

**Factsheet 444 Supporting a person with dementia
who has depression, anxiety or apathy**

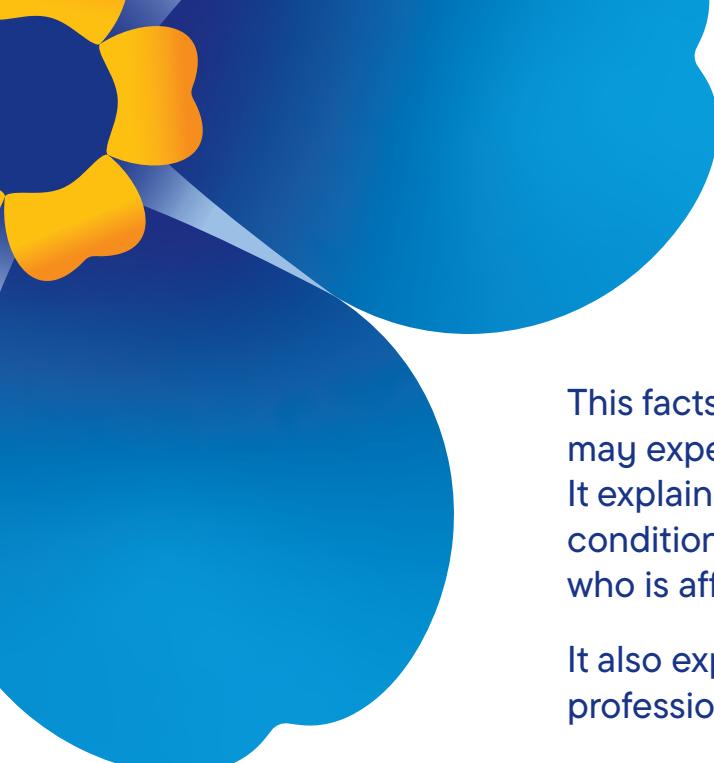
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Supporting a person with dementia who has depression, anxiety or apathy



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



This factsheet looks at how people with dementia may experience depression, anxiety or apathy. It explains the causes and symptoms of these conditions and how you can support someone who is affected by them.

It also explains how to access help from healthcare professionals who can treat mental health problems.

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1 Depression, anxiety, apathy and dementia

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Depression, anxiety and apathy can have a serious impact on a person's emotional and mental wellbeing. Unfortunately, it's common for people with dementia to develop these 'psychological conditions' which can make living with dementia much harder.

Supporting a person with dementia who is experiencing any of these conditions is all about understanding their situation, listening, and getting them help when they need it. It's also about looking out for any signs and symptoms if the person is unable to communicate or express their feelings.

Here are explanations that may help you to understand these conditions, how they affect a person with dementia and the support available.

Carers can also experience emotional and mental health difficulties. If you're caring for someone with dementia, and are concerned for your own mental health, see 'How can talking therapies help carers?' on page 18.

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2 Depression

Most people feel low or sad from time to time, but this is not the same as being depressed. Depression is when a person feels low for a long time, making it harder to do everyday activities. It can also make them lose interest in things they used to enjoy, such as hobbies and being around people.

Depression is a common problem for people with dementia. It is often diagnosed when a person is in the early stage of dementia, but it can develop at any stage.

What causes depression in a person with dementia?

It can be hard to know what is causing depression in dementia. For many people, the challenges of living with dementia can lead to feelings of deep sadness or hopelessness. In addition, the diseases that cause dementia may damage parts of the brain involved in emotions and behaviour.

Other factors that can contribute to depression include:

- traumatic or upsetting events in the person's past
- social isolation or a lack of social support
- a lack of meaningful activities
- not getting enough good-quality sleep
- worrying about money, relationships or the future
- drinking too much alcohol
- living with other long-term health conditions or disabilities
- side-effects of medicines
- bereavement – this can make a person more vulnerable to depression, although grief itself is not normally thought of as a type of depression.

A person with dementia is much more likely to become depressed if they have had depression in the past – particularly if they've had it several times during their life.

People who live in a care home seem to be at particular risk of developing depression. Staff who are well-trained in providing person-centred care, meaningful activities and regular visits from family members and friends can all make a positive difference.

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My grandmother has vascular dementia which is progressing quickly and I am concerned she is depressed.

Family member of a person with dementia

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Symptoms of depression

Depression can affect people in more ways than just feeling sad or hopeless. Other common symptoms include:

- losing interest or pleasure in activities that used to be enjoyable
- feeling worthless, guilty or having low self-confidence
- feeling tearful
- difficulty concentrating or thinking clearly, leading to forgetfulness
- giving up easily when something is difficult
- feeling irritable and prone to angry outbursts
- self-neglect, such as not eating or washing
- tiredness, aches and pains
- sleep problems, such as waking in the very early morning or sleeping during the day.

Older people may have slightly different symptoms of depression than younger people. They are more likely to feel agitated and have health anxiety (worries about their own health). They are also more likely to have physical symptoms, such as aches and pains, which depression can make feel worse.

Depression can increase problems with thinking and memory caused by dementia. It may also contribute to changes in behaviour, such as becoming more agitated or not wanting to eat. For people in the later stage of dementia, symptoms of depression often include tearfulness and poor appetite.

Suicide and depression

Some people with depression will have thoughts about ending their own life. Most people who have these kinds of thoughts don't act on them, but some do. This is why depression should be taken very seriously. It should not be dismissed as a person just feeling 'a bit down'.

Dementia increases the risk of suicide, particularly during the first few months after a dementia diagnosis. Younger people and those with a history of mental health problems are also at higher risk.

The charity Samaritans has useful information on what to do if you're worried about someone. See 'Other useful organisations' on page 22.

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Treatment for depression

Treatments for depression vary depending on how long a person has had it and how severe it is. If they have mild depression, they may be offered a support group or self-help (activities and strategies they can work through themselves). If they have more severe or persistent depression, their GP or mental health professional may prescribe an antidepressant medicine as well as referring them for a talking therapy (see 'Talking therapies' on page 16).

The symptoms of dementia, such as problems with memory and thinking, can make it harder to treat depression. To have the most benefit, talking therapies often need a person to have most of their mental abilities working well. Even so, they can still be effective and worth trying.

Many people find that talking with a professional counsellor or therapist can be helpful in making sense of their thoughts and feelings, particularly during the earlier stage of the condition.

Support groups can also sometimes help. They give people a chance to talk to others who are going through a similar experience and share their thoughts. To find groups in your local area, use our online dementia directory at alzheimers.org.uk/dementiadirectory

Antidepressant medication is widely used to treat depression. However, it doesn't seem to be as effective in people with dementia. Instead, depression may be helped more by improving a person's quality of life through:

- care and support that matches their needs, personality and preferences
- dealing with any underlying issues that may be contributing to depression, such as loneliness or treating pain
- ensuring they have opportunities to do things that provide pleasure or fulfilment.

■ Although medicines for depression are less effective in dementia, there are other things that can help.

Complementary and alternative treatments

If the person wants to try complementary or alternative therapies to manage their depression, they should speak to their doctor first. These include herbal remedies, aromatherapy, massage and bright light therapy.

Most alternative therapies are unlikely to conflict with conventional treatments. However, some may interact with other medicines the person is taking, such as St John's wort or cannabidiol (CBD) oil. That is why they should always check with their GP first.

How to support a person with dementia who has depression

Always involve the person with any decisions and choices to make, whilst encouraging them to:

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● talk about their thoughts and feelings

- The person may find it helpful to talk about how they are feeling.
- Be patient and understanding rather than trying to make them ‘cheer up’. They may need a listening ear more than suggestions.
- If these conversations are too difficult or sensitive, or the person doesn’t feel comfortable talking to someone they know, ask a professional counsellor or therapist for help first (see ‘Talking therapies’ on page 16).

● be sociable and spend time with other people

- Being around others can help them to feel less isolated, as can having one-to-one interaction with another person, such as talking and holding hands.

● stay physically active

- Whether it’s gentle or vigorous, regular physical activity can reduce a person’s feelings of depression, as well as helping with sleeping problems and apathy.
- If they can, support and encourage them to regularly go outdoors and spend time in natural environments (such as a park or garden) and take part in gentle activities, such as walking, cycling, tai chi or pilates.

● do other activities they enjoy

- Some people may benefit from doing life story work or reminiscence therapy, such as making a scrap book or photo album about their life.
- Creative or group activities can also help, such as dancing or singing. Some people may also get a lot of fulfilment from attending regular services with their local faith group.
- Singing for the Brain® and other local support groups can be found using our online dementia directory at alzheimers.org.uk/dementiadirectory

● eat a wide range of healthy foods

- Having an unhealthy diet and drinking too much alcohol or caffeine may make depression worse.
- Make sure the person has healthy, nutritious and enjoyable food to eat, ideally in the company of family and friends if they prefer it that way.

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● continue with treatment.

- Keep taking any anti-depression medication prescribed by the doctor. Some antidepressants can cause unpleasant side effects or changes in behaviour if doses are missed, or stopped too quickly. If you think a medicine isn't working, talk to the doctor first.
- If the person starts a course of talking therapy, encourage them to keep doing it even if they feel the improvement is slow to start with.

Routines and surroundings

People with dementia who are depressed may benefit from having reassuring routines and positive surroundings. Making changes to the home, such as reducing clutter and improving lighting, may also help by making it easier and less frustrating to do everyday tasks. Consider how the person's environment might be contributing to their low mood – for example, if they are not able to see outside.

Having a daily sense of purpose can also be very beneficial, such as helping to look after a pet, working on a community project, or just helping with household chores. For a person with depression and dementia, it's important to involve them in a task they can be successful in, to help their confidence.

Depression can be mentally exhausting though, so it's unlikely that someone feeling very low will have the energy to do lots of activities. For most people it's best to start slow – just doing a bit more than they were doing before. Consider what you know about the person to find ways to help. If they found a particular activity meaningful or enjoyable in the past, perhaps there is a gentle version for them to try slowly.

3 Anxiety

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It's common to feel anxious from time to time. Anxiety is an unpleasant feeling caused by the fear or thought that something bad is about to happen. It can also cause physical changes, such as higher blood pressure, heart rate and sweating.

For most people, these thoughts and feelings are not overwhelming and pass quickly once the source of anxiety is gone. However, for some people these feelings don't go away. Over time, they prevent the person from doing the things they want or need to do. This is when anxiety becomes a mental health disorder.

Anxiety can affect people in different ways. There are several common types:

- generalised anxiety disorder (GAD)
- panic disorder
- irrational fears (phobia) – for example, being afraid of leaving the house.

Some people may also have obsessive thoughts that can make them feel anxious. Others may become anxious in social situations.

Anxiety is common in people who have dementia. It can also make thinking clearly and remembering things even more challenging.

Anxiety seems to be more common in people with dementia who still have good insight and awareness of their condition. It can be particularly common in people with vascular or frontotemporal dementia (FTD) but less so in people with Alzheimer's disease.

What causes anxiety in someone with dementia?

In dementia, the most common causes of anxiety include:

- worrying about difficult issues such as health, money problems or relationships
- damage to the parts of the brain involved in emotions
- stress, pain or exhaustion
- hallucinations (seeing or hearing things that aren't real) and delusions (believing things that aren't true)
- drinking too much caffeine or alcohol
- side effects of certain medicines
- stopping a medicine too quickly – particularly one prescribed for a mental health problem.

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People may also be more likely to have anxiety if they have:

- a history of traumatic or upsetting events, such as violence, abuse or neglect
- had anxiety disorders in the past
- close relations who have had anxiety
- a personality more susceptible to negative feelings
- other long-term medical conditions or disabilities.

People who have had anxiety in the past are more likely to have it again.

In the early stage of dementia, anxiety is often related directly to worries about coping with the condition and what the future holds.

In the later stage of dementia, anxiety may be related more to becoming confused or disoriented. For example, a person may worry that they need to go to work or pick up children from school. They may be cared for by someone they don't recognise or feel comfortable with.

The person may be discouraged from doing things they want to do for reasons they don't fully understand, such as going out of the house, getting up during the night, or cooking without someone to help them. In such circumstances it can be natural for someone to become anxious.

There are things that carers and people around them can do to support a person with dementia to feel less anxious as their condition progresses. For more information see factsheets 417, **Supporting a person in the later stage of dementia** and 524, **Understanding and supporting a person with dementia**.

Symptoms of anxiety

People with dementia who have anxiety may have a range of symptoms. They may feel tired, insecure, or irritable. They may struggle to think as well as usual.

Anxiety can also cause physical symptoms, such as a fast or irregular heartbeat (palpitations), shortness of breath, dizziness, nausea (feeling sick) or diarrhoea.

Anxiety can also cause changes in behaviour, such as becoming agitated or restless. A person may pace, fidget or harm themselves by repeatedly rubbing, picking or scratching their skin or pulling their hair. They may feel the need to hoard certain items in the home.

A person with dementia who is feeling anxious may feel scared to be left on their own and so follow a partner or family member around the home. This can be very difficult to cope with when it happens all the time.

Treatment for anxiety

Anxiety can be treated with a range of approaches, depending on the person's needs. If a person with dementia has mild anxiety, it may help to listen to their worries and reassure them.

Many things can cause anxiety or make it worse. Addressing these as much as possible can help a person to feel less anxious. For example:

- **if they are worried that they will lose their balance and fall**, doing things to stop this from happening can help to make them feel less anxious. This could include encouraging the person to do exercises to become physically stronger, installing grab rails or reducing any clutter in their environment.
- **if pain is contributing to the person's anxiety**, they should have regular pain relief to help them feel more comfortable.
- **if they are worried about being lonely** or cut off from people, their friends and family members can help to make them feel included and remain socially active.

Reducing anxiety can involve a range of people. This can include the person's family and friends as well as professionals, such as GPs, clinical psychologists, psychotherapists, occupational therapists, physiotherapists and social workers.

It may help to adapt a person's home so it feels calmer, safer and less stressful. For more information see booklet 819, **Making your home dementia friendly**. It may also help to create a familiar routine for their everyday life that includes meaningful, stimulating and engaging activities.

People with more severe and persistent anxiety may benefit from psychological therapies such as cognitive behavioural therapy (CBT) (see 'Talking therapies' on page 16). There is also evidence that doing music therapy (with a qualified therapist) reduces agitation, which can be a symptom of anxiety.

Some people may also be prescribed medication to treat their anxiety.

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My mum has been suffering from anxiety of being alone for the past two years. Memory loss is an issue for sure, but the anxiety of being on her own is the major problem. Phone calls to friends and family are often repetitive sometimes calling up to 20 times a day.

Family member of a person with dementia

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How to support a person with dementia who has anxiety

Always involve the person with any decisions and choices to make, whilst encouraging them to:

● **talk about their worries or fears**

- Help the person find the right time and space to share their thoughts.
- If something very upsetting or traumatic has happened recently or in the past, the person may find it helpful to talk about them. If these conversations are too difficult or sensitive, or the person doesn't feel comfortable talking to someone they know, ask a professional counsellor or therapist for help first (see 'Talking therapies' on page 16).

● **continue with treatment**

- Keep taking anti-anxiety medication or using talking therapies offered to them, even if improvement is slow at first.

● **stay active**

- Regular physical activity can reduce feelings of anxiety and also help with sleep problems. Where possible, support and encourage them to regularly go outdoors and spend time in natural environments (they may need support to do this).
- Take part in group activities, such as dancing or singing.

● **eat and drink well.**

- Eat a wide range of healthy foods.
- Drink plenty of fluids to avoid dehydration.
- Drink alcohol and caffeinated drinks moderately, if at all.

Some people with anxiety may also want to try complementary and alternative therapies. This could include aromatherapy, acupuncture, massage therapy and herbal medicines (for example Ginkgo biloba and CBD oil).

There is not much evidence that these therapies are effective for treating anxiety in people with dementia but many people choose to try them anyway. If you have any concerns about the safety of a particular therapy, you should speak to your doctor first.

4 Apathy

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Apathy in dementia is a loss of motivation or drive. A person may need a lot of encouragement just to do seemingly small things. Without this support they may well do nothing.

Some people describe apathy as appearing to ‘give up’ or withdrawing into a shell. It can be very hard to witness as it may feel like losing the person. It can also be difficult to support someone who doesn’t appear to care what happens to them, who doesn’t smile or laugh, or seem to have feelings about other people.

Most people with dementia will develop apathy – particularly during the later stage of the condition. The timing and nature of apathy may differ depending on the type of dementia.

What causes apathy in a person with dementia?

There are several reasons why a person with dementia might develop apathy. A very common reason is that it develops gradually as an emotional response to the difficulties of living with dementia.

Dementia can make many things much harder to do. Simple, everyday activities that used to be easy need a lot more effort and patience – and often things go wrong. This can be very upsetting and can knock a person’s confidence. They may feel ashamed, or even that they are embarrassing others.

For many people, the natural reaction to these negative feelings is to stop trying to do things and allow others to do them instead. While this may feel safer and less stressful, it can end up causing the person to become increasingly isolated from other people and the activities they used to enjoy. They may need a lot of support and encouragement to prevent this from happening. See ‘How to support a person with dementia who has apathy’ on page 14.

For some people with dementia, apathy may be caused by damage to certain parts of the brain involved in motivation. Almost everything we do is driven by decisions about effort and reward. If something is thought to be ‘worth the effort’, this provides motivation which then drives action. However, when these thought processes stop working properly, the person may not be motivated to act or get started with a task. For some people, if they do manage to get started, they may struggle to keep going or become overwhelmed as they forget what they were doing and give up.

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Apathy like this tends to happen more often during the later stage of dementia, although it can happen much earlier in certain types of dementia, such as dementia with Lewy bodies (DLB), Parkinson's disease dementia and frontotemporal dementia (FTD).

Symptoms of apathy

A person with dementia who has apathy will be less motivated to do things. They may:

- sit for long periods without appearing to do anything
- rely on other people to suggest and organise activities
- be less interested in joining conversations or talking to new people
- not be worried about their own problems
- have unemotional responses to news or personal events – they may seem to be uninterested or detached
- have no energy or motivation to do routine or daily tasks, such as brushing their teeth or having a shower
- sleep a lot during the day.

Some of these symptoms overlap with those of depression, such as losing interest in things and lacking energy. This is why it can be hard to know whether a person has depression or apathy, even for a doctor. The main difference between the two conditions is that depression involves more negative feelings, such as sadness or guilt (see 'Symptoms of depression' on page 3).

A person with apathy may not be worried by their symptoms. However, it can reduce their quality of life if they are less able to do things that are enjoyable or fulfilling.

Apathy can also put a strain on family and friends who are trying to help and support them. It can be hard to care for someone every day who doesn't seem to mind what happens to them, or those around them. The Dementia Support Forum is an online place for families, friends and carers of people with dementia to share experiences. Visit **forum.alzheimers.org.uk** or call our Dementia Support Line on **0333 150 3456**.

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I don't worry about it, just... sit here. That's all you can do. She says I don't do nothing, I'm sat here all day. But what else can I do?

A person with vascular dementia

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Treatment for apathy

Apathy is very difficult to treat with medicines or talking therapies. It is generally thought that the most helpful approach is to support a person to stay as active as possible and help them to keep their confidence levels up. This means creating safe spaces where they can try new activities or talk to people without worrying about getting things wrong, and where their dementia is not something to be ashamed of. Even if they find it difficult to take an active role in these activities, they can still benefit from being involved.

Activities designed for people with dementia can be great ways of achieving this – for example, a local Singing for the Brain® group or dementia cafe. These tend to be advertised in local newspapers or parish newsletters. You can also contact your local dementia adviser or adult social services to find out what is available in your area, or visit our online Dementia Directory at alzheimers.org.uk/dementiadirectory

There are also various types of structured therapy that are delivered by a trained professional, such as music therapy, group art therapy, reminiscence and cognitive stimulation. However, these therapies are not available everywhere.

A person with apathy may also be offered an antidepressant medicine. However, there isn't much evidence that these medicines help people with apathy who have Alzheimer's disease, mixed dementia or vascular dementia. In fact, there is some evidence that these medications may make apathy worse.

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My husband was 52 when he was diagnosed with Alzheimer's and experienced many of the symptoms of depression merging into apathy. Not everyone wants to be 'organised' into activities, this depends very much on the nature of the person. An individual companion worked well for him.

Partner of a person with dementia

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How to support a person with dementia who has apathy

- **Try to find tasks and activities they will enjoy and find meaningful.**
 - Have a basic daily routine to provide a reassuring structure to each day.
 - Have a weekly routine with a few activities that suit the person's preferences and personality. This could be a group session or simply visiting the park and seeing grandchildren.
 - Identify activities that the person has a realistic chance of actively contributing to and feeling in control. This will help to rebuild their confidence.
- **Create a safe space where they are free to get things wrong.**
 - Local dementia support groups provide a place where dementia symptoms are accepted and understood, and where no one should have to worry about embarrassing themselves or others.
 - Try to apply these principles to home life by not getting angry or upset when mistakes happen.
- **Break tasks down into simple steps.**
 - Several small steps may be easier than trying to do lots of things at once.
 - Maintaining simple, everyday skills can help bring a sense of achievement and improve self-esteem.
- **Don't blame the person for being 'lazy', unhelpful or uncaring.**
 - Apathy is not a conscious choice.
 - If you feel frustrated, try to remain as calm as you can.
- **Be patient and provide encouragement to keep going.**
 - It can be tempting to take over or do a task for someone who is struggling. While this may get things done more quickly, it can also knock their confidence, and over time they may lose important skills.
 - Be positive and focus on what they achieve, not on what they can't do.

An important part of any support for these conditions is being able to understand the needs of a person with dementia and communicating as effectively as possible. For more information see factsheets 524, **Understanding and supporting a person with dementia**, 525, **Changes in behaviour**, and 500, **Communicating**.

5 Seeing a doctor

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A person with dementia should talk to a healthcare professional, such as their GP, if they are concerned about feeling low or anxious. If they're unable to do this by themselves, a family member or carer can do it for them.

A healthcare professional will talk to the person and, if possible, with a family member or carer. They will try to assess the person's mood, behaviour, and any changes that have happened recently which might be related to their symptoms.

It can be difficult to diagnose depression in a person with dementia because some of the symptoms of depression and dementia can overlap, as can symptoms of apathy and depression.

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6 Talking therapies

In psychological therapy or ‘talking therapy’ sessions, a person will be supported to talk about how their thoughts and feelings affect their mood and behaviour.

How do talking therapies work?

Talking therapy sessions are delivered by a professional, such as a counsellor, a clinical or counselling psychologist, a psychotherapist, or a psychiatrist. People can have some types of talking therapy over the telephone or online. This includes counselling and cognitive behavioural therapy (CBT) (see ‘Types of talking therapy’ on page 17).

The therapy will be adapted to each person. It will be based on them and the therapist working together to find out what might be causing the person’s problems, as well as ways to manage these problems. Sessions can also involve talking together with the person and their partner, or a family member or friend.

Successful therapy depends on developing a trusting relationship between the person and the therapist. It is important that the person is comfortable with the therapist’s approach and manner. Their relationship is confidential. This means the therapist won’t tell anyone what they discuss during therapy. There are some exceptions to this, which the therapist should explain during the first meeting. For example, if the person with dementia gives their consent, they may be accompanied and supported in the sessions by a family member.

Benefits for people with dementia

Talking therapies can be effective for people in the early to middle stage of dementia. They are unlikely to help if a person is in the later stage. This is because the person may have problems with their attention, communication, understanding and memory, which are all key to being able to benefit from talking therapies.

However, there are other ways to support people in the later stage of dementia, such as through sensitive listening or sensory stimulation. See factsheet 524, **Understanding and supporting a person with dementia** for more information.

Talking therapies can give a person with dementia the chance to speak openly about their feelings, including how they feel about a recent diagnosis. This can help them adjust and live with their condition more successfully. They might find it helpful to discuss problems with a therapist rather than their friends or family members.

A therapist can give the person a safe space to explore the reasons why they feel how they do and ways to support them. This can be comforting. It can also help them maintain healthy relationships with their friends and family members.

There is evidence that having talking therapy over several weeks may reduce depression and anxiety in people in the early stage of dementia. It is important that the therapy is adapted to the person's level of communication, understanding and memory. It's therefore likely to be most effective if the therapist has experience of working with people with dementia and a good understanding of the condition.

Suitable talking therapies are not always available in the person's local area. People in care homes may find it particularly difficult to access talking therapy services. See 'How to find a therapist' on page 21 for more information.

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Types of talking therapy

There are many different types of talking therapy. The main ones are explained below. The most suitable type will depend on:

- the difficulties the person is facing
- what the person wants to get out of therapy
- the type and stage of their dementia
- the symptoms they are having
- their personality and feelings about therapy.

Counselling

Counselling is the general term for a range of talking therapies, including individual, group and couples sessions. It aims to help a person better understand their problems and then explore ways to manage them. A counsellor should not give the person 'answers'. They will give them time to think about their problems with the guidance of a professional.

Counselling is often used to help a person cope with events they've found difficult. It can be particularly helpful for people who have recently been diagnosed with dementia. The process of being assessed for suspected dementia can also be confusing, stressful and make the person feel anxious.

Many people with dementia struggle to make sense of their diagnosis and how their life is changing. They may feel lost, confused, vulnerable or anxious. Counselling can help them manage these worries, such as feeling less depressed, more hopeful and accepting of their diagnosis.

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Psychotherapy

Psychotherapy is a term for another range of talking therapies. The type of psychotherapy that a person is offered will depend on what is most appropriate for them.

A psychotherapist will help a person understand how their personality, beliefs and experiences influence their thoughts, feelings, relationships and behaviour. This can change the way they think and behave. It can also help them deal with problems and difficult situations more successfully.

Psychotherapy can support people with dementia to feel less depressed and anxious, maintain a good quality of life and cope with their condition.

Cognitive behavioural therapy

Cognitive behavioural therapy (CBT) is based on the way we think and reason (our ‘cognition’), and the affect this has on how we feel and then how we behave. The therapist will help the person to identify unhelpful thoughts and actions, and replace them with more positive thoughts, new skills and techniques.

CBT for depression or anxiety is most suitable for people in the earlier stage of dementia. They are likely to have fewer difficulties with their memory, communication and reasoning. They are also usually more aware of their condition and their own thoughts and emotions than a person in the later stage of dementia. This will mean they can effectively engage with the therapy.

CBT sessions may need to be adapted to meet the specific needs of the person with dementia. This might include having shorter sessions, using memory aids (such as cue cards or digital devices) and summarising ideas throughout the sessions. If the person with dementia agrees, a family member or close friend may attend sessions with them. This supporter can also help them use CBT strategies outside of the sessions.

How can talking therapies help carers?

Dementia is a complex, unpredictable and progressive condition. Caring for a person with dementia can be very rewarding and fulfilling, but also stressful and exhausting, particularly if there are no or few other people who can help.

Carers may suppress their feelings to protect the person they are caring for and become socially isolated and sleep deprived. This reduces the ability to cope with negative feelings and stress. As a result, it is common for carers to feel anxious and depressed, with feelings of guilt if they want to do things for themselves.

When you are caring for a person with dementia it's important that you look after yourself and take regular breaks. For more information see factsheet 523, **Carers – looking after yourself**, and booklet 600, **Caring for a person with dementia: A practical guide**.

Carers may also find talking therapies useful as a way to acknowledge and explore their feelings in private. This may be especially important when making decisions about how to look after the person with dementia. For example, if the person moves into residential care, the carer may need time to adjust and learn to accept that they now have less responsibility for them. Therapy can also help if a carer is feeling guilty or embarrassed about how they feel about the person with dementia.

Counselling can help carers to:

- **talk openly about their own emotions**, including any grief they are experiencing as the person's dementia progresses.
- **have an uninterrupted block of time to focus on themselves** rather than the person they are caring for.
The counsellor should help the carer to find strategies and approaches to support them in the caring role.
- **be more aware of their thoughts, behaviours and reactions** when dealing with the challenges and unpredictability of dementia. Finding ways to cope more effectively with difficult situations can help reduce tension and stress for both the carer and the person with dementia.

Telephone or online sessions of talking therapy may be more convenient for people who have caring responsibilities than face-to-face ones. Therapy through apps that allow video calls may also be available.

Computerised CBT (cCBT) packages for carers generally aren't specific to each individual. While it's very important that therapy is tailored to the individual and their circumstances, cCBT may still be helpful and should be considered if it is the only available option. For example, when a carer doesn't have much time available for therapy.

Caring for a person with dementia can also affect personal relationships. Therefore, partners may find relationship counselling or couples therapy helpful. Relate offers relationship counselling – see 'Other useful organisations' on page 22 for details.

Some carers find it very helpful to speak to professionals who specialise in dementia care, such as an Admiral Nurse (available in some parts of the UK but not everywhere). There is more information on Admiral Nurses on the Dementia UK website (see 'Other useful organisations' on page 22).

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What to look for in a therapist

It is important for anyone who is having therapy to feel comfortable with both the therapist and their approach. The relationship will depend on a number of factors, including the personalities of the person and the therapist. Find a type and style of therapy that works for the person and what they wish to achieve through therapy.

For both someone with dementia or a carer, it is likely to be most helpful to find a therapist who has experience or an understanding of the condition.

It is important to meet the therapist face to face (for sessions in person) or to speak to them on the telephone or via video call to have a chat to see whether they seem suitable. It may be necessary to speak to several therapists before the most suitable person is found.

Before committing to sessions, ask the therapist questions to ensure that they:

- **are accredited by the relevant professional body** (see ‘Other useful organisations’ on page 22) and abide by their professional code of ethics
- **have regular professional supervision** (a form of mentoring and reflecting on their process) to make sure their practice is safe and ethical
- **explain their approach**, confidentiality, fees (if applicable), length of sessions and responsibilities (theirs and the person who is having the therapy).

Once a therapist is found, if the therapy is not working or if the person is no longer connecting with the therapist, then there is no obligation to continue with the sessions. The person can find a new therapist at any time.

It is important to meet the therapist face to face (for sessions in person) or to speak to them on the telephone or via video call to have a chat to see whether they seem suitable.

How to find a therapist

Many GPs can give people details about therapists in the local area. Some GP surgeries also have talking therapy services based in their practices.

Many of the talking therapies for depression and anxiety mentioned in this factsheet are available through an NHS England programme called NHS Talking Therapies for Anxiety and Depression (previously known as ‘Improving Access to Psychological Therapies’). See ‘Other useful organisations’ on page 22.

A person’s GP can refer them to a local service, which will assess them and offer support. This could include signposting to relevant activities, self-help materials or psychological therapies. Some NHS Talking Therapies services also let people refer themselves without having to go through their GP.

Talking therapies that people access through the NHS are usually free of charge, although there can be a long waiting list.

Some local charities, faith groups and other organisations may also offer counselling or informal support services. A person’s GP or local social services department may have more information about this. Our dementia directory can also help to find local support services for people with dementia and carers — visit alzheimers.org.uk/dementiadirectory

Another option is to find a private therapist. A person’s friends and family members may be able to recommend a therapist they have had sessions with. Someone who has a lower income will generally be charged less than a person who can afford to pay the full rate. Try to ensure that any private therapist is accredited and a member of at least one of the organisations listed on page 22.

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Other useful organisations

British Association for Behavioural and Cognitive Psychotherapies (BABCP)
0330 320 0851
babcp@babcp.com
www.babcp.com

The BABCP can help people find an accredited CBT therapist. It can give them a list of CBT therapists in their local area.

British Association for Counselling and Psychotherapy (BACP)
01455 883300 (10am–4pm Monday–Friday)
bacp@bacp.co.uk
www.bacp.co.uk

The BACP represents counsellors and psychotherapists. It can give people information about counselling and psychotherapy services, including a list of counsellors and psychotherapists in their local area. It can also advise people about what to look for in a therapist.

British Psychological Society (BPS)
0116 254 9568
info@bps.org.uk
www.bps.org.uk

The BPS has a list of clinical and counselling psychologists who offer private therapy services.

Counselling Directory
0333 325 2500 (10am–4pm Monday–Friday)
www.counselling-directory.org.uk

The Counselling Directory website includes a searchable database of counsellors and psychotherapists who are members of a recognised professional organisation. It also has information about how talking therapies may help.

Dementia UK
0800 888 6678 (9am–9pm Monday–Friday, 9am–5pm Saturday–Sunday)
helpline@dementiauk.org
www.dementiauk.org

Dementia UK provides specialist dementia support for families through its Admiral Nurse service.

Health and Care Professions Council (HCPC)
www.hcpc-uk.org/check-the-register
www.hcpc-uk.org**Space for
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The HCPC keeps a register of health and care professionals who meet certain standards for their training, professional skills, behaviour and health. You can search the register to check whether a named psychologist is included, as well as make complaints about registered professionals.

Mental Health Foundation
020 7803 1100
www.mentalhealth.org.uk

Mental Health Foundation is a charity that promotes good mental health. It has information on a range of different areas and support.

Mind
0300 123 3393 (infoline, 9am–6pm Monday–Friday)
info@mind.org.uk
www.mind.org.uk

Mind is a charity that offers information and advice on all aspects of mental health. It provides a range of support services through local Mind associations.

NHS Talking Therapies
<https://www.england.nhs.uk/mental-health/adults/nhs-talking-therapies/>

NHS Talking Therapies for Anxiety and Depression (formerly known as Improving Access to Psychological therapies) is an NHS programme of services for therapies that are approved for depression and anxiety by the National Institute for Health and Care Excellence (NICE). It is only available in England. You can search for services in your area at <https://www.nhs.uk/service-search/mental-health/find-an-nhs-talking-therapies-service>

Relate
www.relate.org.uk

Relate offers relationship counselling for individuals, couples and families in England and Wales. It provides advice and support by phone, face-to-face and through its website. For Relate in Northern Ireland see www.relateni.org or call 028 9032 3454.

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Samaritans

www.samaritans.org

If you need someone to talk to, Samaritans will listen. They won't judge or tell you what to do. Call any time, day or night, or write in by email or letter.

Telephone: **116 123**

Email: jo@samaritans.org

Post: **Freepost SAMARITANS LETTERS**

Samaritans also provide free phone support in Welsh on 0808 164 0123, as well as a letter writing service in Welsh.

UK Council for Psychotherapy

020 7014 9955 (9am–5pm Monday–Friday)

www.psychotherapy.org.uk

The UK Council for Psychotherapy is a UK professional body for psychotherapists and counsellors. The website includes a searchable register of psychotherapists and psychotherapeutic counsellors.

Factsheet 444

Last reviewed: October 2023

Next review due: October 2026

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This factsheet has also been reviewed by people affected
by dementia.

To give feedback on this factsheet, or for a list of sources,
please email **publications@alzheimers.org.uk**

This publication contains information and general advice.
It should not be used as a substitute for personalised advice
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At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information about
Adjusting to caring for someone with dementia.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit alzheimers.org.uk

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit alzheimers.org.uk/donate



Together we are help & hope
for everyone living with dementia

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