

# OBSESSIVE-COMPULSIVE DISORDERS

A Handbook for Patients and Families



# Who Is This Handbook Intended for?

This information guide is for people with Obsessive-Compulsive Disorder (OCD) and Related Disorders, their family members, friends, and anyone else who may find it useful. It is not meant to include everything but tries to answer some common questions people often have about OCD. The information in this guide can also be used to help people and their loved ones discuss OCD with treatment providers in order to make informed choices. We hope that readers will find the information useful.

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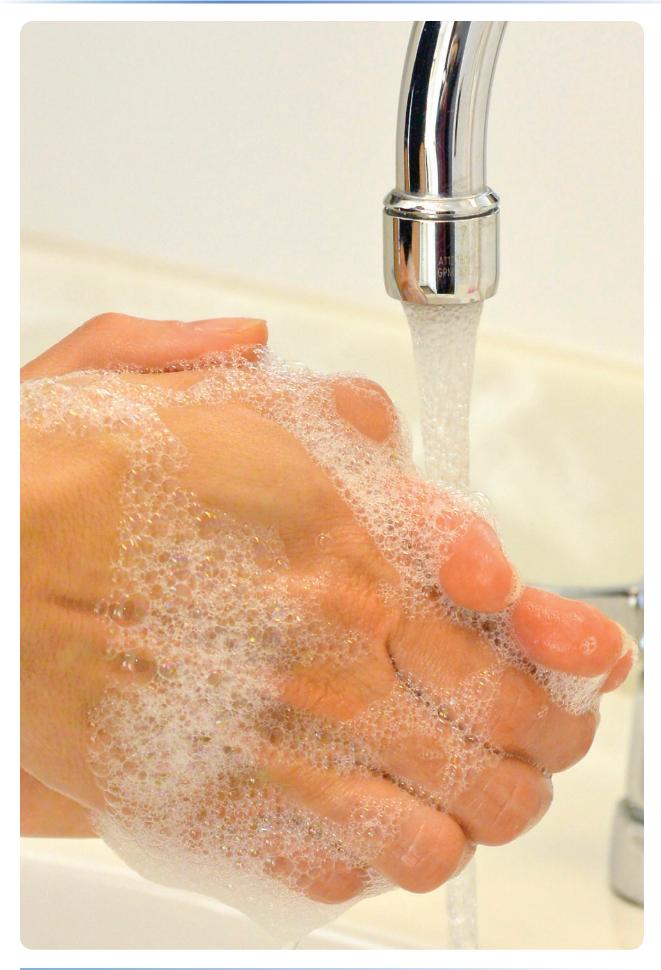
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#### What is OCD?

Bob worried about being responsible for bad things that could happen. He worried about leaving the stove on, which could cause a fire, or hitting someone with his car.

He spent all day repeatedly checking every action to make sure he hadn't done something wrong or dangerous. For example, Bob would circle back in his car to check if had hit someone and rechecked his locks over and over again at home to make sure the doors were locked. Bob also avoided using his oven for fear he might leave it on.

The key features of Obsessive-Compulsive Disorder are **obsessions** and **compulsions**. Most people have both, but for some it may seem as though they have only one or the other.

**Obsessions:** Intrusive, repetitive, distressing thoughts, images, or impulses.

**Obsessions** are thoughts, images, or urges. They can feel intrusive, repetitive, and distressing.

Everyone has bothersome thoughts or worries sometimes (e.g. worry about money or whether or not we remembered to lock the front door, or regret over past mistakes). When a person is preoccupied with these thoughts, and is unable to control the thoughts, get rid of them, or ignore them, they may be obsessions. Obsessions are usually unrealistic and don't make sense. Obsessions often don't fit one's personality; they can feel unacceptable or disgusting to the person who has them. Obsessions cause distress, usually in the form of anxiety. People with obsessive thoughts will often try to reduce this distress by acting out certain behaviours, known as rituals or compulsions.

**Compulsions** are behaviours a person does to relieve the distress they feel because of the obsessions. They can be overt (observable) or covert (hidden). While most people have preferred ways of doing certain things (e.g. a morning routine or a certain way to arrange items on a desk), people with OCD feel they "must" perform their compulsions and find it almost impossible to stop. Usually, people with OCD know the compulsion is senseless. However, he or she feels helpless to stop doing it and may need to repeat the compulsion over and over again. Sometimes this is described as a ritual. Common compulsions include excessive washing and checking, and mental rituals such as counting, repeating certain words, or praying.

While compulsions often help relieve distress in the short-term, they don't help in the long-term. As a person with OCD gets used to doing them, the rituals become less helpful at reducing his or her anxiety. To make them more effective again, the person may perform them more frequently and for longer periods of time. This is why people with OCD can appear to be "stuck" doing the same thing over and over again.

**Compulsions:** things a person does to ease the distress from obsessions.

For someone with severe OCD, these compulsions can take up a considerable amount of time. Even simple tasks can become very time-consuming, having a significant impact on a person's ability to manage their daily lives. These difficulties can result in significant shame, sadness, and frustration.

Obsessive-Compulsive disorder is common: about 2.5% of the population or 1 adult in 40 are afflicted, which makes it about twice as common as schizophrenia and bipolar disorder. It is also the fourth most common psychiatric disorder. It can be severe and debilitating: OCD can invade all aspects of a person's life; family, work, and leisure can all be negatively impacted by the disorder. In fact, the World Health Organization (WHO) considers

OCD to be one of the top 10 leading causes of disability out of all medical conditions worldwide.

Other facts about OCD:

- it affects people from all cultures
- rates of OCD are equal in men and women
- it can start at any age but typical age of onset is adolescence or early adulthood (childhood onset is not rare however)
- tends to be lifelong if left untreated

#### **Common Obsessions**

The list below provides examples of common obsessions but doesn't cover the wide range of thoughts that OCD can include. Obsessions can be about anything... if you can think it, OCD can obsess about it.

#### Contamination

- Fear of contamination by germs, dirt, or other diseases (e.g. by touching an elevator button, shaking someone's hand)
- Fear of saliva, feces, semen, or vaginal fluids

#### **Doubting**

- Fear of not doing something right which could cause harm to one's self or another (e.g. turning off the stove, locking the door)
- Fear of having done something that could result in harm (e.g. hitting someone with a car, bumping someone on the subway)
- Fear of making a mistake (e.g. in an email, or when paying a bill

# Ordering

 Fear of negative consequences if things are not "just right", in the correct order or "exact" (e.g. shoes must be placed by the bed symmetrically and face north)

#### Religious

- Fear of having thoughts that go against one's religion
- Preoccupation with religious images and thoughts

#### Aggressive

- Fear of harming others (e.g. harming a baby, stabbing someone with a kitchen knife, hurting someone's feelings)
- Fear of harming self (e.g. jumping off a bridge, handling sharp objects)
- Fear of blurting out obscenities in public (e.g. saying something sacriligious in church)

#### Sexual

- Unwanted or forbidden sexual thoughts, images, or urges (e.g. urge to touch a parent in a sexually inappropriate way)
- Sexual thoughts involving children or incest

# **Common Compulsions**



# Cleaning/Washing

- Washing hands too frequently or in a ritualized way
- Ritualized or excessive showering; bathing; grooming routines; cleaning of household items or other objects
- Although not a specific ritual, avoidance
  of objects or situations that are considered
  "contaminated" may be a major problem (e.g.
  will not shake hands with others or touch
  elevator buttons)

# Checking

- Checking that nothing terrible did, or will, happen (e.g. checking driving routes to make sure you didn't hit anyone with your car)
- Checking that you don't make mistakes (e.g. rereading everything you have written, or asking oothers whether you said the "wrong" thing

# Ordering/Arranging

 Ensuring that things are "just right" or consistent with a specific rule (e.g. everything in the kitchen must be perfectly lined up; can only wear certain coloured clothes on certain days)

#### **Mental Rituals**

 Needing to count to certain numbers, think certain 'good' or neutral thoughts in response to 'bad' thoughts, or pray repeatedly

# Hoarding\*\*

- Collecting "useless" items such as newspapers, magazines, bottles, or pieces of garbage
- Difficulty parting with unnecessary or excessive belongings (e.g. items that may have been useful once, or have sentimental value even though they are not needed, or are simply excessive, such as 30 black sweaters)
- Inability to throw these items away

\*\*Although hoarding used to be considered a feature of OCD, it is now thought of as a separate but related condition; See Below

# What are Obsessive-Compulsive Related Disorders?

There are several disorders that seem to be related to OCD. They share similar features such as intrusive thoughts and/or repetitive behaviours. Although similar, there are important differences to consider when looking at effective treatments.

Obsessive-Compulsive Related disorders include:

- Body Dysmorphic Disorder
- Trichotillomania (Hair-Pulling Disorder)

- Excoriation (Skin- Picking) Disorder
- Hoarding Disorder

These issues each seem to occur in about 1-4% of the general population, although there is speculation that hoarding may be far more common. Severity ranges but when they impair a person's functioning or when they cause significant distress, treatment may be necessary.

# Body Dysmorphic Disorder (BDD)

No matter how much her mother tried to convince her that it was not true, Keisha really believed that she was ugly. At first she thought her skin was flawed, and then that her nose was too large. Later, whenever she looked in the mirror, she was convinced that she was so disturbing for others to look at that she avoided going out in public.

People with BDD are overly concerned about an imagined or minor flaw in their appearance. The focus of concern is often the face and head, but other body parts can become a focus. While most people would probably like to change one or two aspects of their appearance, people with BDD are very preoccupied with these issues. They feel intense

**Body Dysmorphic Disorder (BDD):** 

preoccupation with an imagined or slight flaw in one's appearance. BDD often includes repetitive behaviours that are done in response to appearance concerns. distress as a result. For many, the concern can cause serious impairment in their day-to-day lives. BDD is considered by mental health professionals to be in the same category of conditions as as OCD, due to their similarity. For example, BDD involves intrusive and recurrent thoughts about one's appearance as well as compulsive behaviours to ease the distress of these thoughts. A person may be very concerned by the shape or size of their nose and repetitively check mirrors, ask for reassurance, or consult with cosmetic surgeons in attempts to relieve their distress. Like the compulsions in OCD, these behaviours may provide short-term relief (e.g. "my nose doesn't look too bad in that mirror") but make things worse in the long run (e.g. increase need to check mirrors).

# Trichotillomania (also known as Hair-Pulling Disorder)

Jasmine first started pulling her hair in her teens, and over time she noticed that the hair had not grown back. She was very embarrassed by her bald spot, and started wearing hats all the time to cover it up. Jasmine also started avoiding social situations because of her appearance but still could not stop.

Trichotillomania involves recurrent hair pulling, resulting in noticeable hair loss. People with compulsive hair pulling may pull hair from any part of their body, including the scalp, eyebrows, eyelashes, pubic area, and legs. Severity ranges broadly: for some, thinning areas are visible only upon close inspection, while others pull to the point of baldness. For some, the urge to pull can be managed with simple tools like relaxation and increased awareness. For others, the urge can be so strong at times that it feels impossible to resist. Many people wear wigs, hats, or scarves to disguise the hair loss on their scalp, while others may use make-up or false eyelashes for hair loss in other areas. The repetitive nature of pulling seems similar to compulsions in OCD. However, the pulling is usually done for different reasons. For some, the need to pull happens in response to feelings of



tension which are relieved after pulling. For others, pulling seems to happen automatically with little awareness and no sense of tension or relief.

**Trichotillomania (Hair-pulling Disorder):** compulsive hair pulling to the point of noticeable hair loss.

# Excoriation (Skin-Picking) Disorder (also known as Dermatillomania; pathological skin picking, neurotic/ psychogenic excoriation)

Ahmed began picking at a spot on his arm where he felt there might be a small bump. Over time he found himself picking at any irregularity or bump on his skin, resulting in scarring and discolouration. This impact on his appearance made it hard for Ahmed to wear short sleeves, or feel comfortable in social settings in warmer weather.

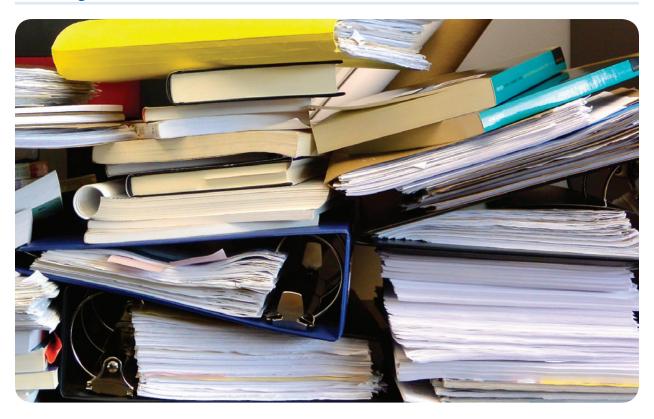
**Excoriation (Skin-Picking) Disorder:** compulsive skin-picking resulting in noticeable damage to the skin.

Similar to hair pulling, skin picking is thought to be compulsive when it becomes recurrent and results in noticeable scarring and/or damage to the skin. People with compulsive skin picking will make repeated efforts to stop or reduce their picking, and are significantly distressed by their behaviour. Skin picking can occur on any part of the body, including the face, scalp, lips, and legs. While it is often done in response to a perceived imperfection, this is not always the case. Regardless, compulsive picking results in pain and damage to the skin.

Hair-pulling and skin-picking disorders fall under an umbrella of similar behaviours called Body-Focused Repetitive Behaviours (BFRBs). Other BFRBs include compulsive nose-picking, cheek-biting, and nail-biting.

**Body-focused Repetitive Behaviours** (BFRB): repetitive behaviours that cause damage to one's appearance and/or physical injury

# Hoarding Disorder



Raoul found it hard to throw things away, especially papers. He worried that he might throw away something that he would need at a later time. He had collected so much paper that there was no room for anyone else in his apartment. He knew that it was a fire hazard and could no longer use his bedroom, but still could not bring himself to throw things away.

People with hoarding disorder have trouble with stuff. They acquire too much stuff and/or have trouble getting rid of it. The types of things that people hoard can vary but are often perceived as potentially useful in the future, valuable or as having sentimental value. Like all the disorders described here, saving and collecting occurs on a continuum. Most people save some items that they consider useful or sentimental but when a space becomes cluttered enough to compromise intended use (e.g. unable to sit on couch in living room due to clutter) or the person is unable to maintain a safe environment for themselves and others, a diagnosis and treatment may be warranted. Potential risks of hoarding include fires, falls, blocked entrances

and exits, infestation with rodents and insects, lung disease, and inability to maintain good hygeine. Hoarding shares some similar features with OCD: some people describe obsessional thinking about their belongings and a compulsive need to acquire items. Also, the distress felt when having to resist acquiring or when discarding items is considered similar to the anxiety in OCD. However, the thoughts are not typically described as intrusive or distressing and the behaviour is not ritualistic and is often considered pleasurable.

**Hoarding Disorder (HD):** persistent difficulty getting rid of possessions because of a perceived need to save them.

# How Do We Know it's OCD? Assessment & Diagnosis

Everyone will have upsetting thoughts and many people have certain ways of doing things. For most, these thoughts and behaviours are not a problem. What makes someone with OCD different? Assessment and diagnosis of OCD involves making the distinction between normal thoughts and behaviours and a diagnosable condition. The big distinctions are the amount of time occupied by obsessions and compulsions, the degree of distress, and/or the level of impairment (e.g. difficulty attending work or school, or inability to socialize).

The American Psychiatric Association (APA) defines OCD in the following way:

The presence of obsessions and/or compulsions which occupy more than one hour per day, cause marked distress OR significantly interfere with functioning.

- Obsessions
  - persistent unwanted thoughts, images, or impulses
  - · Intrusive, uncontrollable/excessive
  - · provoke anxiety
- Compulsions
  - · repetitive behaviours or mental acts
  - performed in response to an obsession, or in ritualistic fashion
  - intended to reduce discomfort or prevent feared event

Mental health professionals use specific interview strategies and questionnaires to determine whether or not a person has OCD. Clinicians are careful to ensure that a person's symptoms are not better accounted for by a different problem, clinicians are careful to "rule out" other possibilities. For example, many anxiety disorders have similarities: fear of specific situations or things; avoidance;

severe anxiety. Sometimes individuals dealing with depression will become intensely preoccupied with thoughts regarding their past failures. Accurate assessment is important because it helps guides treatment. Different challenges require different solutions. It is also important to note that OCD can also occur at the same time as other disorders. Sometimes a clinician may determine that one problem is "primary" which may mean it needs to be treated first before other disorders can be addressed.

As mentioned, OCD is similar to other disorders in some ways. Below is a list of disorders that are commonly confused with, or can occur at the same time as OCD. It may be useful to talk to your healthcare provider about the differences in more detail to make sure you find the right help.

#### Common Anxiety Disorders

- Panic disorder (fear of recurrent, unexpected panic attacks)
- Agoraphobia (fear of specific situations such as buses or trains, crowded places or of leaving home alone)
- Generalized Anxiety Disorder (excessive worry about real-life concerns, e.g. health or money)
- Social Phobia (fear of scrutiny, humiliation or embarrassment in social situations)
- Specific Phobia (fear of a particular object or situation, such as heights or snakes)
- Post-traumatic Stress Disorder (the re-experience of fear following a traumatic event)
- Anxiety disorder due to a general medical condition (anxiety symptoms are directly related to a medical condition; can be ruled out by physician's exam)
- Substance-induced anxiety disorder (anxiety directly related to the effects of a substance, such as cocaine)

# Differentiating OCD from Other Disorders

# Obsessive-Compulsive Personality Disorder (OCPD)

Obsessive Compulsive Personality Disorder and OCD are two different conditions with similar names. A diagnosis of OCPD describes personality traits such as extreme perfectionism, indecision, or rigidity with details or rules. People with OCPD are often highly devoted to work and can become "workaholics". Other features of OCPD include being excessively meticulous and difficulty experiencing affection or enjoyment with others. While many people with OCD report having one or two of these traits, a person who has five or more of these traits will warrant a diagnosis of OCPD. There are important differences between the two diagnoses, particularly in terms of treatment.

#### **Depression**

Thoughts in depression are different than those in OCD: a depressed person is likely to ruminate about past mistakes and perceived failures whereas a person with OCD typically fears things that could happen in the future. Another important difference is that people with depression often brood over their emotional state as a way to understand it better, whereas people with OCD usually try to avoid or neutralize recurrent thoughts.

# How Do People Get OCD?

Like most psychiatric conditions, research indicates that there is no single cause of OCD. Instead, most experts agree that OCD is likely caused by a combination of biological, psychological, and sociocultural factors.

# Changes in Brain Chemistry

Neurons: cells in the brain

**Neurotransmitter**: a chemical in the brain that helps transmit signals from one neuron to another

**Serotonin, dopamine, glutamate**: naturally-occuring neurotransmitters in the brain

Chemical messengers in the brain, known as neurotransmitters, transmit signals between brain cells (neurons). These signals are the biological basis in the brain for most of our experiences, like mood, sleep, memory and learning. Some of these neurotransmitters are believed to play a large role in the development of OCD, hoarding, trichotillomania, compulsive skin picking, and

other related disorders. Serotonin, for example, is a neurotransmitter that is important in the regulation of mood and impulse control. It also affects memory and learning processes. There seems to be a link between decreased levels of available serotonin in certain brain areas and the development of OCD, as well as other conditions such as depression and anxiety disorders. The antidepressant medications used to treat OCD work by raising the level of this messenger in the brain. Dopamine is an important neurotransmitter for the reward systems in the brain, and has also been linked to OCD, and similarly antipsychotic medications which affect dopamine can also sometimes be helpful to OCD. Another major neurotransmitter, glutamate, is now being investigated in its role in the development of OCD.

# Changes in Brain Activity



Researchers and clinicians are able to study the levels of brain activity, or metabolism, with advanced imaging techniques such as Positron Emission Tomography (PET), Single Photon Emission Computed Tomography (SPECT) and functional Magnetic Resonance Imaging (fMRI). Such studies have consistently shown that individuals with OCD have increased levels of activity in three areas of the brain: the basal ganglia, prefrontal cortex, and cingulate gyrus.

The caudate nucleus is a deep brain structure located in the basal ganglia. It is believed to act as a filter, screening messages that it receives from other areas of the brain. It also regulates habitual and repetitive behaviors, such as those observed in OCD and related disorders. Interestingly, the increased level of brain activity in this area normalizes in individuals after successful treatment of OCD, either with medications or cognitive behavior therapy. This demonstrates that changes in 'thinking' that occur in therapy can alter physical functions in the brain.

The prefrontal cortex is another structure implicated in OCD. It is involved in regulating appropriate social behavior. Diminished activity in this area can lead to poor impulse control, impaired judgment and lack of remorse. Increased activity may therefore be related to increased worry about social and moral concerns, such as meticulousness, cleanliness and fears of being inappropriate, all of which are amplified in OCD.

#### Positron Emission Tomography (PET):

A brain imaging technique that produces a three-dimensional images of chemical changes in the brain

**Single Photon Emission Computed Tomography (SPECT):** similar to PET scans, SPECT is a brain imaging technique that can give information about blood flow and chemical reactions.

**functional Magnetic Resonance Imaging** (**fMRI**): measures brain activity by looking at changes in blood flow in the brain.

The cingulate gyrus helps regulate emotion. It is also involved in predicting and avoiding negative outcomes, and recognizing errors. In OCD, increased activity in this brain regionmay be related to the emotions triggered by obsessive thoughts and tofeelings that one has made a mistake or not done something correctly. This area is well connected to the prefrontal cortex and basal ganglia via a number of brain circuits.

#### Genetic Factors in OCD

**Tourette's Syndrome (TS):** a neurological disorder characterized by tics. Tics are repetitive, involuntary, and sudden movements and/or vocalizations.

It is widely agreed that OCD and its related disorders can run in families. Almost half of all cases demonstrate this pattern. Studies show a higher likelihood that close relatives of a person with OCD (e.g. parents, siblings or children) have or will develop the disorder at some point in their lifetimes. Although OCD symptoms can be 'learned' from affected family members, relatives with OCD often have different obsessions and compulsions.

There is also a relationship between OCD and Tourette's syndrome (TS). Family members of individuals with TS often show higher rates of OCD than the general population, also suggesting a genetic relationship between these disorders.

There is a lot of interest in the exact genes involved in OCD. Such potential gene 'candidates' may include genes that are involved in the regulation of serotonin and other brain chemicals. At this point in time, although changes in specific genes have been identified that may contribute to the risk of the illness, the effect of of these variants is too small to be clinically helpful. However in the near future gene testing may be able to help better predict the future course of the illness, or response to treatment.



#### Other Possible Causes

In a minority of children, the development of Group A Streptocococcal infection ('strep throat') has been associated with the onset or worsening of OCD symptoms. In these cases, OCD or TS symptoms develop very abruptly after infection. Some scientists believe this may be an autoimmune response, where the body mounts an immune response by attacking the basal ganglia in the brain. There is currently no evidence that this, or other infectious agents, play a role in the development of OCD in adulthood.

For some women, premenstrual and postpartum periods can lead to the development or worsening of OCD symptoms, suggesting that variations in hormone levels may play a role.

OCD symptoms that develop quickly after a traumatic event have been observed in certain cases. This suggests that stress can contribute to the onset of OCD symptoms.

There have been small studies showing that damage to the brain, such as stroke or traumatic brain injury, in certain areas can also give rise to new OCD symptoms.

# **Psychological Factors**

# **Cognitive Theory**

Cognitive (i.e. thought processes) theory focuses mainly on the thoughts in OCD, instead of the behaviours. It is based on the idea that thoughts impact how we feel. In OCD, this theory suggests that people with OCD misinterpret their thoughts. It is not the obsession itself that is the problem, it is the way the obsession is interpreted.

Research shows that most people without OCD have thoughts, urges, or images similar to the ones reported by people with OCD. Intrusive and disturbing thoughts (e.g. harming a loved one or leaving the stove on and starting a fire) are normal and common. However, for most people, these thoughts don't become a problem because they don't get any special attention; they are easily shrugged off. For people with OCD however, the thought gets special attention. The importance of the thought gets exaggerated, which causes the person to feel anxious. This leads them to react to the thought as though it were an actual threat. They might think, "Since I had that thought of hurting my child, I must be a dangerous person". This interpretation can cause intense anxiety, disgust, and guilt. Once thoughts become interpreted in such a way, people with OCD will try to reduce or eliminate that distress by doing compulsions or by avoiding situations that trigger the disturbing thoughts. In this example, a person

may start to avoid being alone with their child, or must think "good thoughts" to counter the "bad thoughts".

Cognitive theorists have identified several patterns of beliefs that are common in OCD. They may contribute to the ways people with OCD misinterpret their thoughts.

- Over-inflated sense of responsibility: the belief that you are solely responsible for preventing harm to others.
- **Exaggerated sense of threat:** a tendency to overestimate the likelihood of danger
- Over-importance of thoughts: thoughts are very important and must be controlled
- Thought-action fusion: just having a thought increases the chances that it will come true and/ or that I will act on it
- **Perfectionism**: mistakes are unacceptable
- **Intolerance of Uncertainty**: a need for 100% certainty about a given situation

In cognitive therapy (discussed more in Treatment section), people learn to think in more rational and balanced ways. Cognitive therapy is not about trying to think only good thoughts or to assume there are no dangers in the world; it is about using skills that help us look at situations based on facts, not fear.

#### **Behavioural Theory**

Unlike cognitive therapy, which looks at thoughs, behaviour therapy focuses on the behaviours in OCD. According to behaviour theory OCD makes connections between certain situations and fear (e.g. public bathroom = anxiety). In order to reduce that fear, the person learns to avoid those situations or do rituals. A link is formed between the compulsion and feeling better. The more someone avoids or ritualizes in response to this fear, the stronger that link becomes. The stronger this connection, the more likely a person is to continue their avoidance or rituals because they don't have to confront or tolerate that distress... Their avoidance or compulsions become reinforced and the association may start to get triggered in other similar situations like bank machines or public handrails.

In behavioural therapy (discussed in the Treatment section), clients with OCD learn to break these links by confronting and tolerating their anxiety without avoidance or compulsions. This is done using Exposure and Response Prevention (ERP) where clients confront a fearful situation and resist doing compulsions. The more a person is able to expose themselves to anxiety-provoking triggers without ritualizing, the easier it becomes. People learn that their fears may not come true and that they can tolerate the anxiety.

#### Social and Cultural Factors

Research on OCD in different cultural groups suggests that there are no big differences across cultures, age, or between genders. Instead, OCD symptoms often seem related to the things we value most or that are particularly relevant in our lives. For example, obsessions about harming one's baby is common amongst new parents with OCD. Similarly, individuals raised in religious homes may develop obsessions that seem to contradict one's religious beliefs (e.g. sexual thoughts about Jesus Christ).

# What Treatments Are Used for OCD?

Currently there is no cure for OCD. However, with effective treatment, people can learn to manage their symptoms and restore normal functioning. Best practice guidelines for OCD recommend cognitive-behavioural therapy (CBT) and antidepressant medications for OCD treatment. While many people will benefit from using one or the other, those with moderate-to-severe forms of OCD often do best when both treatments are combined.

It is important that people get treatment specific to OCD from a qualified CBT therapist. This type of treatment may be available in either individual or group formats, and each format has advantages and disadvantages. While some forms of traditional psychotherapy may help other aspects of a person's life (e.g. relationships) they are not effective for OCD. In addition to CBT, people with OCD may benefit from supportive counselling and marital or family counselling.

# Psychological Treatment: CBT

Cognitive behaviour therapy (CBT) is widely considered the best psychological treatment available for OCD. Specifically, a form of CBT called Exposure and Response Prevention (ERP), is the most commonly used therapy in major health-care settings. This treatment is based on some known facts about anxiety:

- Anxiety is a response to threat or danger.
  - People with OCD interpret certain situations as dangerous and therefore anxiety gets triggered. When something is perceived as dangerous, the fight, flight, or freeze response kicks into gear.
- Anxiety is adaptive and helpful. We need it to survive.
  - The fight/flight/freeze response is our body's way of staying safe. For example, if a car is racing towards us, anxiety helps us to get out of the way quickly. Or, if necessary, anxiety prepares us to fight off an attacker coming towards us.

- Anxiety is not dangerous.
  - The anxiety itself is not a problem even though it may feel awful.
- Anxiety shows itself in three ways: Mental, Behavioural, Physical
  - Mental: thoughts like "something bad is going to happen"
  - Behavioural: actions like avoidance or compulsions
  - · Physical: sweating, dizziness, breathlessness
- Anxiety cannot continue forever or spiral out of control; it will go down...eventually.
  - Sometime after anxiety has been triggered, there is an automatic response in our bodies that helps to restore a calm feeling.

# How does Exposure and Response Prevention (ERP) work?

In ERP practice, a person will expose themself to a situation that triggers anxiety, and then prevent the usual OCD response (compulsion or avoidance).

ERP is based on the idea that problematic anxiety is often a learned process, and can therefore be unlearned. In ERP, people confront feared situations in a controlled and gradual fashion with the help of a therapist. The first step is to make a list of feared situations. The items on the list are organized in a hierarchy, from least anxiety-provoking to most anxiety-provoking. For example, someone with doubting obsessions might have a list that looks like this:

- leaving the house without checking the door (40% anxiety)
- leaving work without checking office door (70% anxiety)
- 3. leaving house without touching knobs on stove (90% anxiety)

The next step in ERP is to confront to the triggering situations listed in the hierarchy, one at a time, from easiest to hardest. The first exposure session, involving the easiest situation, is usually done with therapist assistance. These sessions can last between 45 minutes to 3 hours.

The person will then be asked to repeat the ERP frequently in order to reinforce the new learning: that nothing bad will happen. When the behaviour gets repeated enough times, a process called habituation occurs. Habituation means it gets easier over time!

As the person becomes less anxious in response to the easier situations, their confidence slowly begins to grow. More difficult situations from the list are introduced, following the same process, until the person achieves significant relief from their symptoms.

When a person only seems to have obsessions, without obvious compulsions, ERPs are tailored to obsessive thoughts. For example, a person with religious obsessions may "expose" themselves to their feared thought by writing it down on paper over and over again.

Sometimes, direct, or "in vivo" exposure is not possible in the therapist's office. For example, for a person with fears of yelling out obscenities in church, the therapist might ask them to use "imaginal" exposure. This is when a person imagines the different situations that provoke anxiety.

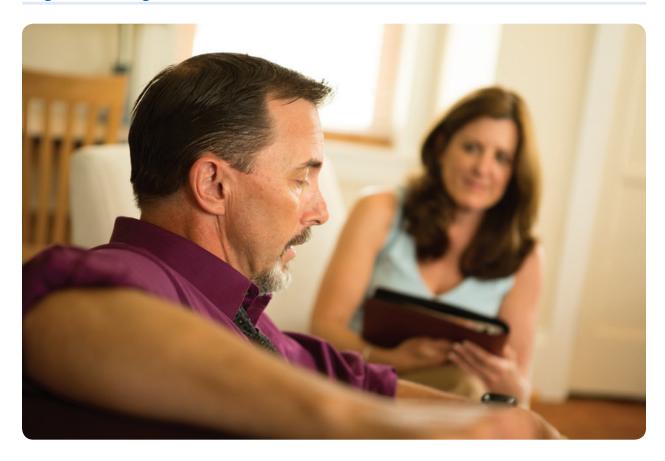
#### Self-directed ERP

For people with mild OCD, ERP can be done successfully without the help of a therapist. There are some very useful self-help books to guide this process. Please see a list of recommended self-help books for OCD and Related Disorders in the Resources section.

#### Is ERP effective?

Research shows that ERP can help a person reduce their OCD symptoms by up to 80%, and maintain this improvement over time. A person's success with ERP therapy depends on several factors, including motivation. Other factors include symptom type and whether other disorders are also present, like depression. Studies indicate that over 75% of patients experience some kind of improvement with ERP treatment.

# Cognitive Strategies



In addition to ERP practice, CBT also involves challenging the unhelpful interpretations in OCD (see Cognitive Theory) and promoting more realistic thinking styles. Using cognitive techniques, people can learn to identify problematic thinking patterns that contribute to OCD.

When cognitive strategies are used along with ERP, patients will usually start by paying attention to thoughts and feelings related to exposure situations. These thoughts are then explored to find out what makes the situation so upsetting. For example, some people with OCD have a tendency to

overestimate danger (e.g. a belief that the likelihood of getting Hepatitis C is very high by touching public doorknobs). Using cognitive therapy techniques helps generate more realistic and helpful interpretations.

There are several cognitive techniques used for OCD. A therapist, or self-help book can help determine which are the best fit for specific obsessions. The Thought Record is a key tool used in OCD.

Thought Record: The Thought Record is a strategy used to challenge unhelpful, distorted thinking patterns. The goal of the thought record is to increase awareness of what we are thinking and then to examine the validity of our thoughts. Steps include rating moods, identifying thoughts that may relate to to the negative or anxious feelings, and looking at evidence that does or does not support the thoughts. Using thought records can help reduce anxiety by challenging the beliefs involved in OCD.

There are many other cognitive techniques that can be used in treating OCD. These include:

- Responsibility Pie
- Continuum Technique
- Probability Estimation
- Double-standard technique and can be read about in some of the self-help books listed at the end of this guide.

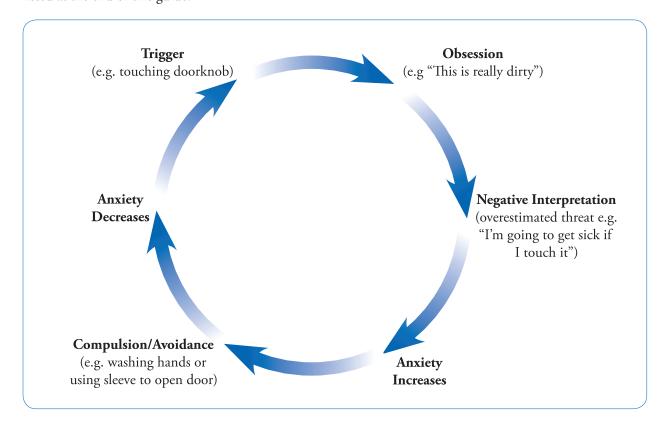
# How effective are cognitive strategies?

Studies show that using cognitive techniques alone, without ERP, can help reduce OCD symptoms. However, experts generally agree that using both cognitive and ERP strategies is most effective. When used together, cognitive and behaviour therapy tools work by learning new ways of thinking and behaving.

The diagram below illustrates the cycle of OCD from a CBT perspective.

#### Treatment model for OCD

In CBT, we break this vicious cycle by challenging those negative interpretations and eliminating the compulsions/avoidance.



#### Medication

#### Medications in the Treatment of OCD

Medications, like cognitive behavioural therapy, can reduce the severity of OCD symptoms and may be an important part of any treatment plan. Although many people do well with psychological treatments alone, others may not feel ready for CBT or may prefer the relative ease of taking a medication. When illness symptoms are more severe, both types of treatment may be combined or provided sequentially.

The first medication found to be effective for OCD was clompramine, a drug used for depression, which increases levels of available serotonin in the brain. Since then, a number of antidepressants that work on the serotonin system have been found to be effective for OCD.

The main class of medications is a large group of antidepressants called serotonin reuptake inhibitors (SRIs). These medications chemically block the absorption of serotonin by neurons, making more serotonin available to transmit messages in the brain. It is believed this change is associated with the improvement in OCD symptoms. Below we describe the three main subtypes of SRI medication: SSRIs, clompramine, and SNRIs.

#### Selective Serotonin Reuptake Inhibitors: SSRIs

This is a large class of antidepressants that work very specifically on the serotonin neurotransmitter system. These include the following:

- Fluoxetine (Prozac)
- Fluvoxamine (Luvox)
- Sertraline (Zoloft)
- Paroxetine (Paxil)
- Citalopram (Celexa)
- Escitalopram (Cipralex/Lexapro)

These medications are considered 1st-line treatment for OCD for a few reasons. 1) There is a lot of evidence supporting their effectiveness in symptom reduction in OCD. 2) They are well tolerated in terms of side effects, compared to other medications for OCD. 3) They are relatively safe, compared to other medications for OCD.

Though these medications each work slightly differently and have different side-effects, they have all been found to be equally effective for OCD. It is very important to remember that one medication may work for one person and not another. It is common for people with OCD to try more than one medication in this category before one is found that improves symptoms with minimal side effects.

#### Clomipramine (Anafranil): SRI

Clompramine is the oldest and best studied SRI for OCD and depression and belongs to a separate class of antidepressants known as tricyclic antidepressants (TCA's). It is found to be equally effective, and in some studies slightly more effective, than SSRI's. About 80% of people taking it note improvement in OCD symptoms. However, it has a wider range of side effects that can make it more difficult to tolerate. As well, there are safety concerns for certain people. Because of this, clomipramine is often seen by treating physicians as a second choice after SSRIs.

# Serotonin and Norepinephrine Reuptake Inhibitors: SNRIs

These are a newer group of SRIs that work on two neurotransmitter systems, serotonin and norepinephrine. These include venlafaxine (Effexor), duloxetine (Cymbalta) and desvenlafaxine (Pristiq). Because of their similarity to SSRIs, they have a similar range of side effects. They are also believed to be effective for OCD, although they have not yet been as well studied as yet as the SSRIs. Because there is less evidence supporting their effectiveness in OCD, they are usually seen as a second-line option after SSRIs.

#### Side Effects

People are often concerned about side effects of such medications and these are an important consideration when choosing the right medication for OCD.

#### **SSRIs**

Because of their chemical similarities, these medications have similar side effects, with slight variations. In general, these effects subside with time and are quite mild. Most noted effects include:

- stomach problems, such as constipation, diarrhea and/or nausea
- insomnia or sedation
- headaches
- increased tendency to sweat
- agitation
- sexual side effects (e.g. loss of interest in sex)

In a minority of people, weight gain can also be an issue with longer term use. Overall, these medications are extremely safe. Due to their slight differences, a person may develop a side effect to one medication and not to another other, so it is recommended to try more than one medication in this category if one experiences uncomfortable side effects with an initial trial.

#### Clomipramine

Clomipramine has similar side effects as the SSRIs. Some patients may experience additional symptoms such as:

- dry mouth
- dizziness with sitting or standing up
- constipation
- blurred vision
- difficulties or delays with urination
- weight gain (more common with clomipramine than SSRI's)
- increased risk of seizures in people who are prone to seizures
- Clomipramine also affects conduction of electrical impulses in the heart, and caution and close medical supervision is advised in individuals who have pre-existing heart conditions.

Despite this list, many patients note that the side effects of clomipramine diminish with time and that this medication is quite well tolerated in the long term.



#### **SNRIs**

SNRI's are generally well tolerated. Similar to SSRIs, the most common side effects individuals experience include:

- nausea
- constipation
- dizziness
- insomnia
- sedation
- sexual side effects
- Venlafaxine (Effexor) may also cause elevated blood pressure in some individuals at higher doses and this should be monitored during treatment.

A potential complication with all the SRIs described above is they can affect the metabolism of other psychiatric and nonpsychiatric medications that are processed by the liver, increasing their levels in the bloodstream. Examples include certain anti-hypertensives, anxiolytic medications, anticonvulsants and anticoagulants. A potentially dangerous interaction exists with the antihistamines Terfenadine (Seldane) and Astemizole (Hismanal); these should be avoided altogether in individuals taking SRIs. Further, SRIs can increase the level of clompramine. When clomipramine is combined with another SRI, care must be taken to start with lower doses of clomipramine and for close monitoing of side effects by a physician.

As with most other medications, it is necessary for any medication changes or additions to be reviewed by a physician before proceeding to reduce the risk of drug interactions and adverse events.

# Important Considerations with SRIs

While SRIs are highly effective in treating OCD, there are a number of points to consider in order to optimize their benefit. Firstly, it can take up to 6-10 weeks to notice improvement in OCD symptoms once the optimal dose is reached. Often, side effects can occur before any improvement is seen, which can be discouraging. It is important for individuals to be patient and continue the medication during this period in order to sustain its effects. When improvement does occur, it does so fairly gradually, with a reduction in intensity of obsessions and compulsions.

A common reason for a poor or limited response to a medication is failure to take them for a sufficient period of time. In general, physicians recommend a trial of 3 months on an SRI before determining if it is effective for OCD. At this point, the individual and physician can assess clinical response and discuss appropriate next steps in treatment. Further, higher dosages of these medications are generally required than are typical for treating depression.

#### When treating OCD with medication:

- It can take 6-10 weeks to see any change in OCD symptoms
- Side effects often occur before improvement
- · Improvement occurs gradually
- Doctors recommend staying on medication for 3 months to see if it's helpful
- OCD usually requires higher doses of medication than other disorders
- Medication will probably not eliminate symptoms completely. The goal is symptom reduction

Finally, while SRIs are very effective in treating OCD, most people note that they do not eliminate obsessions and compulsions completely. The goal of treatment with medication is a reduction in the intensity of obsessions and compulsions and an overall improvement in an individual's functioning and quality of life. For this reason, medications are one component in a comprehensive treatment plan for OCD, which also includes other interventions and strategies discussed here, including cognitive behaviour therapy. When OCD symptoms are severe, however, medication is often the best starting point, potentially alleviating symptoms so that it is more manageable to engage in therapy afterwards.

# **Other Medication Options**

Most doctors recommend that people with OCD start with one of the SSRIs. If the first medication option does not produce a response after a trial of 3 months, it is suggested to **switch** to another SSRI or clompramine. The most common approach is for individuals to try at least three SRI medications described above before switching to other drug alternatives, which will be described below. If an individual experiences only a partial improvement on one medication alone, a secondary agent can be used. Addition of a second medication to a primary one is called **augmentation**. These options will be discussed below.

# Once Response is Achieved

A common question relating to medications for OCD and other psychiatric conditions is **how long** medication(s) need to be continued once there is an improvement in symptoms. It is generally recommended that individuals taking medication for OCD continue for at least twelve months and in some cases, two years or longer term.

There is often concern expressed that these medications are 'addictive' or that one can become 'dependent' on them over time. Neither of these ideas are true. Even if taken long-term, these medications are safe and it is fairly common for individuals to stay on them long-term without such risk.

A major complication of discontinuing medication is the significant risk of relapse, or return, of OCD symptoms. To minimize this risk, doctors recommend a number of strategies. These include gradual reduction of the dose over several weeks to months with close supervision, and regular follow-up with a health care professional, such as a therapist, to monitor symptoms. Doing cognitive behaviour therapy along with medication also helps reduce the riskof relapse after stopping a medication.

#### **Additional Primary OCD Medications**

These are often considered as the third step in treating OCD after two to three trials of SRIs, though some individuals note benefit from these after limited response from earlier treatments. Generally, these medications all impact serotonin levels and pathways in the brain.

Mirtazapine (Remeron) is an antidepressant that works on serotonin and norepinephrine levels in the brain. There is some evidence supporting its use for OCD, though additional studies are required. In general, Remeron is seen as less effective than SRIs in treating OCD.

Monoamine Oxidase Inhibitors have also shown limited benefits on the core symptoms of OCD, though they are very beneficial for treating depression. Studies have shown that they are less effective than SSRIs and have complicated side effects and precautions requiring monitoring.

#### Medications for Augmentation

Addition of a secondary medication can be a very effective way to maximize response to an initial medication for OCD. These options are often non-antidepressants and come from a variety of classes:

**Augmentation:** Adding medication to improve response

# **Antipsychotic Medications**

Antipsychotics have the strongest evidence for benefit as add-on medications to SRIs for OCD symptoms. Older options, including Haloperidol (Haoldol) and Pimozide (Orap), may provide specific benefit for people with OCD and concurrent tic disorders, such as Tourette's disorder. Newer antipsychotics ('atypical antipsychotics') including Risperidone (Risperdal), Olanzapine (Zyprexa) and Quetiapine (Seroquel) have been found to be effective for a broader range of people with OCD. A newer generation of antipsychotics, including an option called Aripiprazole, shows some benefit, thoughfurther studies are needed.

An important consideration with antipsychotics is the short term and longer term risk of side effects. This includes elevated triglyceride and cholesterol levels, weight gain, and diabetes, making some of these medicationsless suitable for people who are at risk for cardiovascular problems, such as heart attacks or strokes. Antipsychotics can also induce tardive dyskinesia, an involuntary movement disorder. However, this risk is less for newer antipsychotics. Sedation is also noted by individuals taking antipsychotics. All patients taking these medications require physician supervision and routine bloodwork and monitoring. Nevertheless, they are an important option to consider for most patients due to their effectiveness as augmenting agents in OCD.

#### Benzodiazepines

These medications tend to alleviate anxiety and help with sleep, though it is unclear if they reduce the core symptoms of OCD. One of the best options in this class is clonazepam (Rivotril), a relatively longeracting benzodiazipine which may alter the balance and availablility of serotonin in the brain. Other medications in this category include lorazepam (Ativan), diazepam (Valium), oxazepam (Serax)and temazepam (Restoril). Because these medications can cause sedation, they are hazardous to take when driving oroperating machinery or during alcohol consumption. Further, they can impact short term memory and learning. Hence they can interfere with one's ability to engage with cognitive behaviour therapy. Finally, there is a risk of dependence on such medications with regular use.

# Other Augmenting Agents

A number of mood stabilizing drugs have been studied as add-on medications in OCD. Lithium is the best studied of these. Though this is very effective in bipolar disorder and as an augmenting agent for depression, it has little impact on reducing the intensity of obsessions and compulsions.

Buspirone (Buspar) is an anxiety alleviating medication that has complex effects on serotonin neurotransmission. Studies show some results in a subset of people with OCD, though there is a lack of consistent evidence and larger studies are required.

Tryptophan is a naturally occurring amino acid found in certain foods, and is related to serotonin production. It has been tried in conjunction with SRIs with very limited effects on OCD. Although safe, it can cause considerable sedation. There is some research indicating that tryptophan might help if combined with lithium or an anti-hypertensive drug called pindolol, in addition to an SRI.

Medications known as stimulants, such as D-amphetamine, and caffeine, show rapid and sustained responses as augmenting agents for OCD in small initial studies. Additional trials are required to assess their effectiveness compared to existing medications.

#### **Newer Medications**

Medications that affect other chemicals in the brain continue to be studied as augmenting agents. For example, medications that affect glutamate, another chemical in the brain, have shown some promising results in small, initial studies. These include memantine, topiramate, and N-acetylcysteine. Larger studies are being designed to help better understand their potential role in the broader treatment of OCD symptoms.

#### **Herbal Therapies**

Herbal remedies have become more widely used in recent years as alternatives to conventional medications. However, there have been no studies to date exploring their effectiveness in treating OCD. Similar to other medications, such treatments pose potential risks of side effects and drug interactions. It is necessary to discuss these with a doctor. Treatments suggested for anxiety that may help with OCD include St. John's Wort, Ginko Biloba, Valerian root and Evening Primrose Oil.

#### Role of Medications in OCD Related disorders

# **Hoarding Disorder**

There is inconsistent evidence for the role of medications, particularly SSRIs in the treatment of hoarding. In general, for people who do respond, the responses to SSRIs are poorer than those with OCD alone. The current approach is to attempt a trial of SSRIs or CBT, which can be helpful for hoarding.

#### **Trichotillomania**

Except for clomipramine, which has shown some proven benefit in studies, SRIs are generally ineffective for trichotillomania. Alternatively, antipsychotics such as those described above, may be beneficial as primary medications for trichotillomania. Studies have also shown promising results for N-acetylcysteine and naltrexone. The main treatment for this condition is a specific type of CBT called habit reversal training.

# **Compulsive Skin Picking**

Similar to other OCD-related disorders, SSRIs may be helpful for compulsive skin picking but with limited effects. N-acetylcysteine and naltrexone have more robust effects, though habit reversal training remains the main treatment with such individuals.

# **Body Dysmorphic Disorder**

Symptoms of body dysmorphic disorder are generally more responsive to SRIs, including SSRIs and clomipramine, with a potential role for augmentation with antipsychotics.

# How Does OCD Effect Family & Friends?



After his first daughter was born, Henry became afraid of doing something inappropriate with his baby. To make sure he didn't do anything wrong, and to avoid the anxiety that he felt, Henry asked his wife to do all the diaper changing, or at least be present when he did it. Soon, Henry's wife began to resent the fact that Henry could not be left alone with their baby. She felt overburdened and began to wonder if she would be better off without him.

We do not live in a vacuum. We are surrounded by others who we have an effect on and who affect us. And the more we care about one another the greater the effect. This might be especially true for people dealing with symptoms of OCD because they are woven through so much of life. All of the worries and repetitive behaviours that are a part of this disorder get played out within relationships and family life.

People with OCD carry around severe and persistent worries in the form of disturbing thoughts, and once they have the thoughts they will try to do whatever they can to get rid of them. The anxiety feels intolerable. This leads to repetitive behaviours in the form of rituals that they hope will undo whatever has made them so fearful. The misplaced logic is clear to partner, family and friends, but they also clearly see their loved one's distress, and so they accommodate.

And this is the problem. The loved one does not intend for the accommodation to become a pattern, but because the distress arises again and again, they find themselves accommodating over and over, until they find that the OCD takes over relationship and family life.

Michelle's family was used to accommodating her OCD. Although they hated having to shower and change their clothes as soon as they came home, they did it because it was easier than arguing with her.

Because OCD and the following accommodations are so interwoven into family life, any OCD treatment plan needs to include, or, at least consider partners, parents, children, extended family and friends. These loved ones are often confused about the disorder itself and about how to provide support without allowing OCD to take over family life. And, because the person with OCD is so obviously suffering, loved ones may not only accommodate, but also find that over time they have ignored with own needs. When this happens the family member still cares deeply for the person in their life who has OCD, but may also experience a mixture of complicated emotions, often including resentment. Additionally, supporters may receive well-intended but uninformed advice from others. This further highlights the need for accurate information and support.

Accommodation: doing things for a person with OCD to help ease their distress.

Accommodation may help in the short-term but makes OCD worse in the long-term.

# Thoughts for Loved Ones

Gail's daughter always wanted a puppy but Gail's fears of contamination made that impossible. At the end of CBT treatment, Gail was excited to tell her therapist that she had finally bought a puppy for her daughter.

When your loved one is first diagnosed you may find that a door has opened and hope arrives along with the possibility of treatment. You may feel that you have been trying to manage this on your own, trying to figure out how to provide support without the niggling fear that you might be making things worse. You may worry that the health professionals might judge you or not appreciate how much stress you have been living with. These are normal worries. Accompanying your relative to one or more visits to the doctor or therapist may be helpful. You can ask for family to be included so that you can be supportive of the care being provided.

It is important to let your loved one know that you have his or her back as they face their fears, while also being realistic that your own feelings will also show up. You may find that you feel resentment at the burden that OCD has imposed on your life, even sometimes feeling that it has stolen time that should have gone toward taking care of yourself or others. Just at the moment that it seems that OCD might no longer be stealing your relative's life, your emotions about the past might surface. All of this is normal, but it does mean that you also need support. Ask your relative's care provider about support for you. It may be in the form of a Family Support and Education Group, a community group, online support or books on OCD and families.

# The Challenge of Dealing with Accommodating, Rituals and Reassurance Seeking

One of the biggest challenges of OCD is the many ways it affects relationships within the family. People struggling with the symptoms of OCD often doubt many of the aspects of daily life that others sail through. For this reason they frequently look to the people closest to them for help in reducing their anxiety. At first it just makes sense to provide reassurance, "Yes, you turned off the kitchen stove." But as it grows to include other things or in intensity, family members may become irritable. Yet, as a family member you may find that family life will slow to a crawl if you do not do things the way the person with OCDdemands, by providing reassurance or participating in rituals. You may find yourself resisting these things some times and getting drawn in at others. You may experience guilt about how you are reacting at any given time and wish that there was a rulebook to guide your actions.

Another complicating factor is that each family member might have a different way of responding, with one person thinking that "tough love" and just saying "no" is the proper response, while another may feel that their loved one is just too distressed to ignore. This is not surprising. There is no one correct way to respond to OCD, especially when the person with OCD is not receiving therapy. Knowing this can be reassuring, but also confusing for family members.

If your family member with OCD is receiving therapy it may be helpful to ask for a family session so that you can gain clarity, understanding and confidence about your own actions. None of us can respond perfectly to all situations within family life, especially when there is emotional pain and stress involved and it can be helpful to have some guidance.

Before everyone got the chance to meet together with Susan's therapist, it seemed that each person who cared about her had a different idea for the best way to support her. Sometimes Susan's mother provided reassurance that Susan had completed her rituals while her father refused. Her mother's experience was that Susan could get "stuck" trying to leave the house without the reassurance and her father could see that the reassurance would interfere with Susan's progress with CBT. When everyone met they got the chance to express their caring for Susan, despite their different approaches to her symptoms, and to make a plan that everyone could support, including Susan. As she progressed the plan also progressed, with additional meetings.

Loved ones may notice that family life can narrow down to their relative's obsessions, rituals and their own accompanying accommodations. A family life that has becomes preoccupied with one person's difficulties is not satisfactory for anyone. Even though it may seem that your loved one is suffering so much that it would be selfish for you to take your attention away, the narrowing of focus can create its own problems. Some research even suggests that

members of a family dealing with OCD are under as much stress as the person who is diagnosed. Taking care of yourself is not selfish but can go a long way to supporting the solutions. Think of a mobile, a work of art made up of several interconnected parts. As suggested at the beginning of this section, when you take care of yourself, your stress is reduced and has a positive effect on everyone in your family.

Mark had gotten used to supporting his partner, Will, by watching him complete rituals. Will felt reassured but it didn't last long, and soon he was asking for reassurance again. Mark attended a support group for family members and soon after learning that accommodation could impede Will's progress, he and Will had a talk about this. They decided together which rituals Mark would no longer participate in. They both knew that this would not be easy, but Will knew that Mark wanted to support his therapy.

# Importance of Taking Care of Yourself

Here are some well-researched stress-reduction strategies:

- Recognize when you are feeling stressed.
   Some signs are increased heart rate and blood pressure, change in sleep patterns, difficulty concentrating, worry, irritability. You may even find that your mood is affected and you feel anxious yourself.
- 2. Mindfulness meditation. Join a Mindfulness-Based Stress Reduction (MBSR) group to help manage stress with a daily meditation practice. They usually meet for eight sessions and help you learn and start developing the habit of practicing mindfulness meditation everyday, which has been shown to help people manage stress.
- 3. Exercise. All forms of exercise have been shown to reduce symptoms of stress, including walking, running, aerobic exercise, yoga, tai chi, chi gung and pilates. Recent research also suggests that exercise may be directly beneficial at reducing OCD symptoms.
- **4. Emotional Support.** Having the opportunity to talk with a nonjudgemental friend or family member is important when stressed. Joining a family support and education group can also be helpful to gain perspective.

- Nature. Research has shown that taking time to be in nature reduces stress. Even a short walk can be helpful.
- **6. No one is perfect.** This may seem obvious, but when there is suffering in a family you can lose perspective and feel that you should not take a break until everyone else is okay.
- 7. Professional counsellors. Professional support, whether in the form of individual, couple or family counseling, can at times be the best help for dealing with stress. If you or someone else in your family is depressed, anxious or having thoughts of harming his or her self or others, this is the time to reach out to a professional.
- 8. Scheduling in time for activities that you enjoy. Often when individuals are trying to support a loved one with a problem like OCD, they may forget to keep up their own interests and pleasurable activities.

# Talking With Children

Jim's kids were worried about him. And they were worried that they might be the cause of his worries. Even when his OCD symptoms were overwhelming to him, Jim took time to remind them that his difficulties with anxiety were not their fault. Their mom agreed and both parents made sure that school activities did not suffer, even when Jim was very involved in his own therapy.

When a parent has OCD we often hope that the children are going about their busy lives without being affected. Because it can be difficult to talk to a child about a adult problems, parents may wish to avoid the topic entirely. But children are observant and almost always aware when there are difficulties in the family. And because children have limited life experience they are likely to see everything through the lens of themselves. Parents are often unaware when children blame themselves for their parent's problems. This need to help them put things in perspective means that it is especially important to have a conversation about OCD, with an emphasis on it not being the child's fault.

Here are some suggestions for helping children make sense of OCD in the family:

- 1. Provide information about OCD, its causes and treatments, using age-appropriate language. In general, as children grow they will be able to understand and process more information. Young children will mostly need to understand that problems are being addressed by their parents.
- Give them reassurance that they did not cause it and are not responsible for fixing their parent's problems.
- 3. It is also important to let them know that their parent's problem is being treated effectively.
- 4. It's especially important for kids to know that their parent has a problem but that it does not interfere with his or her love for them.
- 5. As much as possible provide unstressed time with the parent who is not suffering from symptoms of OCD. This can help them keeps things in perspective.



- 6. Keep their lives going along as normally as possible. School activities, sports and social events can help keep them connected even during difficult times.
- 7. As the parent with OCD improves, it is important for him or her to reinforce their relationship with the child. This will also provide stability, hope and optimism for facing the problems that will need to be faced in life.
- 8. Children are resilient. Everyone faces difficult times in life, including children, and we often gain confidence in our ability to handle the challenges of life when we get some practice as a child. Let them know that they are important and valued family members. Also, spending time with trusted adults, such as grandparents, aunts and uncles can help children maintain confidence that things will be alright.

# Managing Recovery & Preventing Relapse



Rita was proud of joining the CBT therapy group and taking step after step to reducing her symptoms. When things had beenmost difficult she had not been able to go to work. As she regained her health she was able to begin to knit again and spend time with friends, without having OCD on her mind all the time. Although she wished that it would just vanish, her experience told her that OCD had been with her for a long time and that planning for possible set-backs was important. She also knew that staying involved in the parts of her life that reminded her of what she gained was important...

There is so much good news in the treatment of OCD that it would be understandable to think that treatment can provide a simple cure. A cure would mean that you would be able to jump back into life with all of its demands without ever having to think about OCD again. But OCD is not like an infection that completely goes away with a course of antibiotics. It is more like diabetes. When someone has an illness like diabetes, we know that it is treatable, and that that person can can live a full and satisfying life. The same is true with a diagnosis of OCD. There are effective treatments and you

can expect that your life can be full and satisfying. Just as with diabetes, however, taking good care of yourself will be an important part of ensuring this satisfaction and fullness.

Treatments for OCD can give people the tools to make substantial changes in their lives. Changing the way we react to fearful situations can help us make wiser and healthier choices. Research shows that CBT can help people reduce OCD symptoms by up to 80% and keep those changes long-term. However, OCD is also persistent; for most people, OCD will

be a lifelong illness. Therefore, the fight against it involves continual awareness and determination.

Recovery from OCD is a process. In addition to CBT, recovery involves learning about the medications that are prescribed for your care and taking them as prescribed. CBT provides a graduated process and asks that you take steps in confronting situations that you have avoided in the past. At times, you may feel more stressed as you take these steps. Some constructive or positive self-talk can be helpful here, such as reminding yourself that it is natural to feel anxious or unsure as you confront situations that you have been avoiding. Usually, people will need to continue with at least some ERP work on their own. Spontaneous ERPs (e.g. touching doorknobs whenever encountered) and more planned ERP work (e.g. setting aside regular time to intentionally touch "contaminated" things without washing) may both be necessary. Obsessive-Compulsive disorder is sneaky: over time it can change forms (e.g. shift from contamination fears to obsessions about harming a loved one) and creep back in slowly. Learning to recognize its patterns and methods can help ensure you are in control.

You may find that it is helpful to talk with others who are also on the journey of recovery by joining an OCD support group. You may find inspiration in talking with others who have walked this path before you. If you have been trying to manage by keeping others from knowing about your OCD symptoms, it might be hard to reveal your diagnosis. Hearing that others have lived with similar difficulties can help reduce shame and increase pride in your efforts to keep OCD from running your life.

It is important to remember that recovery does not always run smoothly. It can be helpful to make a plan in case you "relapse". It would be unrealistic to expect that recovery always maintains a straight upward line. Without a relapse response plan you might be tempted to feel like a failure for something that is completely normal. People may feel unnecessarily ashamed when they experience a relapse and even withdraw from therapy. Talk over your expectations of therapy and make a relapse response plan with your therapist. And, remember that talking about the possibility of a relapse does not make it more likely to happen.

Most people with OCD have been battling symptoms on their own for quite a long time before seeking treatment. You may have lived a more restricted life and over time grown accustomed to avoiding parts of life that made you uncomfortable. Other people in your life may have taken on responsibilities that you found difficult. Experiencing ambivalence as you take back more of these responsibilities is understandable and normal. It will be helpful to acknowledge this and discuss it with your clinician.

It is also important to have conversations about this with your loved ones. They likely have their own perspective on your changes and may need to express them. If this creates tension or misunderstandings, again, this would not be surprising. Your clinician may suggest couples or family therapy to give everyone a chance to clear the air and work together. Any change is a challenge and will affect everyone differently. Your clinician may be able to help everyone put a potential relapse in perspective. For everyone who has been living with the difficult challenges of OCD it can be frightening when there is a slip into old behaviours. It does not mean that all the progress has been for nothing.

# Some Suggestions for Managing the Challenges of Recovery:

- Learn about the symptoms and treatments for OCD. As the old saying goes, "forewarned is forearmed." The more you understand OCD as a treatable condition, the better able you will be to manage difficulties as they arise.
- 2. When working with your clinician become an expert about your treatment plan. Combinations of treatments can take up a lot of energy and time. Pay attention to the times when it may feel like it is just too much. This information is as important as the times when it all feels good. It can give you clues for when a relapse may be approaching.
- 3. Mindfulness is often added to the treatment plan and relapse-prevention plan for people recovering from OCD. There is good research to support this. Mindfulness meditation, which is often taught in eight-week groups called, Mindfulness-Based Stress Reduction (MBSR) or Mindfulness-Based Cognitive therapy (MBCT), has been

- shown to be helpful for "riding the waves" of symptoms of anxiety without getting caught up in the content of fears. Mindfulness meditation is taught as a helpful lifelong habit for people recovering from the symptoms of OCD.
- 4. Predict relapse. Practice how you can deal with stressful times and situations. Include the people who care about you in the planning. You might ask them to tell you if they notice that things seem to be more difficult.
- 5. If those who care about you have been accommodating OCD symptoms, they may need to express their thoughts and feelings about the changes that are taking place. Sometimes OCD takes over family life to such an extent that life feels completely topsy-turvy when changes begin to happen, even good changes.

#### Self-Care for Now and the Rest of Your Life



There is a lot of information available these days about the importance of nutrition, sleep and worklife balance. For that reason it might feel like you could skip this section. Or, you might feel that you are already doing so much with your treatment plan that you should just postpone these things until you have completed everything else. Additionally, people sometimes feel that their OCD has taken up so much attention from everyone else in the family, that they don't deserve to be doing all these self-centred things.

The fact is that one is more apt to relapse when they are depriving themselves of basic needs for good health. And it is just that word, "deprive" that holds the clues to why this is so. When we feel deprived, every step in treatment is likely to feel like a burden and not like the steps toward freedom that it actually is.

Here are some practical suggestions for taking care of yourself as a part of your plan to minimize relapse:

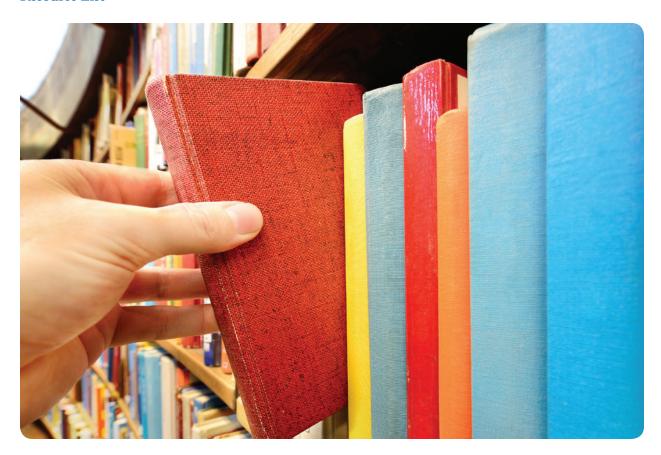
1. The Basics should not be overlooked. Taking care of your body with a healthy diet and fluids isimportant for having the energy to follow through on your treatment plan, and for overall health. You may have been so focused on dealing with your anxiety that you have lost sight of the basics. If you are not sure about diet ask your clinician for a referral to a nutritionist. Having someone who is a specialist on your side can help you to develop and maintain healthy habits.



- 2. Sleep and Exercise. The other Basics that are even more likely to be overlooked are sleep and exercise. There is a strong connection between sleep and anxiety. Depriving someone of sleep can actually bring on symptoms of anxiety. Medications can also have an impact on sleep, in either direction: sleeping too much or with difficulty falling and staying asleep. Discuss sleep problems with your physician. It is important. The same goes for exercise. Symptoms of OCD can lead people to isolate, and become inactive. This can be even more of a problem if you have also experienced depression. Sometimes, the first step in CBT is to become more active. Getting out for a walk may be an important first step, and can help connect you with nature, another important part of self care. Of course, if you are going to start a new vigorous exercise program it will be important to get your doctor's okay, but sleep and exercise are an important part of staying healthy and having the energy to follow your treatment plan.
- 3. Time. Taking time with family and friends, as well as time for yourself, will help you to remember why you are following through on a challenging treatment regime. And as OCD takes up less of your time, you will find that there is more time available for living. And that is the goal of all this work.
- 4. Follow-up with your therapist. Once you feel better, you might think that your therapist is the last person you would want to see. But, continuing care can help you maintain your hard-won gains. Follow-up care also means that you will be able to address set-backs when they first show up, before you can slide back into old habits.
- 5. Life Plans. OCD can take up so much time and energy that it may be easy to forget the rest of your life. Remember that recovering from OCD means that you will have more time and energy to devote for developing and following through on life goals. Make plans for the future, for yourself and with those you love; make those important plans that might not have seemed possible before you began your recovery journey.

# Appendix

Resource List



### Resource List

# Obessive Compulsive Disorder

#### **Books**

BRAIN LOCK: FREE YOURSELF FROM OBSESSIVE-COMPULSIVE BEHAVIOUR Schwartz, J.M. (1996)

FREEDOM FROM OBSESSIVE-COMPULSIVE DISORDER: A PERSONALIZED RECOVERY PROGRAM FOR LIVING WITH UNCERTAINTY. Grayson, J. (2004)

GETTING CONTROL: OVERCOMING YOUR OBSESSIONS AND COMPULSIONS, 3RD EDITION
Baer, L. (2012)

GETTING OVER OCD: A 10-STEP WORKBOOK FOR TAKING BACK YOUR LIFE.

Abramowitz, J.S. (2009)

MASTERY OF OBSESSIVE-COMPULSIVE DISORDER (CLIENT WORKBOOK) Foa, E., & Kozak, M.J. (1997)

OBSESSIVE-COMPULSIVE DISORDERS: A COMPLETE GUIDE TO GETTING WELL AND STAYING WELL

Penzel, F. (2000)

OVERCOMING OBSESSIVE COMPULSIVE DISORDER (CLIENT MANUAL) Steketee, G. (1999)

OVERCOMING OBSESSIVE THOUGHTS: HOW TO GAIN CONTROL OF YOUR OCD Purdon C. & Clark, D.A. (2005)

STOP OBSESSING!

Foa, E., & Wilson, R. (2001)

THE OCD WORKBOOK: YOUR GUIDE TO BREAKING FREE FROM OBSESSIVE-COMPULSIVE DISORDER, 3rd Edition Hyman, B.M, Pedrick, C. (2010)

TREATING YOUR OCD WITH EXPOSURE AND RESPONSE (RITUAL) PREVENTION FOR OBSESSIVE-COMPULSIVE DISORDER, WORKBOOK, 2ND EDITION
Yadin, E., Foa, E. B., & Lichner, T. K. (2012)

WHEN ONCE IS NOT ENOUGH: HELP FOR OBSESSIVE COMPULSIVES
Steketee, G. & White, K. (1990)

WHEN PERFECT ISN'T GOOD ENOUGH: STRATEGIES FOR COPING WITH PERFECTIONISM, 2ND EDITION Antony, M. M. & Swinson, R. P. (2009)

#### For Family/Friends

LOVING SOMEONE WITH OCD: HELP FOR YOU AND YOUR FAMILY Landsman, K.J., Rupertus, K. M., & Pedrick, C. (2005)

#### Internet resources

www.sunnybrook.ca/thompsoncentre Frederick W. Thompson Anxiety Disorders Centre

Thompson Centre Community Event Webcast: OCD & Related Disorders: What Recent Changes in Psychiatry Mean for You (Hosted on October 15, 2013). Link: http://alex2.sunnybrook.ca/Mediasite/Play/81b1cfef03874645bed9dbce568b41b61d

www.canadianocdnetwork.com Canadian OCD Network

#### www.ictoc.org

Canadian Institute for Obsessive Compulsive Disorders

www.anxietycanada.ca

Anxiety Disorders Association of Canada

www.anxietydisordersontario.ca

Anxiety Disorders Association of Ontario

#### www.adaa.org

Anxiety Disorders Association of America

#### www.ocfoundation.org

International Obsessive-Compulsive Foundation website

#### www.nimh.nih.gov/index.shtml

National Institutes of Mental Health

#### www.tourette-syndrome.com

Tourette-Syndrome and related disorders website

#### www.cavershambooksellers.com

Largest mental health bookstore in North America for professionals and consumers of mental health. Books can be purchased online, or at their Toronto store location:

98 Harbord Street, Toronto, ON M5S 1G6 416-944-0962

# OCD Support Group (active as of January 2015)

#### Peer-led support group for OCD

3<sup>rd</sup> Wednesday of every month 120 Carlton Street, Boardroom ocddowntown@hotmail.com Moderated by Rick Silver

#### Toronto-Eglinton Self Help Group

Location: Central Eglinton Community Centre

160 Eglinton Ave., East

Day/Time: 1st Tuesday of each month, 7:00 p.m. – 9:00 p.m. Facilitator: Harold Note: Group closed July and August – no

registration required.

#### Toronto West Self Help Group

Location: The Centre (Romero House)

1558 Bloor Street West

One block west of Bloor and Dundas on the north side. Easy access to the meeting through Bloor and

Dundas subway.

Day/Time: 3rd Thursday of each month, 7:00 – 9:00 p.m.

Facilitator: Tom

Note: Group closed July and August -

no registration required.

#### **Anxiety Empowered - Support Group**

Location: Heart Lake Presbyterian Church, 25 Ruth Avenue, Brampton, Ontario Day/Time: every Tuesday evening (except July & August) 7:00pm - 8:30pm

Contact: Phone: (905) 451-2123

Website: www.cmhapeel.ca, info@cmhapeel.ca Note: A progressive support group for individuals working towards managing their anxiety.

#### **GTA OCD Support Network**

Internet Support Network: Facebook

Contact: Ken Munro munrokb2003@yahoo.com

Note: This is a closed, private Facebook group. To join, please email Ken Munro directly.

# Trichotillomania & Skin Picking

#### **Books**

HELP FOR HAIR PULLERS: UNDERSTANDING AND COPING WITH TRICHOTILLOMANIA

Keuthen, N.J., Stein, D.J., & Christenson, G.A. (2001)

THE HABIT CHANGE WORKBOOK: HOW TO BREAK BAD HABITS AND FORM GOOD ONES

Claiborne, J., & Pedrick, C. (2001)

THE HAIR PULLING "HABIT" AND YOU Golomb, R. & Vavrichek, S. (1999)

THE HAIR PULLING PROBLEM: A COMPLETE GUIDE TO TRICHOTILLOMANIA Penzel, F. (2003)

TRICHOTILLOMANIA: AN ACT-ENHANCED BEHAVIOR THERAPY APPROACH WORKBOOK (TREATMENTS THAT WORK) Woods, D.W. & Twohig, M.P. (2008)

YOU ARE NOT ALONE: COMPULSIVE HAIR PULLING "THE ENEMY WITHIN" Salazar, C. (1995)

# For Family/Friends

WHAT'S HAPPENING TO MY CHILD – A GUIDE FOR PARENTS' OF HAIRPULLERS Salazar, C. (2004)

#### **BFRB Support Group**

(Active as of January 2015)

Day/time: Meetings held every other week, alternating between Tuesday & Wednesday

7:30-9:15pm

Location: North York Civic Centre Contact: Sarah, sarah@canadianbfrb.org

Note: Due to space limitations, meeting locations may vary. Please contact Sarah to receive updated information

#### Internet resources

www.canadianbfrb.org

Canadian Body-Focused Repetitive Behaviours Support Network

#### www.trich.org

Trichotillomania Learning Centre

#### www.StopPulling.com

Interactive website for trichotillomania

Note: Fees involved

#### www.StopPicking.com

Interactive website for skin picking

Note: Fees involved

# **Body Dysmorphic Disorder**

#### **Books**

COGNITIVE-BEHAVIORAL THERAPY FOR BODY DYSMORPHIC DISORDER: A TREATMENT MANUAL

Wilhelm, S., Phillips, K. A., & Steketee, G. (2013)

FEELING GOOD ABOUT THE WAY YOU LOOK: A PROGRAM FOR OVERCOMING BODY IMAGE PROBLEMS
Wilhelm, S. (2006)

THE BDD WORKBOOK: OVERCOME BODY DYSMORPHIC DISORDER AND END BODY IMAGE OBSESSIONS Claiborn, J. & Pedrick, C. (2002)

THE BROKEN MIRROR: UNDERSTANDING AND TREATING BODY DYSMORPHIC DISORDER Phillips, K. (2005)

UNDERSTANDING BODY DYSMORPHIC DISORDER Phillips, K. (2009)

#### **Internet Resources**

www.bddfoundation.org

Body Dysmorphic Disorder Support Network of Ontario

www.meetup.com/Body-Dysmorphic-Disorder-Support-Network

Note: this is a private "Meetup" group. New members must be approved by the Organizer.

# Hoarding

#### **Books**

TREATMENT FOR HOARDING DISORDER, 2<sup>nd</sup> Edition (Workbook) Steketee, G. & Frost, R. (2014)

OVERCOMING COMPULSIVE HOARDING: WHY YOU SAVE AND HOW YOU CAN STOP Neziroglu, F., Bubrick, J. & Yaryura-Tobias, J. A. (2004)

BURIED IN TREASURES: HELP FOR COMPULSIVE ACQUIRING, SAVING, AND HOARDING, 2<sup>nd</sup> Edition Tolin, D. F., Frost, R. O. & Steketee, G. (2013)

STUFF: COMPULSIVE HOARDING AND THE MEANING OF THINGS
Frost, R.O. & Steketee, G. (2010)

#### **Internet Resources**

VHA Home HealthCare (Visiting Homemakers Association (VHA)) www.vha.ca

International OCD Foundation, Hoarding Center http://www.ocfoundation.org/hoarding/Children of Hoarders
http://www.childrenofhoarders.com

# For Family/Friends

DIGGING OUT: HELPING YOUR LOVED ONE MANAGE CLUTTER, HOARDING AND COMPULSIVE ACQUIRING. Tompkins, M.A., Hartl, T.L. (2009)

#### **Community Resources**

VHA Home HealthCare (Visiting Homemakers Association)

www.vha.ca 416-489-2500

Toronto Hoarding Coalition
A group of service providers and advocates who work together finding solutions for people with excess hoarding behaviour

http://www.torontohoardingcoalition.com/

# **Hoarding Documentaries**

My Mother's Garden by filmmaker Cynthia Lester www.mymothersgardenmovie.com

**Stuffed** by filmmakers Arwen Curry and Cerissa Tanner

http://www.amazon.com/Stuffed/dp/B003BYPQZQ

Packrat by filmmaker Kris Britt Montag www.packratthemovie.com

**Grey Gardens** (1975) directed by Ellen Hovde, Albert Maysles, David Maysles and Muffie Meyer

https://www.youtube.com/watch?v=GP2KjNge1FY

# Resources for Other Anxiety Disorders

MIND OVER MOOD: A COGNITIVE THERAPY TREATMENT MANUAL FOR CLIENTS

Greenberger, D. & Padesky, C.A. (1995)

THE ANXIETY & PHOBIA WORKBOOK Bourne, E.J. (1995)

THE FEELING GOOD HANDBOOK, REVISED EDITION
Burns, D.D. (1999)

THE RELAXATION AND STRESS REDUCTION WORKBOOK, SIXTH EDITION Davis, M., Eshelman, E.R. & McKay, M. (2008)

WHEN PERFECT ISN'T GOOD ENOUGH: STRATEGIES FOR COPING WITH PERFECTIONISM, 2<sup>ND</sup> EDITION Antony, M. M. & Swinson, R. P. (2009)

# Resources for Mindfulness and Acceptance and Commitment Therapy (ACT)

#### Mindfulness:

#### **Books**

WHEREVER YOU GO, THERE YOU ARE: MINDFULNESS MEDITATION IN EVERYDAY LIFE
Jon Kabat-Zinn, Hyperion, 1994

FULL CATASTROPHE LIVING. Jon Kabat-Zinn, Bantam, 2013

A MINDFULNESS-BASED STRESS REDUCTION WORKBOOK. Bob Stahl, Elisha Goldstein. New Harbinger Publications, 2010

#### **Videos**

The three minute breathing space is a guided mindfulness meditation that can help you to relax, de-stress, and focus:

The Breathing Space by Jon Kabat-Zinn: A 3 Minute Exercise.

https://www.youtube.com/watch?v=iZIjDtHUsR0

New Mindful Life

https://www.youtube.com/watch?v=Ula0njZIOh4

https://www.youtube.com/watch?v=aTCXcxLjNcA

The body scan is an exercise in mindfulness to help orient you to whole body awareness:

Body scan meditation by Jon Kabat-Zinn: https://www.youtube.com/watch?v=daU-xneLA0g New Mindful Life:

https://www.youtube.com/watch?v=\_vN3wkatdts https://www.youtube.com/watch?v=6W31vHDjyng

# Acceptance and Commitment Therapy (ACT):

#### **Books**

THE MINDFULNESS & ACCEPTANCE WORKBOOK FOR ANXIETY: A GUIDE TO BREAKING FREE FROM ANXIETY, PHOBIAS, AND WORRY USING ACCEPTANCE AND COMMITMENT THERAPY. Forsyth, J. P., & Eifert, G. H. (2008).

THE HAPPINESS TRAP: HOW TO STOP STRUGGLING AND START LIVING. BOSTON, MA: TRUMPETER.

Harris, R. (2008).

Visit the companion website (http://www.thehappinesstrap.com) for additional resources.

GET OUT OF YOUR MIND AND INTO YOUR LIFE.

Hayes, S. C., & Smith, S. (2005).

For a complete list of self-help books on ACT and Mindfulness from the Association for Behavioral and Cognitive Therapies (ABCT) website:

http://www.abct.org/SHBooks

# OBSESSIVE COMPULSIVE DISORDERS

An Information Guide

2015

