy to individuals who may be facing struggles or challenges with their mental health.

### How can workplaces support their workers?

Workplaces have a responsibility to protect [workers’ health and safety](#), including to protect them from any [workplace factor](#) that may impact their mental health. This duty must be balanced with other responsibilities such as fulfilling business and operational requirements. An organization’s key asset is their workers, and ensuring a worker is healthy and able to perform their duties to the best of their ability is usually considered to be the right thing to do. Creating a safe space so the worker can share and discuss their concerns will foster a caring culture of support in which everyone benefits.

## How do I have “that” conversation with a worker?

If a change in a worker’s behaviour or performance is noticed, there is a duty to inquire. A meeting should be scheduled to discuss any concerns and issues that may be noticed. If there are concerns about performance and completing work, this fact should not be the first focus. Start with what you have observed, such as “I’ve noticed lately...” or “You haven’t been yourself lately, are you okay?”

These conversations may not be successful the first time, but continual follow up and discussion should bring about trust and empathy so the employee feels comfortable in sharing if there is something affecting their mental health. Active listening skills are necessary so the worker feels safe and secure in sharing private details about their mental health.

## What are some tips for effective verbal communication?

- Focus your attention on the other person to let them know you are interested in what they have to say.
- Listen carefully. Do not interrupt with unsolicited advice or criticism.
- Be observant. Decide if it is a good time to interrupt, or if you should wait for a more appropriate time to speak.
- Be aware of how you are delivering your words.
- Speak calmly, quietly, and confidently.
- Use common words. Do not use official language, jargon, or complex terminology.
- Encourage the person to talk.
- Remain open minded and objective.
- Acknowledge the person’s feelings. If they appear upset, indicate that you can see they are upset.
- Try to understand. Ask questions like “help me understand why you are upset.” Once you think you understand, repeat it back to the person so they know you understand.
- Remain calm if the situation becomes heated, and try to gently calm the other person (but do not yell “calm down!”). Do not allow the other person’s anger to become your anger.

## What are tips for effective non-verbal behaviour and communication?

- Use calm body language. Have a relaxed posture with unclenched hands and an attentive expression.
  - Position yourself at a right angle to the person, rather than directly in front of them.
  - Give the person enough physical space. This distance varies by culture but normally 2 to 4 feet is considered an adequate distance.
  - Get on the other person's physical level. If they are seated, try kneeling or bending rather than standing over them.
  - Pay attention to the person. Do not do anything else at the same time such as answer phone calls, read e-mails, etc.
  - Do not stand or sit in a challenging stance such as:
    - standing directly opposite someone
    - putting your hands on your hips
    - pointing your finger
    - waving your arms
    - crossing your arms
  - Do not glare or stare. It may be perceived as a challenge.
  - Do not make sudden movements. These movements can be seen as threatening.
- 

## What employers can do for mental well-being in the workplace?

Some strategies for creating a positive space for protecting mental health include:

- Create an organizational culture that values worker input in all aspects, including planning, policy making, and setting goals.
  - Be sure that managers and supervisors act to support the organization's values.
  - Balance job demands with workers' capabilities and resources.
  - Have clearly defined job descriptions to help people understand their roles and what is expected of them.
  - Provide leadership and mental health training for managers and supervisors to learn their roles in promoting positive mental health.
  - Encourage and create opportunities for learning, skill development, personal growth, and social interaction with other workers.
  - Address psychosocial hazards as equally as you would safety or other hazards.
-

- Provide opportunities or programs that assist individuals in maintaining good health, such as a fitness policy or healthy food choices.
- 

## What can workers do to address their mental well-being?

Some strategies for workers to protect their mental health include:

- Seek help when needed. Talk to your supervisor, human resources, or health and safety representative. Use the Employee Assistance Program if available.
  - Participate in planning with your manager to balance work demands and work load.
  - Find a hobby or activity that helps you relax and brings happiness, and then do it regularly.
  - Share your feelings with someone you trust, or write them down in a journal.
  - Acknowledge when things are going well. Celebrate your successes.
  - Get to know who you are, what makes you happy, and what your stress triggers are. Learn to acknowledge what you can and cannot change about yourself or the situation.
  - Develop healthy habits such as regular exercise, adequate sleep, and a balanced diet.
- 

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## Disclaimer

Although every effort is made to ensure the accuracy, currency and completeness of the information, CCOHS does not guarantee, warrant, represent or undertake that the information provided is correct, accurate or current. CCOHS is not liable for any loss, claim, or demand arising directly or indirectly from any use or reliance upon the information.

# Conversations You Need to Have about Mental Illness

Talking  
with a  
friend

Talking  
with a  
co-worker

Talking  
with your  
teen

**camh** Canada's Leading Hospital  
for Mental Health



## What is CAMH?

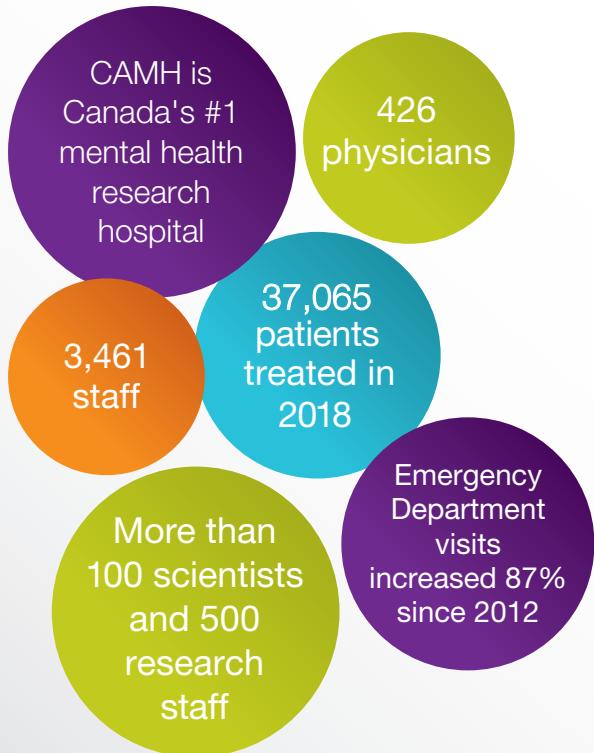


The Centre for Addiction and Mental Health (CAMH) is the largest teaching hospital in Canada focusing on mental illness and addiction. Our research investigates the causes, treatments and prevention of mental illness and addiction at all life stages—from childhood and adolescence, when symptoms of illness most commonly appear, through to adulthood and into old age.

CAMH relies on community support from people just like you. If you'd like to learn more or make a donation, visit [camh.ca](http://camh.ca)

## CAMH by the numbers

i



## What does a mental health problem look like?

We all feel sad, worried, scared or suspicious at times. But these kinds of feelings may become a problem if they get in the way of our daily lives over a long period. Mental health problems can affect anyone, regardless of their age, educational background, income level, gender or culture.

Mental health problems can affect our feelings, our thoughts, our physical well-being and our actions. Although the signs of a mental health problem are often not visible, you may observe some changes in the person.

# Feelings



**Do you think the person is experiencing some of these feelings?**

- Have they been sad or irritable for more than two weeks?
- Have they been talking about excessive worries, fears and anxieties?
- Have they had extreme mood swings—from feeling really great to feeling really low? Really angry?
- Have they been acting apathetic or uninterested in things?
- Have they shared feelings of hopelessness or despair? Maybe they've been crying a lot?

1 in 5 Canadians experience a mental illness or addiction in any given year—we all know and love someone affected.

# Thoughts



**How might their thinking be affected?**

- Are they having distorted or confused thoughts?
- Do they have strange beliefs not based in reality (delusions), or are they hearing, seeing or smelling things that aren't there (hallucinations)?
- Do they have difficulty remembering things and concentrating, which affects work or studies?
- Have they started making poor decisions?



## Actions



- Have they started drinking or using other drugs excessively?
- Do they seem agitated and restless?
- Do they often appear dishevelled?
- Have they been withdrawing from activities and friends?
- Do they cry often?
- Do they have many physical complaints, such as headaches or stomach aches, with no clear cause?
- Have they been having difficulty sleeping?
- Have they made a significant change in eating habits?
- Have they been talking about harming themselves or ending their life?

**camh** Canada's Leading Hospital  
for Mental Health

## Our Vision

Transforming lives

## Our Purpose

At CAMH, we care, discover, learn, and build

## Our Values

Courage. Respect. Excellence.

### Access CAMH

Monday to Friday 8:30 a.m. – 5:00 p.m.  
1 800 463-2338, then press 2

**CAMH Emergency Department**  
250 College St, Toronto, ON

### Experiencing a crisis or emergency?

Visit your local emergency department or call 911

## Talking with a friend

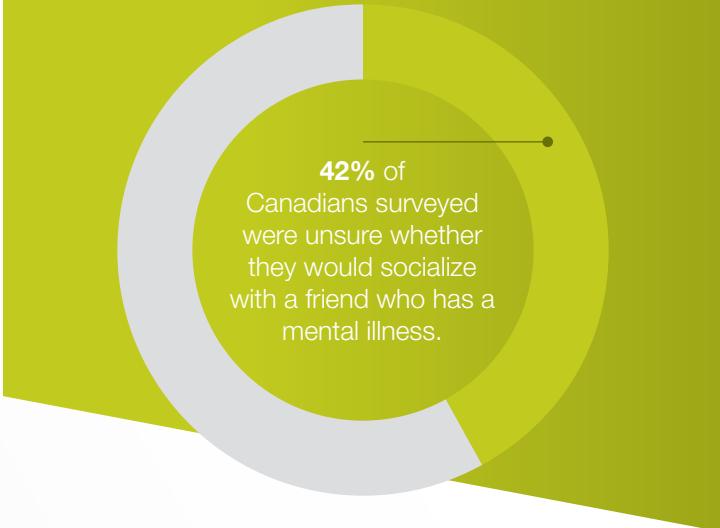
Start by telling your friend what you have noticed or what is concerning you.

**"I have noticed you don't seem to be sleeping much, and you are skipping meals. Is everything OK?"**

Suggest going for dinner or a coffee, if this is the kind of thing that you normally do together, or ask what they would like to do.

If you have struggled with feelings your friend might identify with, you could tell them how you felt, and how you coped in the past.

If your friend does mention that their distress might be mental health related, ask if there is a doctor, counsellor or community or spiritual advisor that they could reach out to.



42% of Canadians surveyed were unsure whether they would socialize with a friend who has a mental illness.



**"Just relax."**  
**"You'll get over it."**

These comments could come across as judgmental or dismissive. Instead, just show your friend you're there to offer support.

## Talking with a co-worker

Ask your co-worker about what you have noticed or what is concerning you.

**“Are you OK? You’ve been acting differently, and I’m worried about you.”**

**“This isn’t like you. Has something happened recently that you want to talk about?”**

Even if your co-worker does not think there is a problem, your question may open up a conversation.

If they do want to chat, find a more relaxed time when you won’t be interrupted. Spend that time listening, without jumping in to problem solve or diagnose. Talk about the effects of their behaviour without lecturing. It is more likely you will be able to help if your co-worker trusts that you are doing this because you care.



**39%** of Ontario workers indicate that they would not tell their managers if they were experiencing a mental health problem.



**“I know how you feel.”**  
**“Maybe you just need a day off.”**

Don’t assume you know what the problem is, or that you experience workplace stress the same way your coworker does. Out of character behaviour may signify a mental health problem or some other kind of stress.

## Talking with your teen

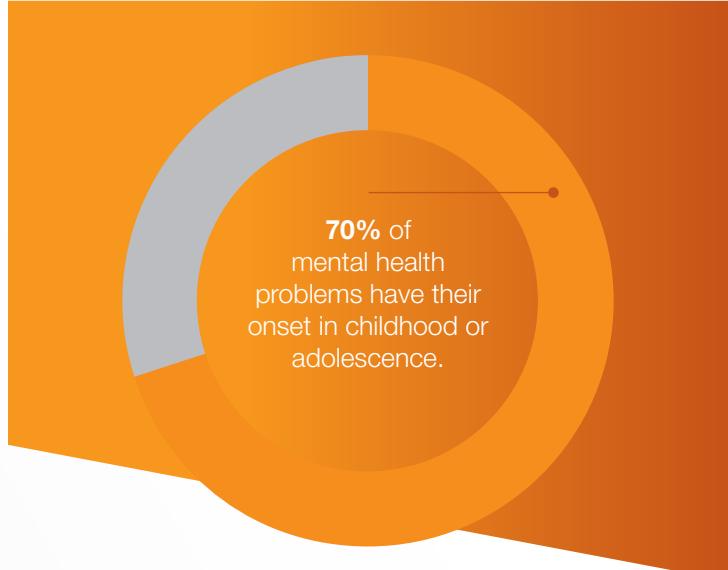
Ask how she or he is doing. And be specific about what you've noticed that is concerning you.

**"It seems like you've been losing weight and becoming more withdrawn. Is everything OK? Do you want to talk? Or is there another adult you trust you'd be more comfortable talking to—maybe one of your teachers, or a counsellor, or your coach?"**

Even if they don't want to talk, tell them that you will be there for them if or when they do. It can be very upsetting to know a young person you care about isn't doing well, and it's natural to want to offer suggestions or solutions. But giving them space is the best way to gain their trust.

Be compassionate. And don't assume you know what they are feeling or thinking. Instead, invite them to tell you themselves.

Offer to do something together that you both enjoy. Support isn't always about talking, but about spending time together.



70% of mental health problems have their onset in childhood or adolescence.



**"Snap out of it."  
"I went through the same thing when I was your age."**

Statements like this may make them feel judged for not being able to make themselves feel better, or may not be well received by a teen who is trying to establish their own identity.

# The Next Steps...

## Seeking professional help



A conversation is a great start, and an important way to let the person know they are not alone. But mental health problems can be just as serious as physical problems, and getting medical attention or other professional help is just as important. A family doctor or primary health care provider is often a good place to start.

There are many things you can do to continue to help:

- **Stay supportive.** Try to make it as easy as possible for them to get the help they need. Offer to help them find resources in their community or get to their appointments.
- **Stay in touch** and follow up regularly to see how they are doing. Being present can make all the difference.
- **Keep the conversation going.** Offer to connect them with counselling services such as ConnexOntario ([MentalHealthHelpline.ca](http://MentalHealthHelpline.ca) or 1 866 531-2600) or Kids Help Phone for children and teens ([KidsHelpPhone.ca/teens](http://KidsHelpPhone.ca/teens) or 1 800 668-6868).

## It could be an emergency



If someone is talking about ending their life, perhaps even describing ways they could do it, this may be a medical emergency.

- **Listen to them and take them seriously.** Don't judge or minimize their feelings. Be positive and hopeful, and remember that suicide can be prevented.
- **Ask them if they are suicidal.** Don't be afraid that you will put the idea in their head. It may be a relief for them to talk about it.
- **Let them know help is available** and that the cause of their suicidal thoughts can be treated.
- **Make a safety plan with them.** Who will they call if their feelings get stronger? Who can stay with them to keep them safe? Make a list of phone numbers of people and services they can call if they feel unsafe.

If someone is in crisis and refuses help, call 911 to ensure his or her safety. **Do not leave them alone.** Try to stay calm until help arrives.

# Eating Disorders

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Care for People of All Ages



Ontario  
Health

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# **Quality Statements to Improve Care**

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# O1

## Comprehensive Assessment

People with signs and symptoms of an eating disorder have timely access to comprehensive mental and physical health assessments. The assessment is used to determine whether they have a specific eating disorder, the severity of their symptoms, the degree of impairment, and whether they have any comorbid conditions, and to establish a plan of care.

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**Sources:** American Psychiatric Association, 2023<sup>1</sup> | National Institute for Health and Care Excellence, 2017<sup>2</sup> | Scottish Intercollegiate Guidelines Network, 2022<sup>3</sup>

## Definitions

Signs and symptoms of an eating disorder can include but are not limited to<sup>2,3,15</sup>:

- Severe dieting or restrictive eating behaviours
- Other behaviours such as laxative, diuretic, or diet pill misuse, self-induced vomiting, and/or excessive exercise
- Rapid weight loss or fluctuating weight
- An unusually low body mass index (BMI; weight in kilograms divided by height in metres squared) or body weight that is considered low for the person's height and age, developmental trajectory, and physical health

*Note: BMI should not be the sole factor in assessing for an eating disorder*

- Family or caregivers reporting a change in eating behaviour or social withdrawal, particularly from situations that involve food
- A disproportionate concern about body weight or body shape
- Problems managing a chronic illness that affects diet, such as diabetes mellitus or celiac disease
- Menstrual or other endocrine disturbances
- Otherwise unexplained gastrointestinal symptoms and/or abdominal pain

- Physical signs of malnutrition, such as poor circulation, dizziness, palpitations, fainting, or pallor
- Unexplained electrolyte imbalance or hypoglycemia

**Timely access to assessment:** People with signs and symptoms of an eating disorder should be assessed as early as possible; ideally, soon after symptoms emerge. Assessments should occur within 4 to 8 weeks of the first point of contact with a health care provider (advisory committee consensus). If a person is medically unstable, they may require more emergent care. Assessments may take place over several visits and results of the assessment are communicated to the person and their family and caregivers when appropriate, including considerations of relevant cultural factors and language needs.

**Comprehensive mental and physical health assessment:** A comprehensive assessment includes both a comprehensive mental health assessment and a comprehensive physical health assessment:

**Comprehensive mental health assessment:** For people with signs and symptoms of an eating disorder, the comprehensive mental health assessment includes but is not limited to an assessment of<sup>2,3</sup>:

- Restrictive eating behaviours, food avoidances, or other changes to pattern of eating (e.g., reduced food variety, elimination of food groups)
- Preoccupation with food, body weight, and/or body shape
- Presence of binge eating, purging (i.e., self-induced vomiting, misuse of laxatives and/or diuretics), excessive or compulsive exercise, or other disordered eating behaviours (e.g., rumination, regurgitation, chewing and spitting, use of medication to change body weight)
- Eating-related fears (e.g., fear of food and weight gain)
- Psychosocial impairment secondary to eating or body image concerns or related behaviour
- Family history of eating disorders, or other mental health or addiction conditions
- Prior treatment for an eating disorder and response to that treatment
- Presence of self-injury behaviours, suicidality, trauma-related symptoms/post-traumatic stress disorder, substance use, and/or other mental health comorbidities

**Comprehensive physical health assessment:** For people with signs and symptoms of an eating disorder, the comprehensive physical health assessment includes but is not limited to<sup>1,2</sup>:

- Vital signs, including temperature, resting heart rate, blood pressure, orthostatic pulse, and orthostatic blood pressure
- Height
- Weight history (i.e., lowest and highest weights, recent weight changes)
- Determining the degree to which the person is under weight/weight suppressed (BMI or percent median BMI, BMI percentile for adults, and growth curve trajectories for children and young people are an important part of the assessment)
- Note: BMI should not be the sole factor in determining the need for care
- Physical appearance, including signs of malnutrition, purging behaviours, and/or problems with teeth and gums
- Laboratory tests, including a complete blood count
- Comprehensive metabolic panel, including but not limited to:
  - Extended electrolytes (includes calcium, magnesium, and phosphate)
  - Liver enzymes and renal function tests
- Hormones (i.e., estrogen, follicle stimulation hormone, luteinizing hormone, testosterone)
- Screening for celiac disease and inflammatory bowel disease
- Electrocardiogram for people with a suspected restrictive eating disorder, people with severe purging behaviours, and people taking medications known to alter electrocardiogram results
- Bone mineral density for those with amenorrhea for 6 months, or males underweight for 6 months

**Comorbid conditions:** People with an eating disorder may have other physical health or mental health or addiction conditions, and these might affect their presenting symptoms and response to treatment. It is important to assess for comorbid conditions and presence of self-injury and risk of suicide.

Physical conditions to assess for may include but are not limited to:

- Diabetes mellitus
- Inflammatory bowel disease
- Celiac disease

Mental health and cognition conditions to screen for and assess (if needed) include but are not limited to:

- Anxiety disorders
- Mood disorders (such as depression or bipolar disorder)
- Obsessive-compulsive disorder
- Substance use disorders
- Attention-deficit/hyperactivity disorder
- Autism spectrum disorder
- Post traumatic stress disorder
- Personality disorders
- Schizophrenia and other psychotic disorders

## Rationale

Early assessment and treatment can prevent long-term negative physical and psychological outcomes,<sup>5,16,17</sup> and it is important that people with signs and symptoms of an eating disorder have a comprehensive assessment as soon as possible—especially if the person is at risk of serious physical harm. For those who are underweight or have lost a significant amount of weight, it is important to understand the severity of the person's low weight or weight loss as part of the assessment. Physical and mental health assessments can take several visits to complete and should be done in-person, if possible.<sup>1,18</sup> However, people in Ontario often wait several months to over a year for an assessment, depending on their location.<sup>9</sup> Access to a comprehensive assessment can be particularly challenging for people in rural and remote areas of Ontario. Furthermore, people with an eating disorder may not have insight into the presence or severity of their own signs and symptoms,<sup>4,19,20</sup> and eating disorders commonly go undiagnosed and undetected unless identification and assessment occur.<sup>1</sup>

Eating disorders can develop at any age; however, the typical age of onset is young adulthood. Pediatricians and primary care providers should ask all children and young people about their eating patterns and body image and be alert to potential signs and symptoms of an eating disorder.<sup>21</sup> People experiencing food

insecurity can also show signs of an eating disorder and there can be trauma associated with feeding and eating. Steps should be taken to identify appropriate supports and provide trauma-informed care.

Additional information from family and caregivers to inform the assessment may help identify eating disorder symptoms, behaviours, and comorbidities as people with an eating disorder may underreport and conceal symptoms (e.g., amount of food consumed, time spent exercising, frequency of binge eating and/or purging), or conceptualize symptoms differently.<sup>1</sup> People can develop an eating disorder, including anorexia nervosa.

For children and young people, it is important to involve families, caregivers, support networks, school personnel, coaches, and health professionals who are in close contact or routinely work with the person. Some symptoms of an eating disorder are cognitive in nature (e.g., fear of weight gain, overvaluation of weight and body shape) and depend on abstract reasoning ability. Children may not have the capacity to articulate such symptoms and more information on behaviours may be necessary from other sources.<sup>22</sup>

## **What This Quality Statement Means**

### **For People With an Eating Disorder and Their Family and Caregivers**

Your health care providers should ask you questions about your thoughts, feelings, behaviours, and physical health. They will do this to find out whether you have an eating disorder, and to make a plan for your care as soon as possible. Your family, caregivers, or other supportive people in your life can be involved in these steps too.

### **For Clinicians**

When a person seeks care for their eating disorder symptoms, assessment should occur as soon as possible—ideally within 4 to 8 weeks of their initial contact. When a person presents with signs and symptoms that you suspect could indicate an eating disorder, conduct comprehensive mental and physical health assessments to determine the severity of symptoms, degree of impairment, and nature of the eating disorder, and to identify any comorbid conditions and determine a treatment plan, if needed. Racism and discrimination can undermine a comprehensive assessment for eating disorders. Ensure that the care delivered is inclusive, affirming, welcoming, and culturally sensitive for Black, Indigenous, and racialized people, people who identify as 2SLGBTQIA+, and other equity-deserving groups where there are known barriers to care.

## For Organizations and Health Services Planners

This care may not be currently available across Ontario, but it is important to ensure that systems, processes, and resources are in place for clinicians to identify and properly assess people who may have an eating disorder as soon as possible. Assessments for eating disorders should be locally available and accessible. Ensure health care professionals in primary care and community-based settings are aware of locally available assessments for eating disorders.

Ensure health care providers have the necessary training, knowledge, and skills to accurately assess for eating disorders

### **QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT**

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- Percentage of people with signs and symptoms of an eating disorder who receive the following:
  - A comprehensive mental health assessment
  - A comprehensive physical health assessment
- Percentage of people with signs and symptoms of an eating disorder who have the following initiated within 8 weeks of the first appointment with their health care provider:
  - A comprehensive mental health assessment
  - A comprehensive physical health assessment
- Local availability of assessments for eating disorders within 8 weeks of a first appointment with a health care provider for signs and symptoms of an eating disorder

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

# 04

## **Psychotherapy**

People with an eating disorder receive timely access to evidence-based psychotherapy that considers their individual needs and preferences.

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**Sources:** American Psychiatric Association, 2023<sup>1</sup> | Couturier et al., 2021<sup>18</sup> | National Institute for Health and Care Excellence, 2017<sup>2</sup> | Scottish Intercollegiate Guidelines Network, 2022<sup>3</sup>

### **Definitions**

**Timely access:** People with an eating disorder should be offered evidence-based psychotherapy delivered by a regulated health care professional as soon as possible. Psychotherapy ideally begins within 4 to 8 weeks of the comprehensive assessment (advisory committee consensus).

**Evidence-based psychotherapy that focuses on eating disorders:** Psychotherapy for eating disorders is typically provided in individual or single-family sessions. However, they can also be provided in group and multi-family formats. The length of evidence-based psychotherapies for eating disorders varies but is typically around 20 sessions. More sessions may be provided to individuals who are significantly underweight to support the weight restoration process.<sup>1</sup> In Ontario, psychotherapy is a controlled act and should only be performed by certain regulated professionals who are authorized to provide it.<sup>30</sup>

The following are examples of psychotherapies that focus on eating disorders and are considered first-line treatments:

**Psychotherapies for children and young people under the age of 18**  
Family-based treatment (FBT) is a treatment for children and young people with anorexia nervosa or bulimia nervosa and typically consists of 18 to 20 sessions over a 1-year period. The needs of the child or young person should be reviewed 4 weeks after treatment begins and then every 3 months to establish the appropriate frequency of sessions and length of treatment<sup>2</sup>

If FBT is ineffective or unsuitable, other therapeutic approaches can be considered, such as cognitive behavioural therapy for eating disorders (CBT-ED) for children and young people with anorexia nervosa, bulimia nervosa, and binge eating disorder. Adolescent-focused psychotherapy is also appropriate for young people with anorexia nervosa.

### **Psychotherapies for adults age of 18 and over**

- Cognitive behavioural therapy for eating disorders targets binge eating, compensatory behaviours, dietary restriction, low weight, and excessive concern with body shape and weight. CBT-ED also helps individuals to establish a regular pattern of eating and an appropriate and therapeutic plan for weight monitoring, and includes psychoeducation, self-monitoring of eating and related behaviours, exposure to avoided foods, and strategies to reduce concerns about shape and weight. CBT-ED also includes strategies to prevent relapse in the future and can be delivered individually or in a group setting.<sup>1</sup> The treatment is typically about 20 sessions, although fewer sessions may also be effective<sup>31</sup>

CBT-ED should be offered for<sup>1-3,15</sup>:

- Adults with anorexia nervosa or bulimia nervosa
- Adults with binge-eating disorder
- Interpersonal psychotherapy (IPT) involves identifying and working on specific interpersonal problem areas currently affecting the individual, including role disputes, role transitions, interpersonal deficits, and unresolved grief. IPT focuses on ways in which binge-eating behaviours are related to current interpersonal problems and includes relapse prevention. The treatment is typically about 20 sessions and can be delivered individually or in a group setting<sup>1</sup>

IPT for eating disorders is recommended for<sup>1,3</sup>:

- Adults with binge-eating disorder

Other therapeutic approaches are included for consideration in clinical practice guidelines, depending on the person's situation. There are lower levels of evidence for these approaches depending on the population and type of eating disorder. Examples include:

- Focal psychodynamic therapy (FPT), Maudsley Anorexia Nervosa Treatment (MANTRA), and specialist supportive clinical management (SSCM) for anorexia nervosa<sup>1-3</sup>

- IPT, integrative cognitive-affective therapy (ICAT), and schema therapy for bulimia nervosa<sup>1,3</sup>
- Brief strategic therapy, dialectical behaviour therapy, ICAT, and schema therapy for binge eating disorder<sup>3</sup>

For many psychotherapies, the evidence base comes from a limited population and may not have been studied in all people who may benefit from these treatments. It is important that all psychotherapies for eating disorders be trauma-informed and culturally sensitive.

## Rationale

Evidence-based psychotherapies for eating disorders are recommended as interventions for all age groups<sup>1-3</sup> and are appropriate in all stages of treatment, including weight restoration and relapse prevention. Medical monitoring during psychotherapy is an important part of care for people with an eating disorder. Accessing evidence-based psychotherapy can be challenging due to the lack of programs that offer these treatments, high demand for these services, the cost of psychotherapy, and long waitlists. Most evidence-based psychotherapies focus on establishing a pattern of regular eating, stopping weight control behaviours, restoring weight, and improving body image.

## What This Quality Statement Means

### For People With an Eating Disorder and Their Family and Caregivers

You should be offered a type of treatment called psychotherapy. It should be available as soon as possible after your assessment. Psychotherapy can:

- Help you establish regular eating patterns
- Provide education about eating disorders and how to get better
- Improve your thoughts and feelings about eating and your body shape and weight

If you agree to psychotherapy, you should not need to wait too long to start treatment.

### For Clinicians

Offer evidence-based psychotherapy to people with an eating disorder in alignment with their needs and preferences. They should begin evidence-based psychotherapy that focuses on eating disorders as soon as possible, ideally within 4 to 8 weeks after the comprehensive assessment.

## For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place for people with an eating disorder to access, timely, evidence-based psychotherapy free of charge, appropriate to their type of eating disorder and their needs and preferences. Ensure health care providers have the necessary training, knowledge, and skills to deliver psychotherapy for people with an eating disorder. Ensure health care professionals in primary care and community-based settings are aware of the locally available psychotherapies for people with an eating disorder.

### **QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT**

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- Percentage of people with an eating disorder who receive evidence-based psychotherapy by a health care professional within 8 weeks of the completion of their comprehensive assessment
- Local availability of evidence-based psychotherapy delivered by a health care professional within 8 weeks of the completion of their comprehensive assessment

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

# 06

## **Support for Family and Caregivers**

Families and caregivers of people with an eating disorder are offered resources, structured support, and education in a way that meets their needs.

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**Sources:** American Psychiatric Association, 2023<sup>1</sup> | National Institute for Health and Care Excellence, 2017<sup>2</sup> | Scottish Intercollegiate Guidelines Network, 2022<sup>3</sup>

### **Definition**

**Resources, structured support, and education:** These should include information about the nature and risks of the person's specific eating disorder diagnosis, the treatments available, and the likely benefits and limitations of those treatments in a format that meets the needs of families and caregivers (e.g., reading level, language preference, format [verbal, written, or video]). If applicable, resources and education should be provided to address misconceptions about eating disorders. Where appropriate, written information and resources should be provided for family and caregivers who do not attend assessment or treatment sessions with the person with an eating disorder.<sup>2</sup> Transitions in care can be an especially challenging time for families and caregivers. They may require additional support and resources during transitions.

Support groups may be beneficial and can be offered where appropriate and available; for example, moderated online caregiver forums, peer support,<sup>1</sup> or the Experienced Caregivers Helping Others (ECHO) model.<sup>2,3,18</sup> Other resources should be offered if desired, such as guided CBT-based self-help and unguided caregiver psychoeducation self-help interventions for families and caregivers of children and young people with an eating disorder.<sup>2,18</sup>

### **Rationale**

Family and caregivers of a person with an eating disorder can experience severe distress and may benefit from an assessment of their own needs to help determine what supports should be offered.<sup>2,35</sup>

Family and caregivers should be given comprehensive information (both verbal and written) about the person's eating disorder, its likely causes, the planned course of treatment, and the plan for treating any comorbid physical health or mental health or addiction conditions, if appropriate. It is especially important to assess and support the needs of family and caregivers of children and young people, including practical support and an emergency plan if the person with an eating disorder is at high medical or mental health risk or at risk of suicide. For adults, the involvement of family and caregivers is determined by the person's preferences, values, and needs, acknowledging that not everyone may want to involve their family and caregivers in their care.

## **What This Quality Statement Means**

### **For People With an Eating Disorder and Their Family and Caregivers**

If your family and caregivers are involved in your care, your health care providers should ask them how they are doing and offer them support if they want it. Support could include:

- Offering them information about your eating disorder, in the language of their choice, if possible
- Helping them find a support group where they can talk with other people who are supporting a person with an eating disorder
- Guided and unguided self-help interventions for family and caregivers of people with an eating disorder based on cognitive behavioural therapy techniques

### **For Clinicians**

Ensure that families and caregivers are offered resources, structured supports, and education about eating disorders. They may benefit from a psychosocial assessment depending on their needs. Families and caregivers should be included in care and treatment planning, especially for children and young people. For adults, involvement of families and caregivers occurs according to the wishes of the person with an eating disorder.

### **For Organizations and Health Services Planners**

Ensure that systems, processes, and resources are in place so that families and caregivers of people with an eating disorder can be offered resources, structured support, and education in a way that meets their needs. Ensure that health care providers have the necessary skills and resources to assess and address any unmet psychosocial needs of family and caregivers. Ensure relevant information and support are available and accessible to family and caregivers.

## QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

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- Percentage of children and young people with an eating disorder whose families and caregivers receive resources, structured support, and education by a health care provider
- Percentage of people with an eating disorder whose families and caregivers are involved in their care and whose families and caregivers report feeling supported and informed about eating disorders

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

# 09

## Care for People Who Are Not Receiving Active Treatment

People with an eating disorder who are not receiving active treatment are offered medical monitoring, support, and follow-up that meets their needs and preferences.

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**Sources:** American Psychiatric Association, 2023<sup>1</sup> | National Institute for Health and Care Excellence, 2017<sup>2</sup>

### Definitions

**Not receiving active treatment:** People with an eating disorder may not be receiving active treatment because they are waiting for treatment, it has ended, it has not helped in the past, or they have declined it.<sup>2</sup> Those who are not receiving active treatment should be connected to primary care and community supports for ongoing monitoring and referral back to eating disorder treatment as indicated.

**Medical monitoring, support, and follow-up:** Medical monitoring is described in quality statement 5. Support can involve guided self-help interventions<sup>2,18</sup> (e.g., workbooks, e-interventions), peer support,<sup>1</sup> and interventions to support readiness for treatment. Regular check-ins and follow-up for a person's eating disorder behaviours are provided by a health care provider.

### Rationale

Eating disorder treatment can be a physically and psychologically challenging experience. Some people may find intensive forms of treatment to be intolerable or unacceptable. Other people may not have benefited from eating disorders treatment despite multiple attempts and may decline further treatment. People with eating disorders whose health is at serious risk may need emergency care and/or admission to hospital. For people with eating disorders whose health is at serious risk but decline care, their capacity to make this health care decision should be considered according to Ontario's Health Care Consent Act<sup>54</sup> and the Ontario Substitute Decisions Act.<sup>55</sup> Signs that a person's health may be at serious

risk include, but are not limited to rapid substantial weight loss, unstable vital signs, electrolyte disturbances, cardiac abnormalities, hemodynamic instability, medical complications of malnutrition, suicidal thoughts or behaviours, and risk of death or imminent risk of serious medical complications.<sup>1,32,33,34</sup> Strengthened primary care and community-based health care can support people in achieving their health goals for those who are not engaged in active treatment. People with an eating disorder and their families and caregivers may access helpful information through websites, chat rooms, and social media.<sup>1</sup> However, in some instances, misinformation exists and professional guidance is important. Health care professionals should inquire about the use of peer- or internet-based support and discuss the information, ideas, and approaches that have been gathered from these sources and the level of evidence to support informed decisions.<sup>1</sup>

## What This Quality Statement Means

### For People With Eating Disorders and Their Family and Caregivers

You may not be receiving active treatment for your eating disorder for any of the following reasons:

- You are waiting for treatment
- You have finished treatment
- Treatment hasn't helped in the past
- You don't want it or aren't ready for treatment

If this is the case, your health care providers should continue to offer you other support that meets your needs and preferences, and connect you with other available resources.

### For Clinicians

Support and collaborate with people with an eating disorder who are not receiving active treatment and their family and caregivers to determine what ongoing follow-up and support best meets their needs.

### For Organizations and Health Services Planners

Ensure that systems, processes, and resources are organized so that people not receiving active treatment for an eating disorder receive appropriate ongoing medical monitoring, follow-up, and support based on their needs.

## **QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT**

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- Percentage of people with an eating disorder who are not receiving active treatment, but receive ongoing medical monitoring at every appointment with their health care provider
- Percentage of people with an eating disorder who are not receiving active treatment, but report feeling supported by their health care provider

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

# Anxiety disorders

## An information guide

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# 1. Anxiety and anxiety disorders

Everyone feels anxiety from time to time. Few people get through a week without some anxious tension or a feeling that something is not going to go well. We may feel anxiety when we're facing an important event, such as an exam or job interview, or when we perceive some threat or danger, such as waking to strange sounds in the night. However, such everyday anxiety is generally occasional, mild and brief, while the anxiety felt by the person with an anxiety disorder occurs frequently, is more intense, and lasts longer—up to hours, or even days.

Unfortunately, anxiety disorders are common. Research shows that up to one in four adults has an anxiety disorder sometime in their life, and that one person in 10 is likely to have had an anxiety disorder in the past year. Anxiety disorders are the most common mental health problem in women, and are second only to substance use disorders in men. Anxiety disorders can make it hard for people to work or study, to manage daily tasks and to relate well with others, and often result in financial strain and profound personal suffering.

People often live with anxiety disorders for years before they are diagnosed and treated. If you suspect that you have an anxiety disorder, it is important to seek professional treatment as soon as possible. Anxiety disorders are treatable, and early treatment can help to ensure treatment success.

The six main categories of anxiety disorders are *phobias*, *panic disorder* (with or without agoraphobia), *generalized anxiety disorder*, *obsessive-compulsive disorder*, *acute stress disorder* and *posttraumatic stress disorder* (American Psychiatric Association [APA], 2000). Each of these anxiety disorders is distinct in some ways, but they all share the same hallmark features:

- irrational and excessive fear
- apprehensive and tense feelings
- difficulty managing daily tasks and/or distress related to these tasks.

In the following examples, Susan, John and Linda\* show these common features, although the precise nature of their fears differ.

Susan has had recurrent and unexpected panic attacks for the past five years:

*It started on a night when I was driving home in the rain. I began to feel shaky and dizzy, and had trouble focusing. At first, I thought it was something that I had eaten earlier, but then my mind started to drift, and I thought, “What if I pass out?” and “What if I’m dying?” I started to shake all over, and it was as if my entire body was wired. I quickly pulled the car over and called my daughter to come and get me. Since then, I’ve had dozens and dozens of these attacks. At first, the attacks occurred just when I was driving, but now I experience them in shopping malls, standing in line-ups and even on the bus. It seems as if I spend most of my day worrying and waiting for the next attack.*

John describes a lifelong pattern of being excessively shy and fearing embarrassment in social situations:

*For as long as I can remember, and as far back as when I was*

\*All names and identifying details have been changed.

*seven years old, I hated being the centre of attention. In class, I tried to remain as invisible as possible, praying that the teacher would not call upon me to answer a question. When it was my turn to make presentations, I wouldn't sleep for a week, worrying that I would forget what I was supposed to say, stumble over my words, and look completely stupid. It's as if nothing's changed: now at work I dread having to attend meetings, meet with the boss, have lunch with colleagues, and the worst, give monthly reports to the team. I'm pretty sure everyone knows how uncomfortable I am, and they all probably think I look weird and sound stupid.*

Linda, a 34-year-old married woman, has struggled with doubting obsessions and checking compulsions since she was 15. She describes her current problems:

*I am worried that unless I take every precaution necessary to prevent harm, I am going to be responsible for something terrible happening. I have to check, recheck, check again, return to check, continue checking—the kitchen stove, the lights, the iron, my curling iron, the TV cable—to ensure that I don't cause a fire. Then, when I'm about to leave the house, it starts with the door locks: check once, check twice, check again, maybe leave, get halfway to work and return to check again, to be 100 per cent sure that I did not leave the door open. At work, I can start, correct and restart a simple e-mail to the boss 20 times to make sure that I don't say the wrong thing.*

To better understand the nature of anxiety disorders such as those experienced by Susan, John and Linda, we need to first explore the nature of “normal” anxiety. Later in this chapter, we’ll describe the key fears and components of each major anxiety disorder.

## What is normal anxiety?

A certain amount of anxiety is normal and necessary; it can lead you to act on your concerns and protect you from harm. In some situations, anxiety can even be essential to your survival. If you were standing at the edge of a curb, for example, and a car swerved toward you, you would immediately perceive danger, feel alarm and jump back to avoid the car. This normal anxiety response, called the “fight or flight” response, is what prompts you to either fight or flee from danger.

When we feel danger, or think that danger is about to occur, the brain sends a message to the nervous system, which responds by releasing adrenaline. Increased adrenaline causes us to feel alert and energetic, and gives us a spurt of strength, preparing us to attack (fight) or escape to safety (flight). Increased adrenaline can also have unpleasant side-effects. These can include feeling nervous, tense, dizzy, sweaty, shaky or breathless. Such effects can be disturbing, but they are not harmful to the body and generally do not last long.

## How does anxiety affect us?

Whenever the fight or flight response is activated by danger, either real or imagined, it leads to changes in three “systems of functioning”: the way you think (cognitive), the way your body feels and works (physical), and the way you act (behavioural). How much these three systems change varies, depending on the person and the context.

1. **cognitive:** Attention shifts immediately and automatically to the potential threat. The effect on a person’s thinking can range from mild worry to extreme terror.

2. **physical:** Effects include heart palpitations or increased heart rate, shallow breathing, trembling or shaking, sweating, dizziness or lightheadedness, feeling “weak in the knees,” freezing, muscle tension, shortness of breath and nausea.
3. **behavioural:** People engage in certain behaviours and refrain from others as a way to protect themselves from anxiety (e.g., taking self-defence classes or avoiding certain streets after dark).

It is important to recognize that the cognitive, physical and behavioural response systems of anxiety often change together. For instance, if you are spending a lot of time worrying about your finances (cognitive), you are likely to feel physically on edge and nervous (physical), and may spend quite a bit of time checking your household budget and investments (behavioural). Or if you're preparing for an important exam, you may worry about doing your best (cognitive), feel tense and maybe even have “butterflies” (physical), and initially avoid studying and then cram at the last minute (behavioural).

The key points to remember about anxiety are that it is:

- *normal* and experienced by every living organism
- *necessary* for survival and adaptation
- *not harmful or dangerous*
- typically *short-lived*
- sometimes *useful* for performance (at low or moderate levels).

## When is anxiety a problem?

Everyone experiences symptoms of anxiety, but they are generally occasional and short-lived, and do not cause problems. But when the cognitive, physical and behavioural symptoms of anxiety are

persistent and severe, and anxiety causes distress in a person's life to the point that it negatively affects his or her ability to work or study, socialize and manage daily tasks, it may be beyond normal range.

The following examples of anxiety symptoms may indicate an anxiety disorder:

1. **cognitive:** *anxious thoughts* (e.g., "I'm losing control"), *anxious predictions* (e.g., "I'm going to fumble my words and humiliate myself") and *anxious beliefs* (e.g., "Only weak people get anxious").
2. **physical:** *excessive physical reactions relative to the context* (e.g., heart racing and feeling short of breath in response to being at the mall). The physical symptoms of anxiety may be mistaken for symptoms of a physical illness, such as a heart attack.
3. **behavioural:** *avoidance of feared situations* (e.g., driving), *avoidance of activities that elicit sensations similar to those experienced when anxious* (e.g., exercise), *subtle avoidances* (behaviours that aim to distract the person, e.g., talking more during periods of anxiety) and *safety behaviours* (habits to minimize anxiety and feel "safer," e.g., always having a cell phone on hand to call for help).

Several factors determine whether the anxiety warrants the attention of mental health professionals, including:

- the *degree* of distress caused by the anxiety symptoms
- the *level of effect* the anxiety symptoms have on a person's ability to work or study, socialize and manage daily tasks
- the *context* in which the anxiety occurs.

## What are the anxiety disorders?

An anxiety disorder may make people feel anxious most of the time or for brief intense episodes, which may occur for no apparent reason. People with anxiety disorders may have anxious feelings that are so uncomfortable that they avoid daily routines and activities that might cause these feelings. Some people have occasional anxiety attacks so intense that they are terrified or immobilized. People with anxiety disorders are usually aware of the irrational and excessive nature of their fears. When they come for treatment, many say, “I know my fears are unreasonable, but I just can’t seem to stop them.”

The major categories of anxiety disorders are classified according to the focus of the anxiety. A brief description of each is given below, based on the diagnostic criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV). Although each anxiety disorder can have many different symptoms, one representative example has been chosen to illustrate the typical cognitive, physical and behavioural symptoms of each disorder.

### PANIC DISORDER (WITH OR WITHOUT AGORAPHOBIA)

#### DESCRIPTION

- Panic disorder involves “repeated, unexpected panic attacks (e.g., heart palpitations, sweating, trembling) followed by at least one month of persistent concern about having another panic attack” (APA, 2000, pp. 432–433).
- Panic attacks may be accompanied by agoraphobia, when someone avoids or endures—with marked distress—specific situations, such as being outside the home alone, being in a crowd or standing in a line.

### EXAMPLES OF SYMPTOMS

#### Cognitive

- “I’m having a heart attack.”
- “I’m suffocating.”

#### Physical

- accelerated heart rate
- chest pain or discomfort
- dizziness or nausea
- trembling or shaking
- shortness of breath

#### Behavioural

- avoidance of places where the person had anxiety symptoms in the past (e.g., a certain grocery store) or similar places (e.g., all grocery stores)
- avoidance of travel, malls, line-ups
- avoidance of strenuous activities (e.g., exercise)

## SPECIFIC PHOBIA

#### DESCRIPTION

- A specific phobia involves a “marked and persistent fear of clearly discernible, circumscribed objects or situations” (APA, 2000, p. 405).
- There are five subtypes of specific phobia: *animal type*, such as fear of mice or spiders; *natural environment type*, such as fear of storms or heights; *blood-injection-injury type*, such as fear of seeing blood or receiving an injection; *situational type*, such as fear of public transportation, elevators or enclosed spaces; and *other type*, such as fear of choking or vomiting.

**EXAMPLES OF SYMPTOMS****Cognitive**

- “This plane will crash.”
- “We are all going to die.”

**Physical**

- sweating
- muscle tension
- dizziness

**Behavioural**

- avoidance of air travel
- need to escape

## SOCIAL PHOBIA

**DESCRIPTION**

- Social phobia involves a “marked and persistent fear of social or performance situations in which embarrassment may occur” (APA, 2000, p. 450).
- Fears might be associated with most social situations related to public performance or social interactions, such as participating in small groups, meeting strangers, dating or playing sports.

**EXAMPLES OF SYMPTOMS****Cognitive**

- “I’ll look anxious and stupid.”
- “People will think I’m weird.”

**Physical**

- blushing
- sweating
- dry mouth

**Behavioural**

- avoidance of social gatherings, parties, meetings
- avoidance of public speaking

## OBSESSIVE-COMPULSIVE DISORDER

**DESCRIPTION**

- Obsessive-compulsive disorder (OCD) involves “recurrent obsessions or compulsions that are severe enough to be time consuming or cause marked distress or significant impairment” (APA, 2000, p. 417).
- Obsessions are uninvited or “intrusive” thoughts, urges or images that surface in the mind over and over again, such as concerns about contamination (e.g., from touching door handles) or doubting (e.g., “Did I lock the door?”).
- Compulsions are behaviours or “rituals” that the person follows to try to reduce or suppress his or her obsessive thoughts (e.g., hand washing, checking).

**EXAMPLES OF SYMPTOMS****Cognitive**

- “I’m going to get sick and infect the entire family if I touch this door handle.”

**Physical**

- muscle tension
- discomfort

**Behavioural**

- excessive washing, cleaning and/or checking
- avoidance of doors and public washrooms

## ACUTE STRESS DISORDER

### DESCRIPTION

- Acute stress disorder can occur after someone has “experienced, witnessed or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others” (APA, 2000, p. 431).
- The disorder occurs within one month of a traumatic event.
- Disturbing memories of the traumatic event cause an emotional reaction and a sense of reliving the event.

### EXAMPLES OF SYMPTOMS

#### Cognitive

- “I’m going to be trapped and die in a car crash.”
- “I’ve escaped being killed once—I won’t be so lucky a second time!”
- “The world is not safe.”

#### Physical

- restlessness, difficulty sleeping and concentrating
- exaggerated startle response
- feeling tense and on edge and/or numb

#### Behavioural

- avoidance of situations that arouse recollections of trauma
- intense emotional reaction or absence of emotional responsiveness

## POSTTRAUMATIC STRESS DISORDER

### DESCRIPTION

- Posttraumatic stress disorder (PTSD) involves the “development of characteristic symptoms following exposure to an extreme traumatic stressor” (APA, 2000, p. 463).

- “The person’s response to the event must involve intense fear, helplessness, or horror” (APA, 2000, p. 463).
- “Symptoms usually begin within three months of the trauma, although there may be a delay of months, or even years before the symptoms appear” (APA, 2000, p. 466).
- The traumatic experience is repeatedly relived through intrusive memories, distressing dreams and flashbacks.

#### EXAMPLES OF SYMPTOMS

##### Cognitive

- “I now realize that I’m never safe.”
- “People aren’t to be trusted.”

##### Physical

- sleep disturbance, nightmares
- irritability or outbursts of anger
- hypervigilance for danger

##### Behavioural

- avoidance of thoughts, feelings, conversations, activities, places or people associated with the trauma (e.g., emergency vehicles, parking lots)

## GENERALIZED ANXIETY DISORDER

#### DESCRIPTION

- Generalized anxiety disorder (GAD) involves “excessive anxiety and worry, occurring more days than not for a period of at least six months, about a number of events or activities” (APA, 2000, p. 472).
- GAD is characterized by “difficulty in controlling worry” (APA, 2000, p. 472).

**EXAMPLES OF SYMPTOMS****Cognitive**

- “Something’s going to go wrong.”
- “This worry is going to make me nuts.”

**Physical**

- muscle tension
- inability to relax
- restlessness, irritability
- sleep disturbed by worry

**Behavioural**

- avoidance of news, newspapers
- restricted activities due to excessive worries about what could happen

## 2. What causes anxiety disorders?

There are no clear-cut answers as to why some people develop an anxiety disorder, although research suggests that a number of factors may be involved. Like most mental health problems, anxiety disorders appear to be caused by a combination of biological factors, psychological factors and challenging life experiences, including:

- stressful or traumatic life events
- a family history of anxiety disorders
- childhood development issues
- alcohol, medications or illicit substances
- other medical or psychiatric problems.

### Psychological factors

The two main schools of thought that attempt to explain the psychological influences on anxiety disorders are the *cognitive* and *behavioural* theories. The ideas expressed by these theories help us to understand cognitive-behavioural treatment, which will be outlined in the next chapter. A third way of looking at the psychological causes of anxiety is the *developmental* theory, which seeks to understand our experience of anxiety as adults by looking at what we learn as children.

## COGNITIVE THEORY

Danger is a part of life. To protect us, evolution has genetically prepared us to fear danger. We know to avoid vicious animals and to be careful at great heights. Cognitive theory suggests, however, that people with anxiety disorders are prone to *overestimate* danger and its potential consequences. For example, people may overestimate the danger of particular animals, such as spiders or snakes, and thus believe that harm from that animal is far greater and more common than it actually is. Thinking of the worst possible scenario, they may imagine that a snake will bite and poison them, when it may be completely harmless. This is known as *catastrophizing*, and is common among people with anxiety disorders.

People who overestimate danger tend to avoid situations that might expose them to what they fear. For example, a person who fears flying will avoid trips that require air travel. Such behaviours are referred to as *safety behaviours* because they momentarily allow a person to feel less anxiety. However, when feared situations are avoided, the fears are strengthened. Cognitive theory suggests that fears can be reduced when people are able to experience the thing that they fear, allowing them to see that it is not as dangerous as they once believed.

## BEHAVIOURAL THEORY

Behavioural theory suggests that people learn to associate the fear felt during a stressful or traumatic life event with certain cues, such as a place, a sound or a feeling. When the cues reoccur, they cause the fear to be re-experienced. Once the association between the fear and the cue is learned, it is automatic, immediate and out

of conscious control. The fear is felt before there is time to tell if danger is near. Such cues may be *external* or *internal*.

An example of an external cue might be a certain smell that occurred at the time of the stressful event. When this smell occurs again, even at a time when there is no danger present, the person is reminded of the event and becomes fearful. Internal cues, such as a rapid heart rate, may also provoke fear if the person's heart raced during the actual threat. Later, when the person's heart beats rapidly during a workout routine, he or she may become fearful.

People with anxiety disorders may go to extreme lengths to avoid such cues. The original cues may even generalize to other similar cues, such as a bad encounter with a bulldog leading to the avoidance of all dogs. When people avoid such cues, they may feel more secure, but in the long run, these avoidance behaviours actually increase the anxiety associated with the cues. Avoidance prevents the person from "unlearning" the association, which can only be done when the person is exposed to such cues in a safe situation.

## DEVELOPMENTAL THEORY

According to developmental theory, the way in which children learn to predict and interpret life events contributes to the amount of anxiety they experience later in life. The amount of control people feel over their own lives is strongly related to the amount of anxiety they experience. A person's sense of control can range from confidence that whatever happens is entirely in his or her hands, to feeling complete uncertainty and helplessness over upcoming life events. People who feel that life is out of their control are likely to feel more fear and anxiety. For example, these people may feel that no amount of preparation or qualifications

will give them any control over the outcome of an upcoming job interview, and they arrive at the interview fearing rejection.

## Biological factors

The biological causes and effects of anxiety disorders include problems with brain chemistry and brain activity; genetics; and medical, psychiatric and substance use issues.

### REGULATION OF BRAIN CHEMISTRY

Research has revealed a link between anxiety and problems with the regulation of various *neurotransmitters*—the brain's chemical messengers that transmit signals between brain cells. Three major neurotransmitters are involved in anxiety: serotonin, norepinephrine and gamma-aminobutyric acid (GABA).

#### SEROTONIN

Serotonin plays a role in the regulation of mood, aggression, impulses, sleep, appetite, body temperature and pain. A number of medications used to treat anxiety disorders raise the level of serotonin available to transmit messages.

#### NOREPINEPHRINE

Norepinephrine is involved in the fight or flight response and in the regulation of sleep, mood and blood pressure. Acute stress increases the release of norepinephrine. In people with anxiety disorders, especially those with panic disorder, the system controlling the release of norepinephrine appears to be poorly regulated. Some medications help to stabilize the amount of norepinephrine available to transmit messages.

### GABA

GABA plays a role in helping to induce relaxation and sleep, and in preventing overexcitation. Medications known as *benzodiazepines* enhance the activity of GABA, producing a calming effect.

## CHANGES IN BRAIN ACTIVITY

Modern brain-imaging techniques have allowed researchers to study the activity of specific areas of the brain in people with anxiety disorders. Such studies have found, for example:

- abnormalities in cerebral blood flow and metabolism, and also structural anomalies (e.g., atrophy) in the *frontal*, *occipital* and *temporal* lobes of the brain
- that serotonin, norepinephrine and GABA activity in the *limbic system*, which controls memory and anxiety and fear responses, is most likely responsible for anxiety about the future
- that activity in the *locus ceruleus* (with a high number of norepinephrine neurons) and the *median raphe nucleus* (with a high number of serotonin neurons) appears to be involved in the production of panic attacks
- that activity in the *norepinephrine systems* in the body and the brain produces physical symptoms of anxiety, such as blushing, sweating and palpitations, which may cause people to become alarmed; these systems have also been linked to the production of flashbacks in people with posttraumatic stress disorder.

## GENETIC FACTORS

Research confirms that genetic factors play a role in the development of anxiety disorders. People are more likely to have an anxiety disorder if they have a relative who also has an anxiety disorder. The incidence is highest in families of people with panic

disorder, where almost half have at least one relative who also has the disorder.

## MEDICAL FACTORS

### ALCOHOL, MEDICATIONS AND ILLICIT SUBSTANCES

Substance use may induce anxiety symptoms, either while the person is intoxicated or when the person is in withdrawal. The substances most often associated with generalized anxiety or panic symptoms are stimulants, including caffeine, illicit drugs such as cocaine, and prescription drugs such as methylphenidate (e.g., Ritalin).

### MEDICAL CONDITIONS

A range of medical conditions can cause anxiety symptoms and result in anxiety disorders. For example, both panic and generalized anxiety symptoms can result from medical conditions, especially those of the glands, heart, lungs or brain. Most often, treatment of the medical condition reduces symptoms of anxiety.

Obsessive-compulsive symptoms in children may occur following strep infections. Obsessive-compulsive symptoms may also result from other infectious and degenerative syndromes affecting the central nervous system, but this is rare.

Mitral valve prolapse (a heart condition in which a heart valve is not working properly) has been associated with panic disorder, but there is no evidence supporting this link.

### PSYCHIATRIC CONDITIONS

People with other psychiatric disorders often also have symptoms of anxiety. Sometimes it is the symptoms of the other disorder, such as depression or psychosis, that heighten a person's anxiety.

In such cases the person may not be diagnosed as having an anxiety disorder.

People who are diagnosed with anxiety disorders may also have other psychiatric disorders; most often, these are other types of anxiety disorders, or substance use disorders or depression.

Two out of three people with panic disorder will have a major depressive episode at some point in their lifetime. When depression occurs in someone with an anxiety disorder, it is of particular concern since these two problems in combination increase the person's risk for suicide.

## Other factors

Studies show that people who are anxious tend to have an irregular pattern of breathing, alternating from hyperventilation to holding their breath. This pattern of breathing contributes to further symptoms (e.g., lightheadedness, dizziness and possibly fainting) and increases the feelings of anxiety. Breathing retraining techniques can help these people cope or manage anxiety symptoms.

## 3 Treatments for anxiety disorders

Many psychological treatments—such as relaxation training, meditation, biofeedback and stress management—can help with anxiety disorders. Many people with anxiety disorders also benefit from supportive counselling or couples or family therapy. However, experts agree that the most effective form of treatment for the anxiety disorders is cognitive-behavioural therapy (CBT). Medications have also been proven effective, and many people receive CBT and medication in combination.

### Cognitive-behavioural therapy

CBT is a brief, problem-focused approach to treatment based on the cognitive and behavioural aspects of anxiety disorders. Typically, CBT consists of 12 to 15 weekly one-hour sessions. In the initial sessions, the person with the anxiety disorder works with the therapist to understand the person's problems. The person's symptoms of anxiety are assessed within a cognitive-behavioural framework, and the goals and tasks of therapy are established. As the therapy progresses, behavioural and cognitive tasks are assigned to help the person with the anxiety disorder learn skills to reduce anxiety symptoms. As the symptoms improve, the therapist also focuses on underlying issues that may pose a risk for "relapse," a term used to describe the return of symptoms.

Homework assignments between sessions can include facing a feared situation alone, recording thoughts and feelings in different anxiety-provoking situations, or reading relevant material. Following treatment, therapists often schedule less frequent “booster” sessions.

## WHAT DOES CBT INVOLVE?

A standard component of CBT treatment is *exposure therapy*, which involves gradually exposing the person, either directly or through the person's imagination, to his or her feared situation that triggers anxiety. For instance, the person who fears dogs will be asked to spend time with dogs, the person who has panic attacks in the mall will be requested to go to malls, and the person who fears embarrassing himself or herself in social situations will be asked to attend gatherings and speak with others.

The rationale behind exposure therapy is that by practising exposure to their fears, people have the opportunity to learn that their fears are excessive and irrational, and that the anxiety decreases with more and more practice. This process is called *habituation*.

Because many people find it hard to face their fears, exposure therapy typically starts with exposing the person to situations that create only mild to moderate symptoms of anxiety, and gradually progresses to exposing the person to situations that create severe anxiety. In the case of someone who fears dogs, therapy may begin with the person discussing dogs, then progress to the person looking at photos of dogs, watching movies that showcase dogs and watching dogs from a distance, until eventually he or she can approach and pat different types of dogs.

Again, with repeated exposure, these situations begin to elicit less and less fear and anxiety for the person, and he or she feels less

of an urge to avoid them. As the person makes progress in conducting exposures with the assistance of the therapist, he or she is increasingly requested to complete exposure tasks as part of homework between sessions. The time it takes for people to progress in treatment may depend on the severity of their fear and their ability to tolerate the discomfort associated with arousing their anxiety.

An important part of CBT is helping people with anxiety disorders to identify, question and correct their tendencies to overestimate danger and their perceived inability to cope with danger. Cognitive strategies are developed in combination with exposure therapy to help people recognize that their thoughts, attitudes, beliefs and appraisals can generate and maintain anxious states.

For example, people who fear dogs may have the mistaken belief that all dogs are dangerous, based on an earlier experience with a single dog bite, and people experiencing panic attacks are likely to overestimate the likelihood of, or the threat associated with, having another panic attack in the mall. People with social phobia tend to overestimate the degree to which they are going to make social blunders and subsequently be judged and ridiculed. People with contamination obsessions and washing compulsions exaggerate the perception of danger associated with benign objects, such as door handles, chairs, money or shoes.

With repeated practice in therapy and then as part of homework, people with anxiety disorders develop skills that enable them to identify anxiety-related thoughts and beliefs, identify common distortions in their thinking, examine the evidence that supports and does not support their fearful appraisals, and develop less-threatening alternative responses to the feared object or situation.

Cognitive restructuring exercises are also introduced to help the person recognize why behavioural avoidance, reassurance-seeking

behaviours and “safety” behaviours (e.g., the person experiencing panic who always carries a cell phone just in case he or she needs to call for help) are unhelpful long-term strategies.

CBT has been found to be effective for all the anxiety disorders. Most people experience a significant reduction in their symptoms and stay well after the treatment ends. Given the success of this therapy and its ability to reduce relapse, CBT is established as the first-choice psychological treatment for anxiety disorders. CBT should be offered to all people with anxiety disorders, except for those who have already completed a course of CBT and failed to improve, those who do not want to try CBT, or people who cannot access a well-trained CBT therapist. Step-by-step workbooks are available for each anxiety disorder. (See pages 46–48 for recommended titles.)

## Medication options

Research has shown that people with anxiety disorders often benefit from medications that affect various neurotransmitters, particularly serotonin, norepinephrine and GABA. Medications can help reduce symptoms of anxiety, especially when combined with CBT.

The main medications used to treat anxiety are selective serotonin reuptake inhibitors (SSRIs), norepinephrine and serotonin reuptake inhibitors (NSRIs) and benzodiazepines (BZDs). SSRIs and NSRIs belong to a class of drugs called “antidepressants,” which are commonly prescribed to treat both anxiety disorders and depression. Benzodiazepines are classed as “sedatives” and are generally used to treat anxiety or insomnia.

Doctors treating anxiety disorders will usually prescribe an SSRI or an NSRI. Research indicates that these medications help reduce

the symptoms of anxiety for about 70 per cent of the people who take them. For those who do not benefit from taking an SSRI or NSRI, other drug treatments can provide relief. In some cases, specific symptoms of anxiety may be addressed with other medications, such as “beta blockers” to reduce hand tremors or slow down the heart rate, or “anticholinergics” to reduce sweating. Such medications can be taken in addition to an SSRI or NSRI.

## ANTIDEPRESSANTS

Antidepressants are usually the first medication prescribed to treat anxiety disorders. These medications are safe, effective and non-addictive, and have not been shown to have any long-term effects. The drawback of antidepressants is that they often have side-effects. For most people, the side-effects are mild and short-lived, an easy trade-off for the benefits of the medication. For others, the side-effects might be more troubling. People often experience the side-effects of an antidepressant within the first few weeks of treatment, before experiencing its benefits.

While SSRIs and NSRIs are the most commonly prescribed antidepressants in the treatment of anxiety disorders, other classes of antidepressants are also effective. These include tricyclic and tetracyclic antidepressants (TCAs) and monoamine oxidase inhibitors (MAOIs). Newer antidepressants are also available, but their effectiveness in treating anxiety disorders has not yet been established.

### WHAT'S INVOLVED IN TRYING ANTIDEPRESSANTS?

For best results, antidepressants should be taken regularly, generally once or twice each day. These and all medications should be taken only as prescribed. Taking more or less than the prescribed amount can prevent medications from working, and may even worsen some symptoms. Most doctors recommend starting at a

low dose and then, if the person tolerates the medication well, slowly increasing the dose until the ideal dose is found. The ideal dose is one that provides the greatest benefit with minimum side-effects.

Once a person has begun taking an antidepressant, he or she should continue for a trial period of at least three months. This allows time for the dosage to be adjusted correctly, for the initial side-effects to subside, and for the benefits of the drug to become clear. When these drugs work, the effects come on gradually. Usually several weeks pass before any change in symptoms is noticed. Then, the anxiety is reduced and it is easier for people to work on changing the way they behave in response to anxiety. It is important to realize that although these medications can be of great help to some people, not all symptoms of anxiety will be relieved.

If no benefits are derived from a particular antidepressant after a trial period of three months, doctors often recommend that another antidepressant be tried. Some people respond well to one drug and not at all to another. If a person does not benefit from the first medication (e.g., an SSRI), a second choice would be another SSRI or an NSRI, and the third choice would be a TCA. It is not uncommon for someone to try two or three antidepressant drugs before finding the one that works best.

The question of whether or not to take an antidepressant while pregnant or nursing should be discussed with your doctor. In some cases, the benefit of the drug clearly outweighs the possible risks.

#### **HOW LONG SHOULD I TAKE AN ANTIDEPRESSANT?**

When the right antidepressant has been found, doctors usually advise taking the medication for at least six to 12 months. In some

cases, the doctor may recommend taking the medication for several years, as there might be a greater risk of relapse if the medication is stopped. Even when taken for the long term, these medications are safe and non-addictive. No long-term side-effects have been associated with the use of antidepressants.

If a person begins to feel better and stops taking medication too soon or too quickly, the risk of relapse increases. The decision to stop taking medication should only be made in consultation with a doctor. The following guidelines can help lower the risk of relapse when a person wants to discontinue using medication:

- Lower the dosage gradually by “tapering,” or reducing, the medication over a period of time, possibly several weeks to months.
- Follow up regularly with a health care professional to help monitor the severity of any recurring symptoms of anxiety.
- Combine CBT with medication and use the skills learned to control any symptoms of anxiety that may arise when medication is discontinued.

#### SIDE-EFFECTS OF ANTIDEPRESSANTS

People who take antidepressants are likely to experience side-effects. Side-effects often begin soon after the person starts treatment, and generally diminish over time. In the early stages of treatment, side-effects may resemble anxiety symptoms, causing some people with anxiety disorders to abandon the treatment before it has had a chance to take full effect. Such side-effects, however, usually only last a couple of weeks. Some side-effects may be reduced by adjusting the dose, or by taking the medication at a different time of the day. If this approach does not improve the side-effects, the doctor may prescribe another medication.

The side-effects of antidepressants are not permanent and will

disappear completely when the medication is discontinued. When taking antidepressants or any medication, it is important to discuss with your doctor any side-effects that are troubling you. Each class of antidepressant and its common side-effects are discussed below.

#### **DRUG INTERACTIONS WITH ANTIDEPRESSANTS**

When taking an antidepressant, or any medication, it is important to check with your doctor or pharmacist for possible drug interactions before taking any other prescription or over-the-counter drugs, or any herbal products. Check also with your doctor before using alcohol or illicit drugs, as these may also interact with certain medications or reduce the effectiveness of treatment. Even on their own, alcohol and illicit drugs can create symptoms of anxiety.

#### **SELECTIVE SEROTONIN REUPTAKE INHIBITORS**

SSRIs are often the first medication prescribed to treat anxiety disorders. These medications are known to reduce symptoms of anxiety, to be safe, and to have milder side-effects than some other antidepressants. SSRIs have their primary effect on serotonin neurotransmitters.

The SSRIs currently available in Canada are: fluoxetine (Prozac), fluvoxamine (Luvox), sertraline (Zoloft), paroxetine (Paxil), citalopram (Celexa) and escitalopram (Cipralex). Of these, citalopram (Celexa) and escitalopram (Cipralex) are the newest on the Canadian market and their effectiveness for all anxiety disorders has not yet been proven through research. These medications are considered to be equally effective, although each may work for some people and not for others. They work less rapidly than benzodiazepines, especially in panic disorder, but are better tolerated in the long term and do not cause dependence.

*Common side-effects:* sexual inhibition, gastrointestinal complaints, weight gain, headaches, anxiety, insomnia or sedation, vivid dreams or nightmares.

#### NOREPINEPHRINE AND SEROTONIN REUPTAKE INHIBITORS

Venlafaxine (Effexor) is used to treat depression and generalized anxiety disorder, and also panic disorder, ocd and social phobia. The only other medication in this class currently available in Canada is duloxetine (Cymbalta), which has not yet been studied for effectiveness for anxiety disorders.

*Common side-effects:* nausea, drowsiness, dizziness, nervousness or anxiety, fatigue, loss of appetite and sexual dysfunction; in higher dosage, venlafaxine may increase blood pressure, and should only be taken on the doctor's advice by people with hypertension or liver disease.

#### TRICYCLIC AND TETRACYCLIC ANTIDEPRESSANTS

Although there are 10 TCAs available in Canada, not all of them have been shown to be effective for the treatment of anxiety disorders. Imipramine (Tofranil), desipramine (Norpramin) and clomipramine (Anafranil) have been the most studied for the treatment of panic disorder, generalized anxiety disorder and posttraumatic stress disorder. Clomipramine is most helpful for treating obsessive-compulsive disorder.

TCAs may interfere with certain medications, especially other mental health or heart medications. Review with your doctor the medications you are currently taking to check for possible interactions.

*Common side-effects:* dry mouth, tremors, constipation, sedation, blurred vision and change of blood pressure when moving from a sitting to a standing position (orthostatic hypotension). Because

TCAs may cause heart rhythm abnormalities, ask your doctor for an electrocardiogram (ECG) before taking this medication.

#### **MONOAMINE OXIDASE INHIBITORS**

MAOIs are highly effective medications for the treatment of depression and anxiety. However, MAOIs are used less frequently than other antidepressants because people who take them must follow a diet that is low in tyramine, a protein found in, for example, foods that are aged, fermented or high in yeast. If tyramine is taken in a too large a quantity while taking an MAOI, it can cause severe high blood pressure, which may be life-threatening. If you are taking an MAOI, your doctor or pharmacist will provide you with a list of foods to avoid. Examples of MAOIs are phenelzine (Nardil) and tranylcypromine (Parnate).

MAOIs also interact with a number of medications. Some painkillers, for example, should be avoided. Ask your doctor or pharmacist for a list of medications to avoid. If you plan to have surgery, let your dentist or surgeon know you are taking an MAOI at least a few weeks before the scheduled date. You may be asked to discontinue the MAOI prior to the surgery to avoid possible drug interactions. If you require emergency surgery, your doctor will monitor and manage any possible drug interactions during and after the surgery.

*Common side-effects:* change of blood pressure when moving from a sitting to a standing position (orthostatic hypotension), insomnia, swelling and weight gain.

#### **OTHER ANTIDEPRESSANTS**

Moclobemide (Manerix) is an antidepressant related to the MAOIs, but which does not require diet restrictions and has fewer drug interactions, making it safer than MAOIs. It is used to treat social anxiety disorder. Mirtazapine (Remeron) and bupropion

(Wellbutrin, Zyban) are newer antidepressants whose effectiveness in the treatment of anxiety disorders has not been established.

## BENZODIAZEPINES

Benzodiazepines are a group of medications that increase the activity of the GABA neurotransmitter system. BZDs reduce anxiety and excessive excitement, and make people feel quiet and calm. They also produce drowsiness, making it easier to fall asleep and to sleep through the night. For a long time, before SSRIs were available, BZDs were the drugs of choice for managing anxiety disorders. However, these drugs have potential for abuse and can be addictive, so the long-term use of BZDs is discouraged.

BZDs are often used to treat generalized anxiety disorder, panic disorder, social anxiety disorder, obsessive-compulsive disorder and posttraumatic stress disorder. They are usually prescribed in addition to an SSRI or other antidepressant for two to four weeks at the beginning of treatment, until the antidepressant becomes fully effective. The advantage of BZDs is that they can rapidly relieve and control anxiety.

The BZDs most commonly used to treat anxiety disorders are clonazepam (Rivotril), alprazolam (Xanax) and lorazepam (Ativan).

*Common side-effects:* drowsiness, sedation, dizziness and loss of balance; effects are most serious when BZDs are combined with alcohol or with other sedative medications.

## OTHER MEDICATIONS

Buspirone (Buspar) can be used to treat generalized anxiety disorder. It works mainly through the serotonin neurotransmitter system and usually takes two to three weeks to become effective.

Antipsychotic medications are rarely used to treat anxiety disorders. When prescribed, they are generally given at a low dose in combination with antidepressants to people with severe anxiety who do not respond to antidepressants alone.

## HERBAL THERAPIES

Over the years, many herbs have been thought to have some effect on mood and mental health. Although many plants may have active ingredients that can be somewhat effective in relieving various symptoms, their effectiveness has not been formally tested. In North America, the herbal industry is unregulated, meaning that the quality and effectiveness of herbal products is not consistent. Adverse effects are possible, as are toxic interactions with other drugs. If you are considering herbal medicines, you should discuss this with your doctor and review the medications you are already taking.

Some herbal products have sedative effects and are believed to reduce symptoms of anxiety. These include German chamomile, hops, kava kava, lemon balm, passion flower, skullcap and valerian. Other herbs without sedating effects, such as St. John's wort, have also been suggested for treating anxiety disorders. The effectiveness of all of these medicines in the treatment of anxiety disorders, and their effectiveness in comparison to antidepressants, have not yet been studied.

## 4 Recovery and relapse prevention

When someone begins treatment for an anxiety disorder, the first goal is to reduce and manage symptoms. The process of achieving this goal, known as “recovery,” often includes a combination of medication, CBT and supportive psychotherapy, and may also include other support such as occupational, recreation and nutrition therapy. Recovery also includes the way you apply the skills learned in treatment to real-life situations. Your idea of what you hope to achieve through recovery is unique to you. Long-term goals may include improved relationships with others, a full and satisfying work life, increased self-esteem and improved overall quality of life.

Once recovery is underway, and you are ready to focus on getting your life back to normal, the next step is “relapse prevention.” Anxiety is not an illness with a “cure.” Medication and therapy can help to bring symptoms under control, but some of the symptoms of anxiety, such as worry and fear, can arise for anyone during everyday life. To prevent relapse, you need to be ready with a plan to manage symptoms as they appear. Moving through the process of recovery and relapse prevention depends on a combination of planning and attitude. Achieving and maintaining your goals is easier when you develop:

- awareness of warning signs and strategies to respond to setbacks
- a healthy lifestyle
- hope and optimism about the future
- self-confidence.

## Preventing relapse and promoting wellness

### SOME THINGS YOU CAN DO TO PREVENT RELAPSE:

1. **Become an expert on your condition.** Learn about your symptoms and how to recognize when symptoms begin. Many resources are available, including books, videos, support groups and information on the Internet. Be aware that not all Internet sites provide reliable information; see the resources section beginning on page 49, for recommended sites and other suggestions for further information.
2. **Develop and stick to a plan for managing symptoms of anxiety.** Maintaining improvements in symptoms of anxiety requires commitment and dedication. Resist the urge to limit your life in the same way that you did when you were in the grips of your anxiety disorder. Develop a plan that includes a commitment to:
  - Take medications as prescribed. Any changes in your medication routine should be discussed beforehand with your doctor.
  - Learn warning signs that the anxiety disorder could be returning (e.g., if you begin again to avoid situations you associated with anxiety).

- Respond to warning signs by using the skills learned during therapy. To remain well, continue to expose yourself to situations you associated with anxiety.
3. **Develop a social support network.** Family, friends and a support group can help you to recognize when stressful situations may trigger anxiety symptoms, and can remind you of your strengths when you feel discouraged.
4. **Learn to cope with stress.** Stress, fatigue and feeling out of control can trigger symptoms of anxiety. Pay attention to which situations are stressful for you. Learn ways to manage stress. Here are some suggestions that can help you to return to a calm state:
- *Diaphragmatic breathing:* One way to do this is to lie on your back with one hand over your navel. Breathe so that your hand rises and falls with each breath, allowing your lungs to completely empty and fill. Ask your clinician about other approaches to this technique.
  - *Pleasurable activities:* Do something you enjoy that is relaxing, such as reading an inspiring book, walking in nature or talking to a supportive person.
  - *Take action:* When you take your mind off the things that cause you stress, it can make them seem less important. Take a class or try a new interest; learn something new.
  - *Become more aware of the present moment:* Yoga and mindfulness meditation are two ways to help you focus your mind on the here and now.
5. **Live a healthy life.** Eat a healthy diet, sleep well and exercise. Regular exercise, including sports, can help to manage stress. Use your faith, religion or spiritual practices to support your

recovery. Remain connected with the aspects of life that nurture you, and explore new ways to nurture yourself.

**6. Focus on developing a well-balanced life**, with time for work, family, friends and leisure activities.

## Relationship with a partner

An anxiety disorder can affect your relationship with your partner. When your symptoms are severe, it may be hard for you to be supportive and intimate. When you are most affected by your anxiety disorder, your partner may take on more responsibilities than he or she feels is fair. Over time, this can lead to distance and even hostility in the relationship. It takes time, patience and effort to rebuild what may have been lost.

Include your partner in your recovery. Let him or her know about your progress, and begin to offer to take on more responsibility again as you make improvements in managing your symptoms. It may be helpful for your partner to meet with your clinician, to better understand your treatment. Your partner may benefit from a family support group as well.

Couple therapy with a marital or couple therapist who understands anxiety disorders can help you to improve communication and to work together as a couple once again. A good therapist can help to remind couples of what brought them together in the first place.

## 5 Help for partners and families

### What happens when someone you love has an anxiety disorder?

When someone in the family has an anxiety disorder, it affects everyone and brings added pressures. Because most people experience some degree of anxiety in life, it may be quite some time before your relative receives an accurate diagnosis and begins to receive treatment. Your relative may have heard well-meaning advice, like, "You worry too much. Relax." Or, "What's the problem with going out of the house? Just do it!" You may even have said these things to your relative. To a person without an anxiety disorder, these statements would be good advice, but having an anxiety disorder involves more than the usual worry. Your relative may require professional help to get well.

It is natural for families and partners to feel resentful or disappointed when anxiety interferes with normal family life. Acknowledging the illness can be the first step toward understanding and making the family work again.

## When your relative is first diagnosed

When a member of your family is diagnosed with an anxiety disorder, you may experience varied and conflicting emotions. Often when a family learns that an anxiety disorder is the cause of their relative's worry and behaviour, they feel relief to finally know what the problem is, but they may also feel uncomfortable emotions, such as sadness, fear, guilt or anger. You may fear how the illness will affect the future for your relative, and for you. If you are the parent of a child or young adult who has been diagnosed with an anxiety disorder, you may feel guilty and blame yourself for the illness. You may fear that you have done something to bring this on, even when health care professionals tell you that this is not the case. Not surprisingly, you may feel angry that an anxiety disorder has disrupted the life of your family.

It is normal to experience this wide range of feelings. Understanding this, and learning to accept and manage your feelings, will reduce your stress and help you to be more helpful to the person who is struggling with the anxiety disorder.

## How to relate to your family member

- 1. Learn as much as you can about the symptoms of and treatments for your relative's anxiety disorder.** This will help you understand and support your relative as he or she makes changes.
- 2. Encourage your family member to follow the treatment plan.** If you have questions about your relative's treatment, ask your relative if it would be possible to speak to a member of his or her treatment team.

3. **Try to keep anxiety from taking over family life.** Keep stress low and family life normal as much as possible.
4. **Be supportive of your relative, without supporting his or her anxiety.** Your relative may look to you for reassurance when he or she is anxious, or ask you to arrange things to help him or her avoid an anxiety-producing situation. If you have helped your relative to reduce or avoid anxiety in the past, it may take time and practice to change this pattern. When you resist supporting your relative's anxiety behaviours, such as avoiding anxiety-provoking situations or performing a ritual to try to block feelings of anxiety, you are supporting his or her efforts to get well.
5. **Communicate with your relative positively, directly and clearly.** You may see things differently from your relative, who may become overwhelmed by fears. Avoid personal criticism even when disagreeing. For example, if your relative does not wish to seek treatment at the time that you think it is needed, take time to listen to his or her concerns. Express your point of view, while respecting your relative's concerns.
6. **Remember that life is a marathon, not a sprint.** Progress is made in small steps. Applaud your relative's progress at confronting anxiety and encourage him or her to use skills learned in treatment to manage symptoms.

Partners and families need to take care of themselves

When family members or partners are caught up in caring for a relative with an anxiety disorder, they may neglect to take care of

themselves. At times they may give up their own activities and become isolated from friends and colleagues. The isolation could go on for some time before they realize how emotionally and physically drained they are from caring for their relative or partner. The stress can result in disturbed sleeping patterns, feelings of irritability and/or episodes of exhaustion.

Family caregivers or partners need to be aware of their personal signs of stress and know their personal limits. They need to take actions to maintain their physical and mental health. Taking time out for oneself and keeping up interests outside of the family, and apart from the relative with an anxiety disorder, can help the family caregiver to recharge. Recovery from an anxiety disorder can be a long process. Caregivers need to set aside feelings of guilt, or of pressure to focus always on the relative who needs help. When caregivers take the time to have their own needs met, they have more energy and patience to support their relative, and are less likely to feel resentful or overwhelmed.

Family and friends can offer valuable support. However, when seeking such support, it is important to be aware that some people are more informed and understanding about mental health problems than others. It is wise to be selective when choosing who to confide in, and what advice to follow.

Family caregivers are encouraged to seek professional support that is specific to families of people with mental health problems. Support could include individual or family counselling, family support and education groups to improve understanding of their relative's anxiety disorder, and self-help groups where families of people with anxiety disorders provide support to each other. Counselling and groups may be offered by a community hospital, clinic or mental health organization.

## Explaining anxiety disorders to children

It can be challenging to explain anxiety disorders to children. Sometimes parents will not tell their children that a family member has been diagnosed with an anxiety disorder because they do not know how to explain it to children or they think children will not understand. In an effort to protect children, they sometimes continue with family routines as if nothing was wrong.

The strategies of saying nothing and continuing with routine activities are difficult to maintain, and over time will only be confusing to children trying to understand their relative's problem. Because children are sensitive and intuitive they will notice when a member of the family has emotional, mental and physical changes. Parents should avoid being secretive about the relative's anxiety disorder, as children will develop their own—often wrong—ideas about their relative's condition.

Children from three to seven years of age tend to see the world as revolving around them. As a consequence they blame themselves for unusual and upsetting events or changes in the family, or for unusual changes that occur with other people. For example, if a member of the family has a fear of heights, and becomes upset when a child climbs a ladder, the child may assume he or she is the cause of the person's unusual behaviour.

To explain anxiety disorders to children, it is important to provide them with only as much information as they are mature or old enough to understand. When providing information to toddlers and preschool children, parents should use simple, short sentences. That is, the sentences should be worded in concrete

language and be free of technical information. For example, “Sometimes your father doesn’t feel well and it makes him upset.” Or, “Your father has an illness that makes him feel upset when he sees someone climb a ladder.”

Children in elementary school can process more information. They are more able to understand the concept of an anxiety disorder as an illness; however, too much detail about the nature of the illness and how it is being treated could overwhelm them. One way to explain anxiety disorders to elementary school children is to say, “An anxiety disorder is a kind of illness that makes people worry a lot about heights and getting sick. Worrying so much makes them avoid tall buildings.”

Teenagers can manage most information, and often need to talk about what they see and feel. They may worry about the stigma of mental health problems and may ask about the genetics of anxiety disorders. Teenagers will engage in conversations about anxiety disorders if information is shared with them.

There are three main areas that are helpful for parents to cover when speaking with children about anxiety disorders:

- i. The parent or family member behaves this way because he or she has an illness.** It is easiest for children to understand an anxiety disorder when it is explained to them as an illness. Tell children that a member of the family has an illness called an anxiety disorder. You may explain it like this: “An anxiety disorder is like a cold, except that you don’t catch it, and rather than giving you a runny nose, it makes you worry a lot, sometimes for no reason. This worry makes people with an anxiety disorder avoid heights, or stay away from things that bother them, or check things over and over. Sometimes, they want others in the family to act the same way that they do. An anxiety disorder

takes a long time to get better. People with an anxiety disorder need help from a doctor or therapist.”

- 2. Reassure the child that he or she did not make the parent or family member get this illness.** Children need to know that their actions did not cause their loved one to develop the illness. People with anxiety disorders may become depressed as they struggle with their symptoms. It is important to reassure children that they did not make their loved one fearful or anxious.
- 3. Reassure the child that the adults in the family and other people, such as doctors, are trying to help the affected person.** It is the responsibility of adults to take care of the family member with an anxiety disorder. Children should not worry about taking care of anyone who is ill. Children need their parents and other trusted adults to protect them. Children should be allowed to talk about what they see and feel with someone who knows how hard it is for a relative to struggle with the symptoms of an anxiety disorder. The changes that occur in a loved one because of an anxiety disorder are often scary to children. They miss the time spent with the person who is ill.

Participating in activities outside the home helps children as it exposes them to healthy relationships. As the relative with an anxiety disorder recovers, and he or she gradually resumes family activities, this will help to improve his or her relationship with the children in the family.

If the relative with an anxiety disorder is a parent, he or she and the other parent should talk with the children about explaining the anxiety disorder to people outside the family. The support of friends is important for everyone. However, because anxiety disorders can be hard to explain, and some families worry about the

stigma of mental illness, family members will have to decide how open they wish to be about their situation.

Some parents who are affected with an anxiety disorder may find that they are less patient and more easily irritated than usual. They may find it hard to tolerate the loud, messy, chaotic play of their children. For them, the family may have to design and develop structured routines to ensure that the parent with an anxiety disorder has quiet and restful time away from situations that might trigger symptoms of the illness. Times should be planned to allow for children to play outside the home, or for the parent with an anxiety disorder to rest for part of the day in a quiet area of the home.

When the relative with an anxiety disorder is in recovery, it helps for the person to explain his or her behaviour to the children. The recovered relative may need to plan some special times with the children to re-establish their relationship and reassure the children that he or she is now more available to them.

# Anxiety

Moodjuice Self-help Guide



Learn more about anxiety and  
skills to cope with it.

## **Self Help for Anxiety**

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- Do you find that you spend large periods of the day worrying?
- Do you often feel nervous, apprehensive or on edge?
- Do you feel that things are getting on top of you?
- Do you find it hard to relax and 'switch off'?
- Do you often experience unpleasant physical sensations such as 'butterflies' in your stomach, muscular tension, dizziness or breathlessness?

If the answer to any of these questions is 'yes', you may be experiencing symptoms of anxiety and you may find this workbook helpful.

This workbook aims to help you to:

- Recognise whether you may be experiencing symptoms of anxiety.
- Understand what anxiety is, what causes it and what keeps it going.
- Find ways to understand, manage or overcome your anxiety.

## **Do I have symptoms of anxiety?**

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If you experience symptoms of anxiety it is likely that you will recognise many of the feelings, physical symptoms, thoughts and behaviour patterns described below.

*Please tick the boxes which regularly apply to you.*



### **Feelings**

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- On edge
- Nervous
- Panicky
- Stressed
- Irritable/low patience threshold
- Uptight

<input type="checkbox"/>



### **Physical Symptoms**

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- Tense body/Muscular pain
- Dizzy/Faint
- Chest tight or painful
- Stomach Churning
- Trembling or tingling sensations
- Heart racing/palpitations
- Breathing faster or slower than usual
- Concentration difficulties

<input type="checkbox"/>



### **Thinking styles**

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- You often worry 'what if' something bad happens
- Your mind jumps from worry to worry
- You often imagine the worst case scenarios
- You are always on the look out for danger

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>



### **Behaviour Patterns**

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- Avoid doing things you would like to
- Pace around/Find it hard to relax
- Snap at people too easily
- Get easily flustered
- Talk very quickly

<input type="checkbox"/>

If you have ticked a number of these boxes you may be experiencing symptoms of anxiety. However don't be alarmed, this is very common and there are things you can do to improve your situation. You will find some useful strategies in this workbook.

## What is anxiety?

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Anxiety is an unpleasant feeling that we all experience at times. It is a word often used to describe when we feel 'uptight', 'irritable', 'nervous', 'tense', or 'wound up'. When we are anxious we normally experience a variety of uncomfortable physical sensations. These include:

- Increased heart rate
- Muscular tension
- Sweating
- Trembling
- Feelings of breathlessness



As well as this, anxiety affects us mentally too. For example, when anxious, we often worry for large periods of time, so much so that our worry can feel out of control. These worries are often about a variety of issues and commonly our mind jumps quickly from one worry to another.

Anxiety also influences how we behave. For instance, when we feel anxious, we often avoid doing things that we want to because we are worried about how they will turn out. Although short experiences of anxiety are part and parcel of daily life, it becomes challenging when anxiety begins to follow people around and is a regular feature in their lives.

## **What causes anxiety?**

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### *Life Events:*

Often we develop anxiety following a series of stressful life events. This is especially true if we experience many different pressures all at once. For example, if someone has work pressures, financial difficulties, and relationship problems, all at the same time, it is perhaps unsurprising that they become anxious. When thinking about it in this way, anxiety is often the result of feeling as though we cannot cope with the demands placed upon us.

In addition, people can learn to be anxious based on their life experiences. For example, if someone has faced workplace bullying in the past, they may be more likely to suffer anxiety when beginning a new job.

### *Thinking Styles:*

Some people may have a thinking style that lends itself to experiencing anxiety. For example, anxious people have a tendency to expect that the worst possible scenario will always occur. They also feel like they must constantly be on guard in case something bad happens. They believe that by thinking about all the things that could go wrong, they will be better prepared to cope if it happens. However thinking in these ways mean they are on regular alert and find it difficult to relax and 'switch off'.

### *Evolutionary Reasons:*

We also experience anxiety because of its evolutionary benefits. Put another way, although anxiety is largely an unpleasant experience, it also has positive benefits that have been useful to humans over the centuries. For example, when we are under threat or feel in danger (e.g. hear a burglar), we automatically become anxious. As a result, our heart beats more quickly which supplies blood to our muscles (which helps us run away from or fight the burglar); we sweat (which cools us down during this process); and our breathing changes (which ensures oxygen is delivered to our muscles quickly, again preparing us for a quick response). When looking at anxiety in this way, you can quickly see how it can be very useful in certain situations.

### *Biological Reasons:*

It has also been suggested that anxiety has familial ties. In other words, if someone in your immediate family is an anxious person, there is an increased chance that you will have similar personality traits.

In reality it is likely that a combination of all these factors influence someone's anxiety levels. However, in some ways it is less important to know what causes anxiety, and more important to know what stops us overcoming it.

## **What keeps our anxiety going?**

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Some people have a style of thinking which lends itself to experiencing anxiety. For example, it appears that some people are more likely to overestimate the likelihood of bad things happening than others. It is easy to see how regularly presuming the worst in this way would make someone feel anxious. Unfortunately, when we do feel anxious, we become even less likely to think as clearly as we would like and a vicious cycle occurs.

Anxious people also sometimes believe that worrying has a protective function. More specifically, they believe that being on the 'look out' for danger can help them to recognise and avoid it. Unfortunately, when searching for danger in this way, they soon begin seeing potential danger in many relatively safe situations which of course makes them feel anxious. They may also believe that by considering everything that could go wrong; they will be better prepared to cope when it does. However, often these beliefs mean a lot of extra time is spent worrying than is necessary, as many of our worries never come true. Of course, the more time we spend worrying, the more anxious we feel.

Another way someone's thinking style can keep their anxiety going is because they become 'worried about worrying'. Here, people tend to worry that they are doing harm to themselves (e.g. going mad) by worrying so often (which is not the case) and a vicious cycle occurs. Similarly, people often worry about the physical symptoms they experience when they are anxious (e.g. breathlessness, rapid heart rate etc). Unfortunately, worrying about these symptoms (which are perfectly safe and natural bodily reactions), only makes them feel worse, again creating a vicious cycle of anxiety.

One other important factor that can keep people's anxiety going is that they often change their behaviour as a result of their anxiety. For example, they may avoid going to a party because they have spotted many potential 'dangers' (e.g. "what if no one likes me"). Similarly, they may put off completing an assignment because they worry about it being negatively evaluated. Unfortunately because people tend to use such avoidance strategies, they can never see that things would often go better than they thought and their anxiety remains as a result.

Not having enough free time to relax and do the things we enjoy we can also contribute to our higher anxiety levels. On the other hand, having too much free time can mean we have lots of opportunities to engage in worry and feel anxious.

When looking more closely at anxiety, you can begin to see that our thoughts, feelings, behaviours and physical symptoms all interact and combine to keep our anxiety going. See the diagram overleaf.

## **How can I reduce my anxiety?**

---

Fortunately, there are a number of strategies that we can use to reduce our anxiety. These include:

1. Understanding more about anxiety.
2. Learning how to challenge your unhelpful thoughts and see things in a more realistic light.
3. Improving your problem solving skills.
4. Learning how to reduce the amount of time you spend worrying.
5. Learning how you can feel more relaxed (physically and mentally).
6. Learning how to stop avoiding the things that make you anxious.

When going through this booklet it can sometimes be more helpful to try out the ideas above one at a time, rather than trying to learn them all at once. However simply take things at your own pace.



## Understanding anxiety

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Anxiety is undoubtedly an unpleasant feeling, but it is something that everyone experiences. Of course, some people experience anxiety more regularly than others, but it is a completely natural experience that is part and parcel of daily life. Due to the unpleasant nature of anxiety, people often worry that experiencing it is harmful. For example they may fear that regularly worrying will make them go mad or that the physical symptoms of anxiety (e.g. heart racing) are signs of a serious health problem. Such fears naturally make people even more anxious which creates a vicious cycle of anxiety.

However, when exploring anxiety more closely, we can see that it is a very healthy response which actually helps to protect us. By learning more about anxiety and why we experience it in the first place, we can see that it is not harmful. This can help us to be less fearful of the symptoms which in turn has a positive affect on our overall anxiety levels. If however you are concerned that some of your symptoms are not caused by anxiety, contact your GP if necessary.

The symptoms we experience when anxious are often referred to as the 'fight or flight' response. This comes from the idea that people primarily experience anxiety to help them either fight or run away from danger. For example, if you saw a burglar, two options open to you would be to either - fight them off (fight) or try to run away (flight). Our fight or flight response would kick in to help us at this point. For example:

- Our hearts would begin beating more quickly (supplying blood to our muscles).
- We would sweat (to cool us down).
- Our muscles would become tense (ready for action).
- We would take deeper breaths (to supply oxygen to our muscles).



In essence, all of these responses would aid our escape or improve our ability to stay and fight the intruder. When considered in this way, we can see how the symptoms of anxiety are helpful to us. Indeed, all of the physical symptoms we experience when anxious play a helpful role in protecting us in such circumstances.



This fight or flight response was likely even more vital to human survival back in the days of early man, when people had to hunt for their food and were under a greater threat from predators. Nowadays we do not face the same threats, but unfortunately, our bodies and minds have not caught up with these changes. As a result, we now experience anxiety in situations where it is not necessarily as helpful because we cannot fight or run away from them (e.g. work or financial pressures). However, the one thing that has stayed true is the fact that these symptoms are not dangerous; it is in many ways the right response but at the wrong time. Remembering this can help you to be less fearful of the symptoms of anxiety which will allow them to pass sooner.

## Challenging unhelpful thoughts

---

The way that we think about things has an impact on our anxiety levels. Many of these thoughts occur outside of our control, and can be negative or unhelpful. It is therefore important to remember that they are just thoughts, without any real basis, and are not necessarily facts. Even though we may believe a lot of our unhelpful thoughts when we are anxious, it is good to remember that they should be questioned as they are often based on wrong assumptions.

The following section will help you begin to recognise if you are thinking about things in an unhelpful or unrealistic way, and discuss how you can start to make changes to this. By doing so, you can learn to see things in a more realistic light which can help to reduce your anxiety levels. You might have unhelpful thoughts about all kinds of things. Here are some examples:

Being judged negatively by others:

- They think I'm useless
- They won't like me

Being unable to cope:

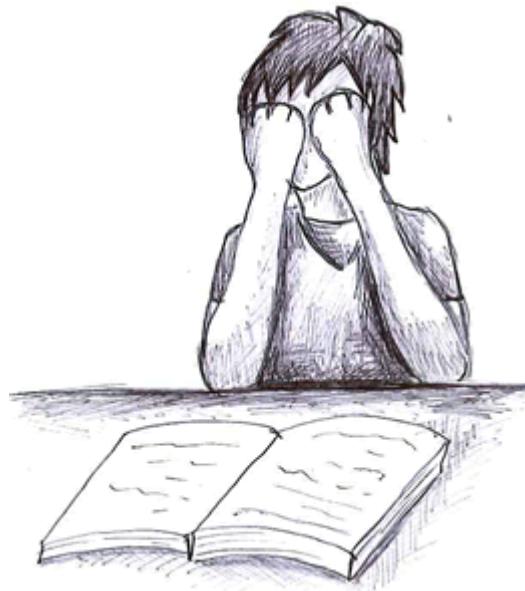
- I'll make a fool of myself
- I'm too anxious to manage that
- I'll have a panic attack

Something terrible happening:

- What if I have an accident?
- What if I lose my job?

It is clear to see how this kind of thinking might make us anxious. Do you ever think in any of the ways outlined above?

Fill in your examples below:



You might find it difficult to identify an unhelpful thought. Try thinking about a time when you were feeling anxious. Consider what was running through your mind at that time.

## **Patterns of unhelpful thinking**

---

First you need to be able to recognise an unhelpful thought. Then you can challenge it. Being aware of the common patterns that unhelpful thoughts follow can help you to recognise when you have them. Here are some of the common patterns that our unhelpful thoughts follow:

### *Predicting the Future:*

When we are feeling anxious, it is common for us to spend a lot of time thinking about the future and predicting what could go wrong, rather than just letting things be. In the end most of our predictions don't happen and we have wasted time and energy being worried and upset about them.

For example:

- Assuming you will perform poorly at your job interview.
- Spending the week before an exam predicting you will fail, despite all your hard work studying and your previous good grades.

### *Mind Reading:*

This means that you make assumptions about others' beliefs without having any real evidence to support them.

For example:

- My boss thinks I'm stupid.
- People think I'm weird.

Such ways of thinking naturally make us apprehensive.

### *Catastrophising:*

People commonly 'catastrophise' when they are anxious, which basically means that they often blow things out of proportion.

For example:

- They assume that something that has happened is far worse than it really is (e.g. that their friend is going to dislike them because they cancelled a night out).
- They may think that something terrible is going to happen in the future, when, in reality, there is very little evidence to support it (e.g. I'm going to get into serious trouble for calling in sick).

### *Focusing on the Negatives:*

Anxious people often have a tendency to focus on the negatives which keeps their anxiety going.

For example:

- They focus on the one person at work who doesn't like them, ignoring that they are very popular with the rest of their colleagues.

*Should Statements:*

People often imagine how they would like things to be or how they 'should be' rather than accepting how things really are.

For example:

- I should have got an A in History.
- I should never be anxious.

Unfortunately when we do this, we are simply applying extra pressure to ourselves that can result in anxiety. Instead it can sometimes help to accept that things can't always be perfect.

*Over Generalising:*

Based on one isolated incident you assume that all others will follow a similar pattern in the future.

For example:

- When enrolling on a college course, you meet a future classmate who you find irritating. As a result, you worry that everyone in the class will be the same and you won't make any friends.

*What If Statements:*

Have you ever wondered "what if" something bad happens?

For example

- What if I have a panic attack at the party?
- What if I don't make friends when I start my new job?

This type of thought can often make us avoid going places or doing the things that we would like.

*Labelling:*

Do you find that you attach negative labels to yourself?

For example:

- I'm weak.
- I'm a waste of space.
- I'm always anxious.

Labels like these really influence how we see ourselves and can heighten our anxiety levels. Do any of your unhelpful thoughts follow some of these patterns? Jot down any examples you can think of into the box below:

Unhelpful Thought	Category
<p>e.g. "My boss thinks I'm useless" "My anxiety means I'm weak"</p>	<p>Mind Reading Labelling</p>

We can learn techniques to challenge these unhelpful thoughts. This can help to reduce your anxiety levels. The next part of this handout will discuss how we can go about challenging our unhelpful thoughts. You may come up with a more balanced thought that is accurate and based on evidence.

## **Problem Solving**

---

You might find it more difficult to cope if you have lots of problems that you can't seem to get on top of. This can have a clear impact on our anxiety levels. Struggling with unresolved problems can often make us feel worse. We can end up worrying or ruminating over our problems without finding a way to resolve them. This can make us feel even more upset, and can end up interfering with our sleep.

It can help to develop a structured way of working through a problem. Beginning to overcome some of your problems might help you to feel better. You can improve your problem solving skills by learning to apply the steps outlined here.



### **Identify your problem**

---

The first thing to ask yourself is "what is the problem?" Try to be as specific as possible.

For example:

- "I owe £400 to my friend"
- "I am going to miss this deadline."



### **Come up with possible solutions**

---

Try to list every way that you can think to overcome your problem. Don't worry about how unrealistic an idea seems. Write down anything and everything. The best solutions are likely to be the ones you think of yourself. This is because nobody really knows your situation as well as you do.

It may help to consider:

- How you might have solved similar problems in the past.
- What your friends or family would advise.
- How you would like to see yourself tackling the problem.



### **Choose a solution**

---

Next you need to select the best solution from your list. Think carefully about each option. It is useful to go through all the reasons 'for' and 'against' each idea. This will help you to make a good decision and select the best solution.

After this you may find that you are still unsure. Perhaps a couple of approaches seem equally good. Try to pick one to begin with. If it doesn't work then you can always go back and try out a different one later.



## Break down your solution

---

To help you carry out your chosen solution, it can be useful to break it down into smaller steps. This can make it easier and more manageable to follow through. The number of steps required will vary depending on the solution and how complex it is.

For example: Someone with debt may have decided to try and resolve their problem by getting a part time job. This would require several steps.

1. Buying a newspaper with job adverts.
2. Choosing which jobs to apply for.
3. Creating a CV.
4. Sending out their CV.
5. Buying interview clothes.
6. Preparing answers to potential interview questions.



## Try out your solution and review the outcome

---

Follow the steps required to carry out your solution. Simply take them one at a time. Go at your own pace and don't allow yourself to feel too rushed.

Once you have completed all the steps, you should then review the outcome. If you have successfully resolved your problem then great. If the problem still exists then don't give up.

- Is there another solution on your list that you could try?
- Is there a different solution that you have yet to consider?
- Can you ask someone else if they have any ideas or advice?
- Can you combine any of your solutions?

It is useful to remember that not all problems are within our control. This can make it really difficult if not impossible to resolve using the steps above. Perhaps you will have to wait, or ask someone else to take action instead. In such a situation, try not to worry. Nothing can be gained from worrying about something that you have no control over.

## **Limiting the time you spend worrying**

---

Anxious people tend to spend much of their time worrying. Sometimes they worry to the point that they find it very hard to 'switch off' and relax. Indeed, one of the most frustrating things about feeling anxious is the seemingly uncontrollable worry that often occurs alongside it. Therefore, if we can reduce the amount of time we spend worrying, we can reduce our anxiety levels.

One way you can do this is to assign 'worry time'. This involves setting aside between fifteen and twenty minutes each day that you will allow yourself to worry. Any worries that pop into your head outside of 'worry time' should simply be noted and forgot about until later that day when you try to resolve them during your 'worry time'. By noting them down, you can feel safe in the knowledge that you won't forget about attempting to resolve them later on. This should free up time during the day that is normally wasted worrying. Then - when your 'worry time' arrives, you should allow yourself to think about the things that have been worrying you that day and try to resolve them. 'Worry time' not only helps to reduce the time you spend worrying, but also proves that you can have more control of whether you engage in worry or not. It also shows that worry is often unnecessary. This is because when you come back to consider your problems with a 'fresh eye', many of them have often resolved themselves or simply seem less important.

See the steps below for more details:

1. Decide a time in the day that you will have your 'worry time'.
2. At other times, simply note down any worries that pop into your head and try to forget about them.
3. Once your 'worry time' arrives, choose how long you will allow yourself to 'worry' (try to keep it no longer than 15-20 minutes). Begin timing yourself so your 'worry time' doesn't overrun.
4. During worry time, try to resolve your worries proactively. Simply try to come up with solutions to your worries if possible. Using a pen and pad to jot down solutions can be helpful.
5. Stop as soon as your 'worry time' is finished. If any worries still feel unresolved, simply carry them over to tomorrow's 'worry time'.

Here are some handy hints to help you with your 'worry time'.

- If you find it difficult to switch off from all of your worries during the day, don't fret, as this should improve with time and practice.
- It may be useful to use the problem solving section in this guide during 'worry time'.
- When it comes to 'worry time', feel free to cut it short if you have resolved all of your worries early.
- Often things that have worried us at one point in the day seem less problematic when we re-visit them during 'worry time'. If this happens "great" simply forget about them.
- Remember, it is usually not possible to resolve every single worry or problem that you have. So if something is outside your control (or has already happened), try not to worry as you have done all you can. There is also the possibility that your worry won't even come true in the first place.

## Relaxation

---

It is important to make time to relax and do activities that are enjoyable. This can help to reduce your anxiety levels by calming the body and mind. It can also help you to sleep. Without taking the time to unwind, it is easy to feel overwhelmed and stressed.

Relaxation can involve doing something that you enjoy, or just being by yourself. Good examples might be reading a book or having a bath. Exercise is also particularly effective at helping us to relax. What you do does not really matter. Try to choose something that you will look forward to and that gives you a break. Doing an activity that you enjoy will also give you less time to spend worrying. Here is a list of activities that might help you to relax.

Suggestions:

- Do some exercise (e.g. swim, cycle)
- Read a book
- Watch your favourite TV show
- Go to the cinema
- Do something creative (e.g. draw, paint)
- Visit a friend or family member
- Have a bath



Try to add some of your own ideas into the box below. You will know what works best for you.

Try to find time to relax every day. This might seem difficult, but it is worth making time for. It can help you to feel a lot better. There are audio relaxation guides available that you might find a helpful support.

There are also some exercises described in the next few pages. They are specifically designed to help you to relax. However, you should stop the exercise if at any time you begin to experience discomfort or pain.

## Controlled breathing

---

This simple technique involves focusing on and slowing down our breathing patterns. Many people find this simple exercise very relaxing. It can be particularly helpful for those who feel dizzy or light headed when they feel worried or stressed. This sometimes happens because people's breathing changes and gets quicker when they feel distressed.

This can be an uncomfortable and unpleasant experience. It can make people even more on edge, and a vicious cycle can occur. Learning controlled breathing exercises can help you to manage these feelings more effectively. It can also help to give your mind and body a chance to calm down.

Remember, you can use this exercise to help you relax at any time. You could even use it to help you get off to sleep. However, it is particularly useful if you ever feel light-headed, dizzy or faint.



### Beginning

---

Get into a comfortable position.



### Middle

---

Work out a stable breathing rhythm. Perhaps try to breathe in for three seconds, hold this breath for two seconds, and then breathe out for three seconds. It can be helpful to count as you do this

e.g. **IN: 1 - 2 - 3, HOLD: 1 - 2, OUT: 1 - 2 - 3, HOLD: 1 - 2.**



### Ending

---

Repeat this action for a few minutes. You should soon begin to feel more relaxed. If you were feeling dizzy then this should also get better after a few minutes.

## Muscular relaxation

---

Tension often builds up when we feel upset or stressed. These symptoms can be painful and can cause anxiety in themselves. Muscular relaxation exercises can help you to control such unpleasant symptoms. They can reduce physical tension and help you to relax in general.

During this exercise you have to tense and then relax different muscles in your body. You should focus on the feelings that you experience whilst doing this. With practice you will then be more able to recognise and respond to the onset of tension.

You can work through as many muscle groups as you like. Don't feel that you have to cover every muscle in your whole body. It can be helpful to stick to the same muscle groups each time you practice. That way you can get into a routine which you can easily remember. If you practice this nearly every day you will probably notice an improvement after a couple of weeks.



### Beginning

---

Find somewhere comfortable and quiet where you won't be interrupted. You can either sit or lie down to practice this exercise. Begin by focusing on your breathing. Try to have a slow and comfortable pace. You could use the controlled breathing technique described earlier. Do this for a few minutes to prepare for the muscular relaxation exercise.



### Middle

---

Try to tense each muscle group for around five seconds. Don't tense the muscle too tight. Focus on the sensations that this brings. Then relax your muscles for a similar length of time, and again, focus on how this feels. Then move onto the next muscle group. Try to remember to keep your breathing at a comfortable pace throughout.

Below are some suggestions of muscle groups that you may wish to work through:

- **Legs** - point your toes and tense your muscles as if you were trying to stand up.
- **Stomach** - tense your stomach muscles.
- **Arms** - make fists and tense your muscles as if you were trying to lift something.
- **Shoulders** - shrug your shoulders. Lift them up towards your ears.
- **Face** - make a frowning expression. Squeeze your eyes shut and screw up your nose. Clench your teeth.



### Ending

---

It can be helpful to spend a few minutes just lying quietly in a relaxed state. See if you can notice any tension in your body and try to relax it. Otherwise, just let the tension be. If your mind wanders, try to bring your concentration back to your breathing.

Finally, count down silently and slowly: **5 - 4 - 3 - 2 - 1 - 0**, and come out of the relaxation in your own time. See if it's possible to carry that relaxed feeling into whatever you do next.

## **Distraction**

---

Distraction is a good technique to fend off symptoms of anxiety and stress when they feel overwhelming. This can also give you space to deal with a situation in a more considered and positive manner. It is also helpful when you don't have the space or time to use a more proactive approach, such as a relaxation exercise.

Distraction simply involves trying to take your mind off uncomfortable symptoms or thoughts. You can do this by trying to focus on something unrelated. Often this helps them to pass. It is still important to remember that the symptoms of anxiety are not harmful or dangerous. Even if you didn't use distraction or relaxation techniques, nothing terrible would happen.

Ideas to help distract you from your troubling thoughts or anxiety include:

- Try to appreciate small details in your surroundings.
- Count backwards from 1000 in multiples of 7.
- Focus on your breathing, for example, how it feels to breathe in and out.
- Count things that you can see that begin with a particular letter.
- Visualise being in a pleasant, safe and comfortable environment (e.g. being on a beach).
- Listen to your favourite music. Try to pick out all the different instruments and sounds that you can hear.

As with any relaxation exercise, it may take a few minutes before you begin to feel like it is working.

# Depression in adults: treatment and management

NICE guideline

Published: 29 June 2022

[www.nice.org.uk/guidance/ng222](https://www.nice.org.uk/guidance/ng222)

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## 1.1 Principles of care

- 1.1.1 When working with people with depression and their families or carers, ensure steps are taken to reduce stigma, discrimination and barriers for individuals seeking help for depression (for example, reducing judgemental attitudes, showing compassion, parity of esteem between mental illness and physical illness, treating people as individuals). **[2009, amended 2022]**

### Providing information and support

- 1.1.2 Provide people with depression with up-to-date and evidence-based verbal and written information about depression and its treatment, appropriate to their language, cultural and communication needs.
- 1.1.3 Consider developing advance decisions about treatment choices (including declining treatment) and advance statements collaboratively with people who have recurrent severe depression or depression with psychotic symptoms, and for those who had treatment under the Mental Health Act 2007, in line with the Mental Capacity Act 2005, and review them regularly. Record the decisions and statements and include copies in the person's care plan in primary and secondary care, and give copies to the person and to their family or carer, if the person agrees. **[2009, amended 2022]**
- 1.1.4 Advise people with depression that they can set up a Health and Welfare Lasting Power of Attorney, and support them to do so if appropriate, so that a trusted person can represent their interests and make decisions on their behalf if they do not have the capacity to make decisions themselves at any point. **[2022]**

## 1.2 Recognition and assessment

- 1.2.1 Be alert to possible depression (particularly in people with a past history of depression or a chronic physical health problem with associated functional impairment) and consider asking people who may have depression if:
- During the last month, have they often been bothered by feeling down,

depressed or hopeless?

- During the last month, have they often been bothered by having little interest or pleasure in doing things?

See also the NICE guideline on depression in adults with a chronic physical health problem. [2009, amended 2022]

- 1.2.2 If a person answers 'yes' to either of the depression identification questions (see recommendation 1.2.1) but the practitioner is not competent to perform a mental health assessment, refer the person to an appropriate professional who can. If this professional is not the person's GP, inform the person's GP about the referral. **[2009]**
- 1.2.3 If a person answers 'yes' to either of the depression identification questions (see recommendation 1.2.1) and the practitioner is competent to perform a mental health assessment, review the person's mental state and associated functional, interpersonal and social difficulties. **[2009]**
- 1.2.4 Consider using a validated measure (for example, for symptoms, functions and/or disability) when assessing a person with suspected depression to inform and evaluate treatment. **[2009]**
- 1.2.5 If a person has language or communication difficulties (for example, sensory or cognitive impairments or autism), to help identify possible depression consider:
- asking the person about their symptoms directly, using an appropriate method of communication depending on the person's needs (for example, using a British Sign Language interpreter, English interpreter, or augmentative and alternative communication)
  - asking a family member or carer about the person's symptoms.

See also the NICE guidelines on mental health problems in people with learning disabilities and autism spectrum disorder. [2009, amended 2022]

## Initial assessment

- 1.2.6 Conduct a comprehensive assessment that does not rely simply on a symptom count when assessing a person who may have depression, but also takes into account severity of symptoms, previous history, duration and course of illness. Also, take into account both the degree of functional impairment and/or disability associated with the possible depression and the length of the episode. [2009, amended 2022]
- 1.2.7 Discuss with the person how the factors below may have affected the development, course and severity of their depression in addition to assessing symptoms and associated functional impairment:
- any history of depression and coexisting mental health or physical disorders
  - any history of mood elevation (to determine if the depression may be part of bipolar disorder); see the NICE guideline on bipolar disorder
  - any past experience of, and response to, previous treatments
  - personal strengths and resources, including supportive relationships
  - difficulties with previous and current interpersonal relationships
  - current lifestyle (for example, diet, physical activity, sleep)
  - any recent or past experience of stressful or traumatic life events, such as redundancy, divorce, bereavement, trauma (also see the NICE guideline on post-traumatic stress disorder)
  - living conditions, drug (prescribed or illicit) and alcohol use, debt, employment situation, loneliness and social isolation. [2009, amended 2022]

## Risk assessment and management

- 1.2.8 Always ask people with depression directly about suicidal ideation and intent. If there is a risk of self-harm or suicide:
- assess whether the person has adequate social support and is aware of

sources of help

- arrange help appropriate to the level of need
- advise the person to seek further help if the situation deteriorates. **[2009]**

1.2.9 If a person with depression presents considerable immediate risk to themselves or others, refer them urgently to specialist mental health services. **[2009]**

1.2.10 Advise people with depression of the potential for increased agitation, anxiety and suicidal ideation in the initial stages of treatment. Check if they have any of these symptoms and:

- ensure that the person knows how to seek help promptly
- review the person's treatment if they develop marked and/or prolonged agitation. **[2009]**

1.2.11 Advise a person with depression and their family or carer to be vigilant for mood changes, agitation, negativity and hopelessness, and suicidal ideation, and to contact their practitioner if concerned. This is particularly important during high-risk periods, such as starting or changing treatment and at times of increased personal stress. **[2009, amended 2022]**

1.2.12 If a person with depression is assessed to be at risk of suicide:

- do not withhold treatment for depression on the basis of their suicide risk
- take into account toxicity in overdose if an antidepressant is prescribed, or the person is taking other medication, and if necessary limit the amount of medicine available
- consider increasing the level of support provided, such as more frequent in-person, video call or telephone contact
- consider referral to specialist mental health services.

For further advice on risk assessment, see the [NICE guideline on self-harm](#).

For further advice on medication, see the [recommendations on antidepressant medication for people at risk of suicide](#). **[2009, amended**

2022]

## Depression with anxiety

- 1.2.13 When depression is accompanied by symptoms of anxiety, which is particularly common in older people, the first priority should usually be to treat the depression. When the person has an anxiety disorder and comorbid depression or depressive symptoms, consult NICE guidance for the relevant anxiety disorder if available and consider treating the anxiety disorder first. [2009, amended 2022]

## Depression in people with acquired cognitive impairments

- 1.2.14 When assessing a person with suspected depression:
- be aware of any acquired cognitive impairments
  - if needed, consult with a relevant specialist when developing treatment plans and strategies. [2009]
- 1.2.15 When providing interventions for people with an acquired cognitive impairment who have a diagnosis of depression:
- if possible, provide the same interventions as for other people with depression
  - if needed, adjust the method of delivery or length of the intervention to take account of the person's ability to communicate, disability or impairment.

For people with depression who also have dementia, see the section on depression and anxiety in the NICE guideline on dementia. [2009, amended 2022]

## 1.3 Choice of treatments

1.3.1 Discuss with people with depression:

- what, if anything, they think might be contributing to the development of their depression (see recommendation 1.2.7 in the section on initial assessment)
- whether they have ideas or preferences about starting treatment, and what treatment options they have previously found helpful or might prefer
- their experience of any prior episodes of depression, or treatments for depression
- what they hope to gain from treatment. [2022]

1.3.2 Help build a trusting relationship with the person with depression and facilitate continuity of care by:

- ensuring they can see the same healthcare professional wherever possible
- recording their views and preferences so that other practitioners are aware of these details. [2022]

1.3.3 Discuss with people with depression their preferences for treatments (including declining an offer of treatment, or changing their mind once a treatment has started) by providing:

- information on what treatments are NICE-recommended, their potential benefits and harms, any waiting times for treatments, and the expected outcomes (see table 1 and table 2 on the recommended treatments for a new episode of less severe and more severe depression)
- a choice of:
  - the treatments recommended in this guideline
  - how they will be delivered (for example individual or group, in person or remotely) **and**
  - where they will be delivered

- the option to attend with a family member or friend when possible, for some or all of their treatment
- the option to express a preference for the gender of the healthcare professional, to see a professional they already have a good relationship with, or to change professional if the relationship is not working. [2022]

1.3.4 Commissioners and service managers should ensure that people can express a preference for NICE-recommended treatments, that those treatments are available in a timely manner, particularly in severe depression, and that they are monitored to ensure equality of access, provision, outcomes and experience. [2022]

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on choice of treatments](#).

Full details of the evidence and the committee's discussion are in [evidence review I: patient choice](#).

## 1.4 Delivery of treatments

### All treatments

1.4.1 When considering treatments for people with depression:

- carry out an assessment of need
- develop a treatment plan
- take into account any physical health problems
- take into account any coexisting mental health problems
- discuss what factors would make the person most likely to engage with treatment (including reviewing positive and negative experiences of previous

treatment)

- take into account previous treatment history
- address any barriers to the delivery of treatments because of any disabilities, language or communication difficulties
- ensure regular liaison between healthcare professionals in specialist and non-specialist settings, if the person is receiving specialist support or treatment.

For people with depression:

- who also have learning disabilities, see the [NICE guideline on mental health problems in people with learning disabilities](#).
- who also have autism, see the [NICE guideline on autism spectrum disorder](#)
- who also have dementia, see the [NICE guideline on dementia](#)
- in pregnancy or the postnatal period, or who are breastfeeding, see the [NICE guideline on antenatal and postnatal mental health](#)
- who are menopausal, see the [NICE guideline on menopause](#)
- and physical health problems, see the [NICE guideline on depression in adults with a chronic physical health problem](#) and also see the [recommendations on collaborative care. \[2022\]](#)

1.4.2 Match the choice of treatment to meet the needs and preferences of the person with depression. Use the least intrusive and most resource efficient treatment that is appropriate for their clinical needs, or one that has worked for them in the past. **[2022]**

1.4.3 For all people with depression having treatment:

- review how well the treatment is working with the person between 2 and 4 weeks after starting treatment
- monitor and evaluate treatment concordance
- monitor for side effects and harms of treatment

- monitor suicidal ideation, particularly in the early weeks of treatment (see also the recommendations on antidepressant medication for people at risk of suicide and recommendations on risk assessment)
- consider routine outcome monitoring (using appropriate validated sessional outcome measures, for example PHQ-9) and follow up. **[2009, amended 2022]**

## Psychological and psychosocial interventions

- 1.4.4 Inform people if there are waiting lists for a course of treatment and how long the wait is likely to be (for example, the NHS constitution advises that treatment should be started within 18 weeks). Keep in touch with people at regular intervals, ensure they are aware of how to access help if their condition worsens, ensure they are made aware of who they can contact about their progress on the waiting list. Consider providing self-help materials and addressing social support issues in the interim. **[2022]**
- 1.4.5 Use psychological and psychosocial treatment manuals to guide the form, duration and ending of interventions. **[2009, amended 2022]**
- 1.4.6 Consider using competence frameworks developed from treatment manual(s) for psychological and psychosocial interventions to support the effective training, delivery and supervision of interventions. **[2009]**
- 1.4.7 All healthcare professionals delivering interventions for people with depression should:
- receive regular clinical supervision
  - have their competence monitored and evaluated; this could include their supervisor reviewing video and audio recordings of their work (with patient consent). **[2009, amended 2022]**
- 1.4.8 When delivering psychological treatments for people with neurodevelopmental or learning disabilities, consider adapting the intervention as advised in the NICE guideline on mental health problems in people with learning disabilities. **[2022]**

- 1.4.9 When people are nearing the end of a course of psychological treatment, discuss ways in which they can maintain the benefits of treatment and ensure their ongoing wellness. [2022]

## Pharmacological treatments

### Starting antidepressant medication

- 1.4.10 When offering a person medication for the treatment of depression, discuss and agree a management plan with the person. Include:

- the reasons for offering medication
- the choices of medication (if a number of different antidepressants are suitable)
- the dose, and how the dose may need to be adjusted
- the benefits, covering what improvements the person would like to see in their life and how the medication may help
- the harms, covering both the possible side effects and withdrawal effects, including any side effects they would particularly like to avoid (for example, weight gain, sedation, effects on sexual function)
- any concerns they have about taking or stopping the medication (also see the recommendations on stopping medication).

Make sure they have written information to take away and to review that is appropriate for their needs. [2022]

- 1.4.11 When prescribing antidepressant medication, ensure people have information about:

- how they may be affected when they first start taking antidepressant medication, and what these effects might be
- how long it takes to see an effect (usually, if the antidepressant medication is

going to work, within 4 weeks)

- when their first review will be; this will usually be within 2 weeks to check their symptoms are improving and for side effects, or 1 week after starting antidepressant medication if a new prescription is for a person aged 18 to 25 years or if there is a particular concern for risk of suicide (see the [recommendations on antidepressant medication for people at risk of suicide](#))
- the importance of following instructions on how to take antidepressant medication (for example, time of day, interactions with other medicines and alcohol)
- why regular monitoring is needed, and how often they will need to attend for review
- how they can self-monitor their symptoms, and how this may help them feel involved in their own recovery
- that treatment might need to be taken for at least 6 months after the remission of symptoms, but should be reviewed regularly
- how some side effects may persist throughout treatment
- withdrawal symptoms and how these withdrawal effects can be minimised (see also the recommendations on stopping antidepressant medication). [2022]

## Stopping antidepressant medication

- 1.4.12 Advise people taking antidepressant medication to talk with the person who prescribed their medication (for example, their primary healthcare or mental health professional) if they want to stop taking it. Explain that it is usually necessary to reduce the dose in stages over time (called 'tapering') but that most people stop antidepressants successfully. [2022]
- 1.4.13 Advise people taking antidepressant medication that if they stop taking it abruptly, miss doses or do not take a full dose, they may have withdrawal symptoms. Also advise them that withdrawal symptoms do not affect everyone,

and can vary in type and severity between individuals. Symptoms may include:

- unsteadiness, vertigo or dizziness
- altered sensations (for example, electric shock sensations)
- altered feelings (for example, irritability, anxiety, low mood tearfulness, panic attacks, irrational fears, confusion, or very rarely suicidal thoughts)
- restlessness or agitation
- problems sleeping
- sweating
- abdominal symptoms (for example, nausea)
- palpitations, tiredness, headaches, and aches in joints and muscles. [2022]

1.4.14 Explain to people taking antidepressant medication that:

- withdrawal symptoms can be mild, may appear within a few days of reducing or stopping antidepressant medication, and usually go away within 1 to 2 weeks
- withdrawal can sometimes be more difficult, with symptoms lasting longer (in some cases several weeks, and occasionally several months)
- withdrawal symptoms can sometimes be severe, particularly if the antidepressant medication is stopped suddenly. [2022]

1.4.15 Recognise that people may have fears and concerns about stopping their antidepressant medication (for example, the withdrawal effects they may experience, or that their depression will return) and may need support to withdraw successfully, particularly if previous attempts have led to withdrawal symptoms or have not been successful. This could include:

- details of online or written resources that may be helpful
- increased support from a clinician or therapist (for example, regular check-in phone calls, seeing them more frequently, providing advice about sleep hygiene). [2022]

- 1.4.16 When stopping a person's antidepressant medication:
- take into account the pharmacokinetic profile (for example, the half-life of the medication as antidepressants with a short half-life will need to be tapered more slowly) and the duration of treatment
  - slowly reduce the dose to zero in a step-wise fashion, at each step prescribing a proportion of the previous dose (for example, 50% of previous dose)
  - consider using smaller reductions (for example, 25%) as the dose becomes lower
  - if, once very small doses have been reached, slow tapering cannot be achieved using tablets or capsules, consider using liquid preparations if available
  - ensure the speed and duration of withdrawal is led by and agreed with the person taking the prescribed medication, ensuring that any withdrawal symptoms have resolved or are tolerable before making the next dose reduction
  - take into account the broader clinical context such as the potential benefit of more rapid withdrawal if there are serious or intolerable side effects (for example, hyponatraemia or upper gastrointestinal tract bleeding)
  - take into account that more rapid withdrawal may be appropriate when switching antidepressants
  - recognise that withdrawal may take weeks or months to complete successfully. **[2022]**
- 1.4.17 Monitor and review people taking antidepressant medication while their dose is being reduced, both for withdrawal symptoms and the return of symptoms of depression. Base the frequency of monitoring on the person's clinical and support needs. **[2022]**
- 1.4.18 When reducing a person's dose of antidepressant medication, be aware that:
- withdrawal symptoms can be experienced with a wide range of

antidepressant medication (including tricyclic antidepressants [TCAs], selective serotonin reuptake inhibitors [SSRIs], serotonin–norepinephrine reuptake inhibitors [SNRIs], and monoamine oxidase inhibitors [MAOIs])

- some commonly used antidepressants such as paroxetine and venlafaxine, are more likely to be associated with withdrawal symptoms, so particular care is needed with them
- fluoxetine's prolonged duration of action means that it can sometimes be safely stopped in the following way:
  - in people taking 20 mg fluoxetine a day, a period of alternate day dosing can provide a suitable dose reduction
  - in people taking higher doses (40 mg to 60 mg fluoxetine a day), use a gradual withdrawal schedule.
  - allow 1 to 2 weeks to evaluate the effects of dose reduction before considering further dose reductions. **[2022]**

1.4.19 If a person has withdrawal symptoms when they stop taking antidepressant medication or reduce their dose, reassure them that they are not having a relapse of their depression. Explain that:

- these symptoms are common
- relapse does not usually happen as soon as you stop taking an antidepressant medication or lower the dose
- even if they start taking an antidepressant medication again or increase their dose, the withdrawal symptoms may take a few days to disappear. **[2022]**

1.4.20 If a person has mild withdrawal symptoms when they stop taking antidepressant medication:

- monitor their symptoms
- reassure them that such symptoms are common and usually time-limited
- advise them to contact the person who prescribed their medication (for example, their primary healthcare or mental health professional) if the

symptoms do not improve, or if they get worse. [2022]

- 1.4.21 If a person has more severe withdrawal symptoms, consider restarting the original antidepressant medication at the previous dose, and then attempt dose reduction at a slower rate with smaller decrements after symptoms have resolved. [2022]

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on starting and stopping antidepressants](#).

For full details of the evidence and the committee's discussion, see the [evidence reviews for the NICE guideline on safe prescribing](#) (evidence review A: patient information; evidence review B: prescribing strategies; evidence review C: safe withdrawal; evidence review D: withdrawal symptoms; evidence review F: monitoring).

## Antidepressant medication for people at risk of suicide

- 1.4.22 When prescribing antidepressant medication for people with depression who are aged 18 to 25 years or are thought to be at increased risk of suicide:
- assess their mental state and mood before starting the prescription, ideally in person (or by video call or by telephone call if in-person assessment is not possible, or not preferred)
  - be aware of the possible increased prevalence of suicidal thoughts, self-harm and suicide in the early stages of antidepressant treatment, and ensure that a risk management strategy is in place (see the [section on risk assessment and management](#))
  - review them 1 week after starting the antidepressant medication or increasing the dose for suicidality (ideally in person, or by video call, or by telephone if these options are not possible or not preferred)
  - review them again after this as often as needed, but no later than 4 weeks after the appointment at which the antidepressant was started

- base the frequency and method of ongoing review on their circumstances (for example, the availability of support, unstable housing, new life events such as bereavement, break-up of a relationship, loss of employment), and any changes in suicidal ideation or assessed risk of suicide. [2009, amended 2022]

1.4.23 Take into account toxicity in overdose when prescribing an antidepressant medication for people at significant risk of suicide. Do not routinely start treatment with TCAs, except lofepramine, as they are associated with the greatest risk in overdose. [2009, amended 2022]

## Antidepressant medication for older people

1.4.24 When prescribing antidepressant medication for older people:

- take into account the person's general physical health, comorbidities and possible interactions with any other medicines they may be taking
- carefully monitor the person for side effects
- be alert to an increased risk of falls and fractures
- be alert to the risks of hyponatraemia (particularly in those with other risk factors for hyponatraemia, such as concomitant use of diuretics).

See also the NICE guideline on dementia: assessment, management and support for people living with dementia and their carers. [2009, amended 2022]

## Use of lithium as augmentation

1.4.25 For people with depression taking lithium, assess weight, renal and thyroid function and calcium levels before treatment and then monitor at least every 6 months during treatment, or more often if there is evidence of significant renal impairment. [2009, amended 2022]

- 1.4.26 For women of reproductive age, in particular if they are planning a pregnancy, discuss the risks and benefits of lithium, preconception planning and the need for additional monitoring. **[2022]**
- 1.4.27 Monitor serum lithium levels 12 hours post dose, 1 week after starting treatment and 1 week after each dose change, and then weekly until levels are stable. Adjust the dose according to serum levels until the target level is reached.
- when the dose is stable, monitor every 3 months for the first year
  - after the first year, measure plasma lithium levels every 6 months, or every 3 months for people in any of the following groups:
    - older people
    - people taking medicines that interact with lithium
    - people who are at risk of impaired renal or thyroid function, raised calcium levels or other complications
    - people who have poor symptom control
    - people with poor adherence
    - people whose last plasma lithium level was 0.8 mmol per litre or higher.
- [2022]**
- 1.4.28 Determine the dose of lithium according to response and tolerability:
- plasma lithium levels should not exceed 1.0 mmol/L (therapeutic levels for augmentation of antidepressant medication are usually at or above 0.4 mmol/L; consider levels 0.4 to 0.6 mmol/L for older people aged 65 or above)
  - do not start repeat prescriptions until lithium levels and renal function are stable
  - take into account a person's overall physical health when reviewing test results (including possible dehydration or infection)
  - take into account any changes to concomitant medication (for example, angiotensin-converting enzyme inhibitors, angiotensin 2 receptor blockers,

diuretics and non-steroidal anti-inflammatory drugs [NSAIDs], or over-the-counter preparations) which may affect lithium levels, and seek specialist advice if necessary

- monitor at each review for signs of lithium toxicity, including diarrhoea, vomiting, coarse tremor, ataxia, confusion and convulsions
- seek specialist advice if there is uncertainty about the interpretation of any test results. **[2022]**

- 1.4.29 Manage lithium prescribing under shared care arrangements. If there are concerns about toxicity or side effects (for example, in older people or people with renal impairment), manage their lithium prescribing in conjunction with specialist secondary care services. **[2022]**
- 1.4.30 Consider electrocardiogram (ECG) monitoring in people taking lithium who have a high risk of, or existing, cardiovascular disease. **[2009]**
- 1.4.31 Provide people taking lithium with information on how to do so safely, including the NHS lithium treatment pack. **[2022]**
- 1.4.32 Only stop lithium in specialist mental health services, or with their advice. When stopping lithium, whenever possible reduce doses gradually over 1 to 3 months. **[2022]**

For a short explanation of why the committee made these consensus recommendations and how they might affect practice, see the [rationale and impact section on use of lithium as augmentation](#).

## Use of oral antipsychotics as augmentation

In June 2022, use of antipsychotics for the treatment of depression was an off-label use for some antipsychotics. See [NICE's information on prescribing medicines](#).

- 1.4.33 Before starting an antipsychotic, check the person's baseline pulse and blood pressure, weight, nutritional status, diet, level of physical activity, fasting blood

glucose or HbA1c and fasting lipids. [2022]

- 1.4.34 Carry out monitoring as indicated in the summary of product characteristics for individual medicines, for people who take an antipsychotic for the treatment of their depression. This may include:
- monitoring full blood count, urea and electrolytes, liver function tests and prolactin
  - monitoring their weight weekly for the first 6 weeks, then at 12 weeks, 1 year and annually
  - monitoring their fasting blood glucose or HbA1c and fasting lipids at 12 weeks, 1 year, and then annually
  - ECG monitoring (at baseline and when final dose is reached) for people with established cardiovascular disease or a specific cardiovascular risk (such as diagnosis of high blood pressure) and for those taking other medicines known to prolong the cardiac QT interval (for example, citalopram or escitalopram)
  - at each review, monitoring for adverse effects, including extrapyramidal effects (for example, tremor, parkinsonism) and prolactin-related side effects (for example, sexual or menstrual disturbances) and reducing the dose if necessary
  - being aware of any possible drug interactions which may increase the levels of some antipsychotics, and monitoring and adjusting doses if necessary
  - if there is rapid or excessive weight gain, or abnormal lipid or blood glucose levels, investigating and managing as needed. [2022]
- 1.4.35 Manage antipsychotic prescribing under shared care arrangements. [2022]
- 1.4.36 For people with depression who are taking an antipsychotic, consider at each review whether to continue the antipsychotic based on their current physical and mental health risks. [2022]
- 1.4.37 Only stop antipsychotics in specialist mental health services, or with their advice. When stopping antipsychotics, reduce doses gradually over at least 4 weeks and

in proportion to the length of treatment. [2022]

For a short explanation of why the committee made these consensus recommendations and how they might affect practice, see the rationale and impact section on use of oral antipsychotics as augmentation.

## Use of St John's Wort

1.4.38 Although there is evidence that St John's Wort may be of benefit in less severe depression, healthcare professionals should:

- advise people with depression of the different potencies of the preparations available and of the potential serious interactions of St John's Wort with other drugs
- not prescribe or advise its use by people with depression because of uncertainty about appropriate doses, persistence of effect, variation in the nature of preparations and potential serious interactions with other drugs (including hormonal contraceptives, anticoagulants and anticonvulsants). [2009]

## Physical treatments and activities

### Use of light therapy

1.4.39 Advise people with winter depression that follows a seasonal pattern and who wish to try light therapy in preference to antidepressant medication or psychological treatment that the evidence for the efficacy of light therapy is uncertain. [2009]

### Activities to help wellbeing

1.4.40 Advise people that doing any form of physical activity on a regular basis (for example, walking, jogging, swimming, dance, gardening) could help enhance their

Treatment	How is this delivered?	Key features	Other things to think about
			<ul style="list-style-type: none"> <li>• Needs a considerable time commitment.</li> <li>• Can help with physical health too.</li> <li>• Avoids potential side effects of medication.</li> </ul>

For a short explanation of why the committee made this recommendation and how it might affect practice, see the [rationale and impact section on treatment for a new episode of more severe depression](#).

Full details of the evidence and the committee's discussion are in [evidence review B: treatment of a new episode of depression](#).

## 1.7 Behavioural couples therapy for depression

- 1.7.1 Consider behavioural couples therapy for people with either less severe or more severe depression who have problems in the relationship with their partner if:
- the relationship problem(s) could be contributing to their depression, **or**
  - involving their partner may help in the treatment of their depression. **[2022]**
- 1.7.2 Deliver behavioural couples therapy for people with depression that:
- follows the behavioural principles for couples therapy
  - provides 15 to 20 sessions over 5 to 6 months. **[2009]**

For a short explanation of why the committee made this recommendation and how it might affect practice, see the rationale and impact section on behavioural couples therapy.

Full details of the evidence and the committee's discussion are in evidence review B: treatment of a new episode of depression.

## 1.8 Preventing relapse

- 1.8.1 Discuss with people that continuation of treatment (antidepressants or psychological therapies) after full or partial remission may reduce their risk of relapse and may help them stay well. Reach a shared decision on whether or not to continue a treatment for depression based on their clinical needs and preferences. See the visual summary on preventing relapse. **[2022]**
- 1.8.2 Discuss with people that the likelihood of having a relapse may be increased if they have:
  - a history of recurrent episodes of depression, particularly if these have occurred frequently or within the last 2 years
  - a history of incomplete response to previous treatment, including residual symptoms
  - unhelpful coping styles (for example, avoidance and rumination)
  - a history of severe depression (including people with severe functional impairment)
  - other chronic physical health or mental health problems
  - personal, social and environmental factors that contributed to their depression (see recommendation 1.2.7 in the section on initial assessment) and that are still present (for example, relationship problems, ongoing stress, poverty, isolation, unemployment). **[2022]**
- 1.8.3 Discuss with people the potential risks of continuing with antidepressants long

term, and how these balance against the risks of depression relapse. These include:

- possible side effects, such as an increased bleeding risk or long-term effects on sexual function
- difficulty stopping antidepressants. [2022]

1.8.4 If a person chooses not to continue antidepressant medication for relapse prevention, advise them:

- how to stop their antidepressant medication (see the recommendations on stopping antidepressant medication) **and**
- to seek help as soon as possible if the symptoms of depression return or residual symptoms worsen. [2022]

1.8.5 For people who have remitted from depression when treated with antidepressant medication alone, but who have been assessed as being at higher risk of relapse, consider:

- continuing with their antidepressant medication to prevent relapse, maintaining the dose that led to full or partial remission, unless there is good reason to reduce it (such as side effects) **or**
- a course of psychological therapy (group CBT or mindfulness-based cognitive therapy [MBCT]) for people who do not wish to continue on antidepressants (follow the recommendations on stopping antidepressants) **or**
- continuing with their antidepressant medication and a course of psychological therapy (group CBT or MBCT). [2022]

1.8.6 For people starting group CBT or MBCT for relapse prevention, offer a course of therapy with an explicit focus on the development of relapse prevention skills and what is needed to stay well. This usually consists of 8 sessions over 2 to 3 months with the option of additional sessions in the next 12 months. [2022]

1.8.7 Relapse prevention components of psychological interventions may include:

- reviewing what lessons and insights were learnt in therapy and what was helpful in therapy
  - making concrete plans to maintain progress beyond the end of therapy including plans to consolidate any changes made to stay well and to continue to practice useful strategies
  - identifying stressful circumstances, triggering events, warning signs (such as anxiety or poor sleep), or unhelpful behaviours (such as avoidance or rumination) that have preceded worsening of symptoms and personal or social functioning, and making detailed contingency plans of what to do if each of these re-occur
  - making plans for any anticipated challenging events over the next 12 months, including life changes and anniversaries of difficult events. **[2022]**
- 1.8.8 Discuss with people who have remitted from depression when treated with a psychological therapy alone, but who have been assessed as being at higher risk of relapse, whether they wish to continue with their psychological therapy for relapse prevention. Reach a shared decision on further treatment. **[2022]**
- 1.8.9 Discuss with people who have remitted from depression when treated with a combination of an antidepressant medication and psychological therapy, but who have been assessed as being at higher risk of relapse, whether they wish to continue 1 or both treatments. Reach a shared decision on further treatment. **[2022]**
- 1.8.10 Continue the same therapy for people who wish to stay on a psychological therapy for relapse prevention (either alone or in combination with an antidepressant), adapted by the therapist for relapse prevention. This should include at least 4 more sessions of the same treatment with a focus on a relapse prevention component (see recommendation 1.8.7) and what is needed to stay well. **[2022]**
- 1.8.11 Review treatment for people continuing with antidepressant medication to prevent relapse at least every 6 months. At each review:
- monitor their mood using a validated rating scale (see the recommendations

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on further-line treatment](#).

Full details of the evidence and the committee's discussion are in [evidence review D: further-line treatment](#).

## 1.10 Chronic depressive symptoms

1.10.1 Be aware that people presenting with [chronic depressive symptoms](#) may not have sought treatment for depression previously and may be unaware that they have depression. Discussions about their mood and symptoms initiated by a healthcare practitioner may help them access treatment and services. See the [visual summary on treatment for chronic depression](#). [2022]

1.10.2 For people who present with chronic depressive symptoms that significantly impair [personal and social functioning](#) and who have not received previous treatment for depression, treatment options include:

- CBT **or**
- SSRIs **or**
- SNRIs **or**
- TCAs (be aware that TCAs are dangerous in overdose, although lofepramine has the best safety profile) **or**
- combination therapy with CBT and either an SSRI or a TCA.

Discuss the options with the person and reach a shared decision on treatment choice, based on their clinical needs and preferences (see also the [recommendations on choice of treatments](#)). [2022]

1.10.3 For people with chronic depressive symptoms, offer cognitive behavioural treatment that:

- has a focus on chronic depressive symptoms
- covers related maintaining processes, including avoidance, rumination and interpersonal difficulties. [2022]

1.10.4 For people who have had, or are still receiving, treatment for depression and who present with chronic depressive symptoms, see the recommendations on further-line treatment. [2022]

1.10.5 If a person with chronic depressive symptoms that significantly impair personal and social functioning cannot tolerate a particular SSRI, consider treatment with an alternative SSRI. [2022]

1.10.6 For people with chronic depressive symptoms that significantly impair personal and social functioning, who have not responded to SSRIs or SNRIs, consider alternative medication in specialist settings, or after consulting a specialist. Take into account that switching medication may mean that an adequate wash-out period is needed, particularly when switching to or from irreversible MAOIs or moclobemide. See the NICE clinical knowledge summary on switching antidepressants. Alternatives include:

- TCAs
- moclobemide
- irreversible MAOIs such as phenleazine
- low-dose amisulpride (maximum dose of 50 mg daily, as higher doses may worsen depression and lead to side effects such as hyperprolactinaemia and QT interval prolongation).

In June 2022, this was an off-label use for amisulpride. See NICE's information on prescribing medicines. [2022]

1.10.7 For people with chronic depressive symptoms that significantly impair personal and social functioning, who have been assessed as likely to benefit from extra social or vocational support, consider:

- befriending in combination with existing antidepressant medication or

psychological therapy; this should be done by trained volunteers, typically with at least weekly contact for between 2 to 6 months

- a rehabilitation programme, if their depression has led to loss of work or their withdrawing from social activities over the longer term. [2009, amended 2022]

1.10.8 For people with no or limited response to treatment for chronic depressive symptoms that significantly impair personal and social functioning who have not responded to the treatments recommended in the sections on further-line treatment and chronic depressive symptoms, offer a referral to specialist mental health services for advice and further treatment. See also the recommendations on collaborative care. [2022]

1.10.9 For people with chronic depressive symptoms that have not responded to the treatments recommended in the sections on further-line treatment and chronic depressive symptoms, and who are on long-term antidepressant medication:

- review the benefits of treatment with the person
- consider stopping the medication (see the recommendations on stopping antidepressants)
- discuss with the person possible reasons for non-response and what other treatments and support (including from other agencies) may be helpful. [2022]

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on chronic depressive symptoms.

Full details of the evidence and the committee's discussion are in evidence review E: chronic depression.

## 1.11 Depression in people with a diagnosis of personality disorder

- 1.11.1 Do not withhold treatment for depression because of a coexisting personality disorder. See the [visual summary on treatment of depression with personality disorder](#). [2022]
- 1.11.2 For people with depression and a diagnosis of personality disorder consider a combination of antidepressant medication and a psychological treatment (for example, BA, CBT, IPT or STPP). To help people choose between these psychological treatments, see the information on them provided in [table 1](#) and [table 2](#). [2022]
- 1.11.3 When delivering antidepressant medication in combination with psychological treatment for people with depression and a diagnosis of personality disorder:
- give the person support and encourage them to carry on with the treatment
  - provide the treatment in a structured, multidisciplinary setting
  - use a validated measure of prospective mood monitoring or a symptom checklist or chart to assess response, or any exacerbation of emotional instability
  - extend the duration of treatment if needed, up to a year. [2022]
- 1.11.4 For people with depression and a diagnosis of personality disorder, consider referral to a specialist personality disorder treatment programme. See the [NICE guideline on borderline personality disorder](#) for recommendations on treatment for borderline personality disorder with coexisting depression. [2022]

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on depression in people with a diagnosis of personality disorder](#).

Full details of the evidence and the committee's discussion are in [evidence review F: depression with coexisting personality disorder](#).

## 1.12 Psychotic depression

In June 2022, use of antipsychotics for the treatment of depression was an off-label use for some antipsychotics. See [NICE's information on prescribing medicines](#).

1.12.1 Offer referral to specialist mental health services for people with depression with psychotic symptoms, where the treatment should include:

- a risk assessment
- an assessment of needs
- a programme of coordinated multidisciplinary care
- access to psychological treatments, after improvement of acute psychotic symptoms.

Discuss treatment options and, for those people who have capacity, reach a shared decision based on their clinical needs and preferences. See the [visual summary on treatment of psychotic depression](#). [2022]

1.12.2 Consider combination treatment for people with depression with psychotic symptoms with antidepressant medication and antipsychotic medication (for example, olanzapine or quetiapine). [2022]

1.12.3 If a person with depression with psychotic symptoms does not wish to take antipsychotic medication in addition to an antidepressant, then treat with an antidepressant alone. [2022]

1.12.4 Monitor people with depression with psychotic symptoms for treatment response (in particular for unusual thought content and hallucinations). [2022]

1.12.5 Consider continuing antipsychotic medication for people with depression with psychotic symptoms for a number of months after remission, if tolerated. The decision about if and when to stop antipsychotic medication should be made by, or in consultation with, specialist services. [2022]

1.12.6 For more advice on prescribing and monitoring antipsychotics see the

recommendations on use of oral antipsychotics as augmentation and the NICE guideline on psychosis and schizophrenia in adults. **[2022]**

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on psychotic depression.

Full details of the evidence and the committee's discussion are in evidence review G: psychotic depression.

## 1.13 Electroconvulsive therapy for depression

1.13.1 Consider electroconvulsive therapy (ECT) for the treatment of severe depression if:

- the person chooses ECT in preference to other treatments based on their past experience of ECT and what has previously worked for them **or**
- a rapid response is needed (for example, if the depression is life-threatening because the person is not eating or drinking) **or**
- other treatments have been unsuccessful (see the recommendations on further-line treatment). **[2022]**

1.13.2 Make sure people with depression who are going to have ECT are fully informed of the risks, and of the risks and benefits specific to them. Take into account:

- the risks associated with a general anaesthetic
- any medical comorbidities
- potential adverse events, in particular cognitive impairment
- if the person is older, the possible increased risk associated with ECT treatment for this age group
- the risks associated with not having ECT.

Document the assessment and discussion. [2022]

- 1.13.3 Discuss the use of ECT as a treatment option with the person with depression, and reach a shared decision on its use based on their clinical needs and preferences, if they have capacity to give consent. Take into account the capacity of the person and the requirements of the Mental Health Act 2007 (if applicable), and make sure:
- informed consent is given without pressure or coercion from the circumstances or clinical setting
  - the person is aware of their right to change their mind and withdraw consent at any time
  - there is strict adherence to recognised guidelines on consent, and advocates or carers are involved to help informed discussions. [2022]
- 1.13.4 If a person with depression cannot give informed consent, only give ECT if it does not conflict with a valid advance treatment decision the person made. [2022]
- 1.13.5 For people whose depression has not responded well to ECT previously, only consider a repeat trial of ECT after:
- reviewing the adequacy of the previous treatment course
  - considering all other options
  - discussing the risks and benefits with the person or, if appropriate, their advocate or carer. [2022]
- 1.13.6 Clinics should only provide ECT if they:
- are Electroconvulsive Therapy Accreditation Service (ECTAS) accredited
  - provide ECT services in accordance with ECTAS standards
  - submit data, including outcomes, on each course of acute and maintenance ECT they deliver as needed for the ECTAS minimum dataset.

Follow the ECT Accreditation Service Standards for Administering ECT.

## [2022]

- 1.13.7 Trusts which provide ECT services should ensure compliance with the ECTAS standards for administering ECT through board-level performance management. **[2022]**
- 1.13.8 Stop ECT treatment for a person with depression:
- immediately, if the side effects outweigh the potential benefits, **or**
  - when stable remission has been achieved. **[2022]**
- 1.13.9 If a person's depression has responded to a course of ECT:
- start (or continue) antidepressant medication or a psychological intervention to prevent relapse and to provide ongoing care for their depression (see the recommendations on preventing relapse)
  - consider lithium augmentation of antidepressant medication (see the recommendations on further-line treatment). **[2022]**

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on further-line treatment.

Full details of the evidence and the committee's discussion are in evidence review D: further-line treatment.

## 1.14 Transcranial magnetic stimulation for depression

- 1.14.1 See the NICE interventional procedures guidance on repetitive transcranial magnetic stimulation for depression.

## 1.15 Treatment-resistant depression

- 1.15.1 See the [NICE interventional procedures guidance on implanted vagus nerve stimulation for treatment-resistant depression](#).
- 1.15.2 Esketamine nasal spray is not recommended in NICE technology appraisal guidance for treating treatment-resistant depression. For full details, see the [guidance on esketamine nasal spray \(TA854, 2022\)](#).

## 1.16 Access, coordination and delivery of care

### Access to services

- 1.16.1 Commissioners and providers of mental health services should consider using models such as [stepped care or matched care](#) for organising the delivery of care and treatment of people with depression. See the [matched care model visual summary](#).

Pathways should:

- promote easy access to, and uptake of, the treatments covered
- allow for prompt assessment of adults with depression, including assessment of severity and risk
- ensure coordination and continuity of care, with agreed protocols for sharing information
- support the integrated delivery of services across primary and secondary care, to ensure individuals do not fall into gaps in service provision
- have clear criteria for entry to all levels of a stepped care service
- have multiple entry points and ways to access the service, including self-referral
- have routine collection of data on access to, uptake of and outcomes of the

specific treatments in the pathway. [2022]

- 1.16.2 Commissioners and providers of mental health services for people with depression should ensure the effective delivery of treatments. This should build on the key functions of a catchment area-based community mental health service and be provided in the context of a coordinated primary and secondary care mental health service, as well as community services (for example social care, education, housing, statutory services and the voluntary and social enterprise sector). This should include:
- assessment procedures
  - shared decision making
  - collaboration between professionals
  - delivery of pharmacological, psychological and physical (for example exercise, ECT) interventions
  - delivery of interventions for personal, social and environmental factors (for example, housing problems, isolation and unemployment)
  - care coordination
  - involvement of service users in design, monitoring and evaluation of services
  - the effective monitoring and evaluation of services. [2022]
- 1.16.3 Commissioners and providers of primary and secondary care mental health services should ensure support is in place so integrated services can be delivered by:
- individual practitioners (including primary care healthcare professionals), providing treatments, support or supervision
  - mental health staff, for team-based treatments in primary care for the majority of people with depression
  - mental health specialists, providing advice, consultation and support for primary care mental health staff

- specialist-based mental health teams, for people with severe and complex needs. **[2022]**

1.16.4 Commissioners and providers of mental health services should ensure pathways have the following in place for people with depression to promote access, and increased uptake and retention:

- services available outside normal working hours
- services provided in community-based settings, for example in a person's home, community centres, leisure centres, care homes, social centres and integrated clinics within primary care (particularly for older people)
- services delivered jointly with charities or the voluntary sector
- bilingual therapists or independent translators. **[2022, amended 2023]**

1.16.5 When promoting access and uptake of services, identify and address the needs of groups who may have difficulty in accessing, or face stigma or discrimination when using some or all mental health services. This may include:

- men
- older people
- lesbian, gay, bisexual and trans people
- people from black, Asian and minority ethnic communities
- people with learning disabilities or acquired cognitive impairments (see the NICE guideline on mental health problems in people with learning disabilities)
- people with physical or sensory disabilities, who may need reasonable adjustments to services as defined by legislation to enable this access; see the Equality Act 2010
- people who have conditions which compromise their ability to communicate
- people who are homeless, refugees and asylum seekers. **[2022]**

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on access to services.

Full details of the evidence and the committee's discussion are in evidence review H: access to services.

## Collaborative care

- 1.16.6 Consider collaborative care for people with depression, particularly older people, those with significant physical health problems or social isolation, or those with more chronic depression not responding to usual specialist care. **[2022]**
- 1.16.7 Collaborative care for people with depression should comprise:
- patient-centred assessment and engagement
  - symptom measurement and monitoring
  - medication management (a plan for starting, reviewing and discontinuing medication)
  - active care planning and follow up by a designated case manager
  - delivery of psychological and psychosocial treatments within a structured protocol
  - integrated care of both physical health and mental health
  - joint working with primary and secondary care colleagues
  - involvement of other agencies that provide support
  - supervision of practitioners by an experienced mental health professional. **[2022]**

## Specialist care

- 1.16.8 Refer people with more severe depression or chronic depressive symptoms, to specialist mental health services for coordinated multidisciplinary care if:
- their depression significantly impairs personal and social functioning **and**
  - they have not benefitted from previous treatments, and **either**
    - have multiple complicating problems, for example unemployment, poor housing or financial problems **or**
    - have significant coexisting mental and physical health conditions. **[2022]**
- 1.16.9 Deliver multidisciplinary care plans for people with more severe depression or chronic depressive symptoms (either of which significantly impairs personal and social functioning) and multiple complicating problems, or significant coexisting conditions that:
- are developed together with the person, their GP and other relevant people involved in their care (with the person's agreement), and that a copy in an appropriate format is offered to the person
  - set out the roles and responsibilities of all health and social care professionals involved in delivering the care
  - include information about 24-hour support services, and how to contact them
  - include a crisis plan that identifies potential crisis triggers, and strategies to manage those triggers and their consequences
  - are updated if there are any significant changes in the person's needs or condition
  - are reviewed at agreed regular intervals
  - include medication management (a plan for starting, reviewing and discontinuing medication). **[2022]**

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on collaborative care and specialist care](#).

Full details of the evidence and the committee's discussion are in [evidence review A: service delivery](#).

## Crisis care, home treatment and inpatient care

- 1.16.10 Consider crisis resolution and home treatment (CRHT) for people with more severe depression who are at significant risk of:
- suicide, in particular for those who live alone
  - self-harm
  - harm to others
  - self-neglect
  - complications in response to their treatment, for example older people with medical comorbidities. [2022]
- 1.16.11 Ensure teams providing CRHT interventions to support people with depression:
- monitor and manage risk as a high-priority routine activity
  - establish and implement a treatment programme
  - ensure continuity of any treatment programme while the person is in contact with the CRHT team, and on discharge or transfer to other services when this is needed
  - put a crisis management plan in place before the person is discharged from the team's care. [2022]
- 1.16.12 Consider inpatient treatment for people with more severe depression who cannot be adequately supported by a CRHT team. See also the [NICE guideline on mental health problems in people with learning disabilities](#). [2022]

- 1.16.13 Make psychological therapies recommended for the treatment of more severe depression, relapse prevention, chronic depressive symptoms and depression with a diagnosis of personality disorder available for people with depression in secondary care settings (including community and inpatient). **[2022]**
- 1.16.14 When providing psychological therapies for people with depression in inpatient settings:
- increase the intensity and duration of the interventions
  - ensure that they continue to be provided effectively and promptly on discharge. **[2009]**
- 1.16.15 Consider using CRHT teams for people with depression having a period of inpatient care who might benefit from early discharge from hospital. **[2009]**

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on crisis care, home treatment and inpatient care](#).

Full details of the evidence and the committee's discussion are in [evidence review A: service delivery](#).

## Terms used in this guideline

This section defines terms that have been used in a particular way for this guideline. For other definitions see the [NICE glossary](#) and the [Think Local, Act Personal Care and Support Jargon Buster](#).

### Acquired cognitive impairments

Cognitive impairments are neurological disorders that affect cognitive abilities (for example, learning, memory, communication and problem-solving). Acquired disorders may be because of medical conditions that affect mental function (for example, dementia, Parkinson's disease or traumatic brain injury).

## Avoidance

An unhelpful form of coping behaviour in which a person changes their behaviour to avoid thinking about, feeling or doing difficult things. This includes putting things off, reducing activities, not tackling problems, not speaking up for oneself, distraction and using alcohol or substances to numb feelings.

## Chronic depressive symptoms

People with chronic depressive symptoms includes those who continually meet criteria for the diagnosis of a major depressive episode for at least 2 years, or have persistent subthreshold symptoms for at least 2 years, or who have persistent low mood with or without concurrent episodes of major depression for at least 2 years. People with depressive symptoms may also have a number of social and personal difficulties that contribute to the maintenance of their chronic depressive symptoms.

## Collaborative care

Collaborative care requires that the service user and healthcare professional jointly identify problems and agree goals for treatments, and normally comprises:

- case management which is supervised and supported by a senior mental health professional
- close collaboration between primary and secondary physical health services and specialist mental health services in the delivery of services
- the provision of a range of evidence-based treatments
- the long-term coordination of care and follow up.

## Depression

In ICD-11, depression is defined as the presence of depressed mood or diminished interest in activities occurring most of the day, nearly every day, for at least 2 weeks, accompanied by other symptoms such as:

- reduced ability to concentrate and sustain attention or marked indecisiveness

- beliefs of low self-worth or excessive or inappropriate guilt
- hopelessness about the future
- recurrent thoughts of death or suicidal ideation or evidence of attempted suicide
- significantly disrupted sleep or excessive sleep
- significant changes in appetite or weight
- psychomotor agitation or retardation
- reduced energy or fatigue

In DSM-5 depression is defined as the presence of 5 or more symptoms from a list of 9 symptoms, during the same 2-week period and where at least 1 of the symptoms is depressed mood or loss of interest or pleasure, most of the day, nearly every day. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning. The 9 symptoms are:

- depressed mood – indicated by subjective report or observation by others
- loss of interest or pleasure in almost all activities – indicated by subjective report or observation by others
- significant (more than 5% in a month) unintentional weight loss or gain or decrease or increase in appetite
- sleep disturbance (insomnia or hypersomnia)
- psychomotor changes (agitation or retardation) severe enough to be observable by others
- tiredness, fatigue, or low energy, or decreased efficiency with which routine tasks are completed
- a sense of worthlessness or excessive, inappropriate, or delusional guilt (not merely self-reproach or guilt about being sick)
- impaired ability to think, concentrate, or make decisions – indicated by subjective report or observation by others
- recurrent thoughts of death (not just fear of dying), suicidal ideation, or suicide

attempts.

In this guideline the term 'people with depression' is used. This includes people with a clinical diagnosis of depression and those who feel themselves to be experiencing depression or depressive symptoms, and recognises that people experience, describe and label their experiences of depression in very individual ways.

## **Less severe depression**

Less severe depression encompasses subthreshold and mild depression, and in this guideline was defined as depression scoring less than 16 on the PHQ-9 scale.

## **Medication management**

Medication management is giving a person advice on how to keep to a regimen for the use of medication (for example, how to take it, when to take it and how often). The focus in such programmes is only on the management of medication and not on other aspects of depression.

## **More severe depression**

More severe depression encompasses moderate and severe depression, and in this guideline was defined as depression scoring 16 or more on the PHQ-9 scale.

## **Personal and social functioning**

Personal functioning represents the ability of an individual to effectively engage in the normal activities of everyday living and react to experiences. Social functioning is the ability to interact with other people, develop relationships and to gain from and develop these interactions.

## **Routine (sessional) outcome monitoring**

This is a system for the monitoring of the outcomes of treatments which involves regular assessment (usually at each contact; referred to as sessional) of symptoms or personal and social functioning using a valid scale. It can inform both service user and practitioner of progress in treatment. It is often supported by computerised delivery and scoring of the measures which ensures better completion of the questionnaires and service level audit

and evaluation. Alternative terms such as 'sessional outcome monitoring' or 'sessional outcomes' may also be used which emphasise that outcomes should be recorded at each contact.

## Rumination

Repetitive and prolonged negative thinking about the depression, feelings and symptoms, the self, problems or difficult life events and about their causes, consequences, meanings and implications (for example 'Why did this happen to me?', 'Why can I not get better?').

## Stepped care or matched care

This is a system of delivering and monitoring treatments, so that the most effective, least intrusive and least resource intensive treatments are delivered first. Stepped care has a built in 'self-correcting' mechanism so that people who do not benefit from initial treatments can be 'stepped up' to more intensive treatments as needed. Matched care follows the principles of stepped care, but also takes into account other factors such as patient presentation, previous experience of treatment, patient choice and preferences.

See the [matched care model visual summary](#).

## Treatment manuals

Treatment manuals are based on those that were used in the trials that provided the evidence for the efficacy of treatments recommended in this guideline.

# Bipolar disorder

## An information guide

REVISED EDITION

CAMH Bipolar Clinic Staff

**camh**  
Centre for Addiction and Mental Health

# 1 What is bipolar disorder?

## Why is bipolar disorder called an “illness”?

Everyone has ups and downs in mood. Feeling happy, sad and angry is normal. Bipolar disorder (or manic-depressive illness, as it used to be called) is a medical condition in which people have extreme mood swings. Their moods may have nothing to do with things going on in their lives. These swings do not only affect mood, they also affect how people think, behave and function.

Bipolar disorder is no one’s fault. It does not come from a “weak” or unstable personality. It is a medical disorder that can be treated.

## How common is bipolar disorder?

You or someone you care about may have been diagnosed with bipolar disorder. You may now feel alone in facing the problems of the illness, but you are not alone. About one to two per cent of adults worldwide suffer from bipolar disorder. Men and women are affected equally.

## When does bipolar disorder begin?

More and more, the first signs of bipolar disorder are being recognized in adolescence or early adulthood. Yet the younger the person is when the symptoms first develop, the less typical the symptoms may be. The symptoms may be mistaken for teenage distress or rebellion, so bipolar disorder is often not diagnosed until adulthood.

In some women, bipolar disorder may appear during pregnancy or shortly after it. Mania, or a “high,” after pregnancy occurs in only about one mother in a thousand. Postpartum depression is more common (see pages 5–9 for symptoms of mania and depression). If you or someone you care about has developed depressive symptoms after giving birth, and these symptoms are severe or last more than two weeks, you or she should seek help.

## 2 The clinical features of bipolar disorder

### The episodes of bipolar disorder

Bipolar disorder is an episodic (that is, recurring) disorder. It typically consists of three states:

- a high state, called **mania**
- a low state, called **depression**
- a well state, during which many people feel normal and function well.

The manias and depressions may be either “pure” episodes (they have only typical manic or depressive symptoms) or they may be **mixed episodes** (they may consist of a mixture of both manic and depressive symptoms at the same time). Traditionally, mixed episodes have been associated with the manic phase of the illness, so terms such as “mixed mania” or “dysphoric mania” are often used to describe mixed states.

## Types of bipolar disorder

Some people experience manic (or mixed), depressed and well phases during their illness. Such people are said to have **bipolar-I disorder**. A milder form of mania is called “hypomania.” People who have hypomania, **depression** and intervals without symptoms, but no full manic phases, are said to have **bipolar-II disorder**.

## Order and frequency of the various states

The manic/hypomanic, mixed and depressive states usually do not occur in a certain order, and their frequency cannot be predicted. For many people there are years between each episode, whereas others suffer more frequent episodes. Over a lifetime, the average person with bipolar disorder experiences about 10 **episodes** of depression and mania/hypomania or mixed states. As the person ages, the episodes of illness often come closer together. Untreated manias often last for two to three months. Untreated depressions usually last longer, between four and six months.

### RAPID CYCLING

About 20 per cent of people with bipolar disorder have four or more (sometimes many more) episodes a year. People with four or more episodes a year are said to be having **rapid cycling**, which is a subtype of bipolar disorder that needs specific treatment. We don't know for certain what causes rapid cycling. Sometimes, its occurrence may be triggered by certain antidepressants, but how the antidepressant causes rapid cycling is not clear. Sometimes stopping the antidepressant may help the person to return to a “normal” cycling pattern.

# 3 The symptoms of bipolar disorder

## Mania

Sometimes, a person may seem abnormally and continuously high, irritable or expansive for at least one week. If this change in mood is accompanied by other symptoms (see below) the person may be in a manic phase of bipolar disorder. *Not everybody who enters a manic phase feels happy or euphoric.* Instead, a person may feel very irritable, or may be terribly angry, disruptive and aggressive.

People in a manic phase do not have only mood symptoms. For a manic episode to be diagnosed, they must also have at least three of the following symptoms to an important degree:

- **Exaggerated self-esteem or feeling of grandeur:** People feel invincible or all-powerful; they believe they understand “how the world works” or how to save it. They may feel they have a special mission in life (e.g., that God has sent them or given them special powers).
- **Less need for sleep:** People feel rested after just a few hours of sleep. Sometimes they may not sleep at all for a few days or even weeks.

- **Increased talking:** People may talk very quickly, too loudly and much more than usual. They may like to tell jokes or rhyme words and may become angry when interrupted. They may keep switching topics and be unable to converse properly with others.
- **Flight of ideas or racing thoughts:** People easily lose their train of thought, and have trouble interacting because they are *easily distracted*. They may be impatient with others who cannot follow their fast thinking and changing plans and ideas.
- **Speeded-up activity:** People may socialize more than usual at work or school, or may be much more active, with seemingly boundless energy. In the early manic phase, they may be productive, but as symptoms worsen, people are more frantic in their activities and start many projects without finishing them.
- **Poor judgment:** People may not be able to control or plan how they act. They may take part in unusual and risky activities without realizing the harmful consequences (e.g., shopping sprees, bad business choices and bad decisions). They may become more sexually active and take less care in choosing their sexual partners. This increased sexual activity may lead to unwanted pregnancies, sexually transmitted diseases, guilt and disrupted relationships.
- **Psychotic symptoms:** People may experience symptoms of **psychosis**, such as **delusions** (beliefs that are not based in reality). They may also have **hallucinations**—most often, they hear voices that are not really there.

## Hypomania

The symptoms of **hypomania** are less severe than those of mania, but may still be disruptive. People may feel happy and have lots of energy, but do not usually get into serious trouble. Hypomania may progress to a full-blown manic episode or a severe depression, and therefore needs treatment.

## Mixed state

Some people do not always have “pure” manic or depressive episodes. Instead, they may experience episodes in which manic and depressive symptoms occur at the same time. This is called a “mixed state.” For example, someone in a mixed state may think and speak very rapidly. At the same time, the person may be very anxious and have suicidal thoughts. Mixed states are hard to diagnose and are very painful for the individual.

## Depression

Depression can take many forms, and it often comes out of nowhere. For a major depressive episode to be diagnosed, the symptoms must last for at least two weeks, and must be present most days and last most of the day. Symptoms of depression in bipolar disorder include at least five of the following:

**Depressed mood:** The mood state in depression differs substantially from normal sadness. In fact, many people experiencing depression say they cannot feel sadness, and many people cannot cry when depressed. Being able to cry again often means the depression is improving.

**Marked loss of interest or pleasure in activities that used to be fun:**

When people have just begun to feel depressed or are mildly depressed, they can still enjoy things, and may also be distracted by pleasurable activities. When people are severely depressed, they lose these abilities.

**Weight loss or weight gain:** Many people lose weight when depressed, partly because they lose their appetite. However, one subgroup feels hungrier, and may develop a craving for carbohydrate-rich and fatty foods. This results in weight gain. Metabolism may also increase or slow down, depending on the type of depression; such changes in metabolism can cause either weight loss or weight gain.

**Sleep problems:** Sleep disturbance is common in depression. Many people suffer from **insomnia**: they have trouble falling asleep, wake up often during the night or wake very early in the morning. People do not see sleep as being restful, and they may wake up feeling exhausted. Other people oversleep, especially during the day; they are said to have “hypersomnia.”

**Apathy or agitation:** Many people with depression develop slowed-down movement, speech or thinking. In severe cases, people with depression may be unable to move, speak and respond to their environment. For some people, the opposite happens, and they are very agitated. They are tormented by a severe inner restlessness—they cannot sit still, they pace, they may wring their hands. They may also show their agitation in other ways. People who feel agitated often feel very anxious, too.

**Loss of energy:** People experiencing depression find it hard to complete everyday chores. It takes them longer to perform at work or at home because they lack energy and drive.

**Worthlessness and guilt:** When depressed, people may lack self-confidence. They may not assert themselves, and they may be overwhelmed by feelings of worthlessness. Many people cannot stop thinking about past events. They obsess about having let others down or having said the wrong things—and they feel very guilty. In severe cases, the guilt may cause delusions; that is, people feel sure that they have sinned and need to be punished for their wrongdoings. Or they may believe that God is punishing them for their past mistakes.

**Inability to concentrate or decide:** These symptoms may be so bad that people cannot do simple tasks. They may have trouble deciding on very small matters.

**Suicidal thoughts:** People who are depressed often think that life is not worth living or that they would be better off dead. The risk of acting upon these thoughts is high, and many people do try to commit suicide when depressed.

**Psychotic symptoms:** Symptoms of psychosis in depression may include false beliefs about being poor or being punished for past sins. People may believe that they have a deadly disease, such as cancer. They may also hear voices (auditory hallucinations) or may see things that do not exist (visual hallucinations).

Depressive symptoms also often include:

- severe anxiety
- worries about small matters
- complaints about physical symptoms, including pain
- many visits to the family doctor for various physical symptoms.

## Other symptoms of a bipolar episode

Some people with bipolar disorder may have problems with movement during their episodes. These disturbances of movement (motor symptoms) occur in up to 25 per cent of patients with depression and up to 28 per cent of patients with mixed or pure manic episodes. These motor problems—called **catatonic symptoms**—vary and may include extreme physical agitation, slowness, or odd movements or postures. Sometimes people can't be slowed down; others may move so little that they refuse even to open their mouth to eat, drink or speak. This is a serious risk to their physical health. In most cases, people become free of catatonic symptoms after specific treatment.

There is a risk that people with catatonic symptoms may be misdiagnosed, because these symptoms have been traditionally associated with schizophrenia, rather than bipolar disorder.

## Comorbidity and its importance

A **comorbid disorder** is an illness or medical condition that occurs together with another illness or medical condition. Comorbid conditions can occur with bipolar disorder—they can start either before a bipolar illness or at the same time. Experts do not know why some disorders co-occur frequently with bipolar disorder and others do not. The severity of the comorbid condition may change over a lifetime, and its symptoms may also vary as the bipolar disorder changes.

For example, one of the most common comorbid conditions is **alcohol or other drug problems**. People with an alcohol problem may drink too much during mania, or they may experiment with other drugs, because they feel free and they are impulsive. They

may also use drugs during depressive phases, because they believe it helps them to feel less depressed. The same people may not abuse alcohol or other drugs during their well phase.

Psychiatric conditions that often co-occur with bipolar disorder:

- panic disorder
- obsessive-compulsive disorder
- binge eating disorder
- substance abuse
- attention-deficit/hyperactivity disorder
- borderline personality disorder

It is important to diagnose comorbidity in bipolar disorder. Comorbid conditions may cloud the clinical picture and complicate treatment of bipolar disorder. Also, the comorbid conditions are often so severe that they too need treating.

## 4 What causes bipolar disorder?

Several factors are involved in causing bipolar disorder, and the precise mechanism is not known. However, there is strong evidence that biological factors, including genetics, play an important role. This does not mean that a person has to inherit the genes: the genes involved may be altered when a person is conceived.

Genes are the blueprint for all the body's cells and their contents. Scientists believe that changes to genes can lead to faulty proteins being produced within brain cells, which may then result in bipolar disorder. Researchers today are looking at genes themselves, as well as various proteins that may be affected in bipolar disorder. These include:

- proteins involved in making **neurotransmitters** ("chemical messengers" in the brain)
- proteins that use neurotransmitters to make cells do something.

We do know that bipolar disorder is not caused by too much stress or difficult family relationships. However, these factors may **trigger** an episode in someone who already has the illness. Nor is bipolar disorder a simple imbalance of neurotransmitters, such as serotonin or dopamine. Yet neurotransmitters may be affected during a flare-up of the illness.

## What is a trigger for a bipolar episode?

Not all episodes can be related to any particular **trigger**, but many can. Triggers are situations that can provoke either mania or depression in someone who has already had an episode of illness. Feeling very stressed or continually losing sleep is an example of this kind of trigger. Other triggers are chemical, and include antidepressants that work “too well” and result in mania; common medications, such as steroids (for instance, prednisone used for treating asthma, arthritis, etc.); and street drugs, such as cocaine and amphetamines.

# 5 Treatments for bipolar disorder

Treatment of bipolar disorder includes biological treatments (e.g., medications) and psychosocial treatments (e.g., **psychoeducation**, **psychotherapy**). Often both types of treatment are needed, but usually biological treatment is needed first to bring symptoms under control.

## Biological treatments

Because bipolar disorder is an illness with a strong biological component, the main forms of treatment are biological. These consist mainly of medications, but also include other treatments, such as **light therapy** (spending time every day under a specially designed light box) **electroconvulsive therapy (ECT)** and **transcranial magnetic stimulation (TMS)**, which is being researched as an alternative to ECT.

## MEDICATIONS

Some of the information in this section is summarized from the CAMH pamphlet series *Understanding Psychiatric Medications*. The pamphlets are designed to help people better understand and make

choices about psychiatric drugs. They discuss what the drugs are used for, the different types and names of drugs, their effects and their place in the treatment of mental health problems. An online version is available at [www.camh.ca](http://www.camh.ca).

Medications are the cornerstone of treatment in bipolar disorder—they are needed to restore and promote wellness, and to prevent the return of symptoms. Several types of medications are commonly prescribed for bipolar disorder. Finding the right medication and the right dose for you will require monitoring and discussion with your doctor.

Bipolar disorder symptoms tend to return if the disorder is not treated. Most people who are untreated will experience another episode within a couple of years. Medications not only treat symptoms but also prevent their return. People are much more likely to stay well if they remain on medications. Recommendations for maintenance, or longer-term, treatment depend on the type of illness. For some people, who have a mild single episode that is not very impairing, staying on medications for one or two years may work. For most other people, longer-term treatment is recommended. In many cases, treatment may be indefinite. Bipolar disorder is potentially a chronic medical condition.

Sometimes, people with bipolar disorder may feel well for a long time. When this happens, it is possible that the illness has entered into a quiet period. Or it may mean that the medication is successfully preventing symptoms. In either situation, it is important to keep taking medication. If a person ends the treatment, there is an 80 per cent risk of **relapse** within two years. Relapse may occur even after many years of stability.

Some people worry about becoming addicted to medications, or experiencing a change in personality. The main treatments for

bipolar disorder are mood stabilizers, antidepressants and anti-psychotics. These medications are not addictive and there is no evidence that they change personality. However, some anti-anxiety drugs carry a risk of addiction if taken regularly for more than a few weeks.

Some of the medications used to treat bipolar disorder may have side-effects. Many of these side-effects lessen with time, and others can be relieved with help from a doctor. The doctor will monitor side-effects and the medication dose, and will sometimes make other checks. With these checks in place, the risk for long-term physical complications from the medications is low. The risks of living with untreated bipolar disorder are much greater.

Medications for bipolar disorder fall into two broad categories—mood stabilizers and adjunct medications. **Adjunct medications** are other medications that can be used to treat specific symptoms, such as depression, poor sleep, **anxiety** and psychotic symptoms. Adjunct medications include antidepressants, **anxiolytics** (anti-anxiety medications), and antipsychotics (formerly called neuroleptics). These medications are often only used for the short term, until the mood stabilizers take their full effect. However, they can also be used in combination with mood stabilizers as longer-term treatments for bipolar disorder.

People with bipolar disorder often require more than one medication. The treatment of other chronic medical conditions such as diabetes or epilepsy often requires a combination of medications.

## **Mood stabilizers**

**Mood stabilizers** are medicines that help reduce mood swings. They also help prevent manic and depressive episodes. The oldest and most studied of the mood stabilizers is lithium, a naturally occurring element in the same chemical family as sodium. Many

drugs that were first developed as anticonvulsants to treat epilepsy also act as mood stabilizers. These include carbamazepine (Tegretol), divalproex (Epival) and lamotrigine (Lamictal). Gabapentin (Neurontin) and topiramate (Topamax) are also anticonvulsants that may act as mood stabilizers, although they are usually only given in addition to other medications.

Some people may be prescribed more than one type of mood stabilizer to take in combination.

How mood stabilizers work is not fully understood; however, it is thought that the drugs work in different ways to bring stability and calm to areas of the brain that have become overstimulated and overactive, or to prevent this state from developing.

The side-effects of mood stabilizers vary depending on the type of medication. With some medications, side-effects are kept to a minimum through regular monitoring of the level of the drug in the blood. Some people experience no side-effects. Others may find the side-effects distressing. Side-effects usually lessen as treatment continues. If side-effects are not mild and tolerable, let your doctor know as soon as possible.

#### LITHIUM

Lithium (Carbolith, Duralith, Lithane, Lithium Carbonate, Lithium Citrate) is found in nature in some mineral waters and is also present in small amounts in the human body. Lithium is used to treat mania and to prevent further episodes of mania and depression. There is increasing research evidence that lithium protects brain cells from the inflammation that occurs in the brains of people with bipolar disorder.

Common side-effects of lithium include increased thirst and urination, nausea, weight gain and a fine trembling of the hands. Less

common side-effects can include tiredness, vomiting and diarrhea, blurred vision, impaired memory, difficulty concentrating, skin changes (e.g., dry skin, acne) and slight muscle weakness. These effects are generally mild and fade as treatment continues. If, however, any of these effects are severe, they should be reported to your doctor immediately. Thyroid and kidney function can be affected by lithium in some people, and must be monitored regularly by your doctor.

#### DIVALPROEX, VALPROIC ACID OR VALPROATE

The differing names for this anticonvulsant medication reflect the various ways it is formulated. Divalproex (and its various forms) is used when people have frequent mood swings or when they don't respond to lithium. Brand names include Depakene and Epival.

Common side-effects of divalproex include drowsiness, dizziness, nausea and blurred vision. Less common side-effects are vomiting or mild cramps, muscle tremor, mild hair loss, weight gain, bruising or bleeding, liver problems and, for women, changes in the menstrual cycle.

#### CARBAMAZEPINE

Carbamazepine (Tegretol) is another anticonvulsant. It is used for mania and mixed states that do not respond to lithium or when the person is irritable or aggressive.

Common side-effects of carbamazepine include dizziness, drowsiness, blurred vision, confusion, muscle tremor, nausea, vomiting or mild cramps, increased sensitivity to sun, skin sensitivity and rashes and poor co-ordination.

A rare but dangerous side-effect of carbamazepine is reduced blood cell counts. People who take this drug should have their blood monitored regularly for this effect. Soreness of the mouth, gums

or throat, mouth ulcers or sores, and fever or flu-like symptoms can be a sign of this effect and should be reported immediately to your doctor. If carbamazepine is the cause of these symptoms, they will go away when the medication is stopped.

Oxcarbazepine (Trileptal), a closely related drug, may have fewer side-effects and drug interactions than carbamazepine, but is not as well studied for bipolar disorder.

#### LAMOTRIGINE

Lamotrigine may be the most effective mood stabilizer for depression in bipolar disorder, but is not as helpful for mania.

The starting dose of lamotrigine should be very low and increased very slowly over four weeks or more. This approach decreases the risk of a severe rash—a potentially dangerous side-effect of this drug.

Common side-effects of lamotrigine include fever, dizziness, drowsiness, blurred vision, nausea, vomiting or mild cramps, headache and skin rash. Although it is rare, a severe skin rash can occur with lamotrigine. Any rashes that begin in the first few weeks of treatment should be reported to your doctor.

### **Antidepressant medications**

**Antidepressants** are medications that were originally found to be useful in treating depression, and more recently have often been found helpful to treat anxiety disorders.

Antidepressants are thought to work primarily by affecting the concentration of chemicals called neurotransmitters in the brain. Key neurotransmitters that are affected include serotonin, norepinephrine, and dopamine. While antidepressants can be used in bipolar disorder during depression episodes, they must be used with caution

since they can also cause a switch into mania and may precipitate a cycle of frequent mood episodes (rapid cycling).

There are several classes of antidepressants; within each class there are many individual medications. The different types of antidepressants are listed below in the order in which they are most commonly prescribed.

#### **SELECTIVE SEROTONIN REUPTAKE INHIBITORS (SSRIs)**

This group of drugs includes fluoxetine (Prozac), paroxetine (Paxil), fluvoxamine (Luvox), citalopram (Celexa), escitalopram (Cipralex) and sertraline (Zoloft). SSRIs are usually the first choice for treatment of depression and anxiety problems.

#### **SEROTONIN AND NOREPINEPHRINE REUPTAKE INHIBITORS (SNRIs)**

This class of medications includes venlafaxine (Effexor), duloxetine (Cymbalta) and desvenlafaxine (Pristiq).

#### **NOREPINEPHRINE AND DOPAMINE REUPTAKE INHIBITORS (NDRIs)**

The medication available in this class is bupropion (Wellbutrin, Zyban). When used to treat depression, it is often given for its energizing effects, in combination with other antidepressants.

#### **NORADRENERGIC AND SPECIFIC SEROTONERGIC ANTIDEPRESSANTS (NASSAs)**

Mirtazapine (Remeron), the medication available in this class, is the most sedating antidepressant.

#### **CYCLICS**

This older group includes amitriptyline (Elavil), maprotiline (Ludiomil), imipramine (Tofranil), desipramine (Norpramin), nortriptyline (Novo-Nortriptyline) and clomipramine (Anafranil).

Because these drugs tend to have more side-effects than the newer drugs, they are not often a first choice for treatment.

### MONOAMINE OXIDASE INHIBITORS (MAOIs)

MAOIs, such as phenelzine (Nardil) and tranylcypromine (Parnate), were the first class of antidepressants. MAOIs are effective, but they are not often used because people who take them must follow a special diet. A newer MAOI, moclobemide (Manerix), can be used without dietary restrictions; however, it may not be as effective as other MAOIs.

### ANTI-ANXIETY MEDICATIONS

Anxiety is common in bipolar disorder. Sleep disturbance is also very frequent during an acute episode. **Benzodiazepines**, a family of medications with mild sedating ability, are often prescribed. Many types of benzodiazepines are available in Canada. All benzodiazepines work the same way; however, the intensity and duration of their effects vary. Benzodiazepines may be used for short periods without causing addiction.

The benzodiazepines most commonly used to treat anxiety are clonazepam (Rivotril), alprazolam (Xanax) and lorazepam (Ativan). Clonazepam is particularly useful for treating the excessive energy and reduced sleep of hypomania.

Benzodiazepines used for the treatment of insomnia include lorazepam (Ativan), nitrazepam (Mogadon), oxazepam (Serax), temazepam (Restoril), triazolam (Halcion) and flurazepam (Dalmane).

Another drug used for insomnia is zopiclone (Imovane). This drug is similar to benzodiazepines and has similar side-effects. Zopiclone may have less abuse potential than some benzodiazepines; however, people can still become addicted to this drug.

## Antipsychotic medications

**Antipsychotic medications** are commonly used in bipolar disorder. These medications have powerful sedating effects, which help control mania, and can treat psychotic symptoms such as delusions of grandeur or persecution, and hallucinations. Antipsychotic medications are generally divided into two categories: first generation (*typical*) and second generation (*atypical*). Most people who take antipsychotics over a longer term are now prescribed the second-generation drugs.

### SECOND-GENERATION (ATYPICAL) ANTIPSYCHOTICS

Medications available in this class include risperidone (Risperdal), quetiapine (Seroquel), olanzapine (Zyprexa), ziprasidone (Zeldox), paliperidone (Invega), aripiprazole (Abilify) and clozapine (Clozaril). Clozapine is exceptional in that it often works even when other medications have failed; however, because it requires monitoring of white blood cell counts, it is not the first choice for treatment.

### FIRST-GENERATION (TYPICAL) ANTIPSYCHOTICS

These older medications include chlorpromazine (once marketed as Largactil), flupenthixol (Fluanxol), fluphenazine (Modecate), haloperidol (Haldol), loxapine (Loxapac), perphenazine (Trilafon), pimozide (Orap), trifluoperazine (Stelazine), thiothixene (Navane) and zuclopentixol (Clopixol).

## Newer medical treatments

Many of the newest medications used as mood stabilizers for bipolar disorder were first developed as anticonvulsants (epilepsy treatments). They include divalproex, carbamazepine, oxcarbazepine, lamotrigine, topiramate and gabapentin. There is variable evidence for the effectiveness of these medications; divalproex and lamotrigine have been investigated more thoroughly than the others.

Two other drugs, ketamine and scopolamine, administered intravenously are being investigated for their antidepressant effect in bipolar disorder.

It is helpful to ask your doctor about new and emerging treatments for bipolar disorder. In some university medical centres, it is also possible to participate in clinical trials of new treatments.

## ELECTROCONVULSIVE THERAPY

**Electroconvulsive therapy (ECT)**, also referred to as “shock therapy,” is perhaps the most controversial and misunderstood of psychiatric treatments, due in part to sensationalized and misleading depictions of the treatment in the popular media. In fact, ECT is a highly effective and safe treatment for both the depressive and manic phases of bipolar disorder, and is sometimes used as a long-term **maintenance treatment** to prevent recurrence of illness after recovery.

ECT does not resemble the shock therapy portrayed in films such as *One Flew over the Cuckoo's Nest*. Now patients are given muscle relaxants and a general anesthetic before a mild electrical current is administered to one or both sides of the brain. There is minimal visible movement in the patient during the procedure. Usually the treatments are administered three times a week over three to four weeks, for a total of eight to 12 treatments. For longer-term maintenance treatment, the treatments may be spread out, for example, once a month, and continued for as long as the patient and doctor feel is appropriate. ECT is usually given to hospitalized inpatients, but outpatients can receive ECT as well.

### **Side-effects**

Patients may have a headache or jaw pain on awakening after ECT, usually requiring only a mild painkiller such as acetaminophen

(Tylenol). Some loss of recent memory or problems with concentration usually occur during treatment (e.g., patients may not recall what they had for supper the night before the treatment), but these symptoms improve quickly after the course of ECT is finished, over a few weeks. Some patients report mild memory problems persisting much longer after ECT treatment has been completed.

### **Uses of ECT in bipolar disorder**

ECT is the most effective and possibly the fastest-acting treatment for severe depression, and is particularly helpful for people who are highly agitated or suicidal, or those with psychotic or catatonic symptoms. Some people receive ECT early in their episode of illness because of the urgency of their situation or their particular symptoms, while for other patients ECT may be used only after various medications have failed. ECT works well for severe mania as well.

While ECT is highly effective at ending an episode of depression or mania, the benefits may not last more than a few weeks or months following treatment. Therefore after a course of ECT, patients usually start or continue treatment with mood stabilizers and/or other medication. Maintenance ECT may be used when medications have not prevented a recurrence of the illness, or for patients who cannot tolerate the side-effects of medication.

## **TRANSCRANIAL MAGNETIC STIMULATION**

Transcranial magnetic stimulation (TMS) involves a series of short magnetic pulses to the brain to stimulate nerve cells. TMS is being tested, but its effectiveness has not yet been proven. TMS is being investigated as an alternative treatment to ECT, but its effectiveness is not yet proven. Unlike ECT, the treatment is carried out without the need for an anesthetic or muscle relaxant.

## COMPLEMENTARY AND ALTERNATIVE TREATMENTS

Some people with bipolar disorder seek non-conventional treatments, often as an adjunct to complement conventional treatments rather than as an alternative. Examples of complementary treatments include herbal medicines, acupuncture, homeopathy, naturopathy, meditation, yoga and Ayurveda. A number of nutritional supplements and vitamins are also available.

Many of these treatments have not been thoroughly tested. St. John's wort has been shown to have some antidepressant effect for mild to moderate **unipolar depression** (depression without mania). In people with bipolar disorder, however, there is the possibility that it may cause a switch from depression to mania. St. John's wort may also interact with a number of conventional medications.

If you are interested in herbal remedies, it is important to talk to your doctor. It is helpful to have a doctor who is knowledgeable about complementary and alternative therapies, because these can interact with other medications you may be taking.

Omega-3 fatty acids (found in fish oils and some other foods) are anti-inflammatory, and diets high in omega-3 are linked with lower rates of depression. There is some evidence that omega-3 fatty acids may be helpful in bipolar depression.

Some people find that practices such as yoga, tai chi and meditation can aid with the control of anxiety and depression.

### **Physical activity**

Physical activity or exercise has been shown to have antidepressant effect. Regular physical activity—even just walking for 30 minutes a day—has profound effects for physical and mental health. Exer-

cise has also been shown to increase the size of the hippocampus, a part of the brain concerned with memory.

## Psychosocial treatments

Psychosocial treatments include psychoeducation, psychotherapy, support groups and rehabilitation.

### PSYCHOEDUCATION

Psychoeducation is a process through which people learn about bipolar disorder, and also have an opportunity to talk about their feelings related to living and coping with the disorder. For example, it is common for people learning about their illness to experience strong feelings of fear or denial. Often, talking openly about these feelings helps people to deal with them and better adhere to a treatment plan that makes sense to them. Psychoeducation can occur in groups or in individual counselling with a doctor, social worker or other mental health care provider. When psychoeducation is offered in a group format it is usually time-limited (8 to 12 sessions) and each session focuses on a different aspect of managing bipolar disorder (for example, signs and symptoms, stress management and problem solving).

Psychoeducation also helps family members or partners understand what the affected person is going through. They learn about the symptoms of bipolar disorder, its treatment, what they can do to be helpful, and the limitations to the help that they can offer. The family can meet with the treating doctor, or attend a family support and education group.

Finally, psychoeducation helps people with bipolar disorder and their families to deal with their concerns about the stigma of mental illness. Although public education in recent years has raised awareness, there are still many people who do not understand mental illness, and feel uncomfortable when it is discussed. It is important that people with bipolar disorder, along with their families, have a safe place to discuss this issue and decide what information they wish to share outside of the family.

## PSYCHOTHERAPY

Psychotherapy is a general term used to describe a form of treatment that is based on talking work done with a therapist. The aim is to relieve distress by discussing and expressing feelings, to help change attitudes, behaviour and habits that may be unhelpful, and to promote more constructive and adaptive ways of coping. Successful psychotherapy depends on a supportive, comfortable relationship with a trusted therapist. Psychiatrists, social workers, psychologists and other mental health providers are trained in various models of psychotherapy and work in hospitals, clinics and private practice.

There are many different models of psychotherapy. They fall into two general categories: **short-term** and **long-term**. Short-term therapies are structured and focus on current, rather than childhood, issues. On average, the treatment lasts for between 10 and 20 sessions. In short-term therapies, the therapist takes an active role in guiding the discussions. Long-term therapy is less structured, and can last for a year or more. The person has the opportunity to talk about a variety of concerns related to both past and present-day issues. In this model, the therapist is less directive and gives minimal advice, guiding the client instead toward his or her own answers. Psychotherapy is a very helpful treatment. For bipolar disorder, though, it only works as

an add-on to medications, not as a substitute. Every patient should get some supportive therapy that involves not only managing medication, but also dealing with the various problems that a person with bipolar disorder may experience. Practical suggestions and emotional support are the main features of supportive therapy.

### **Cognitive-behavioural therapy**

**Cognitive-behavioural therapy (CBT)** is an example of a short-term structured psychotherapy that has worked well for many other disorders. It is based on the idea that deeply held beliefs or thoughts influence how we look at ourselves and the world, and have a strong influence on our mood and behaviour. For instance, if we are depressed and think no treatment will help, then we might not bother to seek treatment. This almost guarantees that we will feel worse. Cognitive therapy attempts to identify and change such thoughts and to improve mood and functioning. It is now being tested in bipolar disorder. The early results are promising, both in preventing future episodes and in treating depression.

Anxiety is common in bipolar disorder, and cognitive-behavioural therapy may be very helpful for more severe anxiety problems, such as panic attacks. It may in fact be needed, because the antidepressants that are also sometimes used to treat anxiety disorders may provoke manic episodes.

### **Insight-oriented or psychodynamic psychotherapy**

Insight-oriented or psychodynamic psychotherapy is an example of a long-term, unstructured psychotherapy. This therapy reduces distress by helping a person gain insight into the underlying motives of his or her overall behaviour. While this is not a specific treatment for bipolar disorder, it can be very helpful because increased self-knowledge and awareness leads to more effective management of the illness.

## Group therapy

Historically, **group therapy** has been used successfully to provide elements of support and psychoeducation. Cognitive therapy may also be provided in a group. However, group cognitive therapy has not yet been tested for people with bipolar disorder.

## Family and couple therapy

Family and couple therapy can help address problems that may have existed before the illness and have become highlighted, or to deal with issues that have arisen as a result of the illness. The timing, however, is very important. During an acute episode, the family or spouse should be given only support and education. Formal family or marital therapy should wait until the person is more stable.

## PEER SUPPORT GROUPS

Peer support groups can be very important to treatment. A peer support group is a group of people who all have bipolar disorder. These people can accept and understand one another, and can share their struggles in a safe, supportive environment. Group members usually develop a strong bond among themselves. People who have recently been diagnosed with bipolar disorder can benefit from the experiences of others. These groups are usually organized through the local chapters of the Mood Disorders Association (see page 66 for more information). Although these groups are often called *self-help*, peer support actually offers a type of help called *mutual aid*.

## Hospitalization

During severe episodes of depression or mania, some people with bipolar disorder may need to be hospitalized. Hospitalization is needed if the illness is out of control and is putting a person at risk

of serious consequences—for example, through aggressive behaviour, risk-taking, failing to look after his or her own basic needs, or suicidal tendencies.

## VOLUNTARY VERSUS INVOLUNTARY ADMISSIONS

Patients are usually admitted to hospital *voluntarily*. This means that they:

- agreed to enter the hospital
- are free to leave hospital at any time.

However, in most places, the law also allows any doctor to admit a person to hospital *involuntarily*. This means the person may not agree that he or she needs help, and does not want to be in the hospital. This can happen if the doctor believes there is a serious risk that:

- the person will physically harm himself or herself
- the person will physically harm someone else.

If no doctor has seen the person, families also have the option of asking a justice of the peace to order a psychiatric assessment, and must provide convincing evidence that the person's illness represents a danger to himself or herself, or to others.

Laws protect the rights of people who are admitted involuntarily. For instance, a rights advisor will visit. The rights advisor will ensure that the person has the chance to appeal the involuntary status before an independent board of lawyers, doctors and laypeople.

The police are sometimes needed to help to get a person to hospital. Family members may agonize over whether to involve the

police. They often feel very guilty about calling the police, even if the police are needed to protect the person's life. Remember, when people threaten suicide, they are usually pleading for help. They are taken seriously. Suicidal thinking is often a temporary feeling. When a person feels suicidal, he or she needs to be kept safe.

## INPATIENT TREATMENT

A typical hospital stay may be anywhere between a few days and several weeks. Usually patients are expected (or required, if they are involuntary) to remain on the psychiatric unit for the first few days of their stay. As they recover they may be granted increasing privileges to visit other parts of the hospital or to walk outside. Later they will be given passes to go home overnight or for the weekend.

Patients participate in a variety of group educational and therapeutic programs, as well as individual sessions with medical, nursing and other professional staff. Medications may be changed or doses adjusted, and families may be interviewed by medical or social work or other staff.

Discharge planning begins immediately following admission to hospital. Patients should expect to leave hospital as soon as reasonable follow-up arrangements are in place and their symptoms have improved enough to ensure they are able to function safely and care for themselves at home. Staying in hospital after symptoms have improved may not benefit the person. It may in fact cause difficulties by reducing the person's connection to family and social supports, and possibly undermining his or her independent living skills.

# 6 Recovery and relapse prevention

The goal in treating bipolar disorder is to help people get well again. This includes:

- treating symptoms until they no longer cause distress or problems
- improving work and social functioning
- reducing the risk of relapse.

## The process of recovery

Some people may recover quickly from a manic, hypomanic, mixed or depressive episode. For many others, recovery is more gradual. Often, it takes a few months for a person's functioning to return to familiar levels, even if symptoms of the most recent episode have ended completely.

The time needed to recover often frustrates people with bipolar disorder. This is especially true for people who expect a lot of themselves, who may feel demoralized by the delay. As a result, people sometimes rush back into a full or even increased range of activities. They may be trying to convince themselves and others that they are fully recovered. But this "flight into health" often overwhelms and

exhausts them. Just as you would increase activities gradually if you were recovering from a broken leg, a gradual increase in activities after a bipolar episode allows you to slowly take on responsibilities and build self-confidence.

Remember that recovery is a process, not a single event. After a bipolar episode, people often feel fragile, vulnerable and at risk of more episodes. *These feelings are a normal part of the recovery phase.* It takes some time before a person's confidence and performance return to normal. At first, you should ease yourself into familiar activities and have modest expectations. Predict that when you return to activities such as socializing and going to school or work, you will probably feel anxious. Allow yourself to make mistakes. A social worker, occupational therapist or nurse can help plan a strategy for recovery that might include volunteer activities, leisure interests, school courses, and part-time or eventually full-time work.

## Preventing relapse and promoting wellness

At this time there is no cure for bipolar disorder, and people with the disorder are at risk of further episodes. *It is important to use periods of wellness as an opportunity to actively prevent relapse.* Bipolar disorder, like illnesses such as diabetes, requires you to pay attention to how you are feeling, so you can catch early warnings of a possible relapse and possibly prevent a full episode.

Many people with bipolar disorder can benefit from counselling, psychotherapy or meeting with an occupational therapist, social worker or nurse. Using such resources can help you find coping strategies to reduce symptoms, cope effectively with day-to-day stress and lower

the risk of recurrence. Health care providers should recommend treatment tailored to your particular situation.

The following tips may help you prevent relapse and have a healthy lifestyle.

- 1. Become an expert on your illness.** Read as much as you can about bipolar disorder and its treatment; if there is something you do not understand, ask your mental health care providers.
- 2. Live healthily.** Do not use alcohol or other drugs, because they increase your risk of relapse. Eat a healthy diet, and exercise regularly (it can have a positive effect on mood).

If you are struggling with falling asleep or staying asleep, it is important for you to develop good sleep routines. Repeating these routines each night can help restore better sleep patterns. Try to go to bed at the same time each night. Avoid stimulating activities close to bedtime; plan on paying bills, completing work or having important discussions earlier in the day. Many people find that relaxation exercises, easy reading or a warm, non-caffeinated beverage just before retiring are ways to promote a relaxed state of mind. Expect that it will take you some time to fall asleep, and try not to anticipate sleep problems, as this will add to your anxiety. For some people, a sleep medication provides relief and allows them the much-needed rest they have been deprived of.

- 3. Continue to take medication until your doctor advises you otherwise.** Often, people begin to feel better and stop taking their medication. Relapse is more likely if medication is discontinued too soon. Recommendations for maintenance, or longer-term, treatment depend on the type of illness. For some people, who have a mild single episode that is not very impairing, staying on medications for one or two years may work. For most other

people, longer-term treatment is recommended. In many cases, treatment may be indefinite.

**4. You can't avoid stress, so find strategies to better cope with stress.** Many people with bipolar disorder tend to use only one coping strategy. For example, they hide their worries and avoid dealing with problems. This may work in some cases, but not in others. Where possible, try different strategies. Deal with some problems as they happen. Avoiding them allows stress to build up. Be realistic about your stress-breaking point. Work toward recognizing what aspects of relationships in your life might be unhealthy and, if possible, try to avoid situations that may trigger relapse.

**5. Avoid isolating yourself and maintain social support.** Some people with bipolar disorder tend to spend too much time alone. This can add to their feeling depressed, demoralized and sad. Strong social networks and social support can serve as a buffer against these feelings. Try to avoid spending too much time alone, and work toward maintaining contact with your social network.

Whom you tell about your illness is a very personal choice. While the stigma of mental illness is much less than it once was, it remains a concern for many people. As a buffer against relapse, however, it is important to have at least one person you can rely on and you can confide in. Along with family and professional support, many people with bipolar disorder find that peer support groups are a valuable part of their social network.

**6. Try to develop a balanced life.** It might seem easy at first to escape from your depression by focusing entirely on one area, such as work or a hobby. Eventually, however, this coping strategy may not work, and you will need to develop other aspects of your life. It is important to keep in contact with all the facets of your life,

such as school, work or volunteer activities, family and friends, and hobbies. As you recover, investing energy in several areas will help you develop a more balanced and satisfying life, which will help you to avoid relapse.

7. **Monitor your symptoms closely.** Many people with bipolar disorder have a consistent pattern of symptoms across episodes. For example, some people learn to recognize the early phase of an impending relapse through signs such as needing less sleep, becoming irritable, or feeling that they no longer need medication. Monitoring such signs closely and seeking medical attention can stop a full-blown episode developing. Often, a mood diary or mood charting app can help. Most healthy people experience a variety of feelings that change from day to day—not all shifts in your mood are due to bipolar disorder. (See also “Recognizing and responding to early warning signs and triggers,” on p. 39.)
8. **Identify family and friends as support.** Insight is commonly lost early in an impending episode. It can be helpful if friends or family can recognize typical bipolar symptoms; they can help you in seeking treatment if necessary.

## Practical aspects of recovery

An episode of either depression or mania usually disrupts daily routines as well as work, school and home life. People may feel that life will never be the same. They may also feel unable to assume their previous responsibilities and involvements. These feelings are natural and understandable. Yet, once they are properly stabilized on medication, most people with bipolar disorder can return to their previous responsibilities and activities.

Planning appropriate goals and setting priorities are essential to making this transition successful. Each plan and set of priorities is individual. However, it is important to discuss your ideas and concerns with your psychiatrist. Taking on too many or too few responsibilities can have an impact on recovery. Sometimes, people are advised to discuss their plans with other care providers, such as an occupational therapist, social worker or psychologist. Family members may also need to know about your plans and concerns. Family can give important support and feedback as you resume responsibilities. The aim is to get the “just right” type of challenge. This is true whether people are returning to school or work, or taking on roles within their family and community.

## SCHOOL

If you are planning to return to school, you should discuss this with your psychiatrist and/or other mental health care provider. Some people they need to resume studies on a part-time basis. Many people experience problems with concentration and memory. Look for ways to improve or adjust your study habits. Study for shorter periods. Avoid noisy or high-traffic areas, as people often find it hard to block out the surrounding sights and sounds.

Letting your teachers know about some of your difficulties may be helpful. Many schools and most colleges and universities have a “special needs” office that may also be helpful. A counsellor at this office will ask about the reason for your absence. This information will help the counsellors work with your teachers and instructors. A counsellor can suggest the best change to a course load and responsibilities. Sometimes it may be helpful to give permission to these counsellors to speak with your health care providers.

## WORK

Returning to work may involve similar challenges and careful planning. It is important to discuss your plans for work with your psychiatrist. You may also need to discuss your concerns and plans with an occupational therapist, who can give you additional advice and support.

It is best to resume your responsibilities gradually, by starting either part-time or with a smaller workload. Your health care provider may recommend specific job accommodations to your work responsibilities and schedule that may also be helpful in this transition. Typical job accommodations include more frequent breaks, time off to attend medical appointments, and a change in non-essential job duties.

Educating your employer and co-workers about some of the typical signs of mood changes may be helpful in some cases. However, some people prefer not to discuss their illness with their employer. This choice will not allow you to ask for accommodations, but it does not mean that you will be unsuccessful in your transition back to work. In this situation it is especially important to have support outside of work to discuss your problems and concerns.

## HOME AND COMMUNITY RESPONSIBILITIES

You may also need to resume home and community duties gradually, in order to find the “just right” challenge of responsibilities and involvements. Reviewing priorities and developing a plan to resume activities may also be necessary. Look at what you can do and have been doing, and plan accordingly.

What you are currently able to do may not match what you were able to do in the past. Although this may be frustrating, set daily goals and monitor your accomplishments. Reflecting on and modi-

fying your expectations is often an important part of this process. In the early stages you may need to rely on family members to absorb some of the daily household and other responsibilities. As recovery continues, you can gradually resume your responsibilities.

## Recognizing and responding to early warning signs and triggers

When you return to school, work, or home and community involvement, it is important to learn to recognize and respond to any subtle changes in your mood. Focusing on ways to concentrate better and to work more efficiently may also help. You may also benefit from decreasing some of the external stresses in your environment.

### DEPRESSION

Typical signs of starting to feel depressed are:

- trouble concentrating and focusing or completing tasks
- lower energy level and confidence
- sensitivity about the comments of others
- increased worry
- doubting the worth of daily involvement in activities
- trouble making fairly simple decisions
- changes in sleep and appetite.

It is also important to learn to identify your personal triggers, and make plans to cope effectively when they arise. Triggers are external events or circumstances that can precede mood changes. Some examples are:

- anniversary dates
- financial problems
- conflict with an important person
- being in an abusive situation
- physical illness, such as flu.

When you are depressed or are experiencing triggers, you may find it helps to:

- recognize some of the symptoms, and speak to your doctor to see if your medications need to be adjusted or if other treatments may be needed
- seek out family members, friends or co-workers to support you and realistically assess your impressions
- focus on completing simpler, concrete tasks, and delay the harder and more challenging tasks if possible
- delay making any important decisions
- limit time in more public and/or socially demanding activities
- structure your day to include more activities that you find rewarding
- set goals to address these mood changes; for example, make sure you are involved in enjoyable activities with people who support you.

## HYPOMANIA

Typical signs of starting to feel hypomanic are:

- decreased need for sleep
- higher energy level and confidence (often includes taking on many tasks)

- trouble settling down to work
- strong feelings or disagreements (more than usual)
- making decisions impulsively (more than usual).

When hypomanic, you may find it helps to:

- recognize some of the symptoms, and speak to your doctor to decide if your medications need to be adjusted or if other treatments may be necessary
- look for ways to make your physical environment less stimulating
- consciously try to get enough sleep and to relax enough
- look for ways to protect yourself against yourself, such as putting away credit cards and avoiding certain social circles
- consider putting off major decisions and cancelling any critical meetings
- plan your day and keep to a limited schedule
- set goals to address these mood changes outside work; for example, find how to work off your extra energy safely with hobbies, exercise, etc.

## CONCENTRATION

Whether you are feeling depressed or hypomanic, you may have trouble concentrating. At these times, you should:

- discuss your problems with your doctor
- recognize that this will not last
- try harder to write out goals and make plans for yourself
- set goals that have flexible time limits
- make your environment less stimulating
- try to become aware of what times you perform best during the day.

## 7 Help for partners and families

### What happens when someone you love has bipolar disorder?

When a family member has a chronic illness, it affects your entire family. This is true of a physical illness, such as diabetes, or a mental illness, such as bipolar disorder. When your relative or partner has a mental illness, you must cope with extra stressors, such as stigma. Fearing prejudice, your family may try to deal with mental illness alone. Furthermore, bipolar disorder will affect your relative's mood and behaviour. At times, your family member's mood disorder can make him or her less able to manage the illness, and the person may become less able to work with you to solve problems. This may include changes in how the person can attend to their usual roles and responsibilities.

As a family member, you will likely find both the manic and depressed phases of the illness very distressing. If your family member has only mild mood swings, you may be able to get through them without too much trouble. But if your relative's mood swings are severe, you will likely find them hard to handle.

# Depression

Seeing a loved one struggle with depression can make people feel sad, concerned, frightened, helpless and anxious. You may experience guilt, anger and frustration. All depressive episodes are upsetting, but the first episode will probably be especially confusing. You may not understand what is happening and why the person is not getting better on his or her own. Without information about depression, you might assume that your relative is lazy, or give well-meaning advice and become frustrated and annoyed when he or she does not act on it. If your relative talks about suicide, you will understandably live with a great deal of worry.

## HOW TO RELATE TO A PERSON WHO IS DEPRESSED

Family members often do not know how to talk to a person who is depressed. They may be afraid to ask too many questions and inadvertently upset their loved one. At the same time, they do not want the ill person to feel that they are not interested or are avoiding him or her.

Try to be as supportive, understanding and patient as possible. Just recognizing that depression is an illness can help your relative to feel less guilty about his or her impaired functioning.

## TIPS FOR COMMUNICATING WITH A PERSON WHO IS DEPRESSED

1. Speak in a **calm quiet voice**.
2. **Focus on one subject at a time.** Your relative or friend may have trouble concentrating.

3. If the person is quiet and withdrawn, break the ice with **neutral, non-threatening statements**, such as “It seems a bit warm in here.”
4. **Be patient and wait.** It may take a while for your loved one to respond.
5. **Your ability to listen is a valuable resource to your relative.** Depression causes people to talk a lot about how bad they feel, yet they may not be ready to discuss solutions to their problems. Listening and letting the person know, in a neutral manner, that you have heard what he or she has said is valuable and supportive. You do not have to offer immediate solutions.
6. **If the person is irritable, you probably need to slow down, adjust your expectations and use a very neutral approach.** Neutral comments about the weather, what you are making for dinner or other routine subjects are the safest way to develop a dialogue. Listen for opportunities to acknowledge or add to your relative’s responses. At these times, conversations about important decisions or issues are unlikely to be productive. You may need to plan to discuss important issues at a later date.
7. **Avoid quizzing people about what made them feel depressed. Do not blame them for the way they feel, or tell them to snap out of it.** People who are moderately depressed may be able to hear your helpful suggestions, but be unable to act on your advice. Quizzing or blaming them will only reinforce their guilt, loneliness and isolation. Often, people with depression cannot identify what made them depressed or what will be helpful.
8. **Pace yourself.** If your relative is severely or more chronically depressed, it is normal for you to find his or her company very draining. Brief, frequent contacts are often the best way to relate to someone with severe depression. If your relative is hospitalized, family members might take turns in visiting.

## Mania

How a person behaves during a manic episode stirs up intense feelings, especially family members. You may feel frustrated, annoyed, angry or even hatred. The strength of your feelings will depend on how severe the episode is. It is particularly frightening if, in a manic episode, the family member you know seems to be replaced by a stranger. For example, a reserved, responsible person can become loud and sexually free; a kind, gentle person can become bossy and cruel.

As well, people experiencing mania usually think that they are right and everyone else is wrong. This aspect of mania is challenging for relatives and others around the person. Your family member may take no responsibility for what he or she says or does. As a result, there may be times when you have to bail the person out. Moreover, your relative may be acutely sensitive to weaknesses in others and can behave in ways that embarrass them. A person with severe mania can easily “blow up,” and being with someone in this state has been compared to walking in a minefield—you never know when there will be an explosion. Hardest of all, when someone is experiencing mania, he or she may have no insight into the manic behaviour.

If your partner has a manic episode, you may find it particularly hard because you, more than anyone, may be the target of his or her anger. You may also become a “buffer” between the person and the community, as others demand that he or she be controlled. If your partner runs up large bills, you may be hounded by creditors. Some people experiencing severe mania have extramarital affairs, which they may flaunt. If this happens, you may feel humiliated and betrayed.

Withdrawing from your partner and considering divorce may seem the only way out of an intolerable situation. But you should not make big decisions, such as whether or not to divorce, when the person is severely ill. The situation will probably change when he or she has recovered.

## HOW TO RESPOND TO A PERSON EXPERIENCING MANIA

Early in a manic episode, a person may be overly happy, energetic and outgoing. Those around the person can easily be caught up in the high spirits. **Stay realistic and do not get carried away by this high mood.** A person experiencing mania feeds on attention and conflict. Try to discourage the person from becoming involved in stimulating situations, such as long talks and parties.

Only a small percentage of people with bipolar disorder experience severe mania. A person with severe mania may become hostile and suspicious, or may explode verbally and physically. Avoid arguing with someone in this state. The person will only become angrier and may even assault you.

Typically, in a manic episode, people may behave without being aware of or considering the dangers to themselves and others. They may take on risky business ventures, overspend, drive recklessly, etc. You may need to step in. The best way of preventing this kind of behaviour is to plan for it when your relative is well. During stable periods, discuss and set rules that may involve safeguards. For example, consider withholding credit cards, banking privileges and car keys. Hospitalization can save the life of a person experiencing mania.

## TIPS FOR COMMUNICATING WITH A PERSON EXPERIENCING MANIA

- 1. Reduce stimulation.** People with mania are easily overstimulated. You may need to have fewer people visit at the same time. Or you may need to reduce noise and activity in the house.
- 2. Keep conversations brief.**
- 3. Deal only with immediate issues.** Do not try to reason or argue.
- 4. Discourage discussing feelings.**
- 5. Try not to be authoritative, but be firm, practical and realistic.**
- 6. Do not jump to the person's demands.**
- 7. Do not get caught up with the person's euphoria or unrealistic expectations.**
- 8. Do not try to convince the person that his or her plans are unrealistic.** At the same time, take steps to ensure his or her safety (e.g., by removing car keys or credit cards).

## Getting treatment for your family member

### FOLLOWING THROUGH WITH TREATMENT

Some people are very relieved when they are finally diagnosed and receive treatment that stabilizes their moods. For others, however, it is a long and bumpy road to accepting that they have a disorder that

must be managed over their lifespan. Some people must endure several manic or depressive episodes before they consistently accept help from doctors and therapists. Mild mania can be seductive because it often includes feeling happy, more confident, more energetic and more creative. The lure of these feelings may keep some people from taking their medication.

As a family member, it can be very difficult to watch this process without trying repeatedly to convince your relative to “take your medication” or “go and talk to your doctor.” Repeated attempts to convince and coax can lead to heated arguments and power struggles. If you are very close to the person with bipolar disorder, and yet you feel that he or she may not be open to your observation that something is wrong, it may be more effective to have another trusted person approach your relative.

## SUICIDAL THOUGHTS

A person with moderate depression will probably agree to medical treatment without needing too much encouragement. However, a person who is severely depressed and suicidal may refuse treatment because he or she feels so hopeless and worthless. In this case, you or another trusted person should insist that the person see his or her doctor or go to the emergency department of a local hospital.

Many people will agree to go to the hospital. If the person refuses, there are a number of options the family can take. For example, you can go to a justice of the peace to get an order allowing police to take the person to hospital for an assessment. If there is an immediate risk of suicide, you should call 911.

Involving the police is a painful and difficult decision, although it is sometimes necessary in order to get an ill person to hospital. Family

members often feel overwhelmingly guilty about this decision. It is important to remember that when people threaten suicide, they are usually making a plea for help, which should be taken seriously. Suicidal thinking is usually a temporary emotional state during which a person needs to be in a place of safety.

## MANIC EPISODES

You may see that your family member is developing hypomania (e.g., being more energetic than usual, sleeping less, talking a lot). If so, encourage the person to see a doctor at once to get medication that will help calm down and stabilize his or her mood. For some people, hypomania leads to mania. If they are treated when they are hypomanic, they may avoid a full-blown manic episode. Once your family member develops full mania, the person may be unable to see that he or she is ill, and so may refuse to see a doctor. Manic episodes can make a person behave dangerously, with potentially serious consequences. People experiencing mania are therefore best treated in hospital.

## YOUR FAMILY MEMBER IN HOSPITAL

Once in hospital, if your relative is quite ill and impaired, it is sometimes better for both the patient and the family if visits are frequent but short. People who are acutely ill do not benefit from long conversations in which they can become overwhelmed as they ruminate, or repeatedly focus on their feelings of hopelessness and negativity. Frequent, brief contacts allow you to stay in touch with your relative, and reassure him or her that you remain supportive.

For some people, being in hospital is very challenging because their movements may be restricted to ensure safety. They may wish to leave the hospital before the professional staff feel their mood and

behaviour are stabilized. For family members, this is particularly difficult as they can foresee the problems at home if the person becomes acutely ill again and requires hospitalization. Some patients will respond to the concerns of friends and family and agree to stay longer in hospital. This is more easily accomplished if there are clear goals to be achieved during the admission. For example, it might be helpful to concretely state that the person must be stabilized on medication and connected with a day program or community therapist before discharge.

Most jurisdictions in North America have mental health legislation that permits involuntary hospitalization of people only if they threaten to harm themselves or other people, or cannot care for themselves. Many ill people who would benefit from hospitalization do not meet these criteria and therefore may refuse to enter the hospital, or leave the hospital against medical advice. Families usually have a very hard time living with a person with mania who refuses treatment and who cannot be legally hospitalized or kept in hospital.

In these situations, try to negotiate with your relative when it might be best to leave the hospital. What must be accomplished during the admission for you to feel it is safe for the person to return home? Could these issues be discussed in a **discharge planning meeting** with your relative, the doctor and any other care providers who work with him or her?

Sometimes, you can slow your relative down by saying that you need this meeting to take place before consenting to his or her returning home. Families often feel guilty at insisting on these conditions, because they worry that their loved one will feel rejected. However, the result of premature discharge and poor discharge planning is frequently a relapse in the illness and a more complicated situation.

## Care for partners and families

When someone has a serious illness, it is natural for family members to feel worried and stressed. In an effort to spend time comforting or helping their loved one, family members may give up their own activities. Unsure of how others may respond to their ill partner or relative, they may also avoid having friends visit their home. Over time, they may become isolated from their own network of friends, or find that most of their own routines and activities have been replaced by the demands of caring for their loved one. Often, they are well into this situation before they realize how emotionally and physically drained they have become. This stress can lead to sleep disturbances, exhaustion or chronic irritability.

It is important to recognize these signs of stress in yourself and look after your own physical and mental health. Recognizing your own limitations and making time for yourself are key elements in “self-care.” Ensure that you have a good support system of reliable friends and relatives. Think about whom you want to share the details of the situation with. Mental illness is a difficult thing for some people to make sense of, so it is understandable if you want to be selective and choose only people who you know will be supportive.

Families and partners need to get as much information as possible about bipolar disorder. Knowledge and understanding will improve your ability to help and support your loved one, deal with your own feelings, and explain the situation to extended family, friends and colleagues. Information is available from the treating doctor, social worker or other mental health care providers. In addition to this publication, there are numerous books written for people with bipolar disorder and their families. They are usually available through public libraries.

Consider getting professional support for yourself, and joining a peer-support group or family support program, which may be offered at a local hospital or community mental health clinic. Keep up your interests outside the family and apart from your ill relative. Acknowledge and accept that sometimes you will have negative feelings about the situation. These feelings are normal and should not be a source of guilt.

## Being ready for a relapse or crisis

Families often avoid talking to their relative about relapses or crises. They fear that talking about a crisis will bring one on, or they simply do not want to upset their relative. However, the best way to handle a crisis is to know what to do before it happens. It is important to focus on maintaining wellness, but some planning for a possible crisis can create a sense of security for the ill person and the family.

When your family member is well, discuss what you will do if he or she should become ill again. Is it possible to visit your relative's doctor together to discuss his or her condition and the possibility of a crisis? If your relative became ill, would you have permission to contact his or her doctor? Would you have consent to take the person to the hospital, and which hospital is preferred? If your loved one were acutely ill, would you be allowed to make decisions? Could you put the conditions of an agreement in writing to ensure that these instructions were followed? A prearranged plan and a good working relationship with your relative's doctor can help to contain an emergency situation.

## Tips for helping your family member and supporting recovery

- 1. Learn as much as you can about bipolar disorder.** Learning about the causes, signs and symptoms, and treatment of bipolar disorder will help you to understand and support your family member in his or her recovery.
- 2. Acknowledge and accept your own feelings.** Having conflicting emotions is normal when a loved one is diagnosed with bipolar disorder. Knowing this can help you control these emotions when you want to support your relative in making steps toward recovery. For example, you may feel sad that your family member has a mental illness, and angry at what has happened and its effect on you. You may fear what the future holds and worry about how you will cope. If you are a parent, you may feel that somehow you caused the bipolar disorder, even though doctors have told you otherwise. It is also normal to feel a deep sense of loss when your relative is behaving in troubling, unfamiliar ways. And you may feel burdened by the extra tasks you have to take on.
- 3. Encourage your family member to follow the prescribed treatment.** If your relative is not showing improvement or is having uncomfortable side-effects, encourage him or her to speak to the doctor about the medication, or to get a second opinion. It is helpful if you can go with your relative to the doctor and share what you have observed.
- 4. Learn the warning signs of suicide.** These signs include your relative showing increasing despair, winding up his or her affairs and talking about “When I’m gone . . .” Take any threats very seriously and get help immediately. Call 911 if the situation gets desperate. Recognize, and help your family member to see, that

suicidal thinking is a symptom of the illness. Always stress how much you value the person's life.

**5. When your family member is well, plan how to try to avoid crises.** Plan together how you will respond to periods of acute illness, including dealing with suicidal behaviour and preventing harmful results of manic behaviour, such as overspending or reckless driving.

**6. Remember your own needs.** Try to:

- take care of yourself
- keep up your own support network
- avoid isolating yourself
- acknowledge, within your family, the stresses of coping with bipolar disorder
- share the responsibility with others
- stop bipolar disorder from taking over family life.

**7. Recognize that recovery from a manic or depressive episode is slow and gradual.** Know that your family member needs to recover at his or her own pace. Try not to expect too much but avoid being overprotective. Remember that stabilizing mood is the first step towards a return to normal functioning. Try to do things *with* your relative rather than *for* him or her. That way, your relative will gradually regain self-confidence.

**8. View bipolar disorder as an illness, not a character flaw.** Treat your relative normally once he or she has recovered. At the same time, watch for possible signs of recurrence. In a caring way, point out any early symptoms and suggest a talk with the person's doctor.

**9. Learn, with your family member, to distinguish a good day from hypomania and a bad day from depression.** Like everybody else, people with bipolar disorder have good and bad days that are not part of their illness.



Bipolar Disorder:  
**Parents'  
Medication Guide**

AMERICAN ACADEMY OF  
CHILD & ADOLESCENT  
PSYCHIATRY

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**PSYCHIATRIC**  
ASSOCIATION



# Assessment & Treatment

## What are the risks of not treating bipolar disorder?

**Suicide** is the most dangerous risk of leaving BD untreated.

- Up to 20% of people with BD die by suicide. This is 10 to 30 times higher than suicide rates in the general population.
- Up to 50% of youth with BD attempt suicide by 18 years of age.
- In any given year, up to 45% of all teens with untreated BD experience suicidal thoughts.
- More than 75% of people with BD report thinking seriously about suicide during their lifetime.

Untreated BD can cause problems with a child's normal emotional and social growth. As a result, children who are not treated for their BD are much more likely to have problems in school, at home, and with friends. Teens with the disorder are at high risk for unplanned pregnancies, gambling, car accidents, drug/alcohol use, problems with authority and the law, and difficulties finding a job.

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## What can we expect during my child's first appointment?

At your child's first meeting with the mental health clinician, you and your child will be asked questions about how your child has been feeling lately and in the past. Common questions from mental health clinicians will include asking about periods of time when your child has not slept for multiple days in a row, felt "too happy," or started to believe that they had special talents or powers, and acted without thinking, irritable, or not like themselves. Questionnaires may also be given to you and your child to fill out.

There are many reasons a child's sleep and behavior may change, and the clinician will ask you and your child questions to figure out what else could be causing these changes. They may also ask about symptoms of other conditions that can share some similarities with BD, such as disruptive mood dysregulation disorder (DMDD), attention-deficit/hyperactivity disorder (ADHD), oppositional defiance disorder (ODD), depression, autism spectrum disorder (ASD), posttraumatic stress disorder (PTSD), anxiety, and substance use. The clinician may also ask about medications and medical conditions that can affect sleep, behavior, and mood. Your child's clinician (physician, advanced practice nurse, or physician assistant) will likely ask for blood tests to ensure that there are no problems with the thyroid gland, liver, kidneys, or blood cells and a urine test to check for any substances that could affect behavior.

## Importance of accurate assessment

Getting a correct diagnosis of any mental health disorder, including BD, is very important. This will require a mental health clinician to review your child's complete history of any medical or mental health issues, and whether any family members have had mental health issues. Your child may also be checked for developmental disorders, stress in the relationship between you and your child, and other stressors as part of the process of figuring out if your child has BD.

## Importance of long-term follow-up

It is very important to continue to keep track of how your child with BD is doing over time. Because of the nature of BD, it will take many visits to your child's mental health clinician to



get a full picture of the symptoms in order to make the best plan to treat the BD. Symptoms of BD can change over time as your child is developing and with periods of high or low mood.

### Importance of a team-based approach

It is important to have a team of healthcare professionals to help treat your child's BD. While there are many treatments, the best plan involves multiple healthcare professionals working together with you and your child. Involving doctors, therapists, teachers, and school counselors can help

to address the medical, academic, and therapy needs of your child with BD. Your child's school may provide an individualized education program (IEP) or 504 plan to support your child.

BD is a lifelong condition, and children and teens with BD benefit from support of their parents and caregivers. You can help your child to: 1) understand their BD symptoms and the treatments that help keep a steady and balanced mood; 2) practice the coping skills that help them deal with stressors; and 3) make good decisions for a healthy lifestyle such as regular sleep, exercise, and healthy diet.

# Taking Medications for Bipolar Disorder

## What types of medications are available to treat bipolar disorder?

There are several psychiatric medications that have been shown to help treat the symptoms of BD and reduce how often your child experiences elevated or depressed mood in the future. The most common medications include lithium, mood stabilizing atypical antipsychotics, and anticonvulsants. These medications usually work best when they are used together with talk therapy.

## Will medications help my child?

There are many medications that work well for adults with BD. Many, but not all of them, also work for BD in children and adolescents.

Currently, the medications that work best for children and teens with manic or mixed mood states include lithium, olanzapine, risperidone, quetiapine, aripiprazole, ziprasidone,

and asenapine. Valproate (valproic acid, divalproex) and carbamazepine appear to be somewhat helpful.

The most effective medications for depressed mood in children and teens with BD include lurasidone, lamotrigine, and the combination olanzapine/fluoxetine.

Lamotrigine and lithium appear to be helpful as added medications for both manic and depressed mood states.

If your child does not get better with one of these medications, it is important to not give up hope since a different medication may work instead. While research shows which medications work at a group level, each person has a unique response to medications. Even if your child has tried all of the possibly effective medications and still has significant BD symptoms, clinical research continues to find



helpful new medications and new uses of medications that are already available.

A complete and thorough approach to treating your child's BD that combines both medication and talk therapy can help your child feel better and reduce family conflict, lower your child's risk of getting into trouble with the law, and improve school performance.

### **Side effects and monitoring**

Medications commonly used to treat BD can cause serious side effects; however, it is important to note that serious side effects are rare, and many children taking the following medications often tolerate them well. Your child's clinician will regularly screen for these side effects by checking lab tests, their vital signs, and your child's growth over time (see the Table below). Based upon your child's age, your clinician may discuss the risk of these medications on pregnancy, may obtain pregnancy tests as part of medication monitoring, and may discuss birth control options. Parents and caregivers need to help monitor, supervise, and secure these medications

to ensure that they are consistently taken and to avoid your child from accidentally or intentionally taking too much medicine.

### **LITHIUM**

Youth taking lithium may notice side effects such as shaking (tremor) in their hands, upset stomach, need to urinate (pee) more often, blurry vision, slurred speech, acne, and weight gain. Youth taking lithium also require regular checking of the level of this medication in their blood as well as making sure that there are no problems with their kidneys and thyroid gland.

### **ATYPICAL ANTIPSYCHOTICS**

Youth taking atypical antipsychotics may notice side effects such as increased appetite and weight gain, tiredness, upset stomach, constipation, and a severe sense of restlessness or trouble sitting still. Youth taking atypical antipsychotics also need to regularly check their blood sugar, cholesterol, liver function, and blood cell counts. The clinician will also check for certain types of body movements that are unexpected and uncontrollable, a side effect of atypical antipsychotics called tardive dyskinesia.

### **VALPROATE**

Youth taking valproate may notice side effects such as increased appetite and weight gain, feeling more tired, upset stomach, tremor, and hair loss. Youth taking valproate also require regular checking of the level of this medication in their blood as well as tests to regularly check their complete blood cell counts and their liver. Changes in blood cell numbers may be a side effect.

### **LAMOTRIGINE**

Youth taking lamotrigine may notice side effects such as feeling very tired and developing headaches, blurry vision, upset stomach, or problems focusing. It has a low risk of weight gain and problems with blood sugar or cholesterol; however, there is a very rare but serious risk of developing a dangerous rash caused by an allergic reaction (called Stevens-Johnson syndrome) that can be life threatening if the medication is not stopped quickly. Youth taking lamotrigine also need to regularly check their blood cell counts and their kidneys and liver. Lower white blood cell levels may be a side effect.

### **Lab tests the physician, nurse practitioner, or physician assistant may order**

Medication	Tests Before Starting Treatment	Monitoring During Treatment	
<b>Lithium</b>	<ul style="list-style-type: none"> <li>• Kidney Function</li> <li>• Thyroid Gland Function</li> <li>• Complete Blood Count</li> <li>• If your child has a heart condition or symptoms, a baseline electrocardiogram (ECG)</li> </ul>	Lithium Blood Level	Every 5 to 7 days until reaching the right blood level; then, every 3 months
		Kidney Function & Thyroid Gland Function	Every 6 months
<b>Atypical Antipsychotics</b>			
<b>Atypical Antipsychotics</b>	<ul style="list-style-type: none"> <li>• Complete Blood Count</li> <li>• Blood Sugar</li> <li>• Cholesterol</li> <li>• Liver Function</li> </ul>	Complete Blood Count	Every 6 months
		Blood Sugar	Every 6 months
		Cholesterol	Every 6 months
		Liver Function	Every 6 months
<b>Anticonvulsants</b>			
<b>Valproate</b>	<ul style="list-style-type: none"> <li>• Liver Function</li> <li>• Complete Blood Count</li> </ul>	Valproate Blood Level	Every 1 to 2 weeks until reaching the right blood level; then, every 3 to 6 months
		Liver Function & Complete Blood Count	3 Months after starting; then, every 6 months
<b>Lamotrigine</b>	<ul style="list-style-type: none"> <li>• Liver Function</li> <li>• Complete Blood Count</li> </ul>	Liver Function & Complete Blood Count	1 Month after starting; then, every 6 months

# Talk Therapy Treatments for Bipolar Disorder

Providing your child with talk therapy in addition to medication can help them to better understand the symptoms of their illness, recognize signs that their mood may be shifting, and manage their treatment needs.

## How can my child benefit from therapy?

**Pharmacotherapy is the mainstay of bipolar treatment and talk therapy is an important supplement to medication to help the child and family manage symptoms of bipolar disorder.** Providing your child with talk therapy in addition to medication can help them to better understand the symptoms of their illness, recognize signs that their mood may be shifting, and manage their treatment needs. It can help teens prepare to manage their own health as young adults and teach them about noticing when they may be at risk for the BD to start worsening moods again.

## What types of therapy are available?

There are several different therapy treatments that can be provided by a licensed therapist (psychologist, social worker, licensed mental health counselor) or psychiatrist to help children and teens with mental health challenges, including BD. These include talk therapies such as supportive therapy, cognitive-behavioral therapy (CBT), family therapy, and group therapy with similar aged children or teens. There are also educational and behavioral tools that can help your child manage stress at school and at home. For children and adolescents with BD, three types of therapy have proven to be helpful: cognitive-behavioral therapy, interpersonal and social-rhythm therapy, and family-focused therapy.

### COGNITIVE-BEHAVIORAL THERAPY

Cognitive-behavioral therapy helps your child or teen notice negative thoughts and behaviors and gives them tools to make healthy changes to each. They are also taught to manage stress that can increase the chances for mood shifts.

### FAMILY-FOCUSED THERAPY

Family-focused therapy helps families notice intense feelings and gives ways to improve family problem solving. This type of therapy has been studied the most in teens with BD. Early studies have shown that teens taking recommended medications and are in family-focused therapy have less BD symptoms and fewer behavioral problems.

### INTERPERSONAL AND SOCIAL-RHYTHM THERAPY

Interpersonal and social-rhythm therapy (or interpersonal therapy) helps your child or teen improve their mood and keep it stable by better understanding the routines (rhythms) in their lives. This therapy teaches them how daily routines and habits can help improve BD. It also teaches how stress and conflict can make it much harder for someone with BD to stay healthy and avoid depression. A therapist will help a child and their family recognize stressful triggers, practice coping skills, and put in place routines to ensure that medication schedules are followed correctly.

# Other Medical Treatment for Bipolar Disorder

## What is electroconvulsive therapy?

Electroconvulsive therapy (ECT) is a treatment that can be used to treat BD symptoms in cases of BD that do not respond to medication management and therapy. It is rarely considered in the first group of treatments. ECT works by giving the brain a brief electrical stimulus while the youth is asleep from anesthesia. ECT often helps the symptoms of BD to quickly get better.

## Summary

All forms of therapy should include education about BD and the importance of making

healthy choices. Discussing self-care, consistent and quality sleep, exercise, a healthy diet, and ways of lowering stress can have an important impact on your child's mood and response to treatment. It is also important to reiterate how important it is for your child to go to appointments and consistently take their medications as prescribed. Therapists will also help you and your child understand what is special about the way their BD affects them, especially early signs of mood shifts that are unique to your child, so that they can remain healthy.



# Schizophrenia

## An information guide

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**camh**

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A Pan American Health Organization /  
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# 1 What is schizophrenia?

*Some people say that schizophrenia is when people hear voices and see things that aren't there, but for me it was different: I experienced difficult and disturbing thoughts. My thoughts made me do things or say things that are not acceptable. At first it seemed like nothing, but then I wasn't doing well in school, and it became distressing. When I went to university I started thinking people were out to get me. I wasn't able to function; I wasn't able to carry out normal everyday activities. — Ann*

Schizophrenia is a complex mental illness that affects how a person thinks, feels, behaves and relates to others. The illness occurs in both men and women, but is slightly more common in men. The first episode typically occurs in the late teens to early twenties—usually earlier for men than for women. People can also develop the illness later in life. As many as one person out of 100 may experience schizophrenia. At any one time, as many as 51 million people worldwide experience schizophrenia, including more than 280,000 people in Canada.

Schizophrenia can be a challenging illness to live with and to understand. Symptoms such as hallucinations and delusions can cause people to lose contact with reality. This experience can be

confusing and distressing for the person with schizophrenia, and for family members, friends and others, who often don't understand what is happening or know how to relate to the person who is ill. People with schizophrenia may also experience changes to the way they think and have trouble expressing themselves and managing basic daily tasks. They may become withdrawn and isolated.

Recovery from schizophrenia is a gradual process that is unique to each person. The symptoms usually improve and become easier to manage over time, though they do not always disappear. A recovery-oriented approach to the treatment of schizophrenia promotes the values of hope, empowerment and optimism. The illness can usually be managed effectively with a combination of medications and psychosocial supports, such as psychotherapy, education and peer support. People with schizophrenia can and do recover, and lead meaningful and fulfilling lives.

*I want others to understand that it is only the worst cases that you see in the news. There are a lot of people who live with it and you wouldn't have any idea they even have it. We are people too. We have feelings. We have endless possibilities, just like anyone. — S*

## How does schizophrenia begin and what is its course?

Schizophrenia often starts so gradually that people experiencing symptoms and their families may not be aware of the illness for a long time. For some, however, the symptoms come on rapidly and are more easily recognized. Schizophrenia has three phases: prodromal (or beginning), active and residual. These phases tend to occur in sequence and to repeat in cycles throughout the illness. The length of each phase varies from person to person.

## 1. PRODROMAL PHASE

When symptoms develop gradually, people may begin to lose interest in their regular activities and withdraw from friends and family members. They may become confused, have trouble concentrating and feel listless and apathetic, preferring to spend most of their days alone. They may also become intensely preoccupied with certain topics or ideas (e.g., persecution, religion, public figures). Family and friends may be upset with this behaviour, not understanding that it is caused by illness. Occasionally, these symptoms reach a plateau and do not develop further but, in most cases, an active phase of the illness follows. The prodromal period can last weeks, months or even years.

## 2. ACTIVE PHASE

During the active, or acute, phase of the illness, people typically experience symptoms of psychosis, such as delusions, hallucinations, jumbled thoughts, and disturbances in behaviour and feelings. However, these symptoms can also be caused by other mental and physical health conditions (e.g., bipolar disorder, drug-induced psychosis, head injury), and so other factors are considered in diagnosing schizophrenia (see page 10).

The active phase of schizophrenia most often appears after a prodromal period, but sometimes the symptoms can appear suddenly.

## 3. RESIDUAL PHASE

After an active phase, when symptoms have settled down, people may be listless and withdrawn, and have trouble concentrating. The symptoms in this phase are similar to those in the prodromal phase.

People with schizophrenia may become actively ill just once or twice in their life, or may have many episodes. Unfortunately, after each active phase, residual symptoms may increase and a person's ability to function normally may decrease. This is one reason it is important to try to avoid relapses (the return of active symptoms) by participating in the recommended treatment and recovery plan.

*You are a totally different person from what people know you as. You just behave completely different. They see you and think: this is not the person I know. Why is he acting like this? But it's from the illness. —*

Moustafa

## What are the symptoms of schizophrenia?

People with schizophrenia experience delusions; hallucinations; disorganized thought, speech or behaviour; and other symptoms that affect their ability to function in their daily activities. Remember though that these symptoms are not specific to schizophrenia—they can also be signs of other mental and physical illnesses.

The main symptoms of schizophrenia are divided into “positive,” “negative” and cognitive categories. People with schizophrenia often also experience some other symptoms.

### POSITIVE SYMPTOMS

The term “positive” is used to describe symptoms that are “added on” by the illness. Positive symptoms include delusions, hallucinations and disorganized thought, speech and behaviour.

## **Delusions**

Delusions are firmly held false beliefs that have no basis in fact or in the person's culture. The person feels so strongly about these beliefs that they will not accept other people's attempts to argue against or disprove the beliefs. Delusions are sometimes understood to be extreme distortions and/or misinterpretations of the person's perceptions or experiences. Common delusions among people with schizophrenia include the beliefs that:

- other people are following or monitoring them or trying to harm them (also referred to as paranoia)
- their bodies or thoughts are being controlled by outside forces
- ordinary events have special meaning for them (e.g., believing that a newspaper story, song lyric or TV character is communicating special messages intended for them)
- they are especially important or have unusual powers
- other people can read their thoughts.

## **Hallucinations**

Hallucinations are disturbances in perception. If a person hears, sees, tastes, smells or feels something that does not actually exist, they are hallucinating. The most common hallucinations among people with schizophrenia are auditory; that is, they hear noises or voices, often talking to them or about them. These voices may be experienced as harmless, with the voices commenting on things or people around the person. For some, the voices may even be comforting. However, it is more common for the voices to be frightening or humiliating, causing the person to be distressed. Voices may also be experienced as commands—ordering the person to perform some kind of action. How distressing the voices are can depend on what the voices are saying and on the meaning the person makes of what they are hearing.

## **Disorganized thought and speech**

Schizophrenia can affect a person's ability to connect thoughts and to communicate with others in a way that is clear and logical. Their thoughts may be jumbled or blocked, and this is expressed through their speech. For example, when talking, they may:

- jump from subject to subject
- make up words that don't make sense
- talk about ideas that seem to be unrelated
- answer questions in ways that are off-topic or irrelevant
- string together rhyming words that make no sense.

## **Disorganized behaviour**

Schizophrenia can affect a person's ability to complete everyday tasks such as bathing, local travel, basic school and work activities, buying groceries and preparing food. People with schizophrenia may be unable to plan their days and to follow through with ordinary tasks.

They may also behave in ways that seem unusual to others. For example, they may become agitated for no apparent reason, or be uninhibited in social situations.

Less commonly, a person may have "catatonic" symptoms. These may include rigid body posture, motionlessness, excessive repetitive movements or not reacting to their environment.

*For me, schizophrenia is jumbled thoughts and doing things I would not normally do. The last time I was admitted to the hospital, I had thrown my furniture out of my apartment: my bed, my tables, my TV, my radio, my computer, and then my clothes. I called the police every day because things were not going right. My furniture was missing—I was putting out my furniture, but why was I doing that? — Ann*

## NEGATIVE SYMPTOMS

Negative symptoms of schizophrenia “take away” from a person’s usual ability to accomplish tasks and enjoy life. They include reduced motivation, social withdrawal, reduced emotional expression, loss of interest and pleasure, and reduced verbal communication.

Negative symptoms tend to last longer than positive symptoms, and often disrupt the person’s ability to work, go to school, take care of others and accomplish daily tasks.

### **Reduced motivation**

A person with schizophrenia may have problems finishing tasks or making and carrying out plans. They may also have less energy and drive, both before and after an active phase of the illness. Some people misinterpret this behaviour as laziness or as “not wanting to try.” They may believe the behaviour is intentional, and become frustrated with the person. But this behaviour is related to the illness and not to the person’s character.

### **Social withdrawal**

One of the earliest symptoms that many people with schizophrenia experience is a change in their sensitivity toward others. A person may become more sensitive to and aware of other people, or they may withdraw and pay little or no attention to others. The person may become suspicious and worried that others are avoiding them, talking about them or feeling negatively toward them. The person may feel safer and calmer being alone. They may also become so absorbed in their own thoughts and sensations that they lose interest in the feelings and lives of others. They may spend more time alone in their room, not engaging with family or friends.

*All that happened was that she said: I'm not going to school any more. She couldn't cope with it. She couldn't articulate what she was feeling because she didn't know. I would say, are you okay? And she'd say, yeah. I did not see how much she was struggling. She isolated herself. She was trying to figure it out. She was just in her room. For her it was very inward.* — Gilda

### **Reduced emotional expression**

Many people with schizophrenia tend to have reduced emotional expressiveness. This may be seen in a lack of facial expression, a monotonous voice, fixed or prolonged staring, and less expressive body language than before the illness began.

### **Loss of interest and pleasure**

Interest in things that once brought satisfaction, pleasure or joy is often reduced or lost for people with schizophrenia. This might include activities like playing an instrument, playing a sport or enjoying a hobby, either with others or alone. However, as people start feeling better, these interests may return.

### **Reduced verbal communication**

Slowed or blocked thoughts may cause a person with schizophrenia to speak very little, even in situations where they are expected to speak. Questions may be answered in short phrases with limited content.

### **Change in habits and ability to function**

A person with schizophrenia may lose interest in their appearance, in the way they dress and in grooming and bathing. They may find it difficult to carry out daily activities such as shopping or going to work.

## COGNITIVE AND OTHER SYMPTOMS

### Changes in cognitive function

Schizophrenia affects how the thinking part of the brain works, known as cognitive function. These changes can be subtle or obvious, and can affect a person's ability to:

- pay attention, concentrate and remember
- interpret their environment
- use reason and judgment
- understand and process information
- express themselves through language
- read social signals and make sense of social interactions
- plan and organize tasks.

Schizophrenia's effect on thinking can affect the person's ability to work or learn, to follow through on activities of daily living, and to interact in social situations. Cognitive symptoms can be challenging because they tend to be long-lasting and may not respond to medications.

*I don't feel like I've improved since I've been on medication. I feel like I've stayed the same. My thoughts are not as jumbled, but my life hasn't improved. I'm still struggling with everyday living. Just going shopping, cooking my meals. — Ann*

### Disturbances of feeling or mood

Many of the symptoms of schizophrenia can make it hard for a person to identify and express their feelings. At times they may have inappropriate or intense bursts of feeling that seem to come out of nowhere, while at other times they may feel empty of emotions.

People with schizophrenia may also experience depression, sometimes with thoughts of suicide (suicide is discussed in more detail

on page 18). Anxiety may also occur, especially if the person is feeling distress as a result of their symptoms. Some may also feel anger.

## Ambivalence

Ambivalence means having conflicting ideas, wishes and feelings toward a person, thing or situation. A person with schizophrenia may feel uncertainty and doubt. It may be hard for them to make up their mind about anything, even common decisions such as what to wear in the morning. Often, even when they are able to make a decision, they find it hard to stick with it.

## Lack of insight

People with schizophrenia may not consider what they are experiencing to be an illness. This lack of insight or awareness may be present throughout the illness, and can contribute to a decision to reject a recommended treatment plan. Family members may find this particularly difficult to understand and accept.

*The first time I went to the hospital, the cops put me in an ambulance. I was a different person the next day, but I didn't accept the diagnosis and I didn't accept medications when I left the hospital a week later. —  
Moshe*

## How is schizophrenia diagnosed?

There is no lab test, scan or physical exam that can be used to diagnose schizophrenia. However, these types of investigations can be used to rule out other medical conditions with similar symptoms.

A diagnosis can be made by any physician. However, it is best made by a psychiatrist or psychologist, as these mental health

specialists have specific training and experience in assessing, diagnosing and treating schizophrenia. Psychologists can assess, diagnose and provide psychotherapy for mental health disorders, but medication can only be prescribed by psychiatrists and other physicians.

To arrive at a diagnosis, the physician or psychologist asks structured questions about how the person is thinking and behaving. This information gathering, called an assessment, may be completed in one meeting or may involve several meetings. The clinician may also gather information from family members or others who are familiar with the person's history. Other clinicians, such as social workers, nurses or occupational therapists, may also help to collect information.

A diagnosis of schizophrenia is based on:

- the information gathered
- ruling out other possible explanations
- the physician or psychologist's clinical judgment
- signs that have been continuously present for at least six months, with at least one month of active (positive and/or negative) symptoms
- symptoms that are severe enough to have an impact on the person's social, educational or occupational functioning and abilities.

The type and severity of symptoms can vary among people with a diagnosis of schizophrenia.

Arriving at a diagnosis can be challenging as there are other related disorders that share some features with schizophrenia (e.g., hallucinations and delusions) while also having important differences. Schizophrenia is now considered to be part of a spectrum of psychological disorders that feature psychosis. There are also medical problems that can cause similar symptoms. The expertise of a physician or psychologist is crucial to arriving at an accurate

diagnosis. Some of the disorders related to schizophrenia (or with similar symptoms) are:

- schizoaffective disorder
- delusional disorder
- schizophreniform disorder
- bipolar disorder
- depression with psychosis
- schizotypal personality disorder
- substance-induced psychosis
- brief psychotic disorder.

Research has shown that the earlier a person can get a correct diagnosis and treatment for schizophrenia, the better the long-term outcome. Family involvement and advocacy can help ensure that the person gets access to a diagnosis and care as soon as possible.

*The GP didn't even have a clue. The psychiatrist said it was addiction. There was no attempt at a mental health diagnosis. It took two years. — Gilda*

*It got so chaotic, and I totally lost it. I had a nervous breakdown, and they diagnosed me with schizoaffective disorder and I don't know why, I'm not sure, but I know my thoughts were chaotic, I was paranoid, and I was extremely anxious, I was wound up, my stress level was high. — Ann*

*There was a family history so when I noticed there were changes I sought help. I do think being able to recognize the signs and getting treatment in the early stages helped. I was able to get a degree, to hold a job and have friends and live on my own. — S*

## Co-occurring issues

People with schizophrenia often have other issues at the same time. These may include physical health problems, substance use or a history of traumatic events in their lives. Even on its own, recovery from schizophrenia can be a significant challenge for the person with the illness and their family. When these co-occurring issues are present, their treatment should be integrated into the overall recovery plan.

### PHYSICAL HEALTH

In general, people with schizophrenia have poorer health and are at higher risk for premature death than the overall population. The most common cause of death is cardiovascular disease. This is partly due to lifestyle factors such as obesity, smoking, diabetes, high blood pressure and high cholesterol. Additionally, some of the medications used to treat schizophrenia can cause weight gain or worsen other risk factors, which can lead to diabetes and other serious health problems.

People with schizophrenia have a harder time accessing health care services, and their physical health issues often don't get proper medical attention. For people with any mental health disorder, regular exercise, a healthy diet and regular visits with a primary health care provider are essential to overall health, wellness and recovery.

### SUBSTANCE USE AND SMOKING

There is no simple explanation why substance use and smoking are more common in people with schizophrenia. Research suggests that substance use may increase the chance of developing schizophrenia,

and also that schizophrenia may increase the chance of developing a substance use disorder. In addition, certain people may have a genetic vulnerability that increases the chance of developing both schizophrenia and a substance use disorder. More research is needed to understand the link.

People with schizophrenia may use substances to:

- “self-medicate” (relieve symptoms or distress)
- relax, increase pleasure, fight boredom or make social connections
- cope with past trauma, poverty, social isolation, homelessness and stigma.

The relationship between substance use problems and schizophrenia is complicated and important. For example:

- Smoking cigarettes contributes to poor physical health outcomes in people with schizophrenia.
- Nicotine may interact with some antipsychotic medications and reduce their effectiveness.
- Cannabis use at an early age may increase the risk of developing schizophrenia.

Substance use by people with schizophrenia can:

- have a negative impact on relationships, employment, finances and physical health
- lead to legal problems
- worsen psychotic symptoms
- worsen depression and anxiety
- reduce the effectiveness of medication and psychosocial treatments
- increase the risk of relapse, hospitalization, housing problems, disruptive behaviour and relationship problems.

Despite the many negative consequences of substance use, a person may still feel that substance use helps them in some way. They may not be ready or willing to reduce or quit their substance use. However,

they may be open to considering ways to reduce the harm of their use (e.g., where they use, how they use, who they use with). This kind of approach can help to start conversations about substance use, and help people to move toward reducing or stopping their use.

The best approach to helping people with schizophrenia quit or make changes to their substance use, including smoking, is one that recognizes the relationship between schizophrenia and substance use. These specialized “concurrent disorders” treatment services are not widely available, however, and can be difficult to find.

## TRAUMA

Childhood trauma, in particular childhood sexual abuse, may increase the risk that schizophrenia will develop in a person who has other risk factors for the illness. (Risk factors are described in Chapter 2.)

For some people with schizophrenia, the experience of acute psychosis (e.g., hearing voices, believing that others are out to harm them) and being hospitalized can be traumatic in itself.

The connection between psychological trauma and schizophrenia is not fully understood. But it is known that the effects of trauma—particularly traumas early in life—can complicate recovery. The best approach to assessment, recovery planning and all aspects of care considers trauma and its impacts. This is referred to as “trauma-informed” care.

## POVERTY

Poverty increases the risk of schizophrenia, and schizophrenia increases the risk of poverty. Poverty can have a negative impact

on mental and physical health. Adequate housing, employment and financial and social support can help to protect people with schizophrenia from the negative effects of poverty.

## STIGMA

Public attitudes, stereotypes and beliefs about schizophrenia can cause stigma—that is, negative and inaccurate beliefs that can have a profound impact on those living with the illness. Common beliefs—that people with schizophrenia are dangerous and violent, or that they are irresponsible and lazy—have a negative impact on individuals' work, housing and social opportunities. Stigma is mostly a result of people misunderstanding schizophrenia.

When people with schizophrenia are negatively and inaccurately judged by others, they can come to believe these negative things about themselves. This can lead to hopelessness, helplessness and a negative self-image, which can hinder recovery.

There are strategies that can help people with schizophrenia and their families to cope with and combat stigma. They include:

- developing a recovery plan
- connecting with peers and family
- maintaining a sense of hope for the future
- educating oneself and others about schizophrenia
- challenging negative beliefs about oneself
- critically reviewing information about schizophrenia portrayed in the media, and encouraging others to do the same
- getting involved in anti-stigma initiatives, such as those led by the Schizophrenia Society, the Canadian Mental Health Association (CMHA) and the Mental Health Commission of Canada.

Combatting stigma is an important way to support the recovery of people with schizophrenia.

*People should understand that schizophrenia could happen to anybody. Mental illness doesn't discriminate, people do. — Moshe*

*There's a sense of self-denial because there's a lot of stigma attached to it, and misconceptions about what it is. People don't want to identify themselves as having it. They're like, that's not me. — S*

## Schizophrenia and violence

### VIOLENCE TOWARD OTHERS

A common myth about people with schizophrenia is that they are violent. In fact, people with schizophrenia are more often the victims of violent crime than they are the perpetrators. Homelessness, substance use and severe symptoms increase the risk that a person with schizophrenia will be victimized.

Aggression and hostility *can* be associated with schizophrenia, though spontaneous or random assault by a person with schizophrenia is rare. It is not possible to predict with certainty who may be violent. However, factors that can increase the risk include:

- a history of violence
- substance use
- not participating in a treatment and recovery plan (e.g., not taking medications)
- impulsivity (tending to act without thinking about the consequences)
- being a younger male
- previous involvement with the criminal justice system.

It is rare, but some people with schizophrenia experience auditory hallucinations that command them to harm others, or delusional

beliefs that compel them to protect themselves through violence. Having these types of hallucinations or delusions does not mean that a person will act on them. If you or someone you know is experiencing symptoms that command or compel violence, get help from a health care provider right away.

## SUICIDE

People with schizophrenia are six times more likely to attempt suicide than the general population. However, this does not mean that a diagnosis of schizophrenia will lead to suicidal behaviour or death by suicide. There are particular risk factors for suicide, including:

- a history of suicidal thoughts or attempts
- positive symptoms (delusions, hallucinations, disorganization of thought, speech or behaviour)
- co-occurring depression or substance abuse
- lack of insight and awareness of schizophrenia's effect on one's mental state
- lack of treatment or downgrading of the level of care
- negative beliefs about medications; not taking medications as prescribed
- chronic pain or illness
- hopelessness
- a family history of suicide
- social isolation or limited external supports
- agitation and impulsivity
- childhood psychological trauma.

People with schizophrenia may require extra support, attention and treatment due to increased risk of suicide when:

- the person is experiencing active and intense psychotic symptoms
- the person is very depressed

- the illness is in its early stages
- the person has been discharged from hospital.

People experiencing suicidal thoughts may attempt to hurt themselves. Suicidal thoughts should be taken seriously and should always be discussed with a health professional or therapist. In the event of an emergency, contact 911 or go to your nearest emergency room. Family members may need support and assistance to cope effectively in such situations.

## 2 What causes schizophrenia?

*We don't know if it's cannabis, if it's stress, if it's biological, or trauma—all those impact it. There's no definitive answer. For me it was stress. I felt a lot of guilt and shame about the way I ended a relationship. I also felt like I was failing in other areas of my life. I feel I created a spiritual fantasy to find a sense of meaning and significance in my life.* — Moshe

It is not known for certain what causes schizophrenia, but like most other mental health problems, researchers believe that a combination of biological and environmental factors contribute to its development.

Because the specific causes of schizophrenia are still unknown, we cannot predict who will get it. However, researchers have discovered that certain factors increase the risk of a person developing schizophrenia. These risk factors are described below.

### Biological theories

Biological theories of the causes of schizophrenia suggest that:

- Genetics plays a role—the risk of developing schizophrenia is higher when a close family member has the illness.

- The symptoms of schizophrenia result from an imbalance of brain chemicals (e.g., the neurotransmitters dopamine and glutamate).
- Structural differences in the brains of people with schizophrenia have been discovered; however, it is not known if these differences are the cause of schizophrenia or if schizophrenia causes the differences.
- Current research suggests that schizophrenia may be influenced by brain development factors before and around the time of birth, and during childhood and adolescence. These different influences are thought to set the stage for schizophrenia, which usually appears in late adolescence or early adulthood.

## Environmental theories

Environmental factors are those that exist outside of a person's body, in their surroundings. Biological factors, such as having a family member with schizophrenia, have long been recognized as important. However, we now know that the picture is more complex. Stressful life events and other environmental factors increase the risk that someone with genetic vulnerability will develop the illness. Research into the role of environmental factors suggests that:

- People who have experienced social hardship or trauma, particularly during childhood (e.g., sexual abuse or lengthy separation from parents), have a higher risk of developing schizophrenia.
- Cannabis use increases the risk of developing schizophrenia in youth and of triggering an earlier onset of the illness in people who are genetically vulnerable.
- Being born or spending one's childhood in an urban environment, rather than a rural one, increases the risk of developing schizophrenia. This may be due to environmental factors such as social isolation and overcrowding.

- Particular immigrant and refugee groups in Ontario may have a higher risk of developing psychotic disorders. As more research is being done, similar findings are emerging internationally.

Exactly how these risk factors interact to cause schizophrenia is not yet fully understood. The presence of one or more of these factors does not mean that schizophrenia will develop. Rather than being caused by a single factor, schizophrenia appears to be influenced by biological and environmental factors that interact in complex ways. As research continues into the causes of the illness, other ways to diagnose and treat it may be revealed.

*I wish people understood that it's not the person's fault  
that they are sick. If I could not be sick, I would choose  
not to be. — Ann*

## 3 Treatments for schizophrenia

*There are two halves to the treatment equation: the medication, and the other half, people, social settings, introspection and reflection, goal setting—the practical stuff. For me, the medication was necessary, especially in the beginning. There was a lot going on inside my head and the medication helped to slow down my thoughts. It gave me a chance to rebuild my life. —*

Moshe

Treatment for schizophrenia often begins with medication. Psycho-social supports, such as psychotherapy, education and peer support, can also promote recovery. Treatment needs to address other health concerns, too—regular check-ups with a family doctor are important.

Families can play an important role in a person's recovery. Family counselling can help people with schizophrenia and their families to understand and manage challenges related to the illness.

Understanding the treatments and supports offered will allow you to discuss them with your treatment team, and to develop your own recovery plan.

## The treatment team

The treatment team can include nurses, doctors (including psychiatrists), social workers, psychologists, pharmacists, occupational therapists, recreational therapists, dieticians, peer support workers and spiritual advisors. The role of the treatment team is to help you build a recovery plan. A collaborative, trusting relationship with the team members can help you to recover your health and re-engage with things that are meaningful to you.

## Medication

The main medications used to treat symptoms of schizophrenia are antipsychotics. They are often used in combination with medications for other mental health symptoms, such as mood stabilizers, sedatives and antidepressants,<sup>1</sup> and medications to help with the side-effects of antipsychotics.

Antipsychotics (previously called neuroleptics) can reduce or relieve symptoms of psychosis, such as hallucinations and delusions. In a person with acute psychosis, these medications can help to control symptoms and to calm and clear confusion within hours or days, but can take up to six weeks to reach their full effect. Over a longer term, antipsychotics can help to prevent further episodes of psychosis.

While they can help most people with schizophrenia, antipsychotics can have serious side-effects. The aim of medication treatment is to reduce and control symptoms while keeping side-effects at a minimum.

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<sup>1</sup> Further information about these types of medications can be found online at [www.camh.ca/en/hospital/health\\_information/a\\_z\\_mental\\_health\\_and\\_addiction\\_information](http://www.camh.ca/en/hospital/health_information/a_z_mental_health_and_addiction_information).

## WHAT DO ANTIPSYCHOTICS DO?

Psychosis is believed to be caused in part by overactivity of a brain chemical called dopamine. Antipsychotics work by blocking this dopamine effect. This helps to relieve the positive symptoms of psychosis, but it does not always make them go away completely. A person may still hear voices and have delusions, but they are more able to recognize what isn't real and to focus on other things, such as work, school or family.

*Some members of my family think that when I'm on medication, I should be 100 per cent normal, which is not true. The medication doesn't cure all the symptoms.*

— Moustafa

## TYPES OF ANTIPSYCHOTICS

Antipsychotic medications are generally divided into categories: first-generation (also called typical antipsychotics) and the newer second- and third-generation (atypical).

The newer, second-generation (atypical) antipsychotics include clozapine (Clozaril),<sup>2</sup> olanzapine (Zyprexa), quetiapine (Seroquel), risperidone (Risperdal), paliperidone (Invega), ziprasidone (Zeldox), lurasidone (Latuda) and asenapine (Saphris). Aripiprazole (Abilify) is classified as a third-generation (atypical) antipsychotic.

The first generation (typical) antipsychotics that are commonly used include chlorpromazine, flupenthixol, fluphenazine, haloperidol, loxapine, perphenazine, pimozide, thiothixene, trifluoperazine and zuclopentixol.

<sup>2</sup> Medications are referred to in two ways: by their generic name and by their brand or trade name. Brand names available in Canada appear here in brackets. Older medications are generally referred to by their generic name.

The newer and older medications work equally well overall, although no drug or type of drug works equally well for everyone who takes it. You may need to try different antipsychotics before finding the one that works best for you.

Clozapine often works even when other medications have failed. However, it is not the first choice for treatment because it requires monitoring of white blood cell counts.

## HOW ARE ANTIPSYCHOTICS TAKEN?

Most of these medications are given in tablet form, some are liquids and others are given as injections. Some are available as long-lasting (“depot”) injections, which may be given anywhere from once a week to once a month.

Treatment begins with a low dose; your response to the medication is monitored closely for any side-effects.

Using substances—including alcohol or tobacco—while taking antipsychotic medication can interfere with the treatment and may make symptoms worse.

## SIDE-EFFECTS

Some people experience no side-effects. If they do occur, they may be noticed within hours, days or weeks of starting treatment. Side-effects vary depending on the medication and on the person taking it. Common side-effects include fatigue, sedation, dizziness, dry mouth, blurry vision and constipation. Though they are bothersome, most side-effects are not serious, and diminish over time.

Some people accept the side-effects as a trade-off for the relief these medications can bring. Others find them distressing and may choose

to speak to their physician about other medication options. Your physician may prescribe a lower dose, add a medication to reduce the side-effects, or recommend a different medication altogether.

If you are troubled by side-effects that are tolerable, continue to take your medication as prescribed and let your physician know as soon as possible. If the side-effects are not tolerable, go to your nearest emergency room.

Treatment with antipsychotics does carry a risk of some more severe side-effects that can affect your physical health. Your physician will check for signs of the following effects at your regular follow-up visits, and treatment can be adjusted. Most side-effects can be minimized with other medications. Changing your medication can also help. Be sure to talk to your doctor about any side-effects you experience.

### **Movement effects**

Some people experience tremors, muscle stiffness and tics. Usually, the higher the dose, the more severe these effects are. The risk of movement effects (also called extrapyramidal effects) may be lower with the second-generation medications than with the older drugs. Other drugs (e.g., benztropine [Cogentin]) can be used to control the movement effects.

### **Dizziness**

Dizziness may occur, especially when getting up from a sitting or lying position, because of temporary lowered blood pressure. Getting up slowly can help prevent dizziness.

### **Cardiac arrhythmias**

Some medications can cause arrhythmias, where the heart beats too fast, too slow or with an irregular rhythm. Cardiac arrhythmias can increase the risk of heart disease.

## **Weight gain**

It is not yet fully understood why people who take antipsychotics put on weight. Whatever the cause, weight gain can increase a person's risk of diabetes and heart disease. These effects are known as metabolic effects. A healthy diet and regular exercise can help to limit weight gain.

## **Diabetes**

Schizophrenia is a risk factor for diabetes. Antipsychotic drugs can increase this risk.

## **Agitation and sedation**

Antipsychotics make some people feel agitated, or “wired,” and unable to stop moving. This side-effect is called akathisia, and may be mistaken for a worsening of the illness. For some people antipsychotics can have the opposite effect, making them sedated or tired. Some people may feel both wired and tired at the same time.

## **Tardive dyskinesia**

Tardive dyskinesia (TD) is a condition that causes people to have repetitive involuntary movements of the tongue, lips, jaw or fingers. The risk of TD is highest with first-generation antipsychotics, although it can occur with the newer drugs as well. If TD does develop, there are ways to identify it at an early stage and to modify treatment. This will reduce the risk that the condition will continue or worsen.

## **Hormonal and sexual side-effects**

Some antipsychotics can cause changes in sex drive, along with other sexual problems, menstrual changes, and the abnormal production of breast milk (in both men and women).

## Neuroleptic malignant syndrome

This is a rare but serious complication. Signs include fever, muscle stiffness and delirium (e.g., disorientation and confusion). This condition can be life threatening and requires immediate treatment.

*Sometimes doctors do not want to change medications if they perceive you as stable, but sometimes finding the right medication for you outweighs not changing. I had a lot of side-effects: weight gain, stiffness and muscle movement from TD; it was pretty bad. Changing the medication helped. I needed to find the right med, and I went through several. I knew how I was feeling. I knew me. People have to advocate for themselves. — S*

## HOW LONG DO I NEED TO TAKE ANTIPSYCHOTICS?

You will be advised to keep taking antipsychotic medications even after the symptoms are controlled. If you stop taking medication too early, there is a high risk that symptoms will return. This may not happen until several months later.

Continuing to take the medication reduces the risk of relapse, and can reduce the intensity of symptoms if you do have a relapse. Preventing relapse helps to promote recovery and to improve the overall outcome of the illness. Talk with your doctor about how long you should continue taking medication.

*If I don't take my medication for a couple months, I end up with another episode. I end up in the hospital. That's why I am strictly religious about taking my medications. I'm going to have to take medication for the rest of my life, and I'm okay with that. When I don't take it, I spin out. — Moustafa*

## HOW MUCH DO MEDICATIONS COST?

The cost of medications varies, depending on the type. Some or all of the cost may be covered if you qualify for a provincial drug benefit program, or if you have a prescription drug benefit plan through your work or through a family member. Students may have drug benefits through their college or university.

For example, in Ontario, the Ontario Drug Benefit is available to people who:

- are on social assistance (Ontario Works)
- are on disability (Ontario Disability Support Program)
- have a low income (Trillium Drug Program)
- are 24 years of age or younger, or 65 or older.

## Electroconvulsive therapy

When symptoms of schizophrenia are not relieved by medication, or when a person with schizophrenia is severely depressed, electroconvulsive therapy (ECT) may be advised.

ECT does not resemble the shock therapy portrayed in older films and TV shows. Now patients are given a muscle relaxant and a general anesthetic before a mild electrical current is applied to one or both sides of the brain. The person being treated shows little visible movement. A course of ECT consists of a number of treatments that most often are given three times a week. The total number of treatments, and how often they are given, is decided in consultation with a physician.

Some people may experience side-effects of ECT, such as a headache or jaw pain when they wake up after the treatment. This usually requires only a mild painkiller such as acetaminophen (Tylenol).

Some loss of recent memory or problems with concentration usually occurs during treatment. These symptoms improve over a few weeks after the course of ECT is finished. Some people report memory problems *after* ECT treatment has been completed, but these problems usually improve within a few weeks or months.

## Transcranial magnetic stimulation

Transcranial magnetic stimulation (TMS) is a newer form of treatment that applies magnetic waves to the brain to stimulate nerve cells. This treatment would be considered in addition to medication. Researchers are still exploring its effectiveness.

## Psychosocial therapies and supports

Psychosocial therapies and supports help people to develop recovery skills, such as setting and achieving goals (e.g., improving self-care, pursuing education, finding or changing a job). The choice of therapies and supports will depend on your unique needs and on what is available in your community.

### PSYCHOEDUCATION

Psychoeducation provides information to help people deal with a mental health condition, such as how to manage symptoms and medication side-effects, and how to prevent relapse. It also provides information on the recovery process, such as how to maintain a sense of well-being and how to develop skills to manage stress and solve problems. Psychoeducation can be offered individually or in groups, and may be tailored to the person with a mental health condition or to family members and friends.

## THERAPIES

Several effective psychosocial therapies for schizophrenia, in individual or group format, are now available to complement treatment with medication. Group therapy can allow you to learn about other people's experiences with the illness, which can help to reduce isolation and promote recovery. Discuss your needs with your service providers to determine which kind of therapy is best for you.

### **Cognitive-behavioural therapy for psychosis**

The way you think about a situation can affect how you feel and how you behave. Cognitive-behavioural therapy for psychosis (CBT-p) explores the connection between your thoughts, feelings and behaviours and your experience of the symptoms of schizophrenia. CBT-p can help you to better manage your symptoms and stress, to understand the impact of the illness on your life, and to recognize how alcohol and other substance use affects symptoms. For some people, CBT-p helps to reduce symptoms and prevent relapse.

### **Cognitive adaptation training**

People with schizophrenia may have cognitive symptoms that affect their ability to remember, focus, pay attention and solve problems. These symptoms can make it hard to carry out everyday functions, such as taking medication and self-care. Cognitive adaptation training (CAT) uses individually customized supports, such as signs and checklists, to help people manage their daily tasks.

Clinicians who provide CAT help clients to:

- identify barriers to their goals
- organize their living space
- set up and practice new routines
- use different types of prompts and reminders.

The goal of this training is to help people with schizophrenia live more independently and to achieve their life goals.

## **Concurrent disorders treatment**

Mental health and substance use issues often occur together. When they do, they are often closely related and affect each other. For this reason, treatment for these co-occurring issues (also called concurrent disorders) is most effective when it addresses both issues at the same time. Concurrent disorders treatment may include counselling, education about substances and the impact of substance use on symptoms, medication management, stress management and relapse prevention. It may also include support in other life areas, such as housing and employment.

## **Family therapy and supports**

Having a supportive family can be a huge help to people with schizophrenia. However, family members themselves often experience significant stress. This can make it harder for them to be supportive and to take care of themselves. Individual and family counselling, psychoeducation workshops and support groups can help people to develop coping strategies and effective communication skills, which allow them to better support the family member and to practice self-care. (See Chapter 6 for more information about family supports.)

## **Peer support**

Peer support workers are people with lived experience of a mental health condition who are trained to provide support that is based on empathy and understanding. Having gone through their own personal recovery, peer support workers are able to help you plan and move through the steps of your own recovery. Support focuses on your strengths, rather than the illness, and on self-empowerment, self-advocacy and promoting hope. Peer support workers are important members of the treatment team. Peer support may be available one-on-one or in groups.

## Complementary approaches

You may wish to add other approaches to conventional treatments. Examples of complementary approaches include herbal medicine, acupuncture, homeopathy, naturopathy, meditation, yoga, Ayurveda (an ancient medical system from India), nutritional supplements and vitamins. However, none of these approaches has been tested to determine the effect on the symptoms of schizophrenia. Check with your treatment team about any complementary or alternative therapies you are taking or thinking about trying—especially herbal medicine or vitamins, which may interfere with the effectiveness of medications.

## Medical care, physical activity and diet

Important ways to manage health problems and to achieve and maintain physical health include:

- regular visits to a family doctor or specialist for medical care
- physical activity
- a healthy diet.

Physical activity positively affects both physical and mental health. Choose any physical activity you enjoy, and adapt it to your fitness level and to any medication side-effects you may experience. A healthy diet can help you manage the health problems often associated with schizophrenia. Look to your family doctor, a dietician or other treatment provider for help with planning your diet and exercise routine.

## 4 Hospital, intensive support and community support

With proper support and medication, schizophrenia may cause few or no interruptions in a person's life. However, a brief time in hospital may be necessary during an active phase of the illness. The goal of admission to hospital is to provide the treatment the person needs to regain their health and return home as soon as possible.

While the person is in hospital, families can play an important role in helping their relative and the treatment team to plan for discharge (leaving the hospital) and beyond. When the person with schizophrenia returns home, intensive and community supports may be available, if needed. These can help the person to make the transition back to the community and provide on-going support.

### Hospitalization

People with schizophrenia may need to be admitted to hospital at times—for example, if the person is aggressive or suicidal or is not looking after their own basic needs.

## VOLUNTARY AND INVOLUNTARY ADMISSION

Patients may be admitted to hospital *voluntarily*. This means that they:

- agree to enter the hospital, and
- are free to leave at any time.

The law also allows any doctor to admit a person to hospital *involuntarily*. This means the person may not agree that he or she needs help, and does not want to be in the hospital. This can happen if the doctor has assessed the person and believes there is a serious risk that the person:

- will physically harm himself or herself, or
- will physically harm someone else, or
- has shown or is showing lack of competence to care for himself or herself.

If no doctor has seen the person, families also may ask a justice of the peace (a local public officer with legal authority) to order a psychiatric assessment. They must provide convincing evidence that the person's illness is a danger to himself or herself or to others. The police are sometimes needed to help to get a person to hospital.

Laws protect the rights of people who are admitted involuntarily. For instance, a rights advisor will visit. The rights advisor will ensure that if the person wishes, he or she has the chance to appeal the involuntary status before an independent board of lawyers, doctors and laypeople.

For more information about mental health laws and patient rights in Ontario, see the website of the Psychiatric Patient Advocate Office [www.sse.gov.on.ca/mohlrc/ppao](http://www.sse.gov.on.ca/mohlrc/ppao).

## INPATIENT TREATMENT

A typical hospital stay may last between a few days and several weeks. During this time, goals and plans for treatment and recovery will be identified.

Patients take part in group educational and therapeutic programs, as well as individual sessions with medical, nursing and other professional staff. Programs and services may vary, depending on the person's needs and location. While the person is in hospital, medications may be changed or doses adjusted. Families may be asked to meet with medical, social work or other staff.

Discharge planning begins as early as possible. Patients can expect to leave the hospital once their symptoms have improved enough that they can safely care for themselves at home, and when ongoing treatment and support has been arranged.

## Intensive supports in the community

In Ontario, intensive supports include assertive community treatment (ACT) teams and intensive case management (ICM). Both work closely with the person with schizophrenia to create a recovery plan, to provide outreach, and to co-ordinate services to help the person work toward their goals. Each person's goals will be different, but they can include improving housing conditions, managing physical health (e.g., weight loss, diabetes care), building coping skills, managing substance use issues, creating healthy social relationships, and returning to school or work. Intensive supports may also be provided through a community treatment order (CTO).

## ASSERTIVE COMMUNITY TREATMENT TEAMS

An ACT team helps to support the person with schizophrenia with day-to-day living. Teams are usually either linked to a hospital or run through a community agency that is linked to a nearby hospital. The team may include a psychiatrist, peer support worker, registered nurse, social worker, occupational therapist, addiction specialist and vocational specialist.

ACT teams provide intensive support and co-ordinate services for people living with serious and ongoing mental health issues. This usually means people who have been hospitalized multiple times, and who may need a high level of support to manage living in the community. ACT team members often meet with clients several times a week, for example, in the client's home, a family doctor's office or a community centre. ACT services aim to promote consistent, ongoing support over a long period.

Patients who need support in the community and who meet other criteria may be referred to an ACT team by their treatment team. The local office of the CMHA or another mental health agency can tell you more about ACT teams in your community. ACT teams are more common in larger cities.

## INTENSIVE CASE MANAGEMENT

ICM is similar to the support provided by ACT teams. The difference is that instead of a team, support is usually provided by an individual case manager (e.g., a nurse, social worker or occupational therapist). Case managers see their clients regularly and help to co-ordinate care and services.

## COMMUNITY TREATMENT ORDER

A CTO is a legal agreement between a physician and a person with a serious mental illness, or the person's substitute decision maker.<sup>1</sup> A CTO is for people who have been in hospital several times, and have benefited from the treatment, but do not continue their treatment after leaving hospital. A CTO sets conditions and provides services that allow the person to receive care and support in the community, rather than in a hospital. If you are a substitute decision maker and you believe your family member would benefit from a CTO, talk to the person's care team.

## Community supports

Programs may be available to help people with schizophrenia live in their own community. The kinds of services offered vary with location, but can include financial, housing, education, employment and social support. The Schizophrenia Society and CMHA keep lists of local programs (e.g., peer support or consumer/survivor initiatives, drop-ins or support groups.) Your treatment team can also help to connect you to the supports you need.

Community supports can be anything from support groups (where people with similar life experiences meet and support each other) to places to go in a crisis. Below you'll find some information about a few types of community support.

## CONSUMER/SURVIVOR INITIATIVES

People who have used mental health services sometimes choose

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<sup>1</sup> When a doctor determines that a person is incapable of making decisions about their own care, a family member (or a public guardian or trustee) may be appointed as a substitute decision maker.

to identify themselves as consumer/survivors (consumers of mental health services and survivors either of their personal mental health issue or of the mental health system—depending on their experience).

Consumer/survivor initiatives are run by and for people who have lived experience (past or current) with the mental health system. These programs were developed as an alternative to traditional mental health services provided by hospitals or community mental health agencies. They offer education, information and support, and often also provide social/recreational opportunities, as well as work/employment opportunities with businesses run by consumer/survivors.

## CLUBHOUSES

Clubhouses are local community centres for people living with mental health issues. Members develop skills and work closely with peers and support staff to run the daily operations of the clubhouse. They prepare meals, build social connections, create newsletters, track members' participation and more. Clubhouses also offer support to help people transition into employment. Clubhouses differ from traditional mental health services in that consumer/survivors partner with staff to run the clubhouse, rather than simply receiving services from staff.

## SUPPORTED EMPLOYMENT / SUPPORTED EDUCATION PROGRAMS

Employment programs support your goal to return to work. They can help you to rebuild your work skills, to build self-confidence and to find jobs that fit your abilities and needs. These programs offer services such as job assessment, career counselling, aptitude testing, job search skills and on-the-job training.

Supported education programs support your goal to return to school with in-class training and skill-building. They are typically offered through community colleges, and mix academic upgrading classes with skills-based classes such as assertiveness training, communication and stress management.

Skills training programs are offered through community colleges, universities, high school upgrading programs, libraries and community centres. These programs work on specific skills (e.g., computer training) as a step toward employment.

## DROP-IN CENTRES

Drop-in centres focus on providing recreational and social opportunities rather than employment opportunities. They may have a structured schedule of recreation, meals and educational sessions, and are typically open to anyone. They can also be used as a place to rest, meet up with friends, or use a phone, computer, shower or laundry equipment. Drop-in centres can often help link you with other community supports.

## SUPPORT GROUPS

Self-help groups (also known as mutual aid or peer support groups) are made up of people who have a common concern, such as a mental health issue. These groups are usually led by people with lived experience of mental health problems and are open-ended, so you can join or leave at any time. Group members meet to give and receive support, and to exchange coping and problem-solving strategies and other information. Support groups help members to feel connected through sharing their experiences with others who can understand what they are going through.

# 5 Recovery and relapse prevention

*Recovery to me means not putting limitations on myself. To feel I can achieve things. What really worked for me is setting goals. I like to make lists of possibilities. It helps you get back into life. — S*

## What is recovery?

Psychiatry has changed over time, and so has the expected role of people receiving mental health services. Historically, it was thought that schizophrenia was a chronic and deteriorating condition and that people needed to be looked after, often in institutions, for the rest of their lives. This way of thinking has shifted.

In the late 1980s, a new way of thinking about recovery emerged from research evidence and the advocacy work of people with lived experience of schizophrenia. Recovery was now seen as a process of gaining control over one's life and finding meaning, rather than as the total absence of symptoms. People with schizophrenia could now expect to be involved in planning their own treatment and making decisions about their lives. They could expect to live in the community and to have meaningful lives.

This concept of recovery is now a guiding principle of mental health care.

## The process of recovery

Recovery is often described as a journey. It is not a straight line from sick to well, but a winding road that follows an individual's experience, including bumps, curves, potholes and smooth sailing. Each person's recovery is unique.

The following five key recovery processes, known as CHIME, were identified from personal recovery stories. Recovery may be seen as moving toward these conditions, rather than being free from symptoms.

- **Connectedness:** Having meaningful social connections, supportive relationships, peer support and being part of a community
  - **Hope and optimism for the future:** Having aspirations, dreams and beliefs that recovery is possible; having motivation to change
  - **Identity:** Having a positive sense of self and overcoming experiences of stigma
  - **Meaning in life:** Having roles, experiences, goals and personal values that bring meaning to your life (e.g., through spirituality, work, education or relationships)
  - **Empowerment:** Recognizing your own strengths and having ownership, responsibility and control over your own life
- (Leamy et al., 2011)

*If a person is not harming themselves or others, then who am I to say what is right for that person? In that context, recovery can mean anything to anybody. It's up to the person. — Moshe*

## Promoting wellness and preventing relapse

Everyone with a serious health problem needs to pay attention to their health, find strategies to maintain health, and prepare for possible relapse (the return of active symptoms). The following strategies can help to promote and maintain wellness for people with schizophrenia:

- **Become an expert on schizophrenia.** Learn about the symptoms, potential treatments and outcomes. Figure out what works for you; this will usually include medication and other support. The websites and other resources listed on page 68 offer information on a variety of schizophrenia-related topics. Consider also asking your service provider to recommend books, support groups or classes that might interest you.
- **Maintain social connections and prevent isolation.** We all need people in our lives who know and care about us. People with schizophrenia sometimes experience symptoms that lead them to become cut off from others. It's important to try to maintain your connections, and to be a part of a community. Besides providing enjoyment, friends may also be able to let you know if they notice changes in your behaviour that could be an early warning sign of relapse. Consider participating in community groups (e.g., cultural, spiritual, religious, special interest) that are meaningful to you.
- **Establish a healthy and active lifestyle.** Eating regular meals and following a balanced, nutritious diet is one of the best ways to take care of yourself. Another is being active. Run, walk, go to the gym, dance or play a sport. Find something that gets you moving that you enjoy. Ask your health care team to help connect you

with resources such as dieticians and food services, if needed (e.g., food banks, free meals or community kitchen programs) and options for free or low-cost physical activity.

- **Get the right amount of sleep.** If you feel you are not getting enough sleep, or that you are sleeping too much, talk to your psychiatrist, family doctor or case manager about education and treatment options for improving your sleep.
- **Reduce or stop substance use.** Consider the role that alcohol and other drugs play in your life, and how they affect your mental and physical health and social relationships. Substance use can make it harder to reach recovery goals and to achieve and maintain wellness. Look to your treatment team for help with addressing substance use issues.
- **Establish a medication plan that works for you.** With schizophrenia, maintaining wellness and reaching your recovery goals can depend on taking medications for a long time. Work with your doctor to find the smallest dose of medication to help control your symptoms with the fewest side-effects. This can be an ongoing process, as your needs may change over time. Take your medications as prescribed and work closely with your prescribing doctor to make adjustments as needed.
- **Develop a wellness plan.** Having a personal plan for maintaining your health is an important way of planning your recovery. Consider these actions when developing your wellness plan:
  - Participate in a WRAP group. WRAP stands for Wellness Recovery Action Plan. WRAP groups are peer-led, which means that the leader, as well as the members, has lived experience of mental health challenges. The leader is trained to help the group members develop an individual wellness plan. Your WRAP might include lists of wellness tools, triggers, early

warning signs and signs of relapse, and also a daily wellness plan and crisis plan.

- Collaborate with members of your health care team, such as your family doctor, psychiatrist, peer support worker, case worker and others. They can contribute to your plan by giving input on, for example, the use of medication for treating symptoms and the use of specific therapies.
- Establish advance directives. Advance directives are instructions to your treatment team that you make when you are well, to let them know your preferences and expectations for treatment if you become unwell. Talk with anyone on your health care team about establishing advance directives.

*I've taken the Wellness Recovery Action Plan program, and now I facilitate it. It has five key concepts of recovery, and one of them is support. There's also hope, education, personal responsibility and self-advocacy. It's not possible to recover without support. — Moshe*

## Practical aspects of recovery

### HOW MUCH SHOULD I SAY ABOUT MY DIAGNOSIS TO FRIENDS, FAMILY AND OTHER PEOPLE?

It's up to you how much information to disclose about your personal health to your friends, family or anyone else. If you are having trouble explaining schizophrenia, or aren't sure what to say, you can direct them to this booklet, or to online resources (see websites listed on page 68).

## WILL I BE ABLE TO WORK OR GO TO SCHOOL?

It is possible that you will be able to attend work or school. However, some symptoms of schizophrenia may affect the way you think, understand and attend to information, so school or work may be interrupted. It can take time to adjust to a new treatment routine, and you may need to learn new skills or strategies to manage tasks that were previously easy. If your symptoms cause interruptions to work or school, you can get help from an occupational therapist (OT), the student accessibility centre at your school, or occupational health supports at work. An OT can help you identify your strengths and develop strategies to address difficulties you may be experiencing, so you can succeed at work or school.

If you receive income supports through social assistance or disability (e.g., the Ontario Disability Support Program), or if you've simply been out of work or school for a long period and would like to return, a variety of resources and programs are available. You can access most programs by connecting with someone from the social assistance program, visiting a local employment support agency, or speaking to someone on your health care team.

See Chapter 4 for information about employment, educational and other types of community supports for people with schizophrenia.

*People say to me, is she working? Is she going to school?  
I had those same expectations. I thought, medication,  
good, everything is great, fast forward: can we go to  
school again? Nope. We think that once you get the  
medication sorted, you're good now. You start expect-  
ing things. You have to adjust your expectations. —  
Gilda*

*I think it's possible to have a good life despite schizophrenia; to have hope. It's possible to achieve things still. It's not the end of the world. — S*

# 6 Support for family and friends

*I'm always thinking that she's going to be okay. I don't think it's a delusion. I think it's good to think that way. to think positive. Never give up hope. — Gilda*

A diagnosis of schizophrenia for a loved one can bring many different emotions. Family members<sup>1</sup> and friends may feel loss, guilt, confusion, fear, sadness or anger; some may have all these feelings at once. All these feelings are normal. Lack of knowledge about schizophrenia, and the myths portrayed in the media about the illness, add to these distressing emotions. Learning about the illness and the treatments available, and about how to support and care for your relative while also taking care of your own needs, can help to promote a more positive outlook for everyone.

The way schizophrenia affects a person can vary depending on the person and on the phase of the illness. The effectiveness of treatments can also vary. Some people with schizophrenia will need ongoing support to live in the community; others are able to resume employment and other responsibilities, and can be as independent as anyone. Having family and friends who offer support and respect

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<sup>1</sup> Although this chapter uses the terms “family,” “family member” and “relative,” the information can also apply to friends.

can make an important difference in the quality of life for people with schizophrenia, and in helping them to achieve their recovery goals.

The person with schizophrenia still has strengths, talents and abilities, even when the symptoms of the illness conceal these qualities. The symptoms may require treatment, and your family member may require support, but they are still the same person, with hopes and goals for the future.

## Confidentiality and legal issues

Family members need a basic understanding of the laws that protect the rights of people with mental illness. For example:

- Privacy laws prevent the health care team from discussing an adult patient's health information with anyone outside the team, including the person's family, unless the patient gives permission.
- Patients have the right to refuse treatment.

Exceptions to these rules include:

- When a person is at risk or harming himself or herself, or others. When risk is involved, the person may be admitted for involuntary treatment for three days.
- When a doctor determines that a person is unable to make decisions about his or her own care. In this situation, a family member or public guardian or trustee may be appointed as a substitute decision maker.

Some laws protecting the rights of mental health patients vary depending on where you live. For more information, talk with your relative's doctor, or check with your local chapter of the CMHA or Schizophrenia Society.

## Common concerns

### **WILL MY FAMILY MEMBER LIVE A PRODUCTIVE AND HAPPY LIFE?**

With treatment and support, people with schizophrenia can and do live productive and happy lives. However, the illness can limit a person's functioning, and the recovery process takes time. People with schizophrenia, or any illness, do best when given time to heal. Reducing your relative's stress may help to prevent another active phase of the illness. Daily responsibilities should be increased gradually. Your patience, understanding and support will help your relative to reach their full potential.

### **WHAT SHOULD I TELL FRIENDS AND RELATIVES?**

How much you and your family tell other people about your relative's illness will depend on your own comfort level, and on your relative's wishes. Look for opportunities to educate friends and family about schizophrenia and how it affects your family member. Share this guide, and the resources listed on page 68, and offer to talk about the illness with friends and relatives. When others better understand your family member's experience, it helps to build their compassion and can bring them into your family member's network of support. A wider support network is better for the family member who is ill, and for everyone involved.

### **WHAT SUPPORTS ARE AVAILABLE TO FAMILIES?**

Any type of serious health diagnosis in the family can be stressful, but the stigma often associated with a mental health diagnosis can make it hard to seek out support. If you or your relative does not feel ready to share information about the illness with friends or

family, there are many community agencies that offer confidential support and counselling. Family support and education groups are especially recommended if your family member is going through an initial, acute phase of the illness. For information about supports available in your community, talk to your family member's care team, or contact your local chapter of the Schizophrenia Society or CMHA. See page 68 for contact information.

## WHAT SHOULD I DO IF MY FAMILY MEMBER DOES NOT BELIEVE THEY HAVE SCHIZOPHRENIA?

Schizophrenia can affect a person's thinking, feeling and behaviour. Sometimes the illness can even affect their ability to understand that they are ill. This is difficult for families who want their loved one to get help—and for the person with schizophrenia, who is being asked to seek help, but does not see the need.

Helping your relative to develop insight into their illness can take time. Be patient, and encourage your family member to talk about their feelings. If the person is resistant to talking about the illness, start with an area of their life that is affected by the illness, and ask about ways to help. Families who have experienced this situation say that it is best not to challenge their family member's thoughts, but rather to work on a mutually agreed issue. Many people do develop insight into their illness, though some may not.

If your loved one appears to be struggling with symptoms but is not currently receiving treatment, just letting the person know that help exists may be enough to get them to seek treatment. For some people, it may take longer to accept that they have an illness that must be managed over their lifespan. Some people may experience several episodes of the illness before they consistently accept help from doctors and therapists.

It can be very difficult to watch the person who is ill struggle without trying to convince them to “take your medication” or “talk to your doctor.” Repeated attempts to convince and cajole can lead to heated arguments and power struggles. If you are very close to the person with schizophrenia, and yet you feel that they may not be open to your observation that something is wrong, it may be more effective to have another trusted person approach them.

If you have your family member’s permission to share information with their health care team, or if you are their substitute decision maker, collaborate with the health care team and your family member to help to the person learn about the illness and about recovery.

*In my role as a peer support worker, I've learned that people are at different stages of their recovery. Everyone's journey is as unique as the person. What works for one person may not work for another. Listening to the person to discover what kind of support is meaningful to them can make a big difference in developing trust and a safe space for the person to grow. — Moshe*

## WHAT CAN I DO TO HELP MY RELATIVE BECOME LESS ISOLATED?

Some people with schizophrenia may become isolated because the illness takes away their motivation. For others it may be because they experience paranoia and fear that others are trying to harm them. Whatever the reason, seeing your relative become isolated can be upsetting and hard to understand. Talk with your relative about how their isolation makes you feel, and ask what you can do to help them enjoy the company of others.

Structure, routine and meaning can help to build motivation and reduce isolation. Think of interests that your relative enjoys, for

example, listening to or making music; being around dogs, cats or other animals; or following sports. Build activities around these interests. Some people may benefit from participating in local programs, volunteering (for example, at a gallery or theatre) or providing peer support to others with schizophrenia.

Your relative's treatment team may be able to help. If you have the person's permission to share information with the treatment team, or if you are the person's substitute decision maker, ask the team to work with you and your relative to understand why he or she is isolated, and to generate ideas for spending more time in the community. If your family member experiences paranoia, the treatment team may be able to suggest ways to decrease the person's distress and triggers.

*There should be a support group to help parents become better advocates. — Gilda*

## WHAT SHOULD I DO IF MY FAMILY MEMBER IS DEPRESSED AND TALKS OF SUICIDE?

Some people with schizophrenia feel depressed, unlovable and hopeless. Occasionally, they may be in serious danger of taking their own lives.

People usually show warning signs that they are thinking of suicide before they attempt or die by suicide. If you can recognize suicidal thinking and other warning signs, you will be better prepared to act quickly and competently in times of crisis. Some of these warning signs are listed below.

People who are feeling suicidal may:

- show a sudden change in mood or behaviour
- show a sense of hopelessness and helplessness

- express the wish to die or end their life
- increase substance use
- withdraw from people and activities that they previously enjoyed
- experience changes in sleeping patterns
- have a decreased appetite
- give away prized possessions or make preparations for their death (for example, creating a will).

These signs should be taken seriously. Don't be afraid to ask your relative about thoughts or plans for suicide. Talk with your relative about what they are feeling, and encourage them to discuss suicidal feelings with their doctor or mental health professional. If immediate help is required and is not available, take your relative to the emergency department of the hospital where treatment was previously provided, or to the nearest general or psychiatric hospital. In the event of an emergency, call 911.

## HOW CAN I SUPPORT MY FAMILY MEMBER IF THERE IS A CRISIS?

Dealing with a crisis is always easier when you are prepared. Communication can be difficult for a person in crisis, so ask your family member at a time when they are stable what comforts and supports would be most helpful in a crisis. Develop a safety plan with your relative to address any potential concerns in advance; this can reduce the level of stress for everyone involved. If you have access to your relative's treatment team, collaborate with them on the safety plan.

In the event of a crisis, bring your family member to the hospital. If additional support is needed, mobile health crisis teams may be available in your community by calling 911 and asking for mental health support. Otherwise, 911 can provide support in bringing your family member to the nearest hospital.

The following tips may help to avoid or de-escalate a crisis:

- Don't challenge delusions.
- Create a calm environment where your family member feels safe.
- Reduce stimulation such as TV, radio, music, computer games or other distractions.
- Don't shout, and don't criticize or insult your relative.
- Suggest activities or distractions that your relative has identified as helpful (e.g., music, breathing exercises, drawing).
- Give your relative physical space.
- Speak slowly and clearly, and use simple sentences.
- Invite your family member to sit down and talk to you about what is bothering him or her.<sup>2</sup>

## How to support your family member

Having family and friends to turn to can improve your relative's quality of life, prevent isolation and help them to engage in the recovery process. Here are some ways to provide support:

- **Communicate openly and often with your family member.** To ensure that communication takes place and is effective, pick a time that is convenient for all involved, when everyone is calm. Set clear expectations: when family members understand what is expected from each other, it helps to decrease stress and conflict. Make sure the point of view of the family member with schizophrenia is made clear, and that everyone has an opportunity to contribute.
- **Keep emotional intensity at a lower level and avoid intense criticism.** People with schizophrenia can be sensitive to intense

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<sup>2</sup> Adapted with permission from: Schizophrenia Society of Canada. (2012). *Learning about Schizophrenia: Rays of Hope. A Reference Manual for Families and Caregivers* (4th rev. ed.). Winnipeg, MB: Author.

emotions in interactions, particularly when these emotions are negative and are linked to criticism. While this is true of many people, it can cause considerable distress for those with schizophrenia.

- **Help your relative to have a positive outlook for the future.** Focus on your relative's strengths and goals, rather than the illness. Identify factors that can help to protect them from relapse. Examples of protective factors include:
  - strong family and community support
  - limiting use of drugs and alcohol
  - getting the appropriate amount of sleep
  - reducing stress
  - taking medication as prescribed.

Work with your family member to identify these protective factors early on and help to keep them in place. Encourage the person to make and reach goals for the future.

- **Make sure your family member feels loved, supported, respected and valued.** Like anyone, people with schizophrenia need to feel accepted for who they are. Be careful to not spend all your time with your family member discussing treatment and recovery. At the same time, be sure the person knows you are there to support the recovery process.
- **Attend appointments with the treatment team.** If you have your relative's permission to share information with the treatment team, or if you are a substitute decision maker, you can provide helpful information to the treatment team. This includes information about your relative's symptoms and how they developed, and about their life and interests before the illness began. You can also learn from the team about the nature of the illness and treatment options, and work with the team and your relative to collaborate on a recovery plan.

- **Help your relative to connect with resources.** If your relative needs treatment, case management or other supports, help them to connect to services in your community. See page 68 for contact information for referral services and mental health agencies. Family doctors can also help with identifying mental health services and with the referral process.
- **Challenge stigma.** Public education campaigns encouraging people to talk openly about mental health have helped to correct myths about schizophrenia. But there are still many people who do not have an educated understanding of the illness. The media still portray people with schizophrenia in misleading ways—often showing them as violent, when statistics show that people with schizophrenia are more likely to be the victims of violence. Try not to let stigma allow you and your relative to become withdrawn, because this can hamper the recovery process. Educate yourself, your family member and others about the illness. Challenge stigma when you encounter it. Each time you do, you help your relative, and you help others with the illness.
- **Promote your relative's self-care and a healthy, active lifestyle.** The negative symptoms of schizophrenia can affect a person's ability to maintain hygiene and other basic self-care needs. While basic hygiene may be your relative's most obvious need, promoting a holistic approach to health may be the best way to ensure self-care. Emotional, spiritual and physical health all play a role in self-care. One way to promote self-care is to encourage positive coping mechanisms such as exercise and the pursuit of creative outlets. If substance use is an issue, it can trigger symptoms and have a negative impact on self-care. Helping your relative get the support needed to cut down or quit using substances can improve their overall health, including their self-care. Keep in mind that the pace of progress for improving health may be gradual, and is different for every person.

- **Help to ensure your relative takes medication as prescribed.** Keeping to a medication routine can be challenging for some people with schizophrenia. Medications help to manage symptoms and to prevent further acute episodes of the illness. Work with your relative to create and participate in a plan for taking medications as prescribed. Help the person to note any possible side-effects of the medication or symptoms that are not managed by the medication. These should be reported to the prescribing physician.

## How to support yourself

Supporting your relative during recovery can be stressful, and is a process that takes time. You may also need support. As the saying goes, “Put your own oxygen mask on first,” so you are in a better position to help your relative and other family members with their “masks.” This will enable you to continue to be an active participant in your relative’s recovery.

Consider the following ways of supporting yourself as you provide care and support to your relative:

- **Attend a support group.** Feelings of fear, uncertainty, isolation, loss or grief are common to families of people with schizophrenia. Being with others who understand and experience similar thoughts and emotions can be reassuring and helpful.
- **Educate yourself about the illness.** Learn all you can about schizophrenia, especially in the early stages of treatment. It will help you to support your relative, and also to get the support you need. The better informed you are about your relative’s illness, the better prepared you will be to navigate the treatment system and to promote the person’s recovery. A better understanding of

the illness can also help you come to terms with what it means to have a family member with schizophrenia. Just as important, knowing more will make it easier for you to talk about the illness and to educate others about how they can help to support your relative, and you.

- **Recognize your stress and learn coping mechanisms.** Family members need to find a balance between supporting their recovering relative and finding time for themselves. This helps to prevent exhaustion and burnout.
- **See a counsellor.** Sitting down with a counsellor, with or without your family member, can provide needed support. Professional counselling lets you express thoughts and feelings that you may not feel comfortable sharing with others, and allows you to feel that you're being heard. Counselling can also help you to improve your coping and communication skills; deal with feelings of depression, fear, anxiety and grief; and improve your sense of well-being. Counselling services may be available through your employer, if they offer an employee assistance program (EAP), or through a community hospital, clinic or mental health organization. You may also seek a counsellor or psychotherapist in private practice, whose fee may or may not be covered by employee benefits.
- **Practise self-care.** Self-care is important for everyone, especially when you are going through a difficult or stressful time. Make a point of taking care of your emotional, physical, spiritual and social needs.
- **Create boundaries.** Setting boundaries is as important as providing unconditional support. As a caregiver, you need to communicate your own needs and allow time for yourself. Setting firm and consistent definitions of unacceptable behaviour is crucial for

the well-being and safety of everyone in the family. Having clear boundaries can provide a structured, predictable and secure environment for your relative.

*Don't try to take on everything. You don't have to be the be-all and end-all. You think you have to be, but it's okay to just step back.* — Gilda

## Working with mental health professionals

When your relative has given consent to your involvement in their care, or you have been assigned as the person's substitute decision maker, consider the following hints for working with mental health professionals:<sup>3</sup>

- Write things down (e.g., names, phone numbers, dates of meetings, questions).
- Ask for meetings with the treatment team—contact the unit social worker or outpatient case manager. When possible, include your family member in these meetings.
- Approach the staff if there are any concerns. If you do not receive a satisfactory response, contact the unit manager or the client relations co-ordinator, whom staff can identify for you.
- Offer your own observations on your relative's progress, including any side-effects they may be experiencing and any medical or social history that might be relevant to how they are coping.
- When you contact a treatment team member, leave your name, contact number and a brief message outlining relevant questions or concerns.

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<sup>3</sup> Adapted from: Baker, S. & Martens, L. (2010). *Promoting Recovery from First Episode Psychosis: A Guide for Families*. Toronto: CAMH. p. 30.

- Respect your relative's wishes (e.g., how often you contact their treatment team).
- Ask for specific information. If you don't understand what you are being told, don't be embarrassed. Ask for clarification.



# Understanding PTSD and PTSD Treatment



## What is PTSD?

**PTSD (posttraumatic stress disorder)** is a mental health problem that some people develop after experiencing or witnessing a life-threatening event, like combat, a natural disaster, a car accident, or sexual assault.

It's normal to have upsetting memories, feel on edge, or have trouble sleeping after this type of event. At first, it may be hard to do normal daily activities, like go to work, go to school, or spend time with people you care about. But most people start to feel better after a few weeks or months.

If it's been longer than a month and you're still having symptoms, you may have PTSD. For some people, PTSD symptoms may start later on, or they may come and go over time.

If thoughts and feelings from a life-threatening event are upsetting you or causing problems in your life, **you may have PTSD**.

**Here's the good news:** you can get treatment for PTSD — and it works. In this booklet, you'll learn about types of treatment that are proven to help.

For some people, treatment can get rid of PTSD altogether. For others, it can make symptoms less intense. Treatment also gives you the tools to manage symptoms so they don't keep you from living your life.

**PTSD treatment can turn your life around** — even if you've been struggling for years.



You're not alone. There's others out there that are going through and have gone through the same types of things that you are going through now. There are people out there that understand.

— Lee Norris  
US Air Force (1993–2010)



## What can cause PTSD?

Any experience that threatens your life or someone else's can cause PTSD. These types of events are sometimes called **trauma**. Types of traumatic events that can cause PTSD include:

- ▶ **Combat and other military experiences**
- ▶ **Sexual or physical assault**
- ▶ **Learning about the violent or accidental death or injury of a loved one**
- ▶ **Child sexual or physical abuse**
- ▶ **Serious accidents, like a car wreck**
- ▶ **Natural disasters, like a fire, tornado, hurricane, flood, or earthquake**
- ▶ **Terrorist attacks**

During this kind of event, you may not have any control over what's happening, and you may feel very afraid. Anyone who has gone through something like this can develop PTSD.

## Trauma can take many forms.

A traumatic event could be something that happened to you, or something you saw happen to someone else. Seeing the effects of a horrible or violent event can also be traumatic — for example, being a first responder after a terrorist attack.

## You're not alone.

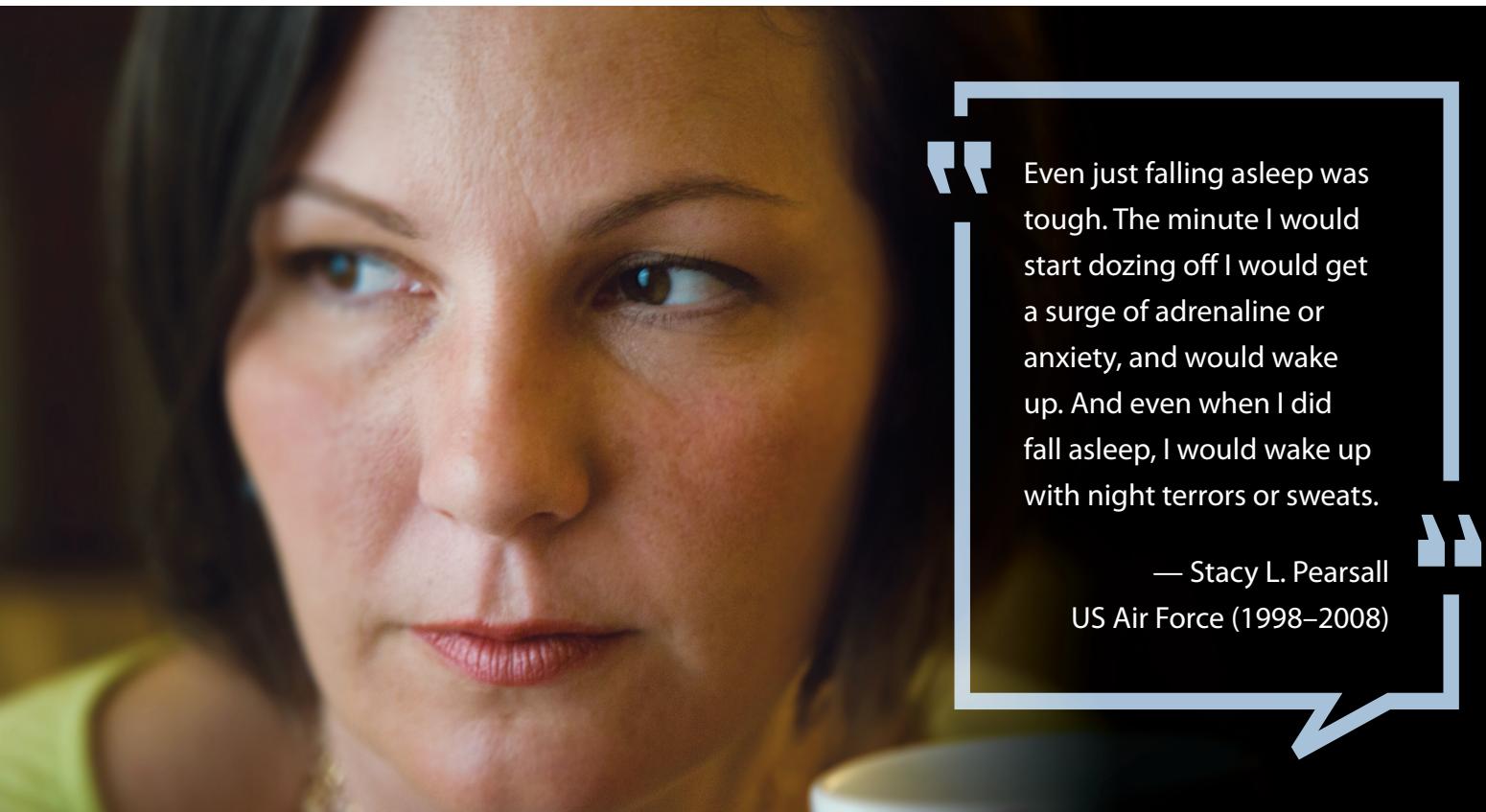
Going through a traumatic event is not rare. At least half of Americans have had a traumatic event in their lives. About 6 out of every 100 people (or 6% of the U.S. population) will have PTSD at some point in their lives.

There are some things that make it more likely you'll develop PTSD — for example, having very intense or long-lasting trauma, getting hurt, or having a strong reaction to the event (like shaking, throwing up, or feeling distant from your surroundings).

It's also more common to develop PTSD after certain types of trauma, like combat and sexual assault. But there's no way to know for sure who will develop PTSD.

I was awarded a Silver Star for bravery. You're not going to tell me I'm a coward. If somebody like me has PTSD, then anybody can have it.

— MAJ Joshua Brandon  
US Army (2002–present)



Even just falling asleep was tough. The minute I would start dozing off I would get a surge of adrenaline or anxiety, and would wake up. And even when I did fall asleep, I would wake up with night terrors or sweats.

— Stacy L. Pearsall  
US Air Force (1998–2008)



## What are the symptoms of PTSD?

There are 4 types of PTSD symptoms, but they may not be exactly the same for everyone. Each person experiences symptoms in their own way.

### 1. Reliving the event

Unwelcome memories about the trauma can come up at any time. They can feel very real and scary, as if the event is happening again. This is called a flashback. You may also have nightmares.

Memories of the trauma can happen because of a trigger — something that reminds you of the event. For example, seeing a news report about a disaster may trigger someone who lived through a hurricane. Or hearing a car backfire might bring back memories of gunfire for a combat Veteran.

### 2. Avoiding things that remind you of the event

You may try to avoid certain people or situations that remind you of the event. For example, someone who was assaulted on the bus might avoid taking public transportation. Or a combat Veteran may avoid crowded places like shopping malls because it feels dangerous to be around so many people.

You may also try to stay busy all the time so you don't have to talk or think about the event.

### **3. Having more negative thoughts and feelings than before**

You may feel more negative than you did before the trauma. You might be sad or numb — and lose interest in things you used to enjoy, like spending time with friends. You may feel that the world is dangerous and you can't trust anyone. It may be hard for you to feel or express happiness, or other positive emotions.

You might also feel guilt or shame about the traumatic event itself. For example, you may wish you had done more to keep it from happening.

### **4. Feeling on edge**

It's common to feel jittery or "keyed up" — like it's hard to relax. This is called hyperarousal. You might have trouble sleeping or concentrating, or feel like you're always on the lookout for danger. You may suddenly get angry and irritable — and if someone surprises you, you might startle easily.

You may also act in unhealthy ways, like smoking, abusing drugs and alcohol, or driving aggressively.



“ The emotional numbness... will just tear away all of the relationships in your life, you know, if you don't learn to unlock them [and] get those emotions out.

— Sarah C. Humphries  
US Army (1994–2012)

## How do I know if I have PTSD?

The only way to know for sure is to talk to a mental health care provider. They will ask you about your trauma, your symptoms, and any other problems you have.

If you think you might have PTSD, answer the questions in the screening tool below.

### PTSD Screen

Sometimes things happen to people that are unusually or especially frightening, horrible, or traumatic. For example, a serious accident or fire, a physical or sexual assault or abuse, an earthquake or flood, a war, seeing someone be killed or seriously injured, or having a loved one die through homicide or suicide.

Have you ever experienced this kind of event?  Yes  No

If yes, please answer the questions below. **In the past month, have you:**

- Had nightmares about the event(s) or thought about the event(s) when you didn't want to?
- Tried hard not to think about the event(s) or went out of your way to avoid situations that reminded you of the event(s)?
- Been constantly on guard, watchful, or easily startled?
- Felt numb or detached from people, activities, or your surroundings?
- Felt guilty or unable to stop blaming yourself or others for the event(s) or any problems the event(s) may have caused?

**If you answered “yes” to 3 or more of these questions, talk to a mental health care provider to learn more about PTSD and PTSD treatment.**

Answering “yes” to 3 or more questions does not mean you have PTSD. Only a mental health care provider can tell you for sure.

## What if the screening tool says I don’t have PTSD?

You may still want to talk to a mental health care provider. If thoughts and feelings from the trauma are bothering you, treatment can help — whether or not you have PTSD.

## What do I do if I have symptoms of PTSD?

After a traumatic event, it's normal to think, act, and feel differently than usual — but most people start to feel better after a few weeks or months. **Talk to a doctor or mental health care provider** (like a psychiatrist, psychologist, or social worker) if your symptoms:

- ▶ **Last longer than a month**
- ▶ **Are very upsetting**
- ▶ **Disrupt your daily life**

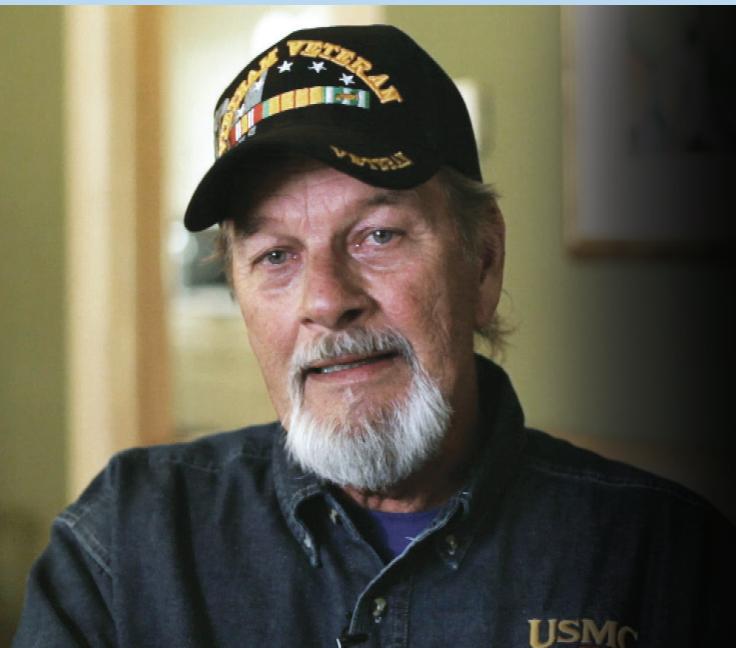
**Treatment can help** — you CAN get better.

## What other problems do people with PTSD have?

Many people who have PTSD also have another mental health problem — like depression, anxiety, alcohol and drug abuse, or thinking about harming themselves or others. It's also common to have problems at work, in relationships, or with your physical health.

Sometimes, these problems happen because of your PTSD symptoms. For example, feeling numb and avoiding places can make it hard to have good relationships with your friends and family.

Getting treatment for PTSD can help with these other problems, too.



“ I have kicked my alcohol. I kicked my drugs. And this is all from the treatment I have been given from the PTSD clinic.

— Craig “Stu” Shipley  
US Marine Corps (1964–1968)



Treatment has turned my life completely around. I'm a lot more comfortable in my own skin.

— Jeremiah Civil  
US Marine Corps (2001–2005)

## Why get treatment for PTSD?

### Treatment works.

There are many treatment options for PTSD. In this booklet, we'll tell you about different talk therapies and medications that are proven to help people with PTSD.

For many people, these treatments can get rid of symptoms altogether. Others find they have fewer symptoms or feel that their symptoms are less intense.

After treatment, most people feel they have a **better quality of life**.

It was difficult, that first time going, because I didn't think I really needed it. But once I got there and spoke with the counselor, I felt better when I left that day. I already felt better after the first session. — Michelle Rentas, US Army (1992–1995)

### When PTSD isn't treated, it usually doesn't get better — and it may even get worse.

It's common to think that your PTSD symptoms will just go away over time. But this is very unlikely, especially if you've had symptoms for longer than a year. Even if you feel like you can handle your symptoms now, they may get worse over time.

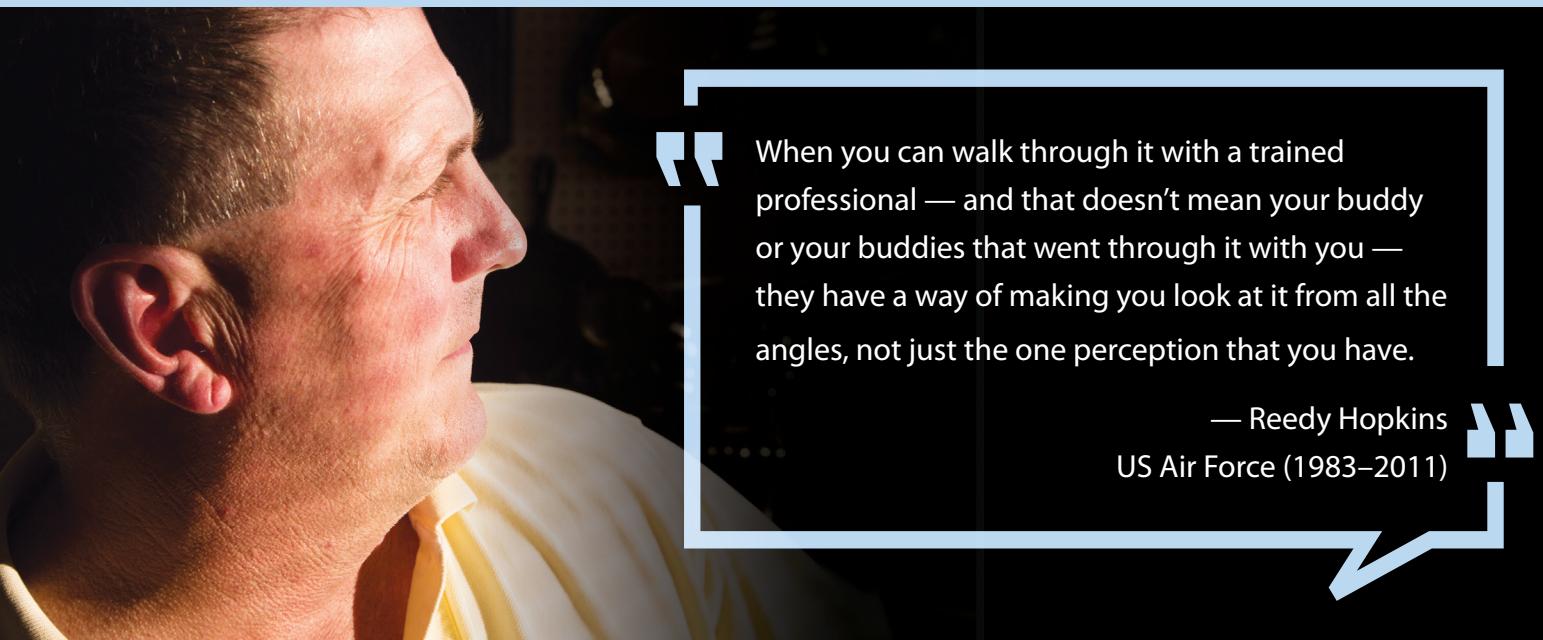
Getting treatment can help keep PTSD from causing problems in your relationships, your career, or your education — so you can live the way you want to.

And she said, 'You're not afraid that it will affect your career?' And I said, 'No, it doesn't matter how it affects my career because I can't go on living the way I'm living...' — Reedy Hopkins, US Air Force (1983–2011)

## Common questions about treatment

### ► Can a therapist really understand what I've been through?

Therapists can treat your PTSD whether or not they have been through trauma themselves. What's important is that your therapist understands how you think about your experience, so they can teach you the skills you need to manage your symptoms.



### ► Is it ever too late to get treatment for PTSD?

It's never too late. Treatment can help even if your trauma happened years ago. And treatment for PTSD has gotten much better over the years. If you tried treatment before and you're still having symptoms, it's a good idea to try again.

### ► What if I don't feel ready for treatment?

It's normal to feel like you're not ready for treatment, or to come up with reasons why now isn't the right time — like you can't afford it or you're too busy. But not wanting to talk or think about the trauma can actually be a symptom of PTSD.

You may never feel truly ready to get help for PTSD — but if you're having symptoms, it's better to get treatment now than to wait. **The sooner you get treatment, the sooner you can start to feel better.**

 Getting ready for treatment is like, how do I know I'm ready to get in better shape? How do I know I'm ready to be a better father? How do I know I'm ready to be a better person? **If you're feeling pain, you're ready for treatment.** — Dr. Ron Acierno, Clinical Psychologist 

# What happens during PTSD treatment?

Your therapist or doctor will start by talking with you about your PTSD symptoms and your treatment options. Once you've chosen a type of treatment, they'll explain what will happen, how it will help you feel better, and why it works. **Remember, you can always ask questions about your treatment.**

Both trauma-focused psychotherapies and medication are proven to treat PTSD.

## Trauma-focused Psychotherapies

Trauma-focused psychotherapies are the most highly recommended treatment for PTSD. "Trauma-focused" means that the treatment focuses on the memory of the traumatic event or its meaning. In this booklet, we'll tell you about 3 of the most effective trauma-focused psychotherapies for PTSD. In each of these psychotherapies, you'll meet with a therapist once or twice a week, for 50 to 90 minutes. You and your therapist will have specific goals and topics to cover during each session. Treatment usually lasts for 3 to 4 months. Then, if you still have symptoms, you and your therapist can talk about other ways to manage them.



PTSD therapy helps change your relationship with the trauma. Therapy isn't for erasing your memories. — Dr. Rebecca Liu, Clinical Psychologist



### ► Prolonged Exposure Therapy (PE)

People with PTSD often try to avoid things that remind them of the trauma. This can help you feel better in the moment, but in the long term it can keep you from recovering from PTSD.

In PE, you expose yourself to the thoughts, feelings, and situations that you've been avoiding. It sounds scary, but facing things you're afraid of in a safe way can help you learn that you don't need to avoid reminders of the trauma.

**What happens during PE?** Your therapist will ask you to talk about your trauma over and over. This will help you get more control of your thoughts and feelings about the trauma so you don't need to be afraid of your memories.

They will also help you work up to doing the things you've been avoiding. For example, let's say you avoid driving because it reminds you of an accident. At first, you might just sit in the car and practice staying calm with breathing exercises. Gradually, you'll work towards driving without being upset by memories of your trauma.



I learned with the Prolonged Exposure, by re-living some of the most scariest moments of my life when I was in Iraq, you learn that it's there, but the intensity of the memory goes away. — Andrew Reeves, US Army (1999–2009)



## ► Cognitive Processing Therapy (CPT)

After a trauma, it's common to have negative thoughts — like thinking what happened is your fault or that the world is very dangerous. CPT helps you learn to identify and change these thoughts. Changing how you think about the trauma can help change how you feel.

**What happens during CPT?** You'll talk with your therapist and fill out worksheets about the negative thoughts and beliefs that are upsetting you. Then your therapist will help you challenge those thoughts and think about your trauma in a way that's less upsetting.

## ► Eye Movement Desensitization and Reprocessing (EMDR)

People with PTSD react negatively to the memory of their traumas. EMDR can help you process these upsetting memories, thoughts, and feelings. You'll focus on specific sounds or movements while you talk about the trauma. This helps your brain work through the traumatic memories. Over time, you can change how you react to memories of your trauma.

**What happens during EMDR?** Your therapist will ask you to choose a memory from the trauma and identify the negative thoughts, emotions, and feelings in your body that go with it.

You'll think about this memory while you pay attention to a sound (like a beeping tone) or a movement (like your therapist's finger moving back and forth). Once the memory becomes less upsetting, you'll work on adding a positive thought.

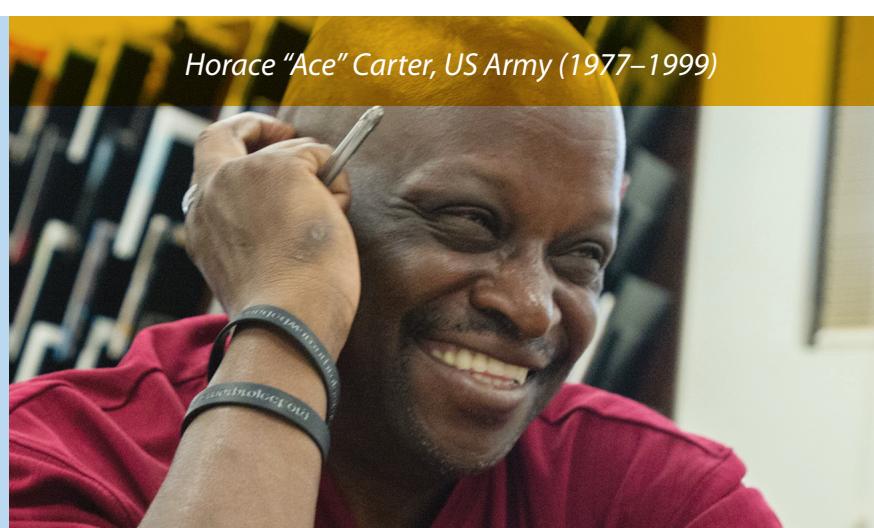
### How can I decide which treatment is right for me?

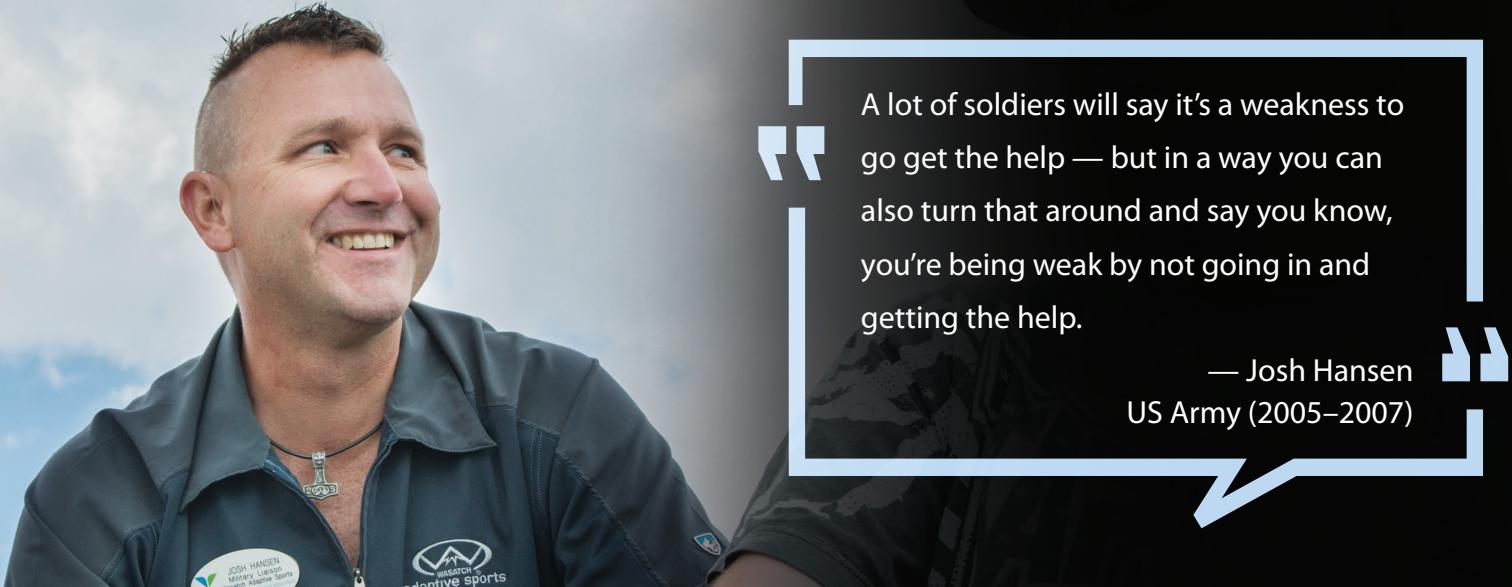
The online PTSD Treatment Decision Aid (<https://www.ptsd.va.gov/apps/decisionaid/>) is a great way to learn about your options and consider which treatment is right for you. You can watch videos of providers explaining how treatments work, then build a personalized comparison chart of the treatments that appeal to you. You can share a printout of the chart with your provider as you decide together which treatment best meets your needs.

## What about support groups?

In a support group, you talk about your day-to-day problems with other people who have had similar experiences. They can be a good addition to PTSD treatment, or something you can do after you've gotten treatment — but they won't treat your PTSD.

Horace "Ace" Carter, US Army (1977–1999)





A lot of soldiers will say it's a weakness to go get the help — but in a way you can also turn that around and say you know, you're being weak by not going in and getting the help.

— Josh Hansen  
US Army (2005–2007)

## Medication

When you have PTSD, you may not have enough of certain chemicals in your brain that help you manage stress. SSRIs (selective serotonin reuptake inhibitors) and SNRIs (selective norepinephrine reuptake inhibitors) are medications that can help raise the level of these chemicals in your brain so you feel better. Sertraline and paroxetine are SSRIs that work for PTSD. Venlafaxine is an SNRI that is effective.

Before starting to take medication to treat PTSD, you'll talk to a psychiatrist (a doctor who specializes in mental health). When you first start taking medication, you'll check in with the doctor often to talk about how the medication is working. You may need to try a few different medications to find one that works.

Medications can treat PTSD symptoms alone or with therapy — but only therapy treats the underlying cause of your symptoms. If you treat your PTSD symptoms only with medication, you'll need to keep taking it for it to keep working.

## What about benzodiazepines?

Some doctors may prescribe a type of anxiety medication called benzodiazepines (or benzos) — but benzodiazepines aren't a good treatment for PTSD. They can be addictive, cause other mental health problems, and make PTSD therapy less effective.

If you've been taking benzodiazepines for a long time, talk to your doctor about making a plan to stop. Ask about PTSD treatments that are proven to work and other ways to manage your anxiety.

# **Post-Traumatic Stress Disorder**



National Institute  
of Mental Health

## **What is post-traumatic stress disorder, or PTSD?**

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It is natural to feel afraid during and after a traumatic situation. Fear is a part of the body’s “fight-or-flight” response, which helps us avoid or respond to potential danger. People may experience a range of reactions after trauma, and most will recover from their symptoms over time. Those who continue to experience symptoms may be diagnosed with post-traumatic stress disorder (PTSD).

## **Who develops PTSD?**

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Anyone can develop PTSD at any age. This includes combat veterans and people who have experienced or witnessed a physical or sexual assault, abuse, an accident, a disaster, a terror attack, or other serious events. People who have PTSD may feel stressed or frightened, even when they are no longer in danger.

Not everyone with PTSD has been through a dangerous event. Sometimes, learning that a relative or close friend experienced trauma can cause PTSD.

About 6 of every 100 people will experience PTSD at some point in their lifetime, according to the National Center for PTSD, a U.S. Department of Veterans Affairs program. Women are more likely than men to develop PTSD. Certain aspects of the traumatic event and biological factors (such as genes) may make some people more likely to develop PTSD.

## **What are the symptoms of PTSD?**

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Symptoms of PTSD usually begin within 3 months of the traumatic event, but they sometimes emerge later. To meet the criteria for PTSD, a person must have symptoms for longer than 1 month, and the symptoms must be severe enough to interfere with aspects of daily life, such as relationships or work. The symptoms also must be unrelated to medication, substance use, or other illness.

The course of the disorder varies. Although some people recover within 6 months, others have symptoms that last for 1 year or longer. People with PTSD often have co-occurring conditions, such as depression, substance use, or one or more anxiety disorders.

After a dangerous event, it is natural to have some symptoms. For example, some people may feel detached from the experience, as though they are observing things as an outsider rather than experiencing them. A mental health professional—such as a psychiatrist, psychologist, or clinical social worker—can determine whether symptoms meet the criteria for PTSD.

## To be diagnosed with PTSD, an adult must have all of the following for at least 1 month:

- At least one re-experiencing symptom
- At least one avoidance symptom
- At least two arousal and reactivity symptoms
- At least two cognition and mood symptoms

### Re-experiencing symptoms

- Flashbacks—reliving the traumatic event, including physical symptoms, such as a racing heart or sweating
- Recurring memories or dreams related to the event
- Distressing thoughts
- Physical signs of stress

Thoughts and feelings can trigger these symptoms, as can words, objects, or situations that are reminders of the event.

### Avoidance symptoms

- Staying away from places, events, or objects that are reminders of the experience
- Avoiding thoughts or feelings related to the traumatic event

Avoidance symptoms may cause people to change their routines. For example, some people may avoid driving or riding in a car after a serious car accident.

### Arousal and reactivity symptoms

- Being easily startled
- Feeling tense, on guard, or on edge
- Having difficulty concentrating
- Having difficulty falling asleep or staying asleep
- Feeling irritable and having angry or aggressive outbursts
- Engaging in risky, reckless, or destructive behavior

Arousal symptoms are often constant. They can lead to feelings of stress and anger and may interfere with parts of daily life, such as sleeping or eating.

### Cognition and mood symptoms

- Trouble remembering key features of the traumatic event
- Negative thoughts about oneself or the world
- Exaggerated feelings of blame directed toward oneself or others
- Ongoing negative emotions, such as fear, anger, guilt, or shame
- Loss of interest in previous activities
- Feelings of social isolation
- Difficulty feeling positive emotions, such as happiness or satisfaction

Cognition and mood symptoms can begin or worsen after the traumatic event. They can lead people to feel detached from friends or family members.

## How do children and teens react to trauma?

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Children and teens can have extreme reactions to traumatic events, but their symptoms may not be the same as those seen in adults. In children younger than age 6, symptoms can include:

- Wetting the bed after having learned to use the toilet
- Forgetting how to talk or being unable to talk
- Acting out the scary event during playtime
- Being unusually clingy with a parent or other adult

Older children and teens usually show symptoms more like those seen in adults. They also may develop disruptive, disrespectful, or destructive behaviors. Older children and teens may feel guilt over not preventing injury or death, or have thoughts of revenge.

For more information on helping children and adolescents cope with traumatic events, see [www.nimh.nih.gov/helpchildrencope](http://www.nimh.nih.gov/helpchildrencope).

## Why do some people develop PTSD and other people do not?

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Not everyone who lives through a dangerous event develops PTSD—many factors play a part. Some of these factors are present before the trauma; others play a role during and after a traumatic event.

**Risk factors** that may increase the likelihood of developing PTSD include:

- Exposure to previous traumatic experiences, particularly during childhood
- Getting hurt or seeing people hurt or killed
- Feeling horror, helplessness, or extreme fear
- Having little or no social support after the event
- Dealing with stressors after the event, such as the loss of a loved one, pain and injury, or loss of a job or home
- Having a personal history or family history of mental illness or substance use

**Resilience factors** that may reduce the likelihood of developing PTSD include:

- Seeking out and receiving support from friends, family, or support groups
- Learning to feel okay with one's actions in response to a traumatic event
- Having a coping strategy for getting through and learning from a traumatic event
- Being prepared and able to respond to upsetting events as they occur, despite feeling fear

## How is PTSD treated?

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It is important for people with PTSD symptoms to work with a mental health professional who has experience treating PTSD. The main treatments are psychotherapy, medications, or a combination of psychotherapy and medications. An experienced mental health professional can help people find the best treatment plan for their symptoms and needs.

Some people with PTSD, such as those in abusive relationships, may be living through ongoing trauma. In these cases, treatment is usually most effective when it addresses both the traumatic situation and the symptoms of PTSD. People who experience traumatic events or who have PTSD may also experience panic disorder, depression, substance use, or suicidal thoughts. Treatment for these conditions can help with recovery after trauma. Research shows that support from family and friends also can be an essential part of recovery.

For tips to help prepare and guide you in talking to your health care provider about your mental health, visit [www.nimh.nih.gov/talkingtips](http://www.nimh.nih.gov/talkingtips).

### **Psychotherapy**

Psychotherapy, sometimes called talk therapy, includes a variety of treatment techniques that mental health professionals use to help people identify and change troubling emotions, thoughts, and behaviors. Psychotherapy can provide support, education, and guidance to people with PTSD and their families. Treatment can take place one on one or in a group setting and usually lasts 6 to 12 weeks but can last longer.

Some types of psychotherapy target PTSD symptoms, while others focus on social, family, or job-related problems. Effective psychotherapies often emphasize a few key components, including learning skills to help identify triggers and manage symptoms.

A common type of psychotherapy called cognitive behavioral therapy can include exposure therapy and cognitive restructuring.

- **Exposure therapy** helps people learn to manage their fear by gradually exposing them, in a safe way, to the trauma they experienced. As part of exposure therapy, people may think or write about the trauma or visit the place where it happened. This therapy can help people with PTSD reduce symptoms that cause them distress.
- **Cognitive restructuring** helps people make sense of the traumatic event. Sometimes people remember the event differently from how it happened, or they may feel guilt or shame about something that is not their fault. Cognitive restructuring can help people with PTSD think about what happened in a realistic way.

Learn more about psychotherapy at [www.nimh.nih.gov/psychotherapies](http://www.nimh.nih.gov/psychotherapies).

## Medications

The U.S. Food and Drug Administration (FDA) has approved two selective serotonin reuptake inhibitors (SSRIs), a type of antidepressant medication, for the treatment of PTSD. SSRIs may help people manage PTSD symptoms, such as sadness, worry, anger, and feeling emotionally numb. Health care providers may prescribe SSRIs and other medications along with psychotherapy. Some medications may help treat specific PTSD symptoms, such as sleep problems and nightmares.

People should work with their health care providers to find the best medication or combination of medications and the right dose. Read the latest medication warnings, patient medication guides, and information on newly approved medications on the FDA website at [www.fda.gov/drugsatfda](http://www.fda.gov/drugsatfda).

## How can I find help?

The Substance Abuse and Mental Health Services Administration (SAMHSA) provides an online resource for finding mental health services in your area at <https://findtreatment.gov>. For additional resources, visit [www.nimh.nih.gov/findhelp](http://www.nimh.nih.gov/findhelp).

If you or someone you know is struggling or having thoughts of suicide, call or text the 988 Suicide and Crisis Lifeline at **988** or chat at [988lifeline.org](http://988lifeline.org). In life-threatening situations, call **911**.

## What can I do to help myself?

You can get better with treatment. Here are some things you can do to help yourself:

- Talk with your health care provider about treatment options and follow your treatment plan.
- Engage in exercise, mindfulness, or other activities that help reduce stress.
- Try to maintain routines for meals, exercise, and sleep.
- Set realistic goals and focus on what you can manage.
- Spend time with trusted friends or relatives and tell them about things that may trigger symptoms.
- Expect your symptoms to improve gradually, not immediately.
- Avoid the use of alcohol or drugs.

## How can I help a loved one with PTSD?

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If you know someone who may be experiencing PTSD, the most important thing you can do is to help that person get the right diagnosis and treatment. Some people may need help making an appointment with their health care provider; others may benefit from having someone accompany them to their health care visits.

If a close friend or relative is diagnosed with PTSD, you can encourage them to follow their treatment plan. If their symptoms do not improve after 6 to 8 weeks, you can encourage them to talk about it with their health care provider. You also can:

- Offer emotional support, understanding, patience, and encouragement.
- Learn about PTSD so you can understand what your friend is experiencing.
- Listen carefully. Pay attention to the person's feelings and the situations that may trigger PTSD symptoms.
- Share positive distractions, such as walks, outings, and other activities.

## Where can I find more information on PTSD?

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The National Center for PTSD, a program of the U.S. Department of Veterans Affairs, is the leading federal center for research and education on PTSD and traumatic stress. You can find information about PTSD, treatment options, getting help, and additional resources for families, friends, and providers at [www.ptsd.va.gov](http://www.ptsd.va.gov).

## Are there clinical trials studying PTSD?

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NIMH supports a wide range of research, including clinical trials that look at new ways to prevent, detect, or treat diseases and conditions—including PTSD. Although individuals may benefit from being part of a clinical trial, participants should be aware that the primary purpose of a clinical trial is to gain new scientific knowledge so that others may be better helped in the future.

Researchers at NIMH and around the country conduct clinical trials with patients and healthy volunteers. Talk to a health care provider about clinical trials, their benefits and risks, and whether one is right for you. For more information, visit [www.nimh.nih.gov/clinicaltrials](http://www.nimh.nih.gov/clinicaltrials).

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# **ADHD in adults: good practice guidelines**

Royal College of Psychiatrists in Scotland

# ADHD as a diagnosis in adults

ADHD is one of a number of NDDs. ADHD and other NDDs frequently overlap; there is significant comorbidity with autism spectrum disorder (ASD), for example (Gillberg, 1983).

An individual's general activity levels, and their ability to pay attention, control impulses and regulate mood, are genetically weighted traits which are present from childhood. These traits are distributed as a spectrum in the population, modified by the environment and changeable with age.

ADHD represents individuals who are at the extreme end of a spectrum in terms of degree of inattention, impulsivity and hyperactivity. Not all who are at these extremes have functional impairments or problems, and in certain circumstances these traits can be advantageous to individuals. However, those with ADHD are at substantially higher risk of developing secondary problems, particularly other psychiatric illnesses, substance misuse, and forensic, occupational, interpersonal and social problems (Kessler *et al*, 2006).

The need to demonstrate functional impairment or secondary disabilities is paramount in defining ADHD that may merit intervention; indeed, this forms part of the necessary diagnostic criteria (American Psychiatric Association, 2013).

Adults have to actively choose to manage their ADHD. Some may validly choose not to modify their ADHD in spite of apparent negative outcomes. The individual remains responsible for their behaviour irrespective of treatment.

There are parallels between ADHD and personality disorders – both are trait-based, dimensional and represent individuals at one end of a spectrum. ADHD assessment can be similar to assessing for personality disorder – both require a longitudinal approach with corroborative evidence for diagnosis, and both require a collaborative approach to longer-term management.

# General principles in assessing and managing adults with ADHD

The general approach to assessing and managing ADHD is similar to that for any other mental disorder.

Assessment of ADHD is not a clinical emergency. A good-quality assessment takes time and is ideally multidisciplinary, involving information gathered from a variety of sources such as third parties, previous school records and previous health assessments. Longitudinal assessment is also advised.

Management of ADHD is proactively planned in collaboration with the patient. From the very start, the clinician should explicitly use an approach aimed at developing the patient's own ability to self-manage over a lifelong period. Management involves a combination of pharmacological, psychological, educational and skills-based interventions.

The clinician's role is to advise on what interventions are likely to be beneficial. A specific task is to evaluate the balance between risk and benefit of prescribing medications. This is of particular importance given the frequent nature of off-licence prescribing. Prescribing should be safe. It is possible, for example, that drug treatment may be desirable, but that other risks (e.g. risk of diversion, poor social support making adherence poor) may outweigh the potential benefits.

It is important to establish a threshold for impairment. This is a diagnostic requirement. Cut-off points for trait-based disorders can be difficult to define.

# Pre-referral recommendations

We recommend that a threshold is set for referral to specialist services, as ADHD is a spectrum disorder and ADHD traits are ubiquitous. There needs to be evidence of a specific cluster of symptoms and significant impairment.

We recommend that local services provide validated screening tools to referrers that confirm symptoms and the presence of impairment in two or more areas of function in those referred for an ADHD assessment. This helps ensure that only those at the more severe end are referred to secondary care services (Box 1).

## Box 1 Screening tests for adult ADHD

- Adult ADHD Self-Report Scale (ASRS) (Kessler *et al*, 2005). This covers DSM-IV items
- Weiss Functional Impairment Rating Scale (W-FIRS) (Weiss *et al*, 2007)
- 10-item Autism Spectrum Quotient (AQ-10) (Allison *et al*, 2012)

We recommend that local services encourage referrers to screen for other NDDs, particularly ASD, because of high rates of comorbidity.

Patients may have had relevant assessments carried out by other health professionals (e.g. educational psychologists). We recommend that these should be made available when the referral is made.

Clinicians should be mindful that there might be external pressures or agencies driving a request for referral. The motivation may not have arisen from the patient themselves. This may have a significant negative impact on engagement and on planning efficacious treatment, at the cost of clinical time.

# Referrals to mental health services

As medication is first-line treatment, a relevant medical history is required of the referrer, particularly in terms of cardiovascular, neurological and hepatic disorders, including a record of the patient's most recent blood pressure and pulse (Box 2). The role of the mental health practitioner in secondary care is to ensure that:

- a satisfactory evaluation for ADHD is conducted and criteria are met
- other psychiatric conditions and other important contributory factors are identified and treated
- there is appropriate liaison with other agencies and disciplines
- a management plan is agreed with the patient; ADHD may not necessarily be the first priority for treatment
- a risk–benefit analysis for ADHD medication is conducted
- medication is titrated to a therapeutic dose while monitoring clinical response and any side-effects.
- appropriate non-pharmacological treatments for ADHD are offered if available.

## Box 2 Physical health checklist

- Blood pressure
- Pulse rate
- Weight
- Height
- History of cardiovascular disease
- History of tics or epilepsy
- Family history of cardiovascular disease before age 55
- History of liver disease

Diagnostic reliability depends on a longitudinal assessment of the patient, together with third-party information. It is usually not possible to diagnose ADHD on the basis of a single assessment only. Assessment should be carried out on a multidisciplinary basis. There are freely available tools that can be used by mental health professionals to guide the assessment of ADHD (see 'Assessment', pp. 11–14).

There are four common scenarios in which psychiatrists may encounter adult patients with ADHD, each group raising specific issues.

## Transition patients

Diagnostic rates of ADHD in children and adolescents in Scotland remain below UK and European averages (0.6% of those below 20 years in 2014), but are rising towards the expected prevalence (ISD Scotland, 2014)

Many young adults benefit from continuing treatment beyond the age of 18 (10% still meet criteria for the full syndrome, with up to 66% in partial remission) (Faraone *et al*, 2006), and are therefore referred to adult services for specialist supervision.

Protocols for transition may vary between areas and suggested standards have been developed by the Royal College of Psychiatrists in Scotland Adult ADHD Working Group (Appendix 1).

Drug treatment for ADHD in adults is often off-licence. The daily management of medication is often passed from the parent/carer to the young adult at this stage.

Many young adults will initially attend with a parent who may have expectations of services based on their experiences of CAMHS. Young adults are frequently highly ambivalent about continuing ADHD treatment, and it is not unusual for young adults to stop treatment (McCarthy *et al*, 2009). For this reason, it is important that part of the interview take place with the young person on their own to allow for expression of views that may differ from those of the parents.

With this patient group, the basic roles of adult services are to:

- evaluate whether medication is still required (e.g. test out the effects of 'drug holidays')
- monitor side-effects and/or adverse effects
- identify and manage any psychiatric comorbidity
- identify and provide appropriate non-pharmacological treatments.

## Patients previously diagnosed in childhood, re-referred for treatment

About 50% of children with ADHD do not require transition to adult services. Additionally, a further proportion may drop out of follow-up and treatment at transition. These adults may be re-referred looking to reinstitute ADHD treatment, particularly at times of life transitions or when experiencing major stressors that may augment the impairment associated with ADHD symptoms (Young *et al*, 2011a).

Historically, such adults were often not referred because of lack of recognition of need, and lack of service provision. It follows that referrals from this group will increase disproportionately as awareness increases.

CAMHS and paediatric services will have pertinent past information. Having this available would greatly reduce the time required to plan the future management of these individuals. Clinicians may need to request this information if it is not provided at time of referral, which may delay an initial assessment.

As with any other medication, clinicians will need to conduct a risk-benefit analysis and discuss this with the patient before recommending pharmacological treatment, incorporating the specific risks associated with stimulant use.

Patients diagnosed in other countries, or in non-NHS settings, should be encouraged to provide previous medical reports confirming diagnosis and treatment before the initial appointment. Without sufficient supporting evidence of a comprehensive diagnostic assessment, a standard assessment for ADHD will need to be carried out. General practitioners (GPs) referring those who have been diagnosed in other countries or in non-NHS settings should inform their patients that they will need to provide relevant medical reports in advance to expedite assessment and treatment.

## **Adult patients referred for assessment of potential ADHD**

Parents of children with ADHD may seek assessment as they recognise their child's traits within themselves or they may be alerted by their child's clinician. This is unsurprising as ADHD is highly heritable.

There is increased awareness in society of ADHD as a condition, which can be a trigger for referral requests. This is of particular relevance given the historical underrecognition of ADHD (Royal College of Psychiatrists in Scotland & Addressing the Balance, 2012) and probable missed diagnoses as a consequence.

## **Individuals already engaged with mental health services**

There is evidence that many adults with undetected ADHD exist on the case-loads of community mental health teams (CMHTs). All members of the multidisciplinary team should have an awareness of the core features of ADHD and the potential for a missed primary or comorbid diagnosis (Deberdt *et al*, 2015).

# Assessment

We suggest that in most cases, assessment and diagnosis of ADHD will require two to three 1 h sessions. It is important to stress that this process does not need to be rushed; by definition, these patients are likely to have experienced these difficulties for many years. For some, evidence for the diagnosis of ADHD may be fairly compelling by the end of the first 1 h appointment. For others, without clear evidence of the disorder, the process will end at this stage or may proceed to consider a different diagnosis.

## General psychiatric history

- Assessment for symptoms of ADHD, with reference to DSM-5 criteria (American Psychiatric Association, 2013).
- Special attention should be paid to the age at onset of symptoms/behaviours (whether onset was before 12 years of age), the developmental history and any family history of ADHD and other NDDs (e.g. ASD, Tourette syndrome, dyslexia, dyspraxia).
- Diagnosis in adults requires the presence of five symptoms, rather than the six required for children, in the categories of inattention, hyperactivity and impulsivity.
- Mental state examination should be completed in the normal way, taking into consideration that, in a novel setting, patients may not overtly display the core symptoms of the disorder.
- Note that non-specific symptoms commonly presenting in adults with ADHD include affective instability.

## Developmental history

A comprehensive developmental history is critical. Contact with the following health professionals in infancy and childhood (up to 5 years of age) may indicate increased vulnerability to NDDs (Gillberg, 2010):

- speech and language therapists because of delayed/peculiar communication difficulties, social skills difficulties
- occupational therapists because of motor skill difficulties, e.g. delays, tics, repetitive movements, stereotypies, coordination difficulties
- health visitor (frequent visits) because of general developmental concerns
- community or hospital-based paediatrics because of problems with toilet training, attention, activity, behaviour, mood and sleep regulation.

See Appendix 2.

## Corroborative history

Because of the diagnostic importance of assessing childhood behaviour and establishing the onset of difficulties before the age of 12 years, obtaining a corroborative history is particularly important in the diagnosis of ADHD in adults. This should be emphasised to the patient and their family.

Ideally, the opportunity should be sought to speak directly with a parent or relative who has known the individual since childhood (face to face or by telephone). This will also allow consolidation of the developmental history. Where this is not possible, other evidence of childhood behaviour, e.g. school report cards and other records, may be sought with patient consent. Some individuals with poor organisational skills may have difficulty facilitating this; consent could be sought to approach relatives or other informants directly.

In certain circumstances, CAMHS and/or paediatric case notes, social work records and current college reports and/or work appraisals can additionally inform the assessment.

Failure to obtain corroborative history should not exclude patients from diagnosis and treatment if these are otherwise indicated.

# Instruments to aid the diagnostic process

We recommend the use of validated instruments to support diagnosis as part of the assessment process, but it is not a substitute for careful history-taking and clinical evaluation of symptoms and degree of impairment. There are several validated tools available (Box 3). Additional screening tools can be sent to the patient in advance of the appointment or given to them to complete in the waiting area prior to the appointment.

The Diagnostic Interview for ADHD in Adults (DIVA) questionnaire (Kooij & Francken, 2010) is the most widely used diagnostic tool in the UK and may be a useful option. This is a structured interview that is simple to administer, and addresses current and childhood behaviours in addition to impairment, based on DSM criteria. It is freely available and, with practice, takes about an hour and a half to complete. Owing to the nature of the condition, completion of the DIVA in one session may not always be possible.

Although neuropsychological assessments – e.g. the Wechsler Adult Intelligence Scale (WAIS) (Wechsler, 2008), test of everyday attention and Stroop test – are not routinely undertaken in the majority of cases, they can be helpful where the diagnosis remains unclear.

## Box 3 Assessment tools

### Retrospective

- Wender Utah Rating Scale (free) (Ward *et al*, 1993)
- Childhood Symptoms Scale (one-off payment) (Barkley & Murphy, 2006; Barkley, 2007)
- Childhood behaviour scales – self-report (Appendix 5) and parent report

### Current self-report

- Conners' Adult ADHD Rating Scales (pay per use) (Conners *et al*, 1999)
- Current Symptoms Scale (one-off payment) (Barkley & Murphy, 2006; Barkley, 2007)
- Adult ADHD Self-Report Scale (free) (Kessler *et al*, 2005)
- ADHD Self-Report Scale (pay per use) (Rösler *et al*, 2006)
- Copeland Symptom Checklist for Attention Deficit Disorders (free) (Copeland, 1987)
- Weiss Functional Impairment Rating Scale (free) (CADDRA, 2014)
- Current Behavioural Scale – self-report (Appendix 5)

### Current observer report

- Brown ADD Rating Scales (pay per use) (Brown, 1996)
- ADHD – Other Report Scale (pay per use) (Rösler *et al*, 2006)
- Current Behaviour Scale – partner report (Appendix 5)

### Diagnostic instruments

- Diagnostic Interview for ADHD in Adults (DIVA) (free) (Kooij & Francken, 2010)
- Conners' Adult ADHD Diagnostic Interview for DSM-IV (Epstein *et al*, 2001)

## Impairment of functioning

The presence of significant impairment of functioning in two or more domains is a requirement for diagnosis. This is addressed in DSM-5 (American Psychiatric Association, 2013); it is also addressed in the DIVA questionnaire. The Weiss Functional Impairment Rating Scale (W-FIRS) is an additional tool that supports this (CADDRA, 2014).

Impairment is particularly relevant in terms of deciding who to treat, and it is important to establish a robust threshold which clinicians can apply consistently. It must be remembered that treatment with medication is not risk free, and that the benefits are likely to be most marked in those with the most significant impairment.

## Differential diagnosis

There is considerable symptomatic overlap between ADHD and other major psychiatric disorders, particularly bipolar disorders, emotionally unstable personality disorder and anxiety disorders (Kessler *et al*, 2006). Up to 90% of adults with ADHD experience mood instability that may resemble mood disorders or borderline personality disorders (Asherson, 2005). Mood instability may respond to treatment with medication for ADHD (Skirrow *et al*, 2009). It is worth considering this diagnosis in those with lifelong difficulties who have significant functional impairment, present atypically and are difficult to treat.

Psychotic symptoms are not core features of ADHD and may represent a comorbid diagnosis; such symptoms should be fully evaluated. Stimulant medication may trigger the emergence of psychotic symptoms.

See Appendix 3 for more details.

# Comorbidity

Adults with ADHD are significantly more likely than the general population to experience other psychiatric disorders. In particular, mood and anxiety disorders, other NDDs and substance use disorders are potential comorbid conditions (Nutt *et al*, 2007). Overlapping symptoms between disorders can make assessment difficult. A longitudinal history is helpful to elicit trait- and state-based symptoms. Symptoms that are not part of an ADHD clinical picture can also be indicators to help with differentiation (see Appendix 3 for frequencies and overlapping and distinguishing features of different psychiatric disorders).

The presence of other comorbid disorders should not be a barrier to conducting an assessment for ADHD. The nature of the comorbid condition will have an impact on the primacy of treatment. Major mood disorders should be treated prior to assessing for ADHD. Mood instability, as opposed to major mood disorder, in the context of ADHD often responds to pharmacological interventions for ADHD (Kooij *et al*, 2010).

# Specific patient groups

When ADHD is complicated by comorbid NDDs such as ASD, which co-exist frequently, management and response to treatment are more complex (Antshel *et al*, 2013). This will often become evident during the course of taking a competent neurodevelopmental history. Where specialist autism services exist, a joint approach is desirable. Comorbid psychosis is less common but can occur and can be more difficult to manage (Donev *et al*, 2011). This document provides generalised guidance (see Fig. 1 for an overview of the assessment pathway); however, practice may need to be individualised for particular patient groups.

## Substance misuse

Substance misuse, mostly involving alcohol and cannabis, may be twice as common among individuals with ADHD as in the general population and tends to begin earlier (Breyer *et al*, 2014). Individuals with untreated ADHD may also describe self-medicating with illicit substances. Some patients report paradoxical calming effects from stimulant drugs such as cocaine and amphetamines.

When prescribed stimulants are used appropriately, there is little evidence of patients becoming dependent, and indeed treating ADHD may reduce the lifetime risk of developing a substance use disorder (Biederman, 2003; Dalsgaard *et al*, 2014).

Controlled misuse should not completely preclude treatment, although careful monitoring will be required. In uncontrolled and chaotic patterns of drug and/or alcohol misuse, stimulant medications can be very difficult to manage safely and are not routinely recommended. Where there is a risk of recreational use of non-prescribed stimulants such as cocaine, amphetamines and some novel psychoactive substances, the patient should be warned of potential dangerous interactions with prescribed medication.

Diversion of stimulants is often cited as a reason not to prescribe for this patient group (Wilens *et al*, 2016). However, therapeutic stimulants, particularly long-acting formulations, appear to have limited street value, possibly owing to their pharmacokinetic properties (being slow to reach peak blood levels, they are not very effective at producing a ‘buzz’). Risk for diversion is significantly reduced with the use of slow-release preparations. Risks can also be minimised by supervised daily administration by third parties. Clinicians should be mindful of the use of these medications as cognitive enhancers in student populations (Wilens *et al*, 2016).

Significant and comorbid substance misuse should be managed jointly between general adult and addiction services in accordance with existing local protocols.

## Intellectual disability

The reported prevalence of ADHD in adults with intellectual disability varies widely. This variability is accounted for by the range of definitions and diagnostic criteria used. Prevalences of 16% have been reported across a wide range of severity (La-Malfa *et al*, 2008).

ADHD in the intellectually disabled population is associated with an increased occurrence of challenging behaviour, stereotypies, self-harm, anxiety, oppositional defiant disorder, tic disorders and sleep problems (Simonoff *et al*, 2013).

Drug and alcohol use during pregnancy, maternal infection, encephalitis and some genetic disorders (William's syndrome, Turner syndrome, fragile-X syndrome and phenylketonuria) have been associated with ADHD in patients with intellectual disabilities (Dichter *et al*, 2012; Green *et al*, 2012). It is important to establish all possible aetiological factors before starting treatment for ADHD, as addressing these can improve symptoms of ADHD.

People with intellectual disabilities have also been shown to be more sensitive to side-effects from medication (Simonoff *et al*, 2013).

## The forensic population

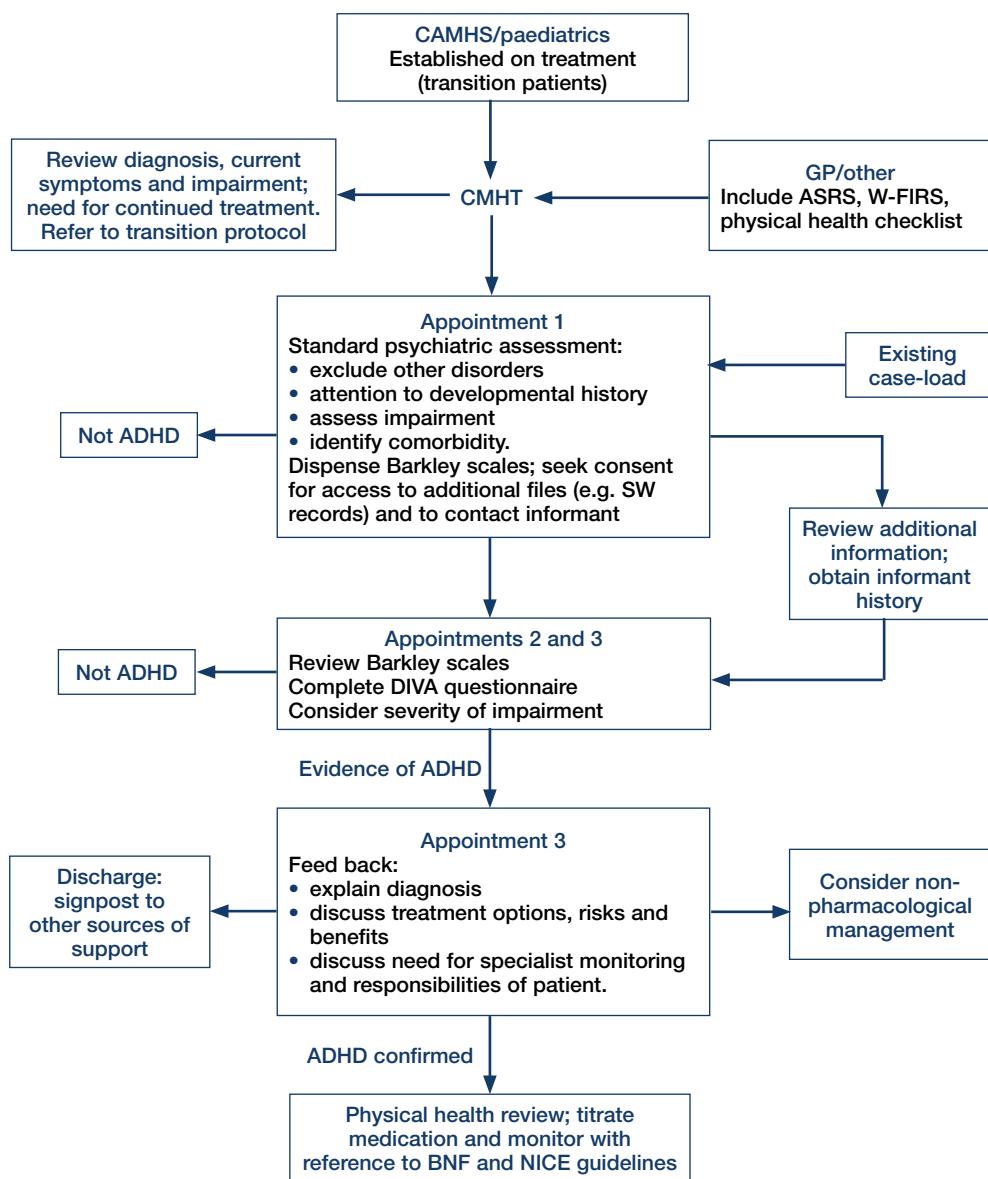
Childhood ADHD has high rates of comorbidity with oppositional defiant disorders and conduct disorders. The presence of conduct disorder, in turn, is associated with the development of dissociative personality disorder in adults (Hofvander *et al*, 2009).

Adults with untreated ADHD are often bored, sensation seeking or impulsive; this combination of states can result in poor judgement, with criminal acts as a consequence. The prevalence of ADHD in the prison population is accepted to be much higher than in the general population, with estimates of between 25 and 40% (Ginsberg *et al*, 2010). ADHD is associated with higher rates of comorbidity, worse quality of life and higher risks of suicidal behaviour (Young *et al*, 2011b). However, it is important to recognise that most people with ADHD do not commit crimes. Evidence suggests that treatment of ADHD in the prison population may reduce the risk of future offending (Lichtenstein *et al*, 2012)

The issue of criminal responsibility often arises. ADHD is not usually regarded as the type of mental condition which would give rise to a 'not guilty by reason of mental disorder' defence, but it has been accepted by at least one court as grounds for abnormality of mind

in the context of a murder trial. It may be raised as general mitigation before the courts, and it may form the grounds for an assessment order under criminal procedure. Compulsory civil detention is not seen as appropriate under the Mental Health (Care and Treatment) (Scotland) Act 2003; our current understanding of the condition would suggest that it does not significantly impair decision-making ability. ADHD is a dimensional condition; its management requires a collaborative approach between clinician and patient that does not readily lend itself to compulsory measures or in-patient treatment.

High rates of substance misuse are also described in this population. Supervised consumption of medication can help manage risks of diversion. Efforts should be made to ensure continuity of treatment on release from custodial settings by liaising with local services in advance.



**Fig. 1** Pathway for assessment of attention-deficit hyperactivity disorder (ADHD) referrals in adults. ASRS, Adult ADHD Self-Report Scale; BNF, British National Formulary; CAMHS, child and adolescent mental health services; CMHT, community mental health team; DIVA, Diagnostic Interview for ADHD in Adults; GP, general practitioner; NICE, National Institute of Health and Care Excellence; SW, social work; W-FIRS, Weiss Functional Impairment Rating Scale.

# Management of ADHD

## Implications of diagnosis

When a new diagnosis of ADHD is made in adulthood, there can often be a sense of relief that an explanation has been found for lifelong difficulties. There may also be resentment that the diagnosis was not made earlier.

It is important to frame ADHD as being a condition that the patient has a responsibility for managing, by promoting a sense of personal agency.

Patients may be required to inform their employer or educational establishment.

ADHD is also a notifiable condition for the DVLA ([www.dvla.gov.uk](http://www.dvla.gov.uk)). Patients should be informed that this is their responsibility. Treatment for ADHD has been shown to significantly improve driving safety (Jerome *et al*, 2006).

Education about ADHD is important. A variety of self-help books and websites exist for adults with ADHD (see Appendix 4 for details).

Although diagnosis alone is all that some patients want, most will want to explore formal treatment options such as medication.

## Treatment

Medication is recommended as the first-line treatment for ADHD in adults with moderate to severe impairment (NICE, 2008). Table 1 gives an overview of medications used in adult ADHD.

Drug treatments can be classified into stimulants (methylphenidate, dexamfetamine) and non-stimulants (atomoxetine, clonidine, bupropion etc.). Stimulants have an immediate action and can therefore be titrated more quickly. The mechanism of action of ADHD treatments involves increased availability of dopamine and/or noradrenaline at the synaptic level, with non-stimulants having a delayed onset of action similar to that of antidepressants. Stimulants have an appreciable positive effect on attention in those without ADHD, and a 'therapeutic trial' therefore has no diagnostic value.

Stimulants have more potential for diversion/misuse, particularly immediate release preparations.

Some treatments used for ADHD in adults are off-license. The Royal College of Psychiatrists has produced a consensus statement for

use of licensed medicines for unlicensed uses (Royal College of Psychiatrists, 2007). Before prescribing, the clinician must ensure that the patient knows of the unlicensed use and understands the potential risks and benefits of the medication, that this is documented clearly, and that the patient is able to give fully informed consent. If prescribing responsibility is to be shared with primary care, the clinician should ensure that the risk assessment and consent issues are communicated to the GP.

At the time of writing, atomoxetine and lisdexamfetamine are licensed for initiation and continuation in adults. Concerta XL (methylphenidate modified release) has a licence for continuation of treatment established in childhood into adulthood (Joint Formulary Committee, 2016).

Although many treatments are not licensed in the adult population, this should not prevent medications being prescribed according to best practice.

Pre-treatment screening should include measuring baseline ADHD symptom severity, impairment, weight, heart rate, blood pressure and sleeping pattern. ADHD treatments can exacerbate seizures and tics. A history of these conditions should be directly asked about.

An electrocardiogram (ECG) is required if any of the following are present: family history or medical history of serious cardiac disease; family history of early cardiac death; or abnormal findings on cardiac exam. Further investigation and/or liaison with cardiology may be indicated in these situations.

See the physical health checklist (Medical Assessment Tool for Adults with ADHD) in Appendix 5.

## Methylphenidate

- Recommended as the first line of treatment for ADHD in adults (NICE, 2008)
- Primarily a dopamine reuptake inhibitor, with some action on noradrenaline and other catecholamines
- It is a controlled drug
- Effect size of 0.5 (Castels *et al*, 2011)
- Immediate release preparations are cheaper and can allow greater fine-tuning of dosing.

Modified release preparations contain a combination of both immediate and slow-release stimulants. These allow once-daily dosing and have less misuse potential. The difference between the various preparations is the ratio of immediate to slow release stimulant and duration of action. Alternatively, a combination of modified and immediate release preparations can be used to fine-tune symptom control at certain times of day.

Dose titration, using immediate or slow release preparations, should be done using the smallest available dose increments over intervals (e.g. every fortnight), until an adequate response is achieved or intolerable side-effects are experienced.

- Typical starting dose (immediate release) 5 mg once or twice a day, increased to three times daily after a week. Dosage increased by about 10–15 mg per week dependent on tolerability.
- Modified release: start at 10mg (27 or 36 mg if Concerta XL), with weekly increases by increments of 10–20 mg (18 mg if Concerta XL) to maximum effective tolerated dose.
- Monitor weight, blood pressure, pulse rate.

## Dexamfetamine

- Alternative stimulant treatment for ADHD in adults with similar efficacy to methylphenidate.
- Used in patients with suboptimal response to methylphenidate.
- Promotes the release, and prevents the reuptake, of dopamine and noradrenaline. It is a controlled drug.
- Dexamfetamine is considered to have more misuse/diversion potential than methylphenidate although there is likely to be less misuse potential with lisdexamfetamine (Blick & Keating, 2007) owing to its pharmacokinetic profile.
- Dose titration follows the same principles as for methylphenidate.

## Atomoxetine

- Non-stimulant treatment for ADHD which is usually considered in adults unresponsive or intolerant to stimulant treatments, or when misuse/diversion of stimulants is a concern.
- A noradrenaline reuptake inhibitor; it is not a controlled drug.
- Delayed onset of action of several weeks with effect size of 0.4 (Asherson *et al* 2014).
- Does not require the same individual fine-tuning of dose that stimulants require and has the advantage of once-daily dosing.
- Side-effects are usually avoided by a gradual dose titration, for example starting at 40 mg and increasing by 20 mg per week.
- Doses above 80 mg have not shown any additional benefit. Some individuals are poor metabolisers of atomoxetine and are sensitive to side-effects at low doses. Acute liver failure and suicidality are rare but significant potential side-effects. All patients should be advised of symptoms of these adverse events.
- Monitor weight, blood pressure and pulse rate at baseline, after each dose change and long-term every 3 months, with weight every 6 months.
- Increased risk of ventricular arrhythmias has been described when used with drugs that prolong the QTc interval.

**Table 1 Medications for ADHD in adults**

	Methylphenidate	Dexafetamine	Atomoxetine
<b>Preparations</b>	<b>Immediate release</b> <ul style="list-style-type: none"> <li><b>Ritalin/Medikinet:</b> 4h duration of action; b.d. or t.d.s.; 5, 10, 20mg tablets, max. 100mg/day</li> </ul> <b>Modified release</b> <ul style="list-style-type: none"> <li><b>Concerta XL:</b> 22% IR: 78% (MR); 10–12h duration of action; o.d.; 18mg tablets; max. 108mg/day</li> <li><b>Equasym XL:</b> (30% IR, 70% MR) 8h duration of action; o.d.; 10mg tablets; max. 100mg/day</li> <li><b>Medikinet XL</b> (50% IR: 50% MR): 8h duration of action; o.d.; 10mg tablets; max. 100mg/day</li> </ul>	<b>Short-acting</b> <ul style="list-style-type: none"> <li><b>Dexamfetamine:</b> effect 4 h; b.d. or t.d.s.; 5 mg tablets; max. 60mg/day</li> </ul> <b>Long-acting</b> <ul style="list-style-type: none"> <li><b>Lisdexamfetamine:</b> effect 12–13h; o.d.; 30, 50, 70mg tablets; max. 70mg/day</li> </ul>	<ul style="list-style-type: none"> <li><b>Strattera:</b> o.d.; 10, 18, 25, 40, 60, 80, 100mg tablets; usual dose 80mg; max. 120mg/day</li> </ul>
<b>Side-effects</b>	Reduced appetite, insomnia, depressed mood, anxiety, headache, irritability, tachycardia, tics, seizures, psychosis	Reduced appetite, insomnia, tachycardia, increased blood pressure, headache, depressed mood, anxiety, irritability, nasopharyngitis, tics, seizures	Reduced appetite, nausea, depressed mood, tachycardia, increased blood pressure, insomnia, dizziness, GI disturbance, sweating, sexual dysfunction, seizures, hepatitis
<b>Contraindications<sup>a</sup></b>	Cardiac disease, cerebrovascular disease, hyperthyroidism, phaeochromocytoma, vasculitis, some mental disorders (weigh risks v. benefits)	Cardiovascular disease, hypertension, arteriosclerosis, hyperthyroidism, history of drug or alcohol misuse	Phaeochromocytoma

a. See British National Formulary for full list. ADHD, attention-deficit hyperactivity disorder; GI, gastrointestinal; IR, immediate release; MR, modified release.

## Other pharmacological options

If there is inadequate response to monotherapy, then combining a stimulant with atomoxetine is occasionally done in clinical practice, although there is a limited evidence base for this. Other potential treatment options, which have less of an evidence base, include:

- bupropion (Zyban) – dopamine and noradrenaline reuptake inhibitor
- modafinil (Provigil) – dopamine reuptake inhibitor
- clonidine – alpha agonist
- nortriptyline or desipramine – potent inhibitors of noradrenaline reuptake.

## **Psychological treatments**

NICE clinical guideline CG72 recommends that drug treatments for ADHD should be part of a comprehensive treatment programme addressing psychological, behavioural, occupational and educational needs (NICE, 2008). However, the evidence base for the effectiveness of individual psychological therapies for ADHD in adults is insufficiently robust at present for NICE to make any specific recommendations.

Nevertheless, approaches utilising cognitive–behavioural therapy and coaching strategies can be useful in practice as adjuncts to medication and in cases where medication is contraindicated or not tolerated. Group-based interventions using these techniques have been developed, e.g. the Young–Bramham programme (Young & Bramham, 2012).

It is also envisaged that many patients with ADHD could potentially benefit from the practical and emotional support offered to other patients by multidisciplinary mental health teams. In particular, the input of occupational therapists can be very useful in terms of helping patients to structure their time and improve organisational skills, and in assisting with access to further education and/or employment. Although it may not be possible with existing resources to offer this consistently to all patients with ADHD, it is important that all multidisciplinary staff within CMHTs begin to develop an understanding of ADHD and its management in adults.

## **Monitoring of medication**

Weight, blood pressure and heart rate, in addition to side-effect monitoring, should be completed at each dose titration review and every 6 months once stabilised. See Appendix 5 for a checklist (Monitoring treatment in ADHD).

## **Assessing response to medication**

During dose titration, enquiry should be made about reduction in core ADHD symptoms (as described in DSM-5), associated symptoms (mood instability, ceaseless mental activity), functioning and possible side-effects. There are side-effect rating scales available; see Appendix 5.

For stimulants, enquiry about how long the effects last is important in tailoring the dose. It is possible to combine a slow release preparation to be given in the morning, with an immediate release preparation in the evening, if additional symptom control in the evening is required.

Not all ADHD symptoms can be ameliorated with treatment; it is important to manage expectations of treatment.

Some patients find the reduction in ADHD symptoms disconcerting; a dose reduction may need to be considered.

Possible scales that may be used in assessing response include the Current Behaviour Scale (CBS) (Murphy & Barkley, 1996) and the Weiss Functional Impairment Rating Scale (W-FIRS) (Weiss *et al*, 2007).

## **Comorbidity**

It is usually preferable to treat any comorbid mental health problem before treating ADHD (see Appendix 3). Stimulants can potentially trigger or exacerbate psychosis, mania and tics, primarily via their dopaminergic effect. However, atomoxetine may in fact be helpful for anxiety disorders (Kratochvil *et al*, 2005).

Before starting ADHD treatments it may be necessary to optimise existing treatments and weigh up the potential risks of starting ADHD treatment.

## **Duration of treatment**

Once an acceptable dose has been achieved that balances efficacy with side-effects, this dose should be continued and reviewed at least annually. With stimulants, the need for ongoing treatment can be evaluated by 'drug holidays'. Often this occurs naturally through omission of doses.

Treatment can allow patients to develop new ways of coping with residual symptoms. This, along with the general trend for symptoms to improve with age, means the need for ongoing treatment should be reviewed. It has been suggested that this be done on an annual basis (Kolar *et al*, 2008).

Discontinuation of treatment should be done gradually with non-stimulants to avoid withdrawal effects, but stimulants can be withdrawn more rapidly.

# CARIBOU Clinician's Guide for the Management of Self-injurious Thoughts and Behaviours

A Component of  
Treatment for Adolescents  
with Depression

**camh** | Cundill Centre for Child  
and Youth Depression



# Introduction

For pages 4 to 12:

Black font refers to clinician-directed content and questions to follow.

*Purple font refers to further notes for the clinician.*

**Teal bold font relates to key points for the clinician to note.**

## Purpose

This clinician's guide and youth handouts for managing self-injurious thoughts and behaviours (SITB) sets out the framework for strategies that youth and caregivers can use to address relevant risk. The guide is meant to be used as part of a comprehensive treatment plan for adolescents with depression, referred to as the CARIBOU Integrated Care Pathway. Here, we use the terms "adolescent" and "youth" interchangeably, typically to refer to people aged 13 to 18, although many concepts in this guide will also apply to a broader definition of the adolescent/youth (e.g., 10 to 24 years old).<sup>1</sup> The strategies outlined in this guide are designed to be discussed in up to four sessions, depending on the context and need. Of course, after the four dedicated sessions, clinicians will likely need to follow up with the youth to see how they are doing with these strategies and help with any "fine tuning." Depending on context (e.g., specific symptom presentation, engagement, pace), specific sessions can be combined into fewer meetings or omitted altogether. This guide is intended to complement the CARIBOU Initial Assessment Guide and CARIBOU CBT manual. Below, we also outline sessions from the CARIBOU Cognitive Behavioural Therapy (CBT) manual that might be relevant for some youth with SITB. All sessions on the management of SITB are intended for the clinician, adolescent and, if the adolescent agrees, a primary caregiver (e.g., parent). **Be mindful that some strategies will resonate with youth and caregivers, and others will not. Optimize opportunities for youth and caregivers to select which concepts fit best for them.**

SITB include suicidal behaviour (SB; i.e., suicide attempts, interrupted suicide attempts, aborted suicide attempts, preparatory behaviour),<sup>2</sup> suicidal ideation (SI; i.e., wish to die, thoughts of killing oneself, intent to kill oneself)<sup>3</sup> and non-suicidal self-injury (NSSI; i.e., direct and deliberate damage to one's body tissue for reasons other than to end one's life).<sup>4</sup>

Clinicians should already have some training in assessing the mental health needs of adolescents presenting to care. Relevant professionals in Canada include social workers, occupational therapists, registered nurses, registered therapists, psychologists and doctors, as well as their trainees. **Newer clinicians (e.g., those with less than one year's experience) will want to arrange for appropriate supervision.**

Youth may not end up revealing some information in the first few assessment meetings. It is important to create space in later sessions to ask if there is any information that they would like to add or clarify from previous sessions.

## Development

As with other CARIBOU materials, this guide integrates NICE guideline recommendations with clinician expertise, and with the input of youth and caregiver partners. The relevant guideline recommendations here are contextualized from the 2022 NICE guideline on managing self-harm.<sup>5</sup> This NICE document was used as a key reference, as its prior edition was systematically appraised as a high-quality clinical practice guideline.<sup>6</sup> After an initial draft of this guide was written, youth and caregiver partners (JR, MP, KC and others) provided feedback on how to frame the information and further revisions were made. This guide is also in keeping with the American Academy of Pediatrics' 2022 *Suicide: Blueprint for Youth Suicide Prevention*.<sup>7</sup>

# Risk Assessment

Details on assessing risk of suicide and self-harm are included in the *CARIBOU Initial Assessment Guide: A Resource for Clinicians Working with Adolescents with Depression*. Note that classifying people's level of risk has limited ability to predict future behaviour. **The risk assessment here is not intended for predictive purposes; rather, to identify modifiable factors that can be used to develop a treatment plan. The 2022 NICE Guideline recommends using the overall formulation to inform treatment planning, rather than using a categorical global risk classification.**

## Process Considerations

Youth who are new to mental health services may find discussions around SITB feel heavy and overwhelming. It is important to look for verbal and non-verbal clues to gauge how the youth tolerate the discussion. For example, limited eye contact, "closed" body posture and brief answers would suggest the young person is not very comfortable with the discussion. These youth may need more time before they are ready to talk about the topic. Other youth are very comfortable and even have open discussions around SITB in the presence of a caregiver. Try to convey your own sense of comfort with discussing SITB themes — through your body language, tone of voice and pacing. Your own comfort level can help to destigmatize these themes, and lead to more open discussions. Some youth may worry about speaking openly because they are concerned that you will have to break confidentiality or even send them to hospital if they express risk of harming themselves, which is a very real concern. Clearly setting out the limits of confidentiality at the outset can help let the young person know your threshold for doing this, which may vary from one clinician to the next.

As described in the *Assessment Guide*, setting is an important consideration when conducting the assessment. Create a welcoming physical and psychological space (whether "in real life" or virtually) where the privacy and needs of the youth will be respected. When asking questions, pay attention to the adolescent's tone of voice, posture and eye contact. If the adolescent is presenting as withdrawn, guarded or irritated, look for ways to make the space less threatening (e.g., lean back in your chair, make less eye contact to appear more casual). It is important to express a sense of warmth and validate distress, while also maintaining the structure of the meeting. **Avoid using the scripts and questions verbatim; instead, personalize the words and tone to your own clinical style so that the discussion feels natural and authentic.**

The decision to involve caregivers in these sessions, and the extent of their involvement, will depend on multiple factors, including youth consent to involve caregivers, extent of engagement in treatment and the imminence of risk assessed. It is important to consider both short-term risk (i.e., addressing immediate physical safety) and long-term risk (i.e., gaining youth's trust to continue full course of treatment) when making these decisions. It can be challenging for caregivers who want to help or protect the youth. Clarify that a form of "helping" may mean allowing private opportunities for the youth to express themselves in a private space. Assist caregivers in understanding their role in the healing process and provide guidance around their role in managing safety-related concepts. *The Caregiver Adolescent Relationship Enhancement (CARE): A Group Program for Caregivers of Youth with Depression* can assist with the complexity of navigating caregiving of adolescents with depression and self-injurious thoughts and behaviours. Note that the 2022 NICE guideline for the management of self-harm recommends a "therapeutic risk management" approach, whereby "overly coercive responses to self-harm are avoided and replaced by a high regard for the [youth]'s autonomy." Clinicians and caregivers should constantly be looking for ways to collaborate with youth in reducing SITB, rather than adopting a "paternalistic" approach.

# Content

**Preparation** is focused on a **Needs Assessment**. Ideally, much of the needs assessment has already been performed in the original assessment at the beginning of the pathway, so this document will simply be consolidating factors to consider. A distinction is made between modifiable and non-modifiable risk factors, with a plan to address the modifiable risk factors accordingly. Risk factors can be discussed with the youth and caregiver as they pertain to the development of a treatment plan.

**Session 1: Planning for Life** builds on the needs assessment and guides the youth in safety planning. The plan is broken down into short-term and long-term management of risk. The *Hope by CAMH* app can also be used as the outline for the app is very similar to content in this session. This app can be accessed at [www.camh.ca/hopebycamhapp](http://www.camh.ca/hopebycamhapp).

**Session 2: Ramping Up — Getting ready for change** starts by exploring motivation to change SITB. It is very much based on concepts typical of motivational interviewing<sup>8</sup> and the “pros and cons” distress tolerance skill in dialectical behaviour therapy (DBT).<sup>9</sup> It is common for youth to be ambivalent about changing SITB, as the thoughts and behaviours often have a function. For example, suicidal ideation is frequently used to cope with unbearable distress; as in, “at least I have a way out if I need it.” Self-harm often has multiple functions, though the most common is to relieve emotional distress, such as anxiety, fear or shame. Other functions of SITB include relieving a feeling of numbness (e.g., from dissociation); punishing oneself out of feelings of guilt; and less frequently, communicating the extent of their pain to other people.<sup>10</sup> It is important to validate the distress that is leading to the SITB, while also eliciting potential reasons for change. Motivation to change may be low initially until the youth can understand and appreciate the alternatives to SITB. Meeting youth “where they are at,” even if pre-contemplative, will help build trust.

**Session 3: Riding the Wave** discusses ways to tolerate distress as it relates to self-harm behaviours (i.e., SB or NSSI) or “riding the wave.” This approach is classically used as a strategy to treat panic attacks and addiction cravings, which both have similarities to acute onset of suicidal ideas or urges to self-harm. It is also used often in DBT within the context of “distress tolerance.” It is very important to clarify that the goal of the skill is to get through the distress “without making things worse”— rather than for quick relief of distress. Young people will often give up on this approach early if they are expecting fast relief, which the NSSI may be providing. Just like any skill, it takes repeated experiences and experimentation to see what helps reduce self-harm. This skill around tolerating distress may also be applied to caregivers, who are often highly distressed about their youth’s self-harm, and whose own reactions are crucial in not exacerbating the youth’s impulses.

**Session 4: Breaking the Chain** examines the relationship between antecedents, behaviours, and consequences of self-harming behaviour (i.e., SB or NSSI). In examining the chain of events surrounding the behaviour of interest, this approach is typically used in both CBT and DBT and is also described in the *Brief Psychosocial Intervention* manual. The idea is to explore in detail a recent episode of self-harm, without judgments, to fully understand it. Collaboratively, the clinician and youth can explore components of this sequence of events to look for ways things could have been done differently— ideally, with a better outcome. The idea is that the antecedents, behaviours and consequences are likely to recur, and planning for their occurrence in the future can change the course of events, so that a youth does not engage in self-harm moving forward. Opportunities to facilitate safe discussions of antecedents, behaviours and consequences between youth and caregivers may also help reduce chances of future self-harm. This session also includes a “Wrap-Up” section, that provides a table listing the techniques described in this guide, and asks the youth to rate the extent to which they have used each technique.

# Optional Sessions: CBT for Depression Underlying SITB

Treating any underlying depression could also reduce risk. Clinicians may decide to highlight skills already described in the CARIBOU CBT Manual for youth with SITB. These include:

- (1) "Power Up" Behavioural Activation, sections in Sessions 3 and 4 with the headings "Personal Values" and "Increasing Activities That Are Important to You in the Long Term." Converting values to long-term goals and then gradually working toward these goals can help provide a greater sense of meaning in life and potentially reduce suicidal ideas.
- (2) "Level Up" Problem Solving, Sessions 1, 2 & 3 (entire sessions). Youth often conceptualize suicide as a potential solution to a problem. The power of this conceptualization can be weakened when youth know how to explore alternative solutions to problems.
- (3) "Level Up" Problem Solving, Session 4 "Acceptance." This skill is included in the DBT distress tolerance skills, though is more of a philosophical approach to managing unbearable distress.
- (4) "Multiplayer" Communication and Relationships, Session 3 "Asking for what you want." If SITB have an interpersonal function, then the assertiveness skills here could be relevant.

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# Needs Assessment



## Preparation

This section is for clinicians to complete only.

The following is informed by NICE recommendations for self-harm 2022 – Section 1.5. Some sections are also included in the “Brief Psychosocial Intervention” manual.

This table provides questions in the left-hand column that the clinician can ask as part of the needs assessment. Note that these questions are also repeated in the CARIBOU Assessment Guide. Clinicians can use previously answered questions to complete this assessment or can re-ask questions for clarification. If the caregiver is in the assessment, you might ask the youth if they would like to discuss this more privately or continue with the caregiver present.

The following can be considered as the clinician collaboratively makes a safety plan (see Session 1: Planning for Life) with the young person.

- Which of the variables identified by the questions below are readily modifiable?
- Which are modifiable but will take more time?
- Which are not modifiable at this time?
- Are there opportunities to work with the youth to limit access to means of self-harm (NSSI or suicide attempts)?
- Are there opportunities to facilitate collaborative discussions between youth and caregivers to establish safety in the home in relation to self-harm?

Question	Direction of Risk	Modifiable
How old are you?	<i>Older age indicates higher risk.</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
What is your gender identity?	<i>Female sex / girl gender represents increased risk for attempted suicide. Male sex / boy gender represents increased risk to die by suicide. Gender diverse (e.g., trans, non-binary) youth are more likely to attempt suicide.</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Has a psychologist, psychiatrist or family doctor ever made a mental health diagnosis?	<i>Depression and/or psychosis can increase risk.</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A

Question	Direction of Risk	Modifiable
Were there stressors that led to changes in mood?	<i>Acute stressors may increase risk (including marginalization-related stress, bullying, family/peer conflict).</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
How do you cope with mental health symptoms? Which coping strategies are helpful for you? Which are unhelpful for you? What supports or strengths do you have right now that might be helping you get through this time?	<i>Adaptive coping strategies and supports decrease risk. Look for ways the youth might be coping, but do not label it as coping.</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Do you feel connected to your friends or family (e.g., you feel understood by them, or can go to them for help or enjoy being with them)? Are there things you are looking forward to in your life right now? What is meaningful for you in your life right now? What gives you a sense of hope? Do you know what you would like to be doing in 2-3 years?	<i>Social isolation and/or hopelessness indicates high risk.</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A

Question	Direction of Risk	Modifiable
<p>Some people with depression struggle with thoughts of suicide or wanting to die.</p> <p>Have you ever struggled with thoughts of suicide, or wishing you were no longer around? How old were you when these thoughts first started? Were there events in your life that first led to these thoughts? Were there events in your life that led to the thoughts getting worse? Has it ever gotten to the point where you developed a plan? When did you make a plan? Have you recently made a plan? What was the plan? Do you have access to the things you need to carry out your plan?</p> <p>If onset started &gt;1 year ago: Do thoughts of suicide always seem to be there for many years? Or are they new?</p>	<p><i>More organized plan indicates high risk. Access to means also indicates high risk.</i></p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
<p>Have you ever made a suicide attempt (i.e., an act of self-harm with any intention to die)?</p> <p>If yes to suicide attempts: Has this occurred more than once? How many times? When was the first one? When was the most recent one? Have you told other people about them? Are there stressors that led to the attempt(s)? Did the attempt(s) result in seeing a mental health professional? In what way(s) did you attempt? Was it something planned or impulsive? Was there anyone around when the attempt happened? Have you ever developed a safety plan if you are having these thoughts? What is the safety plan? Who have you shared it with?</p>	<p><i>Describe details of prior suicide attempts. Prior attempt indicates higher risk. Be mindful of how "extreme" the attempt is, which may indicate risk level.</i></p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A

Question	Direction of Risk	Modifiable
<p>Do you ever end up physically harming yourself without wanting to die? In what ways have you harmed yourself without any suicidal intent (e.g., cutting, burning, banging your head, overdosing on medications)? How old were you when you first self-harmed without intending to die? When was the most recent time? How often have you self-harmed without intending to die in the past 3 months? What did/does it do for you? Is it something you want to decrease? If so, for what reason do you want to reduce or stop? Do any of your friends self-harm? Do you ever watch online videos of people who self-harm?</p>	<p><i>Note that NSSI is a risk factor for suicide. Younger age of onset, more than 5 incidents of NSSI, and using NSSI to regulate emotions (including numbness, guilt, anxiety, sadness) are all indicators of increased risk. Describe each of these factors. Pay particular attention to how youth respond when you list off methods of non-suicidal self-injury and adjust the tone accordingly. Some youth may find it overwhelming; at the same time, it is important to actively ask about methods, as important information is often revealed.</i></p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
<p>To what extent does depression get in the way of your life? Does it cause difficulties with:</p> <ul style="list-style-type: none"> <li>• peer relationships</li> <li>• family relationships</li> <li>• ability to engage in enjoyable activities</li> <li>• ability to engage in school or work?</li> </ul> <p>Does depression interfere with any other goals in your life?</p> <p>Do other people in your life know you struggle with depression? How do they respond when you are showing signs of depression?</p> <p>Would you say that depression interferes with your life a little, a medium amount or a lot?</p>	<p><i>Greater functional impairment represents greater risk.</i></p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A

Question	Direction of Risk	Modifiable
<p>Do you have any challenges with your physical health such as:</p> <ul style="list-style-type: none"> <li>• asthma, diabetes or thyroid problems</li> <li>• seizures</li> <li>• head injuries, including concussions</li> <li>• other neurological conditions</li> <li>• surgeries?</li> </ul>	<p><i>Major medical conditions that are currently disabling or distressing indicate higher risk.</i></p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
<p>What is your pattern of substance use?</p>	<p><i>Higher levels of intoxicating substance use increase risk.</i></p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
<p>Would you consider yourself a spiritual person? How would you describe your religious beliefs?</p>	<p><i>Philosophies and spirituality or religious beliefs that correspond to a greater sense of purpose indicate less risk.</i></p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A

# Planning For Life



## Session 1

### For the remaining sections:

Black font refers to youth-directed content.

*Purple italic font refers to instructions for the clinician.*

Thoughts about suicide and self-harm behaviours are common enough in young people struggling with depression. Getting a good understanding of your experience and communicating this with others can help manage these thoughts and behaviours. This module will guide you through some relevant strategies including safety planning, getting motivated for change, how to “ride out” some of these experiences without acting on them and how to break patterns leading to intense suicidal ideas and/or self-harm. It is best to work with your clinician on these strategies. Safety planning is a good place to start.

If you get stuck while responding to questions in sections A to G below, there are some prompts at the end of this section on pages 18 to 19 that may give you some ideas.

### A Reading the Signs

Greater self-awareness of higher risk times (relative to your typical experiences) can help guide you to next steps. The earlier you catch signs of your own risk, the easier it will be to cope. What are your personal signs that risk for self-harm is getting elevated?

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*Examples if the youth needs further guidance:*

- Thoughts about suicide or self-harm
- Substance use
- Feeling a sense of purposelessness or hopelessness
- Feeling tense, restless, or anxious
- Feeling trapped
- Withdrawal from friends and family
- Uncontrollable anger
- Feeling more impulsive
- Sudden and intense shift in mood
- Uncontrollable negative thoughts
- School stressors
- Family stressors
- Peer stressors
- Personalized sign: \_\_\_\_\_
- Personalized sign: \_\_\_\_\_

## B Feeling Connected

Reminding yourself of people or ideas you are connected to can help you to get through hard times. What are some reasons that help you keep going and motivate you to want to continue living or continue efforts to reduce self-harm?

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*Examples if the youth needs further guidance:*

- |  |  |
|--|--|
| <input type="checkbox"/> Family members                                | <input type="checkbox"/> Experiencing new things     |
| <input type="checkbox"/> Children in my life (e.g., siblings, cousins) | <input type="checkbox"/> Achieving future goals      |
| <input type="checkbox"/> Friends                                       | <input type="checkbox"/> Hobbies or interests        |
| <input type="checkbox"/> Pets  | <input type="checkbox"/> Ideas I am passionate about |
| <input type="checkbox"/> Faith, spirituality or life philosophies      | <input type="checkbox"/> Personalized reason: _____  |
|  | <input type="checkbox"/> Personalized reason: _____  |

## C What Helps You Already

People often have a list of strategies that have worked for them in the past but may need to be reminded of them. What have you done in the past to cope or ease your distress?

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*Examples if the youth needs further guidance:*

- |   |  |
|---|--|
| <input type="checkbox"/> Deep breathing   | <input type="checkbox"/> Meditating or praying   |
| <input type="checkbox"/> Doing exercise   | <input type="checkbox"/> Paying attention to my five senses (e.g., "grounding")                  |
| <input type="checkbox"/> Cold sensation (cold water, ice pack on my face or neck) | <input type="checkbox"/> Doing a relaxation exercise or yoga                                     |
| <input type="checkbox"/> Reaching out to a friend or family member                | <input type="checkbox"/> Connecting with my community  |
| <input type="checkbox"/> Distracting myself with an activity                      | <input type="checkbox"/> Creating a "hope kit" with items that I find that help ease my distress |
| <input type="checkbox"/> Listening to pleasant music or a podcast                 | <input type="checkbox"/> Personalized sign: _____  |
| <input type="checkbox"/> Watching a TV show or movie I like                       | <input type="checkbox"/> Personalized sign: _____  |
| <input type="checkbox"/> Going for a walk   |  |

## D Reframing My Situation

Sometimes a shift in thinking can help. How can you reframe thoughts you are having about your situation?

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*Examples if the youth needs further guidance:*

- Thinking of ways that I got through challenges in the past
- Reminding myself of people who care about me
- Thinking of what I would say to a close friend who was feeling this way
- Reminding myself that, with treatment, I can learn new strategies to cope
- Reminding myself that the pain goes in waves
- Personalized way to reframe thoughts: \_\_\_\_\_
- Personalized way to reframe thoughts: \_\_\_\_\_

## E Support

Knowing who to reach out to in a time of need is key. Who are people you can ask for support? What would you say to them?

Personal (e.g., family, friends, other members of the community):

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Professionals/Organizations (e.g., mental health agencies, local crisis lines):

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## F Staying Safe in the Moment

Strong emotions can often make people more vulnerable to impulsive behaviours, including self-harm. What are some ways you can put a distance between yourself and items used to self-harm? These strategies may make it more difficult for impulsivity to lead to self-harm.

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*Examples if the youth needs further guidance:*

- Locking up or removing items I may use to harm myself
- Avoiding situations or people that upset me
- Removing myself from areas where I am not safe
- Asking someone to help me stay safe
- Removing things that make me feel unstable (e.g., alcohol or other drugs, cues for overwhelming memories, social media, a situation that is overwhelming)
- Personalized strategy: \_\_\_\_\_
- Personalized strategy: \_\_\_\_\_

*Remember that if you have tried these strategies and are still overwhelmed with suicidal thoughts or self-harm, you can call a crisis line (do an online search for “crisis line” and the name of your geographical region) or go to an emergency room for help.*

## G Planning

Writing out your safety plan can help open the mind to solutions that don't involve self-harm.

Using the above information, summarize your short-term personal safety plan:

e.g., Situations like "X" often bring on suicidal thoughts \_\_\_\_\_

e.g., When feeling "X" I can turn to \_\_\_\_\_ and I can avoid \_\_\_\_\_

e.g., To keep safe in the moment, I can \_\_\_\_\_

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What can I do in the long term to reduce my risk?

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Examples if the youth needs further guidance:

- Participating in psychotherapy (including committing to attending and continuing therapy)
- Treat my underlying psychological difficulties
- Involving family members and friends in my care
- Becoming more connected with my community

Working toward longer term goals

Personalized longer-term strategy: \_\_\_\_\_

Personalized longer-term strategy: \_\_\_\_\_

If the youth is willing, look for opportunities to role-play through a moment of distress and subsequent actions or conversations the youth can have. This may help generalize what has been discussed here.

# Other Ways to Respond

The following checklists are here as a reference if you need some ideas to complete the sections A to G above.

## A Reading the Signs

- Thoughts about suicide or self-harm
- Substance use
- Feeling a sense of purposelessness or hopelessness
- Feeling tense, restless, or anxious
- Feeling trapped
- Withdrawal from friends and family
- Uncontrollable anger
- Feeling more impulsive
- Sudden and intense shift in mood
- Uncontrollable negative thoughts
- School stressors
- Family stressors
- Peer stressors
- Personalized sign: \_\_\_\_\_
- Personalized sign: \_\_\_\_\_

## B Feeling Connected

- Family members
- Children in my life (e.g., siblings, cousins)
- Friends
- Pets
- Faith, spirituality or life philosophies
- Experiencing new things
- Achieving future goals
- Hobbies or interests
- Ideas I am passionate about
- Other way to connect: \_\_\_\_\_
- Other way to connect: \_\_\_\_\_

## C What Helps You Already?

- Deep breathing
- Doing exercise
- Cold sensation (cold water, ice pack on my face or neck)
- Reaching out to a friend or family member
- Distracting myself with an activity
- Listening to pleasant music or a podcast
- Watching a TV show or movie I like
- Going for a walk
- Meditating or praying
- Paying attention to my 5 senses (e.g., grounding)
- Relaxation exercise or yoga
- Connecting with my community
- Creating a “hope kit” with items that I find help ease my distress
- Personalized coping: \_\_\_\_\_
- Personalized coping: \_\_\_\_\_

## D Reframing My Situation

- Thinking of ways that I got through challenges in the past
- Reminding myself of people who care about me
- Thinking of what I would say to a close friend who was feeling this way
- Reminding myself that, with treatment, I can learn new strategies to cope
- Reminding myself that the pain goes in waves
- Personalized way to reframe thoughts: \_\_\_\_\_
- Personalized way to reframe thoughts: \_\_\_\_\_

## F Staying Safe in the Moment

- Locking up or removing items I may use to harm myself
- Avoiding situations or people that upset me
- Removing myself from areas where I am not safe
- Asking someone to help me stay safe
- Removing things that make me feel unstable (e.g., alcohol or other drugs, cues for overwhelming memories, social media, a situation that is overwhelming)
- Personalized strategy: \_\_\_\_\_
- Personalized strategy: \_\_\_\_\_

## G Planning for Life

- Participating in psychotherapy (including committing to attending and continuing therapy)
- Treating my underlying psychological difficulties
- Involving family members and friends in my care
- Becoming more connected with my community
- Working toward longer term goals
- Personalized longer-term strategy: \_\_\_\_\_
- Personalized longer-term strategy: \_\_\_\_\_

# Ramping Up: Getting ready for change



## Session 2

Thoughts about suicide and/or self-harm often have a purpose. Sometimes people are hesitant to let them go or work on them. Many people are ambivalent: this means that a strong part of them wants to continue with the thoughts or behaviours and, at the same time, a strong part of them wants to reduce or stop. If you are someone who struggles with ambivalence around suicidal ideation and/or self-harm, this concept is important to understand.



As you work through treatment, you may find your motivations shift. Work through the following sections if they apply to your situation.

### A Thoughts About Suicide

On the line below, indicate with an “X” how strong the urges are to **continue** thinking about suicide.



On the line below, indicate with an “X” how motivated you are to **reduce** thinking about suicide.



On the line below, indicate with an “X” how motivated you are to **stop** thinking about suicide.



With your clinician, work through the following table to explore your relationship to suicidal thoughts.

**Note that this discussion is around the pros and cons of THINKING about suicide — not pros and cons of the act of suicide. This is an important distinction.** This activity runs the risk that pros of thinking about suicide will outweigh the cons. It is still important to validate the youth's underlying distress (as opposed to the thoughts themselves) in this context. You can also express your concern and together be curious about whether they think the balance shifts over time. Avoid getting into confrontations about this.

	Pros	Cons
Continuing to think about suicide	1. (Do this one first.)	3. (Do this one third.)
Reducing suicidal thoughts	4. (Do this one last.)	2. (Do this one second.)

Has working through this table led to any shifts in your motivation?

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What would help increase your motivation to reduce or stop these thoughts?

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How confident are you that you can start making changes?

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What would help make your confidence stronger?

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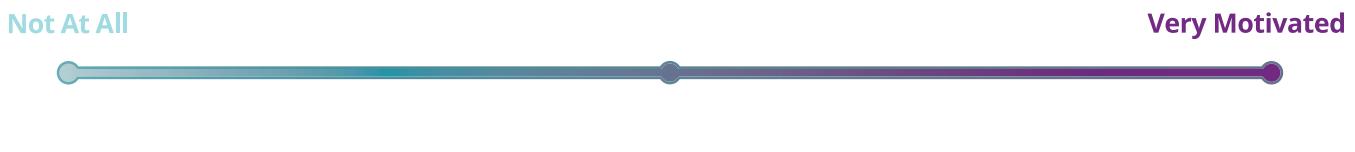
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## B Self-Harm

On the line below, indicate with an "X" how strong the urges are to **continue** self-harming.



On the line below, indicate with an "X" how motivated you are to **reduce** self-harming.



On the line below, indicate with an "X" how motivated you are to **stop** self-harming.



With your clinician, work through the following table to explore your relationship to self-harm.

*Note that this activity runs the risk that pros of self-harming will outweigh the cons. It is still okay to validate the youth's distress (as opposed to behaviour) in this context. You can also express your concern and together be curious about whether they think the balance shifts over time. Avoid getting into confrontations about this.*

	Pros	Cons
Continuing to self-harm	1. (Do this one first.)	3. (Do this one third.)
Coping without self-harming	4. (Do this one last.)	2. (Do this one second.)

Has working through this table led to any shifts in your motivation?

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What would help increase your motivation to reduce or stop the self-harm?

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---

How confident are you that you can start making changes?

---

---

What would help make your confidence stronger?

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## B Vulnerabilities

Next identify the **factors that made you vulnerable to strong emotions or urges** before the self-harm event or period of intense suicidal ideas.

- How was your sleep?\_\_\_\_\_
- What was your eating like?\_\_\_\_\_
- Were you hydrated?\_\_\_\_\_
- Were any substances involved?\_\_\_\_\_
- Had you done any exercise?\_\_\_\_\_
- What emotions were you already having (e.g., loneliness)?\_\_\_\_\_
- Had you recently engaged in any enjoyable activities?\_\_\_\_\_
- Were you worrying about something?\_\_\_\_\_

## C What Was the Threat?

Next identify **what happened just before or when you no longer felt okay** before the self-harm event or period of intense suicidal ideas. Often this can be a conflict with someone, or an experience of isolation or rejection.

- Where were you?\_\_\_\_\_
- Who was there?\_\_\_\_\_
- What were you and others doing?\_\_\_\_\_
- What was said?\_\_\_\_\_
- What emotions were you having?\_\_\_\_\_
- What thoughts were you having?\_\_\_\_\_
- What need was being threatened?\_\_\_\_\_

## D Build Up

Next identify **other experiences you had that made things even harder** before the self-harm event or period of intense suicidal ideas.

- Where were you?\_\_\_\_\_
- Who was there?\_\_\_\_\_
- What were you and others doing?\_\_\_\_\_
- What was said?\_\_\_\_\_
- What emotions were you having?\_\_\_\_\_
- What thoughts were you having?\_\_\_\_\_

## E The Event

Next identify **what was going on** during the self-harm event or period of intense suicidal ideas.

- Where were you?\_\_\_\_\_
- Who was there?\_\_\_\_\_
- What were you and others doing?\_\_\_\_\_
- What was said?\_\_\_\_\_
- What emotions were you having?\_\_\_\_\_
- What thoughts were your having?\_\_\_\_\_
- If you did self-harm, in what way and where on the body?\_\_\_\_\_
- If you did self-harm, what did you expect to be the result?\_\_\_\_\_

## F The Aftermath

Next **describe your experiences after** the self-harm event or period of intense suicidal ideas. Often this can be a conflict with someone, or an experience of isolation or rejection.

- Where were you?\_\_\_\_\_
- Who was there?\_\_\_\_\_
- What were you and others doing?\_\_\_\_\_
- What was said?\_\_\_\_\_
- What emotions were you having?\_\_\_\_\_
- What thoughts were your having?\_\_\_\_\_

## G Rewind

If you could replay the day, is there anything that could be done to:

- Prolong the calm before the storm?\_\_\_\_\_
- Change your vulnerability to self-harm or suicidal ideas?\_\_\_\_\_
- Change the threat?\_\_\_\_\_
- Change the build up?\_\_\_\_\_
- Change the event?\_\_\_\_\_
- Change the aftermath?\_\_\_\_\_



## SUICIDAL THOUGHTS AND BEHAVIOURS: MENTAL HEALTH FIRST AID GUIDELINES

Suicide can be prevented. Most suicidal people do not want to die. They simply do not want to live with the pain. Openly talking about suicidal thoughts and feelings can save a life. Do not underestimate your abilities to help the person, even to save a life.

### HOW CAN I TELL IF SOMEONE IS FEELING SUICIDAL?

It is important that you know the warning signs and risk factors for suicide, and the reasons why a person might have thoughts of suicide.

#### **Signs a person might be suicidal:**

- Threatening to hurt or kill themselves
- Looking for ways to kill themselves: seeking access to pills, weapons, or other means
- Talking or writing about death, dying or suicide
- Hopelessness
- Rage, anger, seeking revenge
- Acting recklessly or engaging in risky activities, seemingly without thinking
- Feeling trapped, like there's no way out
- Increasing alcohol and drug use
- Withdrawing from friends, family or society
- Anxiety, agitation, unable to sleep or sleeping all the time
- Dramatic changes in mood
- No reason for living, no sense of purpose in life

Adapted from Rudd et al (2006).

*Warning signs for suicide: Theory, research and clinical applications. Suicide and Life-Threatening Behavior, 36:255-262.*



## SUICIDAL THOUGHTS AND BEHAVIOURS: MENTAL HEALTH FIRST AID GUIDELINES

### REASONS WHY A PERSON MIGHT HAVE THOUGHTS ABOUT SUICIDE

The main reasons people give for attempting suicide are:

1. Needing to escape or relieve unmanageable emotions and thoughts. The person wants relief from unbearable emotional pain, feels their situation is hopeless, feels worthless and believes that other people would be better off without them.
2. Desire to communicate with or influence another individual. The person wants to communicate how they feel to other people, change how other people treat them or get help.

*Adapted from May & Klonsky (2013) Assessing motivations for suicide attempts: Development of psychometric properties of the inventory of motivations for suicide attempts. Suicide and Life-Threatening Behavior, 43(5), 532-546.*

### RISK FACTORS ASSOCIATED WITH A HIGHER RISK OF SUICIDE

People are at greater risk of suicide if they have:

- A mental illness
- Poor physical health and disabilities
- Attempted suicide or harmed themselves in the past
- Had bad things happen recently, particularly with relationships or their health
- Been physically or sexually abused as a child
- Been recently exposed to suicide by someone else

Suicide is also more common in certain groups, including males, Indigenous people, the unemployed, prisoners, and gay, lesbian and bisexual people.

*Adapted from Hawton K, van Heeringen K. Suicide. Lancet 2009; 373: 1372-1381.*

If you are concerned the person may be at risk of suicide, you need to approach them and have a conversation about your concerns.



## SUICIDAL THOUGHTS AND BEHAVIOURS: MENTAL HEALTH FIRST AID GUIDELINES

### PREPARING YOURSELF TO APPROACH THE PERSON

Be aware of your own attitudes about suicide and the impact of these on your ability to provide assistance (e.g. beliefs that suicide is wrong or that it is a rational option). If the person is from a different cultural or religious background to your own, keep in mind that they might have beliefs and attitudes about suicide which differ from your own.

Be aware that it is more important to genuinely want to help than to be of the same age, gender or cultural background as the person.

**If you feel unable to ask the person about suicidal thoughts, find someone else who can.**

### MAKING THE APPROACH

Act promptly if you think someone is considering suicide. Even if you only have a mild suspicion that the person is having suicidal thoughts, you should still approach them.

Tell the person your concerns about them, describing behaviours that have caused you to be concerned about suicide. However, understand that the person may not want to talk with you. In this instance, you should offer to help them find someone else to talk to. Also, if you are unable to make a connection with the person, help them to find someone else to talk to.

### ASKING ABOUT THOUGHTS OF SUICIDE

Anyone could have thoughts of suicide. If you think someone might be having suicidal thoughts, you should ask that person directly. Unless someone tells you, the only way to know if they are thinking about suicide is to ask.

For example, you could ask:

- “Are you having thoughts of suicide?” or
- “Are you thinking about killing yourself?”

While it is more important to ask the question directly than to be concerned about the exact wording, you should not ask about suicide in leading or judgmental ways (e.g. ‘You’re not thinking of doing anything stupid, are you?’).

Sometimes people are reluctant to ask directly about suicide because they think they will put the idea in the person’s head. This is not true. Similarly, if a person is suicidal, asking them about suicidal thoughts will not increase the risk that they will act on these. Instead, asking the person about suicidal thoughts will allow them the chance to talk about their problems and show them that somebody cares.



## SUICIDAL THOUGHTS AND BEHAVIOURS: MENTAL HEALTH FIRST AID GUIDELINES

Although it is common to feel panic or shock when someone discloses thoughts of suicide, it is important to avoid expressing negative reactions. Do your best to appear calm, confident and empathic in the face of the suicide crisis, as this may have a reassuring effect for the person.

### How should I talk with someone who is suicidal?

It is more important to be genuinely caring than to say 'all the right things'. Be supportive and understanding of the person, and listen to them with undivided attention. Suicidal thoughts are often a plea for help and a desperate attempt to escape from problems and distressing feelings.

Ask the person what they are thinking and feeling. Reassure them that you want to hear whatever they have to say. Allow them to talk about these thoughts and feelings, and their reasons for wanting to die and acknowledge these. Let the person know it is okay to talk about things that might be painful, even if it is hard. Allow them to express their feelings (e.g. allow them to cry, express anger, or scream). The person may feel relief at being able to do so.

Remember to thank the person for sharing their feelings with you and acknowledge the courage this takes.

See the boxes below for tips on how to listen effectively and on things not to do.

#### LISTENING TIPS

- Be patient and calm while the person is talking about their feelings
- Listen to the person without expressing judgment, accepting what they are saying without agreeing or disagreeing with their behaviour or point of view
- Ask open-ended questions (i.e. questions that cannot be simply answered with 'yes' or 'no') to find out more about the suicidal thoughts and feelings and the problems behind these
- Show you are listening by summarising what the person is saying
- Clarify important points with the person to make sure they are fully understood.
- Express empathy for the person.



## WHAT NOT TO DO

### Don't...

- ... argue or debate with the person about their thoughts of suicide
- ... discuss with the person whether suicide is right or wrong
- ... use guilt or threats to prevent suicide (e.g. do not tell the person they will go to hell or ruin other people's lives if they die by suicide)
- ... minimise the person's problems
- ... give glib 'reassurance' such as "don't worry", "cheer up", "you have everything going for you" or "everything will be alright"
- ... interrupt with stories of your own
- ... communicate a lack of interest or negative attitude through your body language
- ... 'call their bluff' (dare or tell the person to 'just do it')
- ... attempt to give the person a diagnosis of a mental illness.

Do not avoid using the word 'suicide'. It is important to discuss the issue directly without dread or expressing negative judgement.

Demonstrate appropriate language when referring to suicide by using the terms 'suicide' or 'die by suicide', and avoiding the use of terms to describe suicide that promote stigmatising attitudes, e.g. 'commit suicide' (implying it is a crime or sin) or referring to past suicide attempts as having 'failed' or been 'unsuccessful', implying death would have been a favourable outcome.

## HOW CAN I TELL HOW URGENT THE SITUATION IS?

Take all thoughts of suicide seriously and take action. Do not dismiss the person's thoughts as 'attention seeking' or a 'cry for help'. Determine the urgency of taking action based on recognition of suicide warning signs. Ask the person about issues that affect their immediate safety:

- Whether they have a plan for suicide.
- How they intend to suicide, i.e. ask them direct questions about how and where they intend to suicide.
- Whether they have decided when they will carry out their plan.
- Whether they have already taken steps to secure the means to end their life.

## SUICIDAL THOUGHTS AND BEHAVIOURS: MENTAL HEALTH FIRST AID GUIDELINES

- Whether they have been using drugs or alcohol. Intoxication can increase the risk of a person acting on suicidal thoughts.
- Whether they have ever attempted or planned suicide in the past.

If the person says they are hearing voices, ask what the voices are telling them. This is important in case the voices are relevant to their current suicidal thoughts.

It is also useful to find out what supports are available to the person:

- Whether they have told anyone about how they are feeling.
- Whether there have been changes in their employment, social life, or family.
- Whether they have received treatment for mental health problems or are taking any medication.

Be aware that those at the highest risk for acting on thoughts of suicide in the near future are those who have a specific suicide plan, the means to carry out the plan, a time set for doing it, and an intention to do it. However, the lack of a plan for suicide is not sufficient to ensure safety.

### HOW CAN I KEEP THE PERSON SAFE?

Once you have established that a suicide risk is present, you need to take action to keep the person safe. A person who is suicidal should not be left on their own. If you suspect there is an immediate risk of the person acting on suicidal thoughts, act quickly, even if you are unsure. Work collaboratively with the person to ensure their safety, rather than acting alone to prevent suicide.

Remind the person that suicidal thoughts need not be acted on. Reassure the person that there are solutions to problems or ways of coping other than suicide.

When talking to the person, focus on the things that will keep them safe for now, rather than the things that put them at risk. To help keep the person safe, develop a safety plan with them (See: box below). Engage the person to the fullest extent possible in decisions about a safety plan. However, do not assume that a safety plan by itself is adequate to keep the person safe.



# SUICIDAL THOUGHTS AND BEHAVIOURS: MENTAL HEALTH FIRST AID GUIDELINES

## SAFETY PLAN

A safety plan is an agreement between the person and the first aider that involves actions to keep the person safe. The safety plan should:

- Focus on what the person *should* do rather than what they *shouldn't*
- Be clear, outlining what will be done, who will be doing it, and when it will be carried out
- Be for a length of time which will be easy for the person to cope with, so that they can feel able to fulfil the agreement and have a sense of achievement
- Include contact numbers that the person agrees to call if they are feeling suicidal, e.g. the person's doctor or mental health care professional, a suicide helpline or 24-hour crisis line, friends and family members who will help in an emergency.

Find out who or what has supported the person in the past and whether these supports are still available. Ask them how they would like to be supported and if there is anything you can do to help, but do not try to take on their responsibilities.

Although you can offer support, you are not responsible for the actions or behaviours of someone else, and cannot control what they might decide to do.

## What about professional help?

Encourage the person to get appropriate professional help as soon as possible. Find out information about the resources and services available for a person who is considering suicide, including local services that can assist in response to people at risk of suicide such as hospitals, mental health clinics, mobile outreach crisis teams, suicide prevention helplines and local emergency services. Provide this information to the person and discuss help-seeking options with them. If they don't want to talk to someone face-to-face, encourage them to contact a suicide helpline.

Don't assume that the person will get better without help or that they will seek help on their own. People who are feeling suicidal often don't ask for help for many reasons, including stigma, shame and a belief that their situation is hopeless and that nothing can help.

**If the person is reluctant to seek help,** keep encouraging them to see a mental health professional and contact a suicide prevention hotline for guidance on how to help them.

## SUICIDAL THOUGHTS AND BEHAVIOURS: MENTAL HEALTH FIRST AID GUIDELINES

**If the person refuses professional help**, call a mental health centre or crisis telephone line and ask for advice on the situation.

**If the person is an adolescent**, a more directive approach may be needed. If an adolescent is reluctant to seek help, make sure someone close to them is aware of the situation (i.e. a close friend or family member). If the adolescent refuses professional help, also get assistance from a mental health professional.

For people at more urgent risk, additional action may be needed to facilitate professional help seeking. **If you believe the person will not stay safe**, seek their permission to contact their regular doctor or mental health professional about your concerns. If possible, the health professional contacted should be a professional the person already knows and trusts. **If the person has a specific plan for suicide, or if they have the means to carry out their suicide plan**, call a mental health centre or crisis telephone line and ask for advice on the situation.

**If the person has a weapon**, contact the police. When contacting the police, inform them that the person is suicidal to help them respond appropriately. Make sure you do not put yourself in any danger while offering support to the person.

Be prepared for the person to possibly express anger and feel betrayed by your attempt to prevent their suicide or help them get professional help. Try not to take personally any hurtful actions or words of the person.

### **WHAT IF THE PERSON WANTS ME TO PROMISE NOT TO TELL ANYONE ELSE?**

You must never agree to keep a plan for suicide or risk of suicide a secret. If the person doesn't want you to tell anyone about their suicidal thoughts, you should not agree but give an explanation why (for example, "I care about you too much to keep a secret like this. You need help and I am here to help you get it"). Treat the person with respect and involve them in decisions about who else knows about the suicidal crisis.

If the person refuses to give permission to disclose information about their suicidal thoughts, then you may need to breach their confidentiality in order to ensure their safety. In doing so, you need to be honest and tell the person who you will be notifying.

Keep in mind that it is much better to have the person angry at you for sharing their suicidal thoughts without their permission, in order to obtain help, than to lose the person to suicide.

### **WHAT SHOULD I DO IF THE PERSON HAS ACTED ON SUICIDAL THOUGHTS?**

If the person has already harmed themselves, administer first aid and call emergency services, asking for an ambulance.

Keep in mind that despite our best efforts, we may not be successful in preventing suicide.



## SUICIDAL THOUGHTS AND BEHAVIOURS: MENTAL HEALTH FIRST AID GUIDELINES

### THE PERSON I AM TRYING TO HELP HAS INJURED THEMSELVES, BUT INSISTS THEY ARE NOT SUICIDAL. WHAT SHOULD I DO?

Some people injure themselves for reasons other than suicide. This may be to relieve unbearable anguish, to stop feeling numb, or other reasons. This can be distressing to see. There are guidelines in this series [Non-Suicidal Self-Injury: Mental Health First Aid Guidelines](#) which can help you to understand and assist if this is occurring.

### TAKE CARE OF YOURSELF

After helping someone who is suicidal, make sure you take appropriate self-care. Providing support and assistance to a person is exhausting and it is therefore important to take care of yourself.

#### An important note:

Self-injury can indicate a number of different things. Someone who is hurting themselves may be at risk of suicide. Others engage in a pattern of self-injury over weeks, months or years and are not necessarily suicidal. These guidelines are to assist you if the person you are helping is suicidal. If the person you are assisting is injuring themselves, but is not suicidal, please refer to the guidelines entitled [Non-Suicidal Self-Injury: Mental Health First Aid Guidelines](#)

# Obsessive- compulsive disorder

## An information guide

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# Introduction

This guide is for people with OCD, their families, partners, friends and anyone else who might be interested. This book will answer some common questions about many aspects of OCD and help readers discuss obsessive-compulsive disorder with treatment providers.

# 1 What is obsessive-compulsive disorder?

*I obsess about causing harm to others through some unintentional act. I worry that I have hurt someone with my sloppy or ineffectual words and will cause them to become seriously unhappy. Or that I have left a cigarette burning in my house or an appliance on and that my house will explode and wipe out the whole neighbourhood. This causes me to check things more than once before I leave the house, and then to go back into the house to check again. — Mary W.*

Obsessive-compulsive disorder (OCD) is a severe and debilitating mental illness characterized by the presence of obsessions and compulsions. OCD affects about two per cent of the population. It exists throughout the world and it affects women at a slightly higher rate than males in adulthood. Symptoms usually begin gradually and about a quarter of people with OCD start to develop the disorder in early adolescence.

## What are obsessions?

Everyone has bothersome worries now and again. We may worry about a problem at work or school, about money, health, relationships or a family member. People with OCD, however, can become consumed by worry. These worries are not like those that people would normally expect to have; they are not worries about real-life problems.

When worries consume someone, we call them “obsessions.” Obsessions are uninvited or “intrusive” thoughts, urges or images that surface in the mind over and over again. People with OCD know their obsessions are unrealistic creations of their own minds, but they can’t get rid of them, they can’t control them, and they can’t ignore them. Some of the more common obsessions afflicting people with OCD are:

### CONTAMINATION

- fear of contamination by dirt, germs or other diseases (for example, by shaking hands)
- fear of own saliva, urine, feces, semen or vaginal fluids

### REPEATED DOUBTING

- fear of having done (or not done) a specific act that could result in harm (for example, hurting someone in a traffic accident, leaving a door unlocked or not turning off the stove)
- fear of having made a mistake

## ORDERING

- fear that things will not be “just right,” and distress when things are shifted or touched
- focus on exactness and order

## RELIGIOUS

- fear of having blasphemous thoughts
- preoccupation with religious images and thoughts

## AGGRESSIVE

- fear of harming oneself (for example, while eating with a knife or a fork, handling sharp objects or walking near glass windows)
- fear of harming others (for example, poisoning people’s food, harming babies, pushing someone in front of a train or hurting someone’s feelings)
- fear of blurting out obscenities in public

## SEXUAL

- forbidden or unwanted sexual thoughts, images or urges (for example, experiencing recurrent sexually explicit images)
- being obsessed with sexual thoughts that involve children or incest
- fear of being homosexual

People with OCD may regard their obsessions as unwanted, unacceptable and sometimes disgusting, causing them significant feelings of distress and anxiety. To relieve these feelings, people with OCD often engage in repetitive behaviours, mental acts or rituals.

## What are compulsions?

Many people have rituals, or specific ways of doing things. We may read the paper when we wake up in the morning, or arrange pencils and erasers in a particular order on our desk. For people with OCD, such rituals may become “stuck” and last for hours.

Even though the person performing the ritual often knows it makes no sense, he or she feels compelled to enact it over and over again. When taken to this extreme, rituals are called “compulsions.” Acting out these compulsions does not give people with OCD pleasure, but it can help them feel less anxious or distressed.

Compulsions can be very rigid and involve elaborate steps. They are either not realistically connected with what they are meant to stop or they are extreme beyond reason. Although this is by no means an exhaustive list, common compulsions include:

### CLEANING/WASHING

- washing hands too often or in a ritualized way; showering; bathing; brushing teeth; grooming a lot or having detailed toilet routines; cleaning household items or other objects
- avoiding objects and situations considered “contaminated”

### CHECKING

- checking that you don’t harm others or yourself; checking that nothing terrible happens; checking that you don’t make mistakes

## ORDERING/ARRANGING

- making sure things, such as bed sheets or notes on the desk, are “just right,” or consistent with a specific rule

## MENTAL RITUALS

- mentally repeating special words, images or numbers
- special prayers
- mental reviewing
- mental undoing, or replacing bad thoughts with good thoughts

## How does OCD affect people?

The impact of OCD on a person's quality of life is strikingly high. Every aspect of a person's life can be affected, including the way the person thinks, feels or behaves. People with OCD may avoid situations that could trigger symptoms, and because they are often aware that their thoughts and actions are unrealistic, they may have difficulty sharing their concern or seeking help for their problems. The intensity of the symptoms can range from mild to severe, and the symptoms usually wax and wane over time. In severe cases (up to 20 per cent of those with the diagnosis) obsessions and compulsions can occupy the entire day and result in profound disability.

People with OCD often live with the disorder for many years before it is diagnosed and treated. Fortunately, treatment is now widely available and can be very effective in lifting the burden of this demanding and devastating illness.

## Diagnosing OCD

Many people have unwanted thoughts, worries and behavioural routines. We may dwell on unpleasant thoughts, worry about our loved ones or bite our nails. An accurate diagnosis of OCD, however, must differentiate between these behaviours and the actual psychiatric condition.

The American Psychiatric Association (2013) defines obsessive-compulsive disorder in its diagnostic reference, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), as follows:

*OCD is characterized by the presence of obsessions and/or compulsions. Obsessions are recurrent and persistent thoughts, urges, or images that are experienced as intrusive and unwanted, whereas compulsions are repetitive behaviors or mental acts that an individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly. . . . These obsessions or compulsions are time-consuming (e.g. take more than 1 hour per day) or cause clinically significant distress or impairment in social, occupational, or other important areas of functioning (pp. 235–237)*

Clinicians are skilled at using psychiatric examinations and questionnaires to determine the seriousness of the obsessions and compulsions, and the extent to which these symptoms cause distress and interfere in the person's day-to-day life. Before making a diagnosis of OCD, however, clinicians are careful to check whether the problems might be better explained by other disorder(s) that have symptoms similar to those of OCD. This process of elimination is called *differential diagnosis*. Below is a list of disorders that may have OCD-like symptoms. Note: While these conditions are different from OCD, many can occur at the same time as OCD.

## Conditions with symptoms similar to OCD

### OBSESSIVE-COMPULSIVE PERSONALITY DISORDER

Obsessive-compulsive personality disorder (OCPD) is a personality disorder commonly confused with OCD, though the majority of people with OCPD do not have OCD. OCPD is characterized by personality traits reflecting extreme perfectionism, indecision and preoccupation with details and rules. People with OCPD must have things their way with family, friends and colleagues; they may show excessive devotion to work and are often considered workaholics. They may be over-conscientious and show little expression of affection or enjoyment with others, and some people may characterize those with OCPD as “stingy.” While most people with OCD may report having one or two of these traits, a diagnosis of OCPD requires that the person have five of these traits, and there are clear and important differences between the two diagnoses.

### OBSESSIVE-COMPULSIVE RELATED DISORDERS

Obsessive-compulsive related disorders (OCRDS) is a group of disorders involving repetitive thoughts and/or behaviours that are difficult to ignore or suppress, and that cause significant distress or impairment in social, occupational or other areas of functioning. Although different from OCD, OCRDS are closely related to and often co-occur with OCD. They include:

- **Body dysmorphic disorder:** Characterized by excessive worry about appearance and what are perceived to be physical defects or flaws that are not observable or appear minimal to others. This preoccupation often leads to excessively repetitive behaviours or mental acts, such as mirror checking, grooming, requests for reassurance or seeking cosmetic procedures.
- **Trichotillomania:** Characterized by pulling out hairs from regions in which hair grows (for example, the scalp, eyebrows, eyelids

and limbs), resulting in hair loss, despite repeated attempts to decrease or stop. While compulsions in OCD are performed to reduce distress associated with obsessions, in trichotillomania the compulsive behaviour is not aimed at neutralizing obsessions.

- **Excoriation (skin picking) disorder:** Characterized by recurrent skin picking that results in skin lesions, despite repeated attempts to decrease or stop.
- **Hoarding disorder:** Characterized by persistent difficulty in discarding or parting with possessions, regardless of their value. This results in excessive accumulation of possessions that clutter living areas.

*Things keep coming in to my home but nothing goes out. I don't think I even know what I have because of everything being so mixed up. NO ONE has been in the apartment for years. I'm sure my landlords would throw me out if they saw the condition of my place. I often think, what if there was a fire? I don't dare light candles and I love candles. I'm fearful of meeting someone I could care about because I could never bring him here to my home and he would be as disgusted with me as I am with myself. — Aubrey D.*

## TIC DISORDERS

Tics are sudden, rapid motor movements or vocalizations. Similar to trichotillomania, tics are not preceded by obsessions and are not engaged in to reduce obsessional distress. Tic disorders are common in people with OCD, especially when the OCD began in childhood, and some complex tics can be difficult to distinguish from compulsions. However, tic disorders differ from OCD in that tics are not preceded by obsessions, and are not aimed at neutralizing obsessions.

## PSYCHOTIC DISORDERS

Psychotic disorders are characterized by the presence of delusions, hallucinations, disorganized thinking and disorganized or abnormal motor behaviour. Although some individuals with OCD have poor insight or even delusional beliefs that may appear to stem from a psychotic disorder such as schizophrenia, OCD differs from psychotic disorders in that levels of insight can change with severity of OCD. Moreover, other symptoms of psychotic disorders—such as auditory and visual hallucinations, and difficulties with speech—are not commonly observed in people with OCD.

## DEPRESSION

People with depression often ruminate about past mistakes and perceived failures, which may be confused with obsessions. However, unlike people with OCD—who experience distress and the urge to neutralize and/or avoid recurring thoughts or images—people with depression often brood over their depressed state to better understand its causes and consequences. Moreover, depression is usually accompanied by other symptoms that are not present in OCD, such as loss of interest in activities, fatigue, and appetite and weight changes.

## ANXIETY DISORDERS

People with OCD often experience symptoms of anxiety and, conversely, people with anxiety disorders can experience symptoms of OCD, such as recurrent thoughts and avoidant behaviours. However, the two disorders differ in that worries in anxiety disorders are normally about real-life concerns, and are not accompanied by compulsions.

Common anxiety disorders include:

- **Generalized anxiety disorder:** Characterized by excessive anxiety or worry about real-life concerns, such as finances or health.
- **Panic disorder:** Characterized by recurring panic attacks, which may occur with or without agoraphobia (fear of leaving secure places).
- **Social phobia:** Fear of embarrassment or humiliation in social situations.
- **Specific phobia:** Fear of a particular object or situation, such as spiders or heights.
- **Posttraumatic stress disorder:** Fear and anxiety re-experienced in flashbacks of traumatic events.

## 2 What causes OCD?

*As far back as I can remember, my family and friends referred to me as a worrywart. When I was about the age of 16, my experiences with OCD began. I had just started high school and things were stressful with all the changes. A friend of mine had been afflicted with a case of food poisoning, and that was when I acquired my fear of being poisoned. I can still remember how it started as a tiny concern, and proceeded to snowball into the major preoccupation of my life.* — Cecilia D.

Despite considerable research into the possible causes of OCD, no clear answer has emerged. As with most psychiatric conditions, different factors may be involved. At present, the most we can say is that OCD appears to be caused by a combination of psychological and biological factors. We will explore the theories in this chapter and the related treatments in Chapters 3 and 4.

### Psychological factors

Many psychological theories have been introduced to explain the development of OCD. The two that have received the greatest support are the behavioural and cognitive theories.

## BEHAVIOURAL THEORY

The behavioural theory suggests that people with OCD associate certain objects or situations with fear, and learn to avoid the things they fear or to perform rituals that help reduce the fear.

This pattern of fear and avoidance or ritual may begin when people are under periods of high emotional stress, such as starting a new job or ending a relationship. At such times, we are more vulnerable to fear and anxiety. Often things once regarded as "neutral" may begin to bring on feelings of fear. For example, a person who has always been able to use public toilets may, when under stress, make a connection between the toilet seat and a fear of catching an illness.

Once a connection between an object and the feeling of fear becomes established, people with OCD avoid the things they fear, rather than confronting or tolerating the fear. For instance, the person who fears catching an illness from public toilets will avoid using them. When forced to use a public toilet, he or she will perform elaborate cleaning rituals, such as cleaning the toilet seat, cleaning the door handles of the cubicle or following a detailed washing procedure. Because these actions temporarily reduce the level of fear, the fear is never challenged and dealt with and the behaviour is reinforced. The association of fear may spread to other objects, such as public sinks and showers.

In behavioural therapy (discussed in detail in the next chapter), people with OCD learn to confront and reduce their anxiety without practising avoidance or ritual behaviour. When they learn to directly confront their fears, they become less afraid.

## COGNITIVE THEORY

While the behavioural theory focuses on how people with OCD make an association between an object and fear, the cognitive theory focuses on how people with OCD misinterpret their thoughts.

Most people have intrusive or uninvited thoughts similar to those reported by people with OCD. For example, parents under stress from caring for an infant may have an intrusive thought of harming the infant. Most people would be able to shrug off such a thought. Individuals prone to developing OCD, however, might exaggerate the importance of the thought, and respond as though it represents an actual threat. They may think, "I must be a danger to children if I have thoughts of harming children." This can cause a high level of anxiety and other negative emotions, such as shame, guilt and self-disgust.

People who come to fear their own thoughts usually attempt to neutralize feelings that arise from their thoughts. One way they do this is by avoiding situations that might spark such thoughts. Another is by engaging in rituals, such as washing or praying.

Cognitive theory suggests that as long as people interpret intrusive thoughts as catastrophic, and as long as they continue to believe that such thinking holds truth, they will continue to be distressed and to practise avoidance and/or ritual behaviours.

According to cognitive theory, people who attach exaggerated danger to their thoughts do so because of false beliefs learned earlier in life. Researchers think the following beliefs may be important in the development and maintenance of obsessions:

- "exaggerated responsibility," or the belief that one is responsible for preventing misfortunes or harm to others

- the belief that certain thoughts are very important and should be controlled
- the belief that somehow having a thought or an urge to do something will increase the chances that it will come true
- the tendency to overestimate the likelihood of danger
- the belief that one should always be perfect and that mistakes are unacceptable.

*When I first experienced my OCD, I thought I was losing my mind. I had never worried about these ideas before and now I was totally enveloped with them. I knew what I was feeling was unreasonable but I still had this terrifying feeling of “what if?” What if it was at all possible for these things to happen? I knew that the odds were .0001 per cent but I would still be overwhelmed with the fear that something disastrous might occur to me or someone else.*

— Bryan B.

In cognitive therapy (discussed in detail in the next chapter), people “unlearn” their mistaken beliefs and change their patterns of thought. By doing so, they are able to eliminate the distress associated with such thoughts and to discontinue their compulsive behaviours.

## Biological factors

### REGULATING BRAIN CHEMISTRY

Research into the biological causes and effects of OCD has revealed a link between OCD and certain brain chemicals, or neurotransmitters. The neurotransmitters that are particularly important in OCD include serotonin, dopamine and glutamate.

Serotonin is one of the brain's chemical messengers that transmits signals between brain cells. Serotonin plays a role in the regulation of mood, aggression, impulse control, sleep, appetite, body temperature and pain. All of the medicines used to treat OCD raise the levels of serotonin available to transmit messages. The roles of dopamine and glutamate are being further researched.

## CHANGES IN BRAIN ACTIVITY

Modern brain imaging techniques have allowed researchers to study the activity of specific areas of the brain. Such studies have shown that people with OCD have more than usual activity in three areas of the brain. These are:

- the **caudate nucleus** (specific brain cells in the basal ganglia, deep in the centre of the brain). This area of the brain acts as a filter for thoughts coming in from other areas. The caudate nucleus is also considered to be important in managing habitual and repetitive behaviours. When OCD is successfully treated with drugs or therapy, the activity in this area of the brain usually decreases. This shows that both drugs and psychotherapy can alter the physical functioning of the brain.
- the **prefrontal orbital cortex** (in the front area of the brain). The level of activity in the prefrontal orbital cortex is believed to affect appropriate social behaviour. Lowered activity or damage in this region is linked to feeling uninhibited, poor judgment and a lack of guilt. More activity may therefore cause more worry about social concerns, such as being meticulous, neat and preoccupied with cleanliness, and being afraid of acting inappropriately. All of these concerns are symptoms of OCD.
- the **cingulate gyrus** (in the centre of the brain). The cingulate gyrus is believed to be involved in detecting potential errors as well as contributing to the emotional response to obsessive thoughts. Essentially, this area of the brain tells you that you have made a

mistake and to perform a behaviour to correct it. This region is highly interconnected with the prefrontal orbital cortex and the basal ganglia, via a number of brain cell pathways.

The basal ganglia, the prefrontal orbital cortex and the cingulate gyrus all have many brain cells affected by serotonin. Researchers believe that medicines that raise the levels of serotonin available to transmit messages may change the level of activity in these areas of the brain.

## STREPTOCOCCUS AND OCD

Some researchers believe that cases in which children suddenly develop OCD or Tourette's syndrome may be linked to a recent infection with Group A streptococcus, the bacteria that causes the common strep throat. In these cases, the body may be forming antibodies to the infection, which may mistakenly react to the basal ganglia, an area of the brain linked to OCD.

There is no evidence, however, that streptococcus plays a role in adult-onset OCD. And in most cases where children develop OCD, the symptoms begin gradually, not suddenly as described above. At this time, then, the link between streptococcus infection and OCD is not certain.

## GENETIC FACTORS

OCD often seems to run in families. In fact, almost half of all cases show a familial pattern. Research studies on families of people with OCD, as well as data from national health registries, indicate that first-, second- and third-degree relatives of people with OCD have a greater chance of developing OCD than does someone with no family history of the disorder.

When a medical disorder runs in families, it can be due either to genes that are passed on (hereditary) or to shared environment (“taught” by one family member to another). In OCD, it is believed that genetic factors play an important role in the tendency to develop obsessions and compulsions. Evidence for this belief comes from twin studies, which show that if one twin has OCD, the other twin is far more likely to develop the disorder if they are identical twins (who share 100 per cent of genetic material) than if they are fraternal twins (who share about 50 per cent of genetic material).

Research studies on the genetics of OCD indicate that there is no one gene specifically linked to OCD. Rather, it appears that multiple combinations of different genes can contribute to the total risk of developing OCD. These include variants of genes that regulate neurotransmitters such as serotonin, dopamine and glutamate. However, much of the genetic contribution to OCD remains unknown.

## 3 Therapy for OCD

Modern treatments for OCD have radically changed how the disorder is viewed. While in the past OCD was regarded as chronic and untreatable, a diagnosis of OCD may now be regarded with hope. Cognitive-behavioural therapy (CBT) and antidepressant medications are currently used to treat the disorder. Neither provide a cure for OCD, but they control the symptoms and enable people with OCD to restore normal function in their lives.

Treatment for OCD ideally involves a combination of CBT and drug therapy. It is important that people with OCD receive treatment that is specific to OCD, from a fully qualified therapist. Some forms of traditional psychotherapy are not effective at relieving symptoms of OCD. CBT is often delivered in a group setting because there are benefits in meeting and working with people who have the same difficulties.

Many people with OCD benefit from supportive counselling in addition to treatments aimed at reducing the symptoms of OCD. Individuals may see a therapist one-on-one, or counselling may also involve the partner, spouse or family. For more information on supportive counselling, see Chapter 5.

# Cognitive-behavioural therapy

Cognitive-behavioural therapy (CBT) refers to two distinct treatments: cognitive therapy and behavioural therapy. The most widely practised behavioural therapy for OCD is called exposure and response prevention (ERP).

Although these treatments are increasingly offered in combination, we will discuss them separately.

## EXPOSURE AND RESPONSE PREVENTION

The “exposure” part of this treatment involves direct or imagined controlled exposure to objects or situations that trigger obsessions that arouse anxiety. Over time, exposure to these obsessional cues leads to less and less anxiety and eventually arouses little anxiety at all. This process of getting used to obsessional cues is called “habituation.”

The “response” in part refers to the ritual behaviours that people with OCD engage in to reduce anxiety. In ERP treatment, patients learn to resist the compulsion to perform rituals and are eventually able to stop engaging in these behaviours.

### How does ERP work?

Before starting ERP treatment, patients make a list or “hierarchy” of situations that provoke obsessional fears. For example, a person with fears of contamination might create a list of obsessional cues that looks like this:

- 1) touching garbage
- 2) using the toilet
- 3) shaking hands

Treatment starts with exposure to situations that cause mild to moderate anxiety, and as the patient habituates to these situations, he or she gradually works up to situations that cause greater anxiety. The time it takes to progress in treatment depends on the patient's ability to tolerate anxiety and to resist compulsive behaviours.

Exposure tasks are usually first performed with the therapist assisting. These sessions generally take between 45 minutes and three hours. Patients are also asked to practise exposure tasks between sessions for two to three hours per day.

In some cases, direct or "in vivo" exposure to the obsessional fears is not possible in the therapist's office. If, for example, a patient were being treated for an obsession about causing an accident while driving, the therapist would have to practise what is called "imaginal" exposure. Imaginal exposure involves exposing the person to situations that trigger obsessions by imagining different scenes.

The main goal during both in vivo and imaginal exposure is for the person to stay in contact with the obsessional trigger without engaging in ritual behaviours. For example, if the person who fears contamination responds to the anxiety by engaging in hand-washing or cleaning rituals, he or she would be required to resist these activities after an exposure task—first for hours and eventually for days. The therapy continues in this manner until the patient is able to abstain from ritual activities altogether.

To track progress during exposure tasks, patients are trained to be experts in rating their own anxiety levels. Once they have made progress in treatment, participants are encouraged to continue using the ERP techniques they have learned, and to apply them to new situations as they arise. A typical course of ERP treatment is between 14 and 16 weeks.

### **Self-directed ERP**

For people with mild OCD, self-directed ERP may be as effective as seeing a therapist. Two excellent self-directed ERP manuals with step-by-step strategies are *Getting Control* and *Stop Obsessing!*" (See "Suggested Reading" on page 53.)

### **How effective is ERP?**

Even patients with long-standing and severe symptoms of OCD can benefit from ERP treatment. Success depends on a number of factors and requires that the patient be motivated to get well.

Studies documenting the benefits of ERP treatment have found that upwards of 75 per cent of patients experience improvement in their OCD symptoms during treatment. The majority show long-term improvement two and three years after treatment.

Patients who benefit less from ERP include those who do not exhibit overt compulsions and those with moderate-to-severe depression.

## **COGNITIVE THERAPY**

As mentioned earlier, people with OCD often become anxious about their thoughts (or obsessions) when they interpret such thoughts as dangerous and likely to occur. Thoughts of leaving the house with the stove on, for example, can result in a debilitating anxiety that sends the person running back to check again and again.

### **How does cognitive therapy work?**

In the treatment of OCD, cognitive therapy is most often done in combination with ERP.

Patients create a hierarchy of situations that cause distress and when they participate in exposure tasks, they are asked to pay

particular attention to thoughts and feelings related to these situations.

In cognitive therapy, the focus is on how participants interpret their obsessions: what they believe or assume to be true about them, what their attitude is toward them and why they think they have these obsessions. For example, a person who fears shaking hands may believe it will pass on germs that may cause him to become ill. This interpretation of this fear can be challenged and re-interpreted so that he no longer views shaking hands as a high-risk activity. Achieving these results takes time, but can provide effective relief.

Cognitive therapy also helps participants identify and re-evaluate beliefs about the potential consequences of engaging or not engaging in compulsive behaviour, and work toward eliminating this behaviour. For example, someone who compulsively washes her hands for 30 minutes at a time may believe that she is doing so to guard against infection. When this belief is challenged and confronted as false, it can help to control the behaviour.

One tool used in cognitive therapy to help people identify, challenge and correct negative interpretations of intrusive thoughts is the thought record. In the thought record, participants record their obsessions and their interpretations associated with the obsessions. The first step is for the person to begin to record each and every time they experience an intrusive thought, image or idea. The important details to record include:

1. Where was I when the obsession began?
2. What intrusive thought/image/idea did I have?
3. What meaning did I apply to having the intrusive thought/image/idea?
4. What did I do?

## An example of a thought record

SITUATION: Sitting at home watching television.

INTRUSIVE THOUGHT: "God doesn't care."

APPRAISAL OF INTRUSIVE THOUGHT:

1. I am a bad person for thinking blasphemous thoughts.
2. God will punish my family and me.
3. I must be losing my mind if I can't stop these thoughts from happening.

RITUAL: Engage in prayer. Engage in behaviours of atonement.

After the person learns to identify intrusive thoughts and the meanings they apply to them, the next steps are:

- Examine the evidence that supports and does not support the obsession.
- Identify cognitive distortions in the appraisals of the obsession.
- Begin to develop a less threatening and alternative response to the intrusive thought/image/idea.

These patterns are identified in session together with the therapist, and again during actual exposure exercises. Then the person continues to record information on the thought record between sessions.

## How effective is cognitive therapy?

Studies have shown that cognitive therapy is an effective treatment for OCD. Although cognitive and behavioural therapy can be separate, many therapists combine the two strategies. Patients can benefit from both cognitive restructuring and exposure exercises.

*My experience in group therapy has been extremely beneficial, as I have gained much greater insight into my disorder and have been given many useful tools by*

*my therapists to help me to learn to live with OCD. Although the weekly homework was particularly difficult for me, being a list maker and a checker, it afforded me plenty of practice learning to alleviate the anxiety that it caused. Meeting other people who suffer from OCD has allowed me to experience a shared empathy, which has helped me shift my focus outside of myself. Their understanding and support has made my struggle far less lonely and hopeless.*

*Thanks to the strategies learned in the group I now know I can have control over my OCD. Although at first it was very difficult to confront my fears, doing this has paid great dividends in the reduction of my symptoms. Working through my OCD challenges with others in the group has made me feel that I am by no means alone or unusual in this struggle. Listening to the challenges and triumphs of the other group members has motivated me to challenge myself more and continue to loosen the grip OCD has had on my life.*

— Changying X.

## 4 Medications

If left untreated, OCD can be a disabling and chronic illness. In addition to cognitive-behavioural therapy, drug therapy can help to reduce symptoms of OCD.

As outlined in the section “Regulating Brain Chemistry” (page 14), research has shown that people with OCD often benefit from drugs that increase the levels of serotonin available to transmit messages in the brain.

The main medications that do this are known as serotonin reuptake inhibitors (SSRIs). They are the most commonly prescribed drugs in the treatment of OCD, and are also used to treat depression. SSRIs belong to a class of drugs called antidepressants.

Most doctors treating OCD with medication will prescribe an SSRI. This medication helps to reduce the symptoms of OCD for a majority of the people who take it. For those who do not benefit from taking SSRI drugs, other drug treatments may provide relief. Other drugs may also be prescribed to address specific symptoms, and taken in addition to SSRIs. This chapter gives an overview of drug therapy options, including discussion of side-effects and other concerns.

## Serotonin reuptake inhibitors

There are two types of serotonin reuptake inhibitors (SRIs). The newer kinds are known as *selective* serotonin reuptake inhibitors (SSRIs) because their primary effect is on serotonin neurotransmitters. The SSRIs currently available in Canada are fluoxetine (Prozac), fluvoxamine (Luvox), sertraline (Zoloft), paroxetine (Paxil), citalopram (Celexa) and escitalopram (Cipralex). These medications are considered to be equally effective, although some may work for certain people but not for others.

Clomipramine (Anafranil) is the oldest and best studied of the SRI medications. It belongs to a class of medications called tricyclic antidepressants. Research indicates that clomipramine may be slightly more effective for OCD than the SSRIs, with about 80 per cent of people who take it reporting a reduction in symptoms. However, clomipramine has a more complicated set of side-effects than the SSRIs. While all SRIs are effective, most doctors advise patients with OCD to try one of the SSRIs first, because they generally have more tolerable side-effects.

### WHAT'S INVOLVED IN TRYING SRIS?

For best results, SRIs should be taken regularly, generally once each day. Most doctors recommend starting at a low dose and then, if the patient tolerates the medication well, slowly increasing the dose. People who take SRIs may experience side-effects, so the ideal dose is one that provides the greatest benefit with a minimum of side-effects.

For people with OCD, the response to medication may take longer than for depression or anxiety disorders—sometimes between eight and 12 weeks. That is why a person who has begun to take

an SRI should continue for at least three months. This allows time for the dosage to be adjusted correctly and for the benefits of the drug to become clear. When these drugs work, the effects come on gradually. Usually several weeks pass before any change in symptoms is noticed, although some individuals may see a more rapid improvement.

Typically, obsessions and compulsions slowly become less intense. It is important to realize that although these medications can be of great help to some people, only rarely do they provide relief from all symptoms of OCD.

If no benefits are derived from a particular SRI medication after a trial period of three months, doctors often recommend that another SRI be tried. Some individuals respond well to one drug and not at all to another. If a person does not benefit from the first medication, a second choice may be clomipramine.

It is not uncommon for someone to try two or three SRI drugs before finding the one that works best. People usually try at least three drugs in the SRI class before considering other drugs.

The question of whether or not to take SRIs while pregnant or nursing should be discussed with your doctor. In some cases, the benefit of the drug clearly outweighs the possible risks.

## HOW LONG SHOULD I TAKE AN SRI?

When the right SRI drug has been found, doctors usually advise taking the medication for at least six to 12 months. In some cases, it may be best to take the medication for the long term, as there may be a high risk of relapse if the medication is stopped. Even when taken long term, these medications are not addictive.

If the person begins to feel better and stops taking the medication too soon or too abruptly, the risk of relapse increases. The decision to stop taking medication should only be made in consultation with a doctor. These guidelines can help to lower the risk of relapse when a person stops using medication:

- Lower the dosage gradually by tapering or reducing the medication over time, possibly several months.
- Follow up with a health care professional regularly to help monitor the severity of any symptoms of OCD.
- Combine cognitive-behavioural therapy with medication and use the skills learned to control any symptoms that may arise when medication is discontinued.

## SIDE-EFFECTS OF SRIs

People who take SRIs may experience side-effects. For some, the side-effects are mild, an easy trade-off for the benefits of the medication. For others, the side-effects may be more troubling. People often experience the side-effects of SRIs before they experience the benefits.

In general, the side-effects of SRIs diminish over time, allowing people to tolerate these medications quite well over the long term. Some side-effects may be reduced by adjusting the dose or by taking the dose at a different time of day. The side-effects of SRIs have no permanent effect and will disappear completely when the medication is discontinued. When taking SRIs or any medication, it is important to discuss any side-effects that are troubling you with your doctor.

The possible side-effects of the newer SSRIs are generally considered to be more manageable than those of the older SRI, clomipramine. Many of the common side-effects of the newer and older drugs

are the same. They include dry mouth, sweating, constipation, drowsiness, tremor and sexual side-effects, such as lower sex drive, delayed orgasm or inability to have an orgasm.

Weight gain is considered to be more of an issue with clomipramine, although it can also occur with long-term use of SSRIs.

Other common possible side-effects of SSRIs are nausea, sleeplessness and headaches.

Other common possible side-effects of clomipramine are dizziness with sudden changes in posture, and blurred vision. Possible, but rare, side-effects are manic episodes and seizures. Individuals with a history of certain heart problems should use clomipramine with caution, as this drug affects how electrical impulses are conducted through the heart.

## DRUG INTERACTIONS WITH SRIs

When taking SRIs, or any medication, it is important to check with a doctor or pharmacist for possible drug interactions before taking any other prescription or over-the-counter drugs.

Generally, SRIs are safe drugs to use. However, taking the antihistamines terfenadine (Seldane) and astemizole (Hismanal) while taking SRIs can be dangerous. Other types of antihistamines are safe. SRIs are also known to interfere with the effectiveness of some commonly prescribed drugs.

When taking SRIs, it may be wise to avoid alcohol. SRIs may intensify the effect of alcohol, making it more difficult to control how alcohol affects your behaviour. Alcohol may also interfere with the effectiveness of SRIs.

## Other medications

For those who try several SRIs without benefit, there are other medications that may help. In some cases, other types of antidepressants may be helpful. In others, a second drug is given in addition to an SRI.

### OTHER ANTIDEPRESSANTS

These drugs also affect the brain chemical serotonin, but they work differently from the SRIS.

#### **Serotonin-norepinephrine reuptake inhibitors**

This class of antidepressants (SNRIs for short) also works on norepinephrine and can be quite tolerable. Medications in this group include venlafaxine (Effexor), desvenlafaxine (Pristiq) and duloxetine (Cymbalta). However, we have less information about their effectiveness for OCD, so if they are used, it may be as a second or third choice.

#### **Monoamine oxidase inhibitors**

Monoamine oxidase inhibitors (MAOIs) are effective antidepressants and are known to have some limited benefits in OCD. The two MAOIs available are phenelzine (Nardil) and tranylcipramine (Parnate). Both are less effective against obsessions than are SRIS, and both have more complicated side-effects than SRIS, as well as requiring a special diet, so they are typically used only if SRI medications fail.

## Secondary medications

In some cases, a second medication in combination with an SRI can be very helpful in treating the symptoms of OCD. Adding a second drug to a primary drug is known as augmentation.

## DRUGS TO RELIEVE ANXIETY

### **Antipsychotics**

There is growing evidence that combining antipsychotic medication with an antidepressant may further reduce symptoms of OCD. As a result, it is becoming more common to add a medication from this class for people who have had only a partial response to an antidepressant. There are two types of antipsychotics: the older “typical” and the newer “atypical” antipsychotics.

Typical antipsychotics, such as haloperidol (Haldol), may be especially helpful in relieving symptoms for people who have both OCD and tic disorder or Tourette’s syndrome. There are also several atypical antipsychotics available in Canada, including risperidone (Risperdal), olanzapine (Zyprexa), quetiapine (Seroquel) and aripiprazole (Abilify). Risperidone currently has the best evidence for effectiveness in treating OCD, although the others are also frequently used.

Unfortunately, these drugs are not without risk or side-effects. Antipsychotics can be quite sedating, and so hard to tolerate. They also carry longer-term risk, particularly the atypical drugs. Specifically, there are metabolic risks, including increased appetite, weight gain, elevated triglyceride and cholesterol levels, and diabetes. These risks mean that regular monitoring and blood work is important. Although it is less common with the newer drugs, some people who take antipsychotic medication for a long time may develop involuntary movements, a condition known as tardive dyskinesia. For every year that a person receives antipsychotic medication, there is a five per cent chance of developing tardive dyskinesia. The effects cannot always be reversed.

### **Benzodiazepines**

These medications have a calming effect and can help to reduce anxiety and make it easier to get to sleep. But it is not clear whether

they reduce the intensity of obsessions or compulsions. People trying to improve their symptoms through cognitive-behavioural therapy should avoid benzodiazepine drugs, because they may affect short-term memory and learning.

While these drugs can help to reduce anxiety, they should be used with caution. When starting one of these drugs, avoid driving or operating machinery until you are used to the effect. Also avoid using alcohol while taking benzodiazepines, because this combination can be dangerous. Long-term use of benzodiazepines may lead to dependence in some people. Withdrawal from these drugs should be monitored by a doctor.

Of these medications, clonazepam (Rivotril) may specifically affect serotonin balance and is a good choice for people with OCD. Other alternatives that are commonly prescribed include lorazepam (Ativan), alprazolam (Xanax), diazepam (Valium), oxazepam (Serax) and temazepam (Restoril).

## Herbal treatments

Certain herbs may have some benefit in reducing symptoms of OCD, but their effectiveness has not yet been tested. For a couple of reasons, people who wish to explore alternative treatments should consult with a knowledgeable doctor:

- As with all medications, herbal treatments can have unwanted side-effects and may interact with prescription or over-the-counter medications or other botanicals.
- In North America, the herbal industry is unregulated, meaning that the quality and effectiveness of herbal products is not consistent.

## HERBAL TREATMENTS WITH SEDATING EFFECTS

The sedating effects of some herbal medicines are believed to reduce symptoms of anxiety. These plants include German chamomile, hops, kava, lemon balm, passion flower, skullcap, valerian and gota cola. Compounds in these traditional medicines are known to act on systems in the brain in a similar way to the benzodiazepine class of medications.

Although these plants appear to be safe, they should be used with caution, because they can increase the sedating effects of other medications, as well as alcohol.

## HERBAL TREATMENTS WITHOUT SEDATING EFFECTS

St. John's wort has been suggested as a treatment for mild to moderate depression, though recent research suggests that it is actually ineffective for treatment of OCD.

Other herbs, such as Ginkgo biloba and evening primrose oil, have also been suggested for the treatment of OCD, also with little evidence for their effectiveness.

## 5 Recovery and relapse prevention

### The process of recovery

While cognitive-behavioural therapy and medication usually help to reduce the symptoms of OCD, there are aspects of living with the illness that these therapies do not fully address. The process of recovery from OCD, like the onset of the illness, is gradual and ongoing.

OCD affects every part of a person's life. It may disrupt your ability to function at work, in social situations and in the family. Once the symptoms improve and you approach a return to normal life, it can be difficult to address the practical and emotional issues that may have arisen out of a long illness.

A lengthy illness can lower a person's self-confidence, making him or her feel insecure and vulnerable in situations that were once familiar and comfortable. OCD can cause people to become quite dependent on those around them. People are often surprised at how frightened they are at the prospect of being independent and resuming their responsibilities. These reactions are a normal part of the recovery phase of OCD.

Recovery is a process, not a discrete event. At first, you should ease into familiar activities with modest expectations. Slowly take on responsibilities and build your self-confidence. When you return to activities such as socializing and going to school or work, you will probably feel anxious. Allow yourself to make mistakes.

## RETURNING TO WORK

The support of a therapist can be helpful in dealing with a return to work or school, and in rebuilding relationships with family and friends. For example, you may feel quite anxious about returning to your job. Some of the work-related issues often raised by people with OCD are:

- How do I explain my absence to co-workers?
- Is it normal to feel insecure and struggle with a lack of confidence?
- How do I understand and manage these feelings and issues without needing to engage in compulsive behaviours?

You may have more, or different, questions about returning to work. Once you have raised your concerns with your therapist, work together on a strategy for a successful return to work.

Ideally, your therapist should be knowledgeable about OCD. Many mental health professionals are not as informed about OCD as they are about other disorders. If a knowledgeable therapist is not available in your community, one who is open to learning about the disorder can give you the support you need.

It is best to resume your responsibilities gradually. Do this by starting back to work part-time or with a reduced workload. Your health care provider may recommend specific job accommodations that could be helpful in this transition, such as more

frequent breaks, time off to attend medical appointments and a reduction in non-essential job duties.

It may be helpful to educate your employer and co-workers about some of the typical signs of OCD, though some people prefer not to discuss their illness with employers. If you remain private about your illness, you will not be able to ask for any job accommodations, but it does not mean your transition back to work won't succeed. It can be especially important in this situation to have people outside of work with whom you can discuss your problems and concerns.

## Effective relapse prevention

OCD, like physical illnesses such as diabetes, is a chronic condition. Although the symptoms can be reduced and controlled with medication and therapy, you need to take precautions to prevent the symptoms from returning.

It is important to be aware of how you are feeling. Anxiety, stress, fatigue and feeling out of control can trigger a relapse. For some people, certain situations or conditions can trigger symptoms. Another common cause of relapse is stopping medication too soon or too fast.

Once the symptoms of OCD have improved, a number of strategies can help to maintain the gains you have made.

### **I. Become knowledgeable about OCD.**

Read as much as you can about OCD and its treatment. See the list of recommended reading and websites on page 53. If there is something you do not understand, ask your mental health care providers.

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**2. Resist compulsive urges; learn and use healthy strategies for coping with stress and fears.**

Once the symptoms of OCD have improved, maintaining these gains requires commitment and determination. Unhealthy strategies for coping with stress and fears must be replaced with healthy ones. Resist the urge to perform compulsions.

Using skills learned in therapy, continue to work to eliminate obsessive patterns of thought and compulsive behaviours. Do not be satisfied with only partial improvement of symptoms. This leaves you vulnerable to relapse.

**3. If medication has been prescribed, continue to take it until your doctor advises you otherwise.**

When patients begin to feel better, they often stop taking medication. Relapse is more likely if you stop taking your medication too soon. Doctors usually recommend that medication be taken for six months to a year. In some cases, antidepressants may be recommended for several years. If you are experiencing side-effects, you may be tempted to stop taking your medication. It is particularly important not to stop your medication abruptly.

Rather than making decisions on your own, work with your doctor to develop a treatment plan you can live with.

**4. Involve some family and friends in your recovery.**

If you allow yourself to become isolated and keep your inner world a secret, you will create an ideal breeding ground for symptoms of OCD. When family and friends are aware and involved in your struggle, they can help in a number of ways. For example, they can help you control compulsive urges, help you

guard against a recurrence of symptoms and give you support and encouragement.

Who you tell about your illness is a very personal choice. As a buffer against relapse, however, have at least one person you can rely on and confide in.

Along with family, friends and professional support, many people struggling with OCD find that self-help and support groups are a valuable part of their social network. (See the Internet resources on page 53 for information on how to find out if there is an OCD group in your community.)

**5. Adopt a healthy lifestyle that includes proper nutrition, exercise and good sleep habits.**

Your eating, sleeping and exercise habits play a role in how you feel and in your ability to handle stress. Nourishing yourself physically, emotionally and spiritually helps you to feel alert, calm and able to deal with problems as they arise. Yoga, other movement therapies and meditation reduce anxiety. They can also increase energy, concentration and a feeling of well-being.

**6. Try to develop a well-balanced life with enough time for work, family, friends and leisure activities.**

It might seem easy at first to escape from OCD by focusing entirely on one area, such as work or a hobby. Eventually, though, this coping strategy may not work and you will need to develop other aspects of your life. It is important to keep in contact with all the facets of life, such as school, work or volunteer activities, family and friends, and hobbies. As you recover, investing energy into several areas will help you to develop a more balanced and satisfying lifestyle, which will help you to avoid relapse.

**7. Get follow-up treatment.**

Continuing with treatment, even when the symptoms have improved, can help maintain the gains and prevent a relapse. Depending on your needs, you may also benefit from individual, group or family therapy, or a support group.

**8. Plan for your time and your future.**

The struggle with OCD can eat up your time and distract you from thinking about your future. When the symptoms improve, it can be difficult to know what to do with the time that is suddenly available to you. The possibilities can seem endless and perhaps overwhelming.

Building a life that is not absorbed by OCD depends on engaging in activities that matter to you and that will help you to maintain the gains you've made. Some people may be able to pick up where they left off, and return to work, studies or other interests that were set aside by the illness. For others, the choice may be more difficult. In some cases, seeking the services of an occupational therapist or career counsellor can help you to narrow the possibilities and make choices that let you look forward to the days to come.

**9. Prepare for setbacks.**

If you continue to practise the skills learned in therapy and follow the tips in the points above, OCD will probably not gain control of your thoughts and actions again. However, with OCD, the possibility of relapse is always there. If you feel as though OCD is beginning to take over your life again, take action.

Have a plan for early intervention. Consult with your doctor or therapist. An adjustment in medication, or revisiting some of the behavioural strategies learned in therapy, can avert a full relapse.

## Relationship with a partner or spouse

OCD can affect your relationship with a partner or spouse. During the stage of the illness when symptoms are moderate or severe, it may be hard to be supportive and intimate with your partner.

Over time, this can lead to distance and even hostility in the relationship. It takes time and work to rebuild what might have been lost during the worst stages of the illness, and while the affected person was in treatment.

Couples therapy with a therapist who knows about OCD can be very helpful. A therapist open to learning about OCD can also be effective. You may need someone to help you talk about the problems in the relationship constructively, rather than angrily. A good therapist can open up communication and help couples rediscover what brought them together in the first place. OCD is an illness that must be managed over a person's lifetime. It affects people's activities and goals. Couples may need to grieve the loss of what they imagined their relationship would be like. They may need a new vision of how they will move forward together.

## Relationship with children

At its worst, OCD can really affect your personal relationships. It might affect your ability to act as a parent. Routine things such as changing diapers, preparing meals or spending time with your children might become very difficult. You may become isolated from your children's social network and will need to reconnect to school staff, extracurricular activities and neighbours. What, if anything, do you say to people? Your role as parent can be difficult to readjust to when you are recovering from an illness. Talking with a therapist can help you to manage any anxiety that may arise.

## 6 Help for partners and families

*In Mary's family, Mary's OCD became the uncomfortable centrepiece of family life. Mary's fear of contamination led her to wash her family's clothes over and over again. If she didn't, she feared they would become ill and it would be her fault. As Mary's OCD symptoms worsened, she was so afraid of causing the family harm by touching their clothes that she was no longer able to wash their clothes herself. Her husband took over this chore, performing it under Mary's careful supervision. Sometimes someone in the family would become angry and confront Mary over what she agreed were irrational fears, but she was powerless to change. When Mary's OCD was at its worst, she felt that none of her family's clothes were cleaned sufficiently to be worn safely, and she would not allow any of them to leave the house.*

### What happens when someone you love has OCD?

When someone in a family is ill, everyone is affected, not just the person with the illness. This is true whether the illness is diabetes

or OCD. A mental illness brings added pressures. Fearing prejudice, families can become isolated as they struggle to make sense of the diagnosis and treatments.

The symptoms of OCD may not be diagnosed for a long time. Many of the thought patterns and behaviours of OCD are common among the general population, but are within normal limits. If a person complains that their spouse cleans too much or that their son hoards newspapers, people may not take them seriously. A common response might be, "I wish my partner would clean around the house more often" or "Why complain if your son saves newspapers? Is it really any of your business?" When untreated, the symptoms of OCD interfere with normal family life, often to a great degree. It is not unusual for a family to suffer for years before these symptoms are finally diagnosed.

Once an accurate diagnosis is made, getting effective treatment can be difficult. Your community may have few professionals experienced in treating the disorder and no groups available to provide support. Even when the appropriate treatment is found, sometimes people with OCD are reluctant to be treated. They may also reject attempts the family makes to work together to manage the illness.

It's natural for families to feel resentful or disappointed when OCD interferes with normal family life. Acknowledging the illness can be the first step toward feeling less isolated and freeing your energy for caring for both your relative and yourself.

## How families are affected by OCD

People with OCD often try to involve family members in compulsive rituals. To keep the peace, family members may play along or

help out with behaviours such as hoarding, checking and washing. When a family helps their relative in this way, they are “accommodating” OCD. For example, in one family a wife may buy extra detergent so her husband can wash clothes over and over again. In another, family members may agree not to throw away the piles of newspapers filling the living room.

Accommodating often begins with small compromises. Once it starts, it can be difficult to stop. For example, if a mother’s fear of contamination makes grocery shopping an ordeal, her son may go to the grocery store for her. At first, the son does the shopping as an occasional favour, but as his mother’s symptoms worsen, he takes it on as a regular chore. Eventually, he does all the shopping. His mother stays home, never leaves the house and becomes completely isolated.

Another way families respond to OCD is with disbelief or denial. They may find it difficult to understand why the person with OCD can’t just stop acting out the ritual that so clearly makes everyone unhappy. A family member may say, “I was able to quit smoking; why can’t you just stop all that checking?”

Families faced with the behaviours associated with OCD often experience complex and uncomfortable emotions. As the symptoms of OCD become more severe, the emotions that family members have may also become more intense. These emotions strain relationships and affect all aspects of family life. If allowed to escalate, the tension can become as hurtful as the disorder itself.

## When your relative is first diagnosed

When someone in your family is diagnosed with OCD, you may feel many things. A diagnosis can bring a feeling of relief to finally

know what the problem is. On the other hand, finding out that mental illness is the cause of your relative's worry and behaviour can make you feel sad. You may fear how the illness will affect the future—for your relative and for you. If you are a parent of a child or young adult who has been diagnosed with OCD, you may feel guilty and responsible. You may fear that you have done something to bring this on, even when professionals tell you that this is not the case. Not surprisingly, you may feel angry that OCD has disrupted family life.

It's normal to experience these varied and conflicting emotions. Understanding this, and learning to accept and manage your feelings, reduces the stress on you and helps you to provide more effective care for the person who is struggling with OCD.

Here are some tips that can help you to cope with the uncomfortable emotions that often arise when someone in your family has OCD. You can use these tips to help your relative recover.

## How to relate to your family member with OCD

1. **Learn as much as you can about OCD and its treatment.** Being informed will help you to understand the illness and help your relative to make changes. See the list of recommended reading and websites beginning on page 53.
2. **View your relative's obsessive-compulsive behaviours as symptoms, not character flaws.** Remember that your relative is a person with a disorder, but is healthy and able in many other ways. Focus on them as a whole person.

3. **Do not allow ocd to take over family life.** As much as possible, keep stress low and family life normal.
4. **Do not participate in your relative's rituals.** If you have helped with rituals in the past, it may take time and practice to change this pattern. In order for people with ocd to make progress, family and friends must resist helping with ritual behaviours. Supporting the rituals, including reassurance rituals, hinders progress.
5. **Communicate positively, directly and clearly.** State what you want to happen, rather than criticizing your relative for past behaviours. Avoiding personal criticism can help your relative to feel accepted while he or she is making difficult changes.
6. **Keep calm.** Not losing your temper creates a good atmosphere.
7. **Remember that life is a marathon, not a sprint.** Progress is made in small steps. There are times when no progress is made at all. Applaud progress when times are good and provide encouragement when times are bad. Your support benefits your relative.
8. **Mix humour with caring.** Support doesn't always have to be serious. People with ocd know how absurd their fears are. They can often see the funny side of their symptoms, as long as the humour does not feel disrespectful. Family members say that humour can often help their relative to become more detached from symptoms.
9. **Know the signs that show your relative is struggling with his or her ocd.** Here are some of the signs noted by family members:
  - doing tasks over and over
  - having trouble completing a task

- arriving late because of repeatedly checking
- feeling too responsible for harm that may come to others
- constantly asking for reassurance
- saving and hoarding
- washing too much
- avoiding being with people
- avoiding certain places or activities
- becoming irritable when rituals are interfered with.

10. **Support your relative's medication and treatment program.**
11. **Don't forget that you are only human.** While you do your best to support your relative, you will sometimes find yourself participating in a ritual or giving reassurance. Try not to judge yourself when you fall into old routines, in the same way you try not to judge your relative. Just start again. No one is perfect.
12. **Take care of yourself.**
  - Keep your own support network.
  - Avoid becoming isolated.
  - Know what situations within your family are most stressful as you cope with your relative's OCD.
  - Develop interests outside the family.
  - Create a low-stress environment for yourself.
  - Take a little time each day just for you.

*Mary's family was relieved when her OCD was finally diagnosed. Mary herself was relieved to discover there were treatments available. At first, she doubted the treatments could really help her, but she genuinely wanted to lead a more satisfying life and knew her problems made life difficult for the whole family. She made a firm commitment to follow through on the therapy recommendations.*

*Her family recognized that they were going to need some help as well. They wanted to be able to support Mary. They attended support groups, read books about OCD and followed through on the recommendations. For the first time, they were able to openly discuss Mary's OCD as a problem for the whole family. With the support of her family, Mary was able to remain committed to her treatment program. Everyone benefited as family life began to improve.*

## Taking care of yourself

Caught up in concern and caring for the person who is ill, family members may not take proper care of themselves. They may give up their own activities and become isolated from their friends and colleagues. This may go on for some time before they realize they are emotionally and physically drained. The stress can lead to sleeping problems, exhaustion and constant irritability.

You need to know these signs of stress and look after your own physical and mental health. Recognizing your own limits and making time for yourself are keys to self-care. Make sure you have support from reliable friends and relatives. Mental illness is a hard thing for some people to grasp. You may want to confide only in people you know to be supportive.

Sometimes it is wise to get professional support. Join a self-help organization or support program for relatives of people with OCD. Such programs may be offered by a community mental health organization, clinic or local hospital.

Keep up your interests outside of the family and apart from your ill relative. Know and accept that sometimes you will feel negative

about the situation. These feelings are normal and should not have to cause guilt.

## Explaining OCD to children

Explaining OCD to children can be awkward and difficult. Parents may say nothing because they don't know how to explain it, or perhaps think that children couldn't understand. They may try to protect children from OCD and continue with family routines as if nothing were wrong.

It is difficult to maintain this strategy over time because the symptoms of OCD show up in behaviour. Children are very sensitive and intuitive. They notice when someone in the family has changed, or when tension surfaces. If the atmosphere in the family suggests that the subject should not be discussed, children will develop their own, often wrong, ideas.

Young children often see the world as revolving around themselves. This is especially true of children between three to seven years. If something happens that upsets people in the family, they may think it is their fault. For example, if someone fears contamination and becomes upset after a child touches a "contaminated" object, the child may assume he or she is the cause of the ill person's extreme behaviour.

To explain mental illness and OCD to children, it is important to tell them only as much as they are mature enough to understand. Toddlers and preschool children can understand simple, short sentences. These need to be worded in concrete language without much technical information. For example: "Sometimes daddy feels sick and it makes him upset." "When mommy is sick, touching the sink makes her upset."

Elementary-school children can process more information. They are able to understand the concept of OCD as an illness, but may be overwhelmed by details about therapies and medications. OCD could be explained to children of this age group like this: “OCD is a kind of illness that makes people worry a lot about germs and getting sick. Worrying so much makes them do things over and over again.”

Teenagers are generally able to manage most information. They often need to talk about what they see and feel. They may ask about the genetics of OCD, or they may worry about the stigma of mental illness. Sharing information creates more dialogue.

When speaking to children, it is helpful to cover three main areas:

- 1. The parent or family member behaves this way because he or she is sick.** It is important to tell children that the family member has a sickness called obsessive-compulsive disorder. OCD should be explained as an illness. You might explain it like this: “OCD is like chicken pox or a cold, except that rather than giving people spots or a runny nose, it makes them worry a lot, sometimes for no reason. This worry makes people with OCD check things over and over, or stay away from things that bother them, or collect stuff. Sometimes, they want people in their family to behave the same way. OCD takes a long time to get better. People with OCD need help from a doctor or therapist.”
- 2. Reassure the child that he or she did not make the parent or family member get this illness.** Children need to know they did not cause their loved one to develop the illness through something they did or did not do. People with OCD may become depressed as they struggle with their symptoms. Reassure children that they did not make their loved one sad.

3. **Reassure the child that adults in the family and other people such as doctors are trying to help the affected person.** Taking care of someone with OCD is an adult responsibility. It is not something children should have to worry about. Children need the well parent and other trusted adults to shield them from the effects of living with someone with OCD. Children should talk about what they see and feel with someone who knows how hard it is for their mother, father or relative to struggle with the symptoms. Many children are scared by the changes they see in their loved one. They miss the time spent with that person. Doing activities outside the home helps because it exposes children to other healthy relationships. As the ill parent recovers, slowly resuming family activities can help to mend the relationship between the child and the ill parent.

Both the ill parent and the well parent should talk with their children about explaining the illness to people outside the family. Support from friends is important for everyone, but OCD can be hard to explain and some families worry about the stigma of mental illness. How open you and your children want to be is a very individual choice.

Finally, some parents struggling with OCD may find that they are less patient and more easily irritated. For them, the loud, messy, chaotic play of children may be very hard to tolerate. Structured routines ensure the ill parent has quiet, restful time, away from situations that might trigger stress and conflict. You may need to plan time for the children to play outside the home, or arrange for the ill parent to rest for part of the day in a quiet area of the house.

Once into recovery, it helps for the parent who was ill to explain his or her behaviour to the children. The recovered parent may need

to plan some special times with the children. He or she may need to re-establish the relationship and reassure the children that he or she is now more available to them. In some instances, working with a therapist to formulate a plan can be very helpful.

# **Obsessive-Compulsive Disorder (OCD)**

Suggestions on what to discuss with your health care providers to help you receive high-quality care





# What is obsessive-compulsive disorder?

We all have habits that keep our day-to-day lives on track. But some people may experience repeated thoughts, images, or urges that they can't control. When these obsessions and compulsions become too much, they can have a negative effect on a person's life. This can be a sign of a mental health condition known as obsessive-compulsive disorder, or OCD.

## What's an obsession?

Obsessions are repeated thoughts, images, or urges. They can make life challenging. For example, if you're preoccupied with germs or contamination, doing simple things—like brushing your hair or putting on shoes—can be complicated. And obsessions can be upsetting. For example, you might have unwanted thoughts about sex, religion, or violence that interrupt simple conversations with friends, or your work.

## What's a compulsion?

Compulsions are specific actions or rituals meant to soothe the fear or distress surrounding an obsession. For example, you may feel the urge to count things over and over or check that the front door is locked. Or you may want constant reassurance that you haven't done something bad.

Although it may be difficult, talking with your health care providers about your concerns and symptoms can help you get effective treatment and feel better. The most common treatment options for OCD include self-help, education, cognitive behavioural therapy, or medication. Your health care providers can help you manage symptoms and get back to a healthy and rewarding life.



## Did you know?

Most people have some obsessive thoughts or compulsions at some point. But OCD affects only about one in 40 adults.

This guide can help you get ready for conversations with your health care providers. It shares what you can expect and suggests things to discuss, like:

- [Getting help or a diagnosis](#)
- [Treatment options](#)
- [Follow-up care and planning for the future](#)
- [Helpful resources](#)

The questions included in this guide are optional. You're in control, so you can choose which ones you want to ask. There may also be other questions you want to add.



## Are you in crisis? If you feel you need immediate help:

Contact your family doctor or nurse practitioner

Go to the nearest hospital or emergency room

Call 9-1-1

Call Telehealth Ontario at 1-866-797-0000

Call a helpline:

- Kids Help Phone: text CONNECT to 686868 or call 1-800-668-6868
- ConnexOntario: 1-866-531-2600
- [Ontario Distress Centres](#): Find a number for a crisis centre near you

## If you're a family member or friend:

You're an important part of the care team, and this guide can help you support your family member or friend as they manage and treat their OCD. Throughout the guide, there are questions you can ask their health care providers, too.



# Talking about: getting help or a diagnosis

Many people don't ask for help until their OCD symptoms have a serious effect on their lives. Reaching out to a health care provider, such as your family doctor or nurse practitioner, is a good first step. Try to share as many details about your symptoms as you can. Building a strong relationship with your health care provider can help you get the care and support you need.

Remember, OCD is about more than its symptoms. Tell your health care provider about yourself: your physical health, your emotional health, and anything else that can create a complete picture of your condition. For example, you can share:

- Whether you're scared or self-conscious about talking about your symptoms
- Whether certain things at home, work, or school make your symptoms better or worse
- How your OCD symptoms affect your relationship with family, co-workers, and friends
- Whether there's a family history of OCD or any mood disorders like depression or bipolar disorder
- Any treatments you've tried in the past, and whether they worked
- If drug or alcohol use is having a negative impact on your life

This information will help your health care provider decide if you show signs of OCD. If you do, they will do a more formal assessment (or refer you to someone who will) to confirm whether you have OCD, how severe it is, and what the next steps should be.

## Questions you can ask your health care provider:

- How do we figure out if I have OCD?
- What do I need to know about OCD? What do people with OCD usually experience over time?
- Will I get better?
- What should my family and significant others know about my OCD?

*There were so many things that I had assumed were just part of my personality or part of my brain. Like, I just had an overactive brain and would see horrible things happening to people. Doing the assessments was so useful ... That really opened up to me all the things that I could work on.*

PERSON WITH OCD



## Write it down

It can help to take notes during the visit. If it's hard to get down all the details, ask a friend or family member to take notes for you. That way, you can focus on the conversation with your health care provider and go back to the notes later.

## If you're a family member or friend:

You can play an important role in helping your family member or friend with OCD to manage their symptoms. Find out how you can offer support and make sure you feel supported, too. Questions you can ask the health care provider include:

- What do I need to know about this diagnosis?
- What can I do to help and support my family member or friend with OCD?
- As a parent or guardian of a child with OCD, how can I support them both at home and at school?
- Who should I contact if I have questions?
- What resources or support groups can help me as I support someone with OCD?

## What is accommodation?

It's common for people to reassure a friend or family member with OCD. Changing your own behaviour to soothe their worries is known as accommodation. For example, if they're concerned about germs, you might "accommodate" that worry by taking a shower as soon as you get home every day. Or, if they're distressed about intrusive thoughts, you may be constantly reassuring them by telling them everything's okay.

These actions are meant to help, but they only work in the short term. To help your friend or family member in the long term, it may be important to limit or stop accommodation behaviours. Don't stop these behaviours suddenly. Instead, talk with your friend or family member, and their health care provider, about how to work together to reduce these accommodation behaviours.

## You can ask a health care provider:

- Where can I learn more about accommodation behaviours and OCD?
- How can I best support my friend or family member with OCD?



# Talking about: treatment options

There are different ways to treat OCD, and your treatment plan will be designed just for you. The more you know about OCD, the more you'll understand about what's happening and how to manage going forward. With the right information, self-help resources, and support from health care providers, you can develop ways to cope and make decisions about your care.

Self-help, therapy, and/or medication can help you manage your symptoms and get back to a healthy and fulfilling life. A specific type of therapy, called “cognitive behavioural therapy,” or CBT, is very helpful, and should include “exposure and response prevention.” This therapy helps with addressing your repeated thoughts, images, or urges, and finding other ways to respond to them.

## Education and self-help

Learning about OCD is the first step. Your health care provider will recommend educational resources, like books, online tools, or support groups that can help you manage your symptoms as part of your treatment.

### Questions you can ask your health care provider:

- What education or self-help resources, such as workbooks or websites, can help me manage my OCD?
- What support groups are available in my area?



## Resources for self-help and peer support

- [Anxiety Canada](#): Includes self-help tools and resources to help you manage your OCD:
  - [For adults](#)
  - [For children](#)
- [Big White Wall](#): A safe and anonymous online peer support community that's available anytime, anywhere

## Cognitive behavioural therapy (CBT)

CBT teaches you to notice negative thinking patterns and learn how to replace them with more positive ones. For OCD, this type of therapy usually includes guided exercises and tasks to help you find ways to respond to situations that trigger anxiety. This approach is known as exposure and response prevention.

CBT is very helpful for treating OCD for the long term. On its own, it can be just as helpful as medication; or it can be part of a treatment plan that includes medication.

### Questions you can ask your health care provider:

- Is CBT with exposure and response prevention a good choice for me?
- Who provides CBT with exposure and response prevention? What kind of training do they have? How can I find a health care provider who is a good fit for me?
- Will I have to pay for treatment? Are there free or low-cost options?

*[The therapy] was presented to me kind of like fitness. Like, ‘We’re going to teach you how to exercise, and then you go forth and you exercise. And if you want to keep building skills, you keep doing these things’ ... And that was just so helpful. It’s been many years now, and taking care of my mental health has been really enjoyable ... It’s about building health instead of waiting for an illness to [then] manage. I found that was such an effective approach.*

”

**PERSON WITH OCD**

## **Medication**

Your health care provider might prescribe medication, too. For some people, taking medication for OCD may seem like a big step, but it is an effective treatment option that can help you feel better by reducing your symptoms. A common type of medication used to treat OCD is a selective serotonin reuptake inhibitor (SSRI). SSRIs are also called “antidepressants,” but they are used to treat many different conditions, including OCD.

Depending on a few different factors, like how well you’ve responded to other treatment, how severe your OCD is, and your preferences, your doctor may advise that you take medication right away. But many people try non-medication options first, like self-help or CBT with exposure and response prevention.

If your health care provider suggests medication, they should explain the risks and benefits so that you can make an informed decision about what’s right for you.

### **Questions you can ask your health care provider:**

- Why might medication be a good choice for me?
- What are the side effects of this medication?
- When will I start to feel better? What should I do if I don’t feel better or my symptoms are getting worse?
- I’m feeling better; can I stop taking the medication?



# Talking about: follow-up care and planning for the future

Education, self-help, CBT, and/or medication can help you manage your OCD. As you start to feel better, your health care provider should monitor your progress to make sure the treatment is helping.

With treatment, recovery from OCD is possible, but symptoms may change over time. You may feel better for some time, only to have old symptoms return or new symptoms develop. Your treatment plan should let you know how to spot signs of returning symptoms before they get worse, how to manage them, and when you should reach out for support. The more you know and the more you plan, the better prepared you will be to face any challenges in the future.

## Questions you can ask your health care provider:

- What should I expect as things get better?
- What can I do to prevent my symptoms from getting unmanageable again?
- How often do I need to see my health care provider if I'm doing well?
- If symptoms return, can I get care right away, or will I be on a wait list?

## If you're a family member or friend, ask the health care provider:

- What are signs of symptoms that I can watch for?
- How can I support my family member or friend during this time?

# What's next?

## **Remember, everybody is different.**

The support you need and the care plan you develop with your care providers will be unique to you.

## **This conversation guide is only a starting point.**

You may have other topics you want to cover with your care providers. It's important to speak to them about any other questions or concerns.

## **Need more information?**

If you have any questions or feedback about this guide, please contact us at [qualitystandards@hqontario.ca](mailto:qualitystandards@hqontario.ca) or 1-866-623-6868.

For more reading on obsessive-compulsive disorder, read the quality standard at: [hqontario.ca/qualitystandards](http://hqontario.ca/qualitystandards)



## Conversation Guide – Talking to People who Use Substances

### With Gratitude

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IH Peer Advisors (people with lived and living experience of substance use) guided the creation of this resource to support clinical staff to feel better equipped to talk to, collaborate with, and care for people who use substances (PWUS).

We would also like to acknowledge Vancouver Coastal Health for their contributions to this resource.

If you have questions or feedback about this guide, please do not hesitate to reach out to the following email contacts. We are here to support you and the people you care for.

[harmreduction.coordinator@interiorhealth.ca](mailto:harmreduction.coordinator@interiorhealth.ca)

[decriminalization@interiorhealth.ca](mailto:decriminalization@interiorhealth.ca)

[IHSubstanceUseServices@interiorhealth.ca](mailto:IHSubstanceUseServices@interiorhealth.ca)

### Content

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1. Purpose
2. Expert Advice from IH Peer Advisors
3. The ‘SUD’s of talking to People who use Substances
4. Conversations in Health Care
5. Glossary of Terms
6. Additional Learning Resources

### Purpose

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This guide intends to support frontline staff who provide care to people who use substances (PWUS). It contains key information from IH Peer Advisors - people with lived and living experience of substance use - on how they want to be treated, spoken to, and collaborated with when accessing services. The new [AK5000 Harm Reduction – People Who Use Substances Policy](#), along with the provincially implemented [Decriminalization of People Who Use Drugs](#), have brought a significant paradigm shift in how we think about substances and people who use them.

**This guide is intended to support how to have *conversations* with people who use substances,** including legal substances such as alcohol.

It **does not** provide [guidance on clinical care procedures or clinical decision-making](#).

The term ‘person’ is used in this guide and includes patients, residents, clients and visitors.

It’s normal to feel awkward or uncomfortable when changing how we do things, or entering into a new area of practice. For some of us, the recommendations in this guide are a new or different way to approach our work. These conversations will become more natural the more and more you have them and as you build rapport with individual people.



## Expert Advice from IH Peer Advisors

“Change doesn’t happen overnight, but that doesn’t mean it is not happening. Your interaction might not make a change that *you can see right away*, but it could be a meaningful step in someone’s wellness journey.”

“Success isn’t just if a person wants to quit after you talk to them. It is also when they want to engage with you, feel safe to openly speak about their use, if they stay in hospital to complete treatment, and if they leave feeling seen, heard and cared for.”

“When a person discloses to you that they use substances, they have taken a courageous step. Your response will influence whether or not they will trust you, and other health professionals, during this hospital visit and future ones. Be mindful of the way you speak to and about people – as it lets others around you know whether you are a safe person to be vulnerable with.”

“If a person is struggling to abstain and is using substances while receiving care, they may have a substance use disorder (SUD). Using their own substances may be an indicator that their substance use needs are not being met. It’s likely *not* meant to be confrontational or disrespectful to you, or your team. This is an opportunity to communicate with the person to understand their experience, and to explore options that align with their goals.”

“A culturally safe and trauma-informed approach is important. Many people who use substances have had negative experiences in healthcare settings, and with other people in authority punishing them for their substance use.”

“Big feelings and reactions are not about you as a care provider. They are influenced by a person’s social determinants of health, underlying harms and their past experiences with health care and authority figures. Even if you say/do all the ‘right things,’ talking about their substance use can be frightening for people. It is not uncommon to be met with a trauma-response (fight, flight or freeze), especially if you haven’t had time to build rapport. Do your best to not take things personally or respond defensively.”

“You don’t have to know it all. People don’t care what you know, they just want to know that you care. Recognize that the person who uses substance is the expert in their substance use, and take the opportunity to learn from them if they are willing to share. Approach with care and curiosity.”



## The 'SUDs' of talking to People who use Substances

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When in doubt, just remember the 'SUDs'

S	U	D
<u>Self-reflection</u>	<u>Understand the Person's Experience</u>	<u>Discuss Options</u>
Before approaching the person, ask yourself what assumptions or beliefs you bring to the interaction.	Before offering solutions, inquire about the person's experience and acknowledge their expertise.	Engage the person in person-centred care planning and informed decision making.
Enter conversations from a place of <i>non-judgement</i> and <i>curiosity</i> .	How do they understand their relationship with substances, their concerns, and what are <i>their</i> goals?  Listen to learn.	Collaborate and explore options together that build on the person's strengths and <i>their</i> goals.
Reflect on expertise shared with you by people with lived and living experience of substance use.		As you build rapport and trust, you may be able to delve deeper and find more meaningful solutions. Don't be afraid to revisit these conversations.

## Conversations in Health Care

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Below we have outlined some scenarios, using the 'SUDs' (self-reflection, understand the person's experience, discuss options) that might help you find the words to talk to people accessing care. This section contains key insights into what people with lived and living experience (PWLLE) of substance use want health-care staff to reflect upon and consider when interacting with people who use substances. These suggestions are to support *conversations*, *rappor building* and guidance on *how* to engage with people who use substances. It does **not** provide clinical guidance.

Given the size of the Interior Health region, the differences between rural and urban settings, and different practice areas – we acknowledge that not all conversation points will be applicable to you, and that we aren't able to capture every situation you might encounter. Some care scenario examples used throughout this guide may refer to services that are not available in your area. It is important to **only offer what your site/team can deliver**. We encourage you to familiarize yourself with local resources and reach out to your leadership if you have questions.



## 1. I want to screen someone for substance use.

DO NOT break confidentiality by disclosing their use to others outside the care team, be rude or roll your eyes.

SUD: Self-Reflection-Understand-Discuss	Example Phrasing
<b>Self-Reflection</b> How do you approach sensitive conversations with people who are new to you?	<i>"Substance use is a part of our regular screening process. Would it be okay with you if I ask you a few questions about your substance use?"</i>
<b>Understand the Person's Experience</b> <ul style="list-style-type: none"><li>Ask permission before inquiring about substance use and explain <i>why</i> you are asking.</li><li>Be gentle and discrete. Have this conversation in private.</li><li>Ask if the person has any immediate needs.</li></ul>	<i>"Is there anything you need regarding your substance use while you are here? What do you need to feel better, or more comfortable?"</i>  <i>"Are you interested in hearing about resources that might help? We could get the addiction medicine doctor to see you."</i>
<b>Discuss Options</b> <ul style="list-style-type: none"><li>Share information on supports available to the person while they are receiving care and provide referral(s) if the patient consents</li></ul>	<i>"Do you know where the nearest Overdose Prevention Site (OPS) is?"</i>



People may be hesitant to disclose their substance use due to prior negative experiences in healthcare.

## 2. A person is upset by my screening questions or the words I used.

DO NOT take it personally, or respond defensively.

SUD: Self-Reflection-Understand-Discuss	Example Phrasing
<b>Self-Reflection</b> How is my body language during this assessment? What tone am I using? Have I used non-stigmatizing language? Check in with yourself and observe your initial response. Take a moment to calm/ground yourself if you feel activated.	<i>"Did something I ask upset you? I know this can be hard to talk about."</i>  <i>"This is a very personal and sensitive subject. I don't mean to make you uncomfortable. I am asking you about this because I want to help you be safe and receive the best care here."</i>
<b>Understand the Person's Experience</b> <ul style="list-style-type: none"><li>Listen to learn from their feedback.</li><li>Learn what words the person prefers to describe their relationship with substances.</li><li>Take responsibility for the hurt caused and learn from the experience.</li></ul>	<i>"Thank you for sharing this with me; it was not my intention to make you feel judged or less than. I am really sorry. I am still learning and really appreciate you sharing this feedback with me."</i>
<b>Discuss Options</b> <ul style="list-style-type: none"><li>Acknowledge and apologize for hurt caused by your interaction and/or other healthcare interactions.</li><li>Express humility and acknowledge you are still learning.</li><li>Acknowledge the impact disclosing personal information can have.</li></ul>	People may have emotional responses to questions because of stigma, past traumas, and harm at the hands of the social and health system.





### 3. A person discloses they are worried about going into withdrawal.

DO NOT: dismiss their concerns, or shame them.

SUD: Self-Reflection-Understand-Discuss	Example Phrasing
<b>Self-Reflection</b> What beliefs do you hold about alcohol and other substance use that might be a barrier for you in taking these concerns seriously or meeting the person with care and compassion?	<p><i>"Thank you for trusting me with this information. Let's see what we can do to make this a bit better for you."</i></p> <p><i>"Do you mind if I ask what withdrawal looks like for you. Have you experienced it before? When does it usually start? What helps?"</i></p> <p><i>"I can understand why you wouldn't want to go through withdrawal. That sounds awful! Let's see what we can come up with so you don't have to go through that if you don't want to."</i></p>
<b>Understand the Person's Experience</b> <ul style="list-style-type: none"><li>• What is withdrawal like for them? What symptoms do they have?</li><li>• Accept that each person has the autonomy to consent or decline the care you are offering.</li></ul>	<p><i>"Are you open to talking to someone more about this? Alcohol withdrawal can be dangerous and we want to help keep you as safe as possible."</i></p> <p><i>"Let me know if this changes or gets worse. I want to support you through this."</i></p>
<b>Discuss Options</b> <ul style="list-style-type: none"><li>• Share available supports that align with the person's goals.</li><li>• Encourage them to continue to reach out for support.</li></ul> <p>If a person perceives they have to choose between the medical care you are offering and forced withdrawal, they may choose to leave.</p>	

### 4. A person is leaving the site temporarily and I suspect they are leaving to use substances.

DO NOT try to talk them out of leaving, use fear tactics or threaten that someone will lose their bed/access to care through discharge/eviction.

SUD: Self-Reflection-Understand-Discuss	Example Phrasing
<b>Self-Reflection</b> Why are you asking? What is the medical or safety reason to be asking about this and is it necessary to ask?	<p><i>"Could we discuss some ways for you to be safer while you are out there?"</i></p> <p><i>"It sounds like it's hard to not use, especially in a stressful place like this. Let me know if there is anything I can do."</i></p> <p><i>"What do you normally do to reduce your risk of drug poisoning (overdose)?"</i></p>
<b>Understand the Person's Experience</b> <ul style="list-style-type: none"><li>• Ask the person if they need anything to be safe while off site.</li><li>• Inquire what the person is already doing to reduce risk and build on strengths.</li></ul>	<p><i>"Do you know where you can get your drugs checked?"</i></p> <p><i>"Have you heard of the Lifeguard App? If you haven't, do you think we could look at it together?"</i></p>
<b>Discuss Options</b> <ul style="list-style-type: none"><li>• Offer to make a plan with them to stay safe while they are out.</li><li>• Ensure they are informed of any contraindications if they use alcohol or other substances while offsite.</li></ul>	



<ul style="list-style-type: none"><li>Offer harm reduction supplies and support options (drug checking, OPS, Lifeguard app)</li><li>Offer additional supports that align with the person's goals.</li></ul>	<p><i>"Have you considered a supported way to manage your alcohol use, like a managed alcohol program? Then you wouldn't have to worry about going offsite and can stay here to focus on getting better."</i></p>
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## 5. A person's substances are out in the open in a care setting and people have complained.

**DO NOT:** break confidentiality, prioritize the comfort of one person over another, or shame them.



SUD: Self-Reflection-Understand-Discuss	Example Phrasing
<b>Self-Reflection</b> How do you normally address complaints from one person about another?	<p><i>"Hi _____, I see you have substances on you. Would you like to hear about some support options?"</i></p>
<b>Understand the Person's Experience</b> <ul style="list-style-type: none"><li>Check-in with them about their substances.</li><li>Ask about any unmet needs including substance use needs.</li></ul>	<p><i>"Could you please put these supplies somewhere out of sight? You're not doing anything wrong, we just want to make sure it doesn't get misplaced or taken."</i></p>
<b>Discuss Options</b> <ul style="list-style-type: none"><li>Ask them to store their substances and supplies out of sight, offer storage options if available.</li><li>Offer supports that align with their goals.</li></ul>	<p><i>"Good morning _____, just calling to remind you to put away any used drug use supplies before your home visit today. Do you need a new disposal box?"</i></p>

Most people prefer discretion, due to stigma and potential targeting for theft.

## 6. Someone was previously using a substance indoors.

**DO NOT** assume ill-intent, be confrontational, automatically confiscate substances, search belongings or shame them.



If a person is using substances while in care, they may have a substance use disorder and require additional support. Using onsite may be a safety precaution, and is not intended to be confrontational or disrespectful.

SUD: Self-Reflection-Understand-Discuss	Example Phrasing
<b>Self-Reflection</b> What are your beliefs about why people use substances while receiving care?	<p><i>"Hi _____, are you doing okay? I am going to return and check on you in a little bit to make sure you are safe, if that's okay with you?"</i></p>
<b>Understand the Person's Experience</b> <ul style="list-style-type: none"><li>What is going on for the person? Are there unmet pain needs, withdrawal symptoms, high stress that could be addressed medically?</li><li>How can you help the person feel safer and share options while here?</li></ul>	<p><i>"I recognize it can be hard to stop smoking substances, especially in stressful situations, like being here. It's okay if you need to use, you just need to do it outside and away from the building."</i></p>
<b>Discuss Options</b> <ul style="list-style-type: none"><li>Acknowledgement for the need to continue using substances while receiving care.</li></ul>	<p><i>"Are you open to discussing some safety strategies?"</i></p> <p><i>"Do you have the supplies you need?"</i></p>



<ul style="list-style-type: none"><li>• If smoking substances, provide information about why IH has a smoking policy and discuss alternatives.</li><li>• Discuss what the person's unmet needs are and provide support/referrals that align with their goals. Offer harm reduction supplies and disposal containers.</li></ul>	<p><i>"If you are having a hard time not using while you are here, would you like to talk about how we might be able to help? You don't have to choose between using your substances and getting medical care."</i></p> <p><i>"We have a place where you can use just down the hall. Can I show you where they are and introduce you to the nurse there?"</i></p> <p><i>"I understand you'd prefer to use your own substances. Is there another way, besides smoking them that you could do while you are here?"</i></p>
<p>Our system has not caught up to the need for appropriate spaces to consume substances on-site.</p> 	

## 7. A person self-disclosed that they use(d) a substance(s) that you think might interfere with their treatment/procedure

DO NOT use fear tactics to promote abstinence, refuse care outright, or shame them.

SUD: Self-Reflection-Understand-Discuss	Example Phrasing
<p><b>Self-Reflection</b></p> <p>Is there possibly stigma in how you are considering this situation? Is it up to you to decide whether or not to withhold interventions?</p>	<p><i>"Thank you so much for telling me, I need to ask you some more questions so that we understand what is in your body and how it might react with your treatment."</i></p>
<p><b>Understand the Person's Experience</b></p> <ul style="list-style-type: none"><li>• Do they know and understand the risk?</li><li>• Clarify that you are asking to ensure their safety, not out of judgement.</li><li>• Understand the person is weighing the risk of withdrawal and needing the treatment. This is not an easy choice.</li></ul>	<p><i>"I can't safely help you with your shower right now. We'll come back tomorrow and try again."</i></p> <p><i>"Is there anything we could do to help you prepare for the appointment/treatment?"</i></p>
<p><b>Discuss Options</b></p> <ul style="list-style-type: none"><li>• Keep the conversation about informing the person of risks, instead of trying to encourage or discourage their drug use.</li><li>• Inquire if the person has any concerns about their ability to temporarily abstain from substances (if required). Is there a risk of withdrawal?</li><li>• Collaborate with person and care team to find practical solutions to mitigate risks.</li></ul>	<p><i>"If your OAT medication makes you too drowsy in the morning, would it help to schedule your appointment for the afternoon?"</i></p> <p><i>"Hey _____, your doctor said that this treatment won't work as well in combination with some of the drugs you are using. Do you want to talk about some ways we can figure this out together?"</i></p>

It can be difficult to balance the risk of substances being used during treatment against the risk of patient going through withdrawal or declining treatment to avoid withdrawal. Thoroughly discussing these risks should be a part of the informed consent process with the person and involve the whole care team.





## 8. Last time you interacted with *this* person while they were under the influence of substances, they acted erratically.

DO NOT take it personally, assume ill intent, shame substance use, make accusations or scold them.

SUD: Self-Reflection-Understand-Discuss	Example Phrasing
<b>Self-Reflection</b> Is the behaviour bothersome or is there a safety risk? Does the behaviour <i>need</i> to be addressed? Is this the <i>right time</i> to address the behaviour?	<p><i>"I noticed you weren't being like yourself last time you were here. Can you help me understand what was going on for you that day so that we can make this a better experience for you?"</i></p>
<b>Understand the Person's Experience</b> <ul style="list-style-type: none"><li>• What was the context of the behaviour and were there any underlying unmet needs that increased distress?</li><li>• Approach with curiosity, listen to learn.</li></ul>	<p><i>"This infection has gotten worse since last time you were here, we're really glad you returned to get it looked at."</i></p> <p><i>"You told me you were quite anxious last time you came in, is there anything we could do to help with that?"</i></p>
<b>Discuss Options</b> <ul style="list-style-type: none"><li>• Validate medical needs and goals.</li><li>• Focus on the behaviour, not the substance.</li><li>• Explore strategies to meet their needs, offer supports for substance use if person consents.</li></ul>	<p>Considering the social determinants of health helps orient you to factors that may inhibit a person's ability to cope in stressful situations, like being unwell and accessing care.</p> 

## 9. A person regained consciousness *after* an intervention for overdose/drug poisoning event.

DO NOT search their belongings, confiscate their substances, shame them, or force them to stay.

SUD: Self-Reflection-Understand-Discuss	Example Phrasing
<b>Self-Reflection</b> Consider your understanding of why/how people overdose. Do you have unconscious bias towards people who have experienced drug poisoning? Acknowledge the impact it has had on you as well as the person who is recovering.	<p><i>"Hi _____, how are you feeling? Can I get you a blanket or a cup of water?"</i></p> <p><i>"You experienced an overdose in the waiting room. I am so glad you are okay. We (insert intervention) and then we moved you over here for a little more privacy."</i></p>
<b>Understand the Person's Experience</b> <ul style="list-style-type: none"><li>• How are they doing and what do they want or need?</li></ul>	<p><i>"The toxic drug supply is so unpredictable. I am sorry this happened to you, but I am glad it happened here, where we could help you right away."</i></p> <p><i>"Do you mind if I come back when you are feeling a little better, to talk about some options we have here to support your substance use needs?"</i></p>
<b>Discuss Options</b> <ul style="list-style-type: none"><li>• Offer to make a plan with them to stay safe while they are out.</li><li>• Offer harm reduction supplies and support options (drug checking, OPS, Lifeguard app)</li><li>• Offer additional supports that align with the person's goals.</li></ul>	<p>After a medical emergency, like an overdose event, the person may be experiencing withdrawal, physical pain, shame, and emotional distress. Be gentle and calm.</p> 



## Autism and mental health A guide to looking after your mind

Your mental health is just as important as your physical health. It affects how you think, feel and act.

A quarter of the general population have problems with their mental health at some point in their life. In autistic people, this number is much higher with almost 80% of autistic adults experiencing mental health issues during their lives. For many people with autism, mental illness can be more difficult to recognise and treat effectively. It's widely recognised that much more needs to be done to support autistic people with their mental health.

That's why we've produced this short guide to help autistic people and their families to understand mental health problems in autism, learn to manage them and know where to get help.

### What sort of mental health problems affect autistic people?

Research shows that autistic people are at increased risk of mental health problems. Anxiety and depression are particularly common. This might be because autistic people's brains are slightly different, or it could be due to the problems that they have interacting with the world around them. Either way, it's a serious problem which impacts lives. The issues are likely to be different for every person.

Most people find it hard to talk about their mental health and autistic people may have specific challenges in understanding and communicating their feelings. But it's crucial that anyone



experiencing stress, depression or anxiety finds someone to talk to, whether it's a relative, carer or doctor. Talking about problems is the first step to overcoming them.

### Practical tips to manage your mental health

#### See your doctor

Going to the doctor can be stressful, particularly for autistic people who feel that health professionals do not understand their needs. But visiting your doctor when you are having mental health problems is an important step towards looking after yourself.

There are simple things you can do to reduce anxiety about going to the doctor. Visit before your appointment so you get to know the journey and the environment. Ask to book the first or last appointment of the day so you won't have to wait too long. Book a double appointment as extra time may be needed. See if there is a quiet area to wait in rather than the busy waiting room. If you make reception staff aware of your autism, they should do everything they can to help you. You can read more about preparing for a visit to the doctor here: [autism.org.uk/about/health/doctor](https://autism.org.uk/about/health/doctor)

#### Get the most appropriate treatment

Hopefully you can get support which matches your needs and is autism-friendly. If you are diagnosed with a mental health problem, you may be offered psychological treatment (like talking therapy), or medication or both. You can discuss these issues confidentially with your doctor or therapist. If you wish, you can ask for a family member or carer to be involved in the treatment.

Make sure you always tell professionals about your autism because it may affect the treatment you are prescribed and how your doctor communicates with you.

## Try mindfulness

One technique that can help those with anxiety is 'mindfulness'. This practice aims to retrain the way you think to help you pay attention to the present moment. It's about listening to and accepting your thoughts and feelings. It can help you to enjoy the world around you more and understand yourself better. You can practice mindfulness techniques anywhere and should do so daily in order for it to be successful. There are books, apps, and online videos and courses to teach yourself to be mindful, or you can find a professional trainer. The Mental Health Foundation provides information and resources at [bemindful.co.uk](http://bemindful.co.uk)



## Exercise regularly

Regular exercise is essential as part of a healthy lifestyle. It makes you feel good. Exercise may also help you manage your anxiety and mood, as well as improving self-esteem.



## Eat well

Eating well is important because it affects how you feel in your body and mind. You should eat as many different foods as you can, including plenty of fruit and vegetables, fish and starchy carbohydrates such as potatoes, bread, rice, pasta and cereals. You should try and have six to eight drinks a day, and water is the best choice because it contains no calories.



## Get a good night's sleep

A good sleep every night is crucial to your physical and mental health, but 40–80% of autistic people have sleep problems. Make sure your sleep environment is comfortable and not too bright, hot or cold. Try to go to bed at the same time every night so your body gets into a pattern. If you are anxious, concentrate on taking long deep breaths until you feel calmer. If you have tried all of these things and still have sleep problems, visit your doctor.



## Structure your days

Life can be overwhelming. Having structures in your life can be helpful. Having a daily routine makes the world a more predictable place and reduces anxiety. Research shows that uncertainty can be difficult for autistic people, and so you can make this more bearable by planning it in advance.



## Talk to support groups or family

It might be difficult to tell people how you are feeling, but talking to someone can really help you to feel better. If you can't talk to a family member or a friend, contact a support group. Many autistic people have found that sharing their experiences with other autistic people has been particularly valuable. You'll find the contact details of organisations that offer advice and support in this leaflet.



## Know how you're feeling

It can be difficult to recognise mental health problems, even if you are feeling bad. For some autistic people, limited verbal communication can make it hard to easily communicate their thoughts and fears. The company Beyond Words has created a series of books that explain health problems in pictures: [booksbeyondwords.co.uk](http://booksbeyondwords.co.uk)



## What to do if you have suicidal thoughts

Many people think about suicide at some point in their life – either in an abstract way or actually making plans.

It can be difficult to tell someone if you are having suicidal feelings. Being autistic brings extra challenges. Many autistic people who feel suicidal do not feel depressed. This means that it falls to their family and carers to be watchful. Feeling suicidal is often a sign that you are not well. The earlier you tell someone about these feelings, the quicker you'll get some help and start to feel better.

When you are feeling suicidal, it's a good idea to remove anything you could use to harm yourself. Talk to someone – a family member, a carer, a helpline or even a pet. Mind, the mental health charity, have useful suggestions for what to do when you're feeling suicidal. See: [mind.org.uk/information-support/types-of-mental-health-problems/suicidal-feelings](http://mind.org.uk/information-support/types-of-mental-health-problems/suicidal-feelings)

The following organisations offer advice and support online or over the phone:

### Samaritans:

116 123 (freephone) or  
[jo@samaritans.org](mailto:jo@samaritans.org)/[samaritans.org](http://samaritans.org)

### Mind:

0300 123 3393 or [info@mind.org.uk](mailto:info@mind.org.uk)  
or text 86463 [mind.org.uk](http://mind.org.uk)

### The National Autistic Society:

0808 800 4104 [autism.org.uk](http://autism.org.uk)

You can also take a look at our other information leaflets at:

[autistica.org.uk/autism/useful-information](http://autistica.org.uk/autism/useful-information)

## Get involved in research

To improve our understanding of autism we rely on volunteers to take part in research studies. Taking part in research can be something as simple as completing a survey, or trying a new drug or therapy intervention. How you decide to be involved is up to you. If you, your child or your family would like to take part in research, please visit: [autismspectrum-uk.com](http://autismspectrum-uk.com)

## Support our work

Autistica are working hard to fund vital new studies so we can help everyone affected by autism to live longer, healthier, happier lives. If you would like to support our work, visit [autistica.org.uk/get-involved/](http://autistica.org.uk/get-involved/) or contact us at [info@autistica.org.uk](mailto:info@autistica.org.uk)

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