

Managing anxiety and depression in a person living with dementia



When someone is diagnosed with dementia, they may go through a range of emotions – both immediately after the diagnosis and as their condition progresses. This is completely natural. But for some people, low mood and anxiety can become persistent and have a significant impact on their quality of life.

It is often assumed that people with dementia do not experience depression or anxiety but that is not the case, so if someone with the diagnosis is struggling with their mood, it is important they get support.

What is depression?

Depression is a state of low mood that lasts for weeks or months, rather than days, and that typically interferes with a person's daily life. Sometimes it has an obvious trigger – such as being diagnosed with a condition like dementia, work issues, bereavement or relationship stress – but there may be no obvious cause.

The psychological symptoms of depression include:

- persistent low mood or sadness
- feeling helpless or hopeless
- low self-esteem
- tearfulness
- · feelings of guilt
- irritability
- withdrawing from friends and family
- · loss of motivation
- difficulties with decision-making
- lack of enjoyment of life –
 including things that the person
 used to enjoy
- feeling anxious or worried
- · thoughts of self-harm
- · thoughts of suicide
- psychosis in some people (hallucinations, delusions, unusual thoughts)

Depression can also cause physical symptoms, including:

- sleep problems either struggling to sleep or sleeping too much
- slow speech and movement
- changes in appetite and weight – usually decreased, but sometimes increased
- · aches and pains

- constipation
- low energy
- low sex drive
- · changes in menstrual cycle

Doctors generally class depression as mild (some impact on daily life), moderate (a significant impact on daily life) or severe (coping with daily life feels almost impossible).

What is anxiety?

Anxiety is a feeling of fear or unease. It is a normal feeling for all of us to an extent, but it can become so intense that it gets in the way of everyday life.

Anxiety has psychological symptoms including:

- · feelings of restlessness
- a sense of dread or things being out of control
- constantly feeling 'on edge'
- · problems concentrating
- irritability

Physical symptoms may include:

- dizziness
- difficulty sleeping
- heart palpitations
- · tense or achy muscles

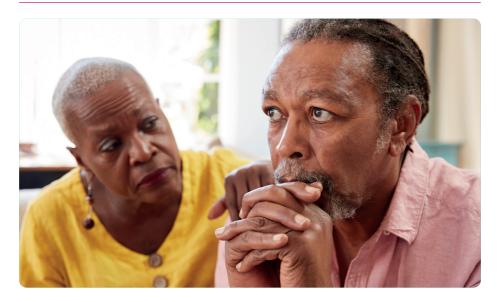
- trembling
- sweating
- stomach ache or nausea
- headaches
- pins and needles
- · shortness of breath
- panic attacks

As with depression, anxiety may have an obvious trigger such as health worries, relationship problems, work or financial stress or a phobia, but there may not be a clear reason for it. If feelings of anxiety are constant, not linked to a specific issue, and have an impact on daily life, it is known as generalised anxiety disorder (GAD).

Who does anxiety and depression affect?

Anxiety and depression can affect anyone, at any time. About 5% of people have GAD, and around 10% will experience depression during their lifetime.

Both anxiety and depression are slightly more common in women than men, and in people who have a family history of either condition.



The link between anxiety, depression and dementia

There are many reasons why a person with dementia or suspected dementia may experience anxiety or depression. These include:

- worries about symptoms such as confusion or memory loss, and what is happening to them
- fear of getting a dementia diagnosis and how it will affect their life
- receiving a dementia diagnosis
- the effects of dementia on their work, relationships, finances and social life
- worries about how dementia will affect them in the future

- worsening dementia symptoms
- becoming socially isolated
- lacking mental stimulation
- their needs not being met

Mood changes can also be a symptom of some forms of dementia, such as vascular dementia and Lewy body dementia – please see Sources of support on p10 for more information on types of dementia.

How do anxiety and depression affect a person with dementia?

People with dementia may have difficulty expressing in words that they are feeling anxious or depressed. However, there may be clues in their behaviour.

A person with dementia who is experiencing anxiety may pace up and down, fidget or become agitated. They might follow the person they live with around the house, seeking reassurance, and may feel the need to go to a place where they feel safe.

Many people with dementia also experience 'sundowning', which is a sense of intense confusion and anxiety in the evening. They have a strong feeling of being in the wrong place or time – for example, they may feel like they need to go home, even if they are already at home, or believe that it's time to go to work even if they are retired.

A person with dementia who is depressed may experience disturbed sleep or sleep considerably more. They might become very withdrawn, stop eating or eat excessively, and may experience physical pain. The person may seem to retreat into themselves and lose interest in everyone and everything. They may be tearful, irritable or intolerant of the people around them.

Because some of the symptoms of dementia are similar to those of anxiety and depression, the changes in someone's behaviour may initially be put down to these conditions, resulting in a delay in diagnosing dementia. For instance, poor concentration, changes in appetite, sleep disturbance and changes in mood and behaviour can sometimes be misdiagnosed as depression.

This can be a particular issue for people who develop dementia symptoms before the age of 65 (known as young onset dementia), as some healthcare professionals lack awareness of dementia in younger people and how it presents. The symptoms of dementia may also be mistaken for perimenopause/menopause, which can cause low mood, depression and anxiety.

Similarly, depression or anxiety may be overlooked in a person with dementia if the symptoms are put down to their dementia. Depression-related psychosis may also be missed, as symptoms such as hallucinations and delusions may occur in dementia – particularly Lewy body dementia.

Getting a diagnosis of anxiety or depression

Identifying anxiety and depression means the person with dementia can be treated and supported in the correct way. Untreated, these conditions can lead to further distress or deterioration in their health, including their dementia symptoms.

Alleviating anxiety or depression can:

- improve appetite
- promote good quality sleep
- increase motivation so the person feels able to take part in activities they enjoy
- help them to cope better at work, and improve their performance and workplace relationships
- enable them to engage with family members and friends
- make it easier for the family to support the person by making them more willing to be involved in everyday life
- improve the overall quality of life of the person and their family members

Many people wait a long time before seeing their GP about anxiety or depression, but if it is affecting someone's daily life, it is important to seek help.

It may be useful to take a selfassessment quiz first, and to keep a diary of symptoms, including what they are, when they happen (time and date), and whether there is any trigger. Please see Sources of support on p11 for details of the NHS selfassessment test for depression.

It is not always possible for a person affected by anxiety or depression to recognise the symptoms in themselves. This can be even more difficult for someone who also has dementia, so it is important for family members and friends to make a note of any changes they see.

It may also be helpful for a family member or friend to go to the appointment with the person to offer emotional support, help them communicate their concerns, and let the GP know of any symptoms or changes they have noticed.

The GP should ask the person about

their symptoms and:

- how they are affecting them mentally and physically
- how long they have had them
- how often they are happening
- if there are any reasons for the way they are feeling
- whether there is a family history of anxiety or depression

A GP can usually make a diagnosis of anxiety or depression based on what the person tells them. They may also take blood tests to rule out certain conditions that may cause similar symptoms, such as thyroid problems or a vitamin deficiency.

Treating anxiety or depression

If depression or anxiety are diagnosed, the doctor may suggest 'watchful waiting' for around two weeks to see if the symptoms improve naturally.

If the symptoms persist, there are several different treatments that may be effective, although people in the mid- to later stages of dementia may find it hard to engage with them.

Exercise: this is proven to release stress and tension and trigger the production of hormones called endorphins, which improve mood.

Relaxation exercises: these could include guided meditation using videos, music or apps; breathing exercises; or yoga, Pilates or Tai Chi.

Diet: there is evidence that mental health can be affected by what we eat, so it is important to eat a healthy diet with regular, balanced meals. Please see Sources of support on p11 for information from the Association of UK Dietitians (BDA).

Talking therapy: this can be helpful if the person has tried self-help measures but their symptoms have not improved. The most common types of therapy are:

- cognitive behavioural therapy (CBT): this helps to change the ways someone thinks and acts, breaking the pattern of negative thoughts. It may be offered oneto-one, in a group or online
- counselling: this helps the person explore the problems they are having and ways to manage them. It tends to be more

helpful if the person's anxiety or depression have a particular trigger – which may include a dementia diagnosis

The person may be referred for NHS talking therapy by their GP or can refer themselves – please see Sources of support on p1o for details.

There may be a long wait for NHS therapy, so some people decide to see a private therapist. Make sure that the therapist is registered with a professional body – please see Sources of support on p11.

Mindfulness: the practice of paying close attention to the present moment, including your thoughts, feelings and the world around you, which can improve mental wellbeing. Mindfulness therapy may be carried out in person (one-to-one or in a group), online or using apps or workbooks.

Alternative therapies: some people find that complementary therapies like acupuncture or reflexology or herbal remedies such as St John's wort help with anxiety or depression, but it is advisable to speak to the person's GP before

they try these.

Medication: for some people, medication may help with anxiety or depression. There are various types, with antidepressants being the most commonly prescribed in the first instance. Antidepressants may also be prescribed for the symptoms of frontotemporal dementia. Medication is often offered alongside talking therapies.

Supporting a person with dementia who has anxiety or depression

If a person with dementia is experiencing anxiety or depression, your support can help them manage their symptoms and improve their wellbeing. These tips might help:

- Support the person to exercise
- ideally five days a week, for 30
minutes a day. If they like to run
or cycle but are vulnerable if they
go out alone, consider whether
you or someone else could be
their exercise buddy. If they
have mobility problems, they
may be able to do chair-based
exercises or simple stretching.
Everyday tasks like housework

- and gardening also count
- If the person drinks alcohol, encourage them to drink only in moderation, as alcohol can lower mood. Consider alternatives such as alcohol-free beer or wine or mocktails
- Help the person with planning and preparing healthy meals as both dementia and mental health problems can affect appetite and weight
- Encourage them to limit caffeine in drinks like tea, coffee and cola, especially in the evening – too much caffeine can worsen anxiety and disturb sleep
- Try to spend time with the person, even if they are withdrawing from social contact, and ask other family members or friends to do the same, as being lonely and isolated can worsen depression and anxiety
- Look into mental health or dementia support groups, in person or online – connecting with others in a similar situation can be a great source of support
- If the person is given medication for depression or anxiety, support them to take it

- as prescribed pill organisers, wall charts or reminders on their phone or smart speaker can be useful
- Spend time reminiscing about happy experiences or occasions in their life. You can use props like photos, videos, treasured objects or meaningful music.
 See Sources of support on plo for information on creating a 'life story' record for a person with dementia
- Help the person engage in activities that bring comfort and enjoyment, such as walking, volunteering, singing, dancing, gardening, art, music etc
- If the person is still working, encourage them to inform their manager about their depression or anxiety so support can be given in the workplace
- If the person is self-harming or showing signs of being suicidal, contact their GP as soon as possible. If you are concerned that they are at imminent risk of harming themselves or they have done so already, take them to A&E or call 999 for an ambulance

Sources of support

To speak to a dementia specialist Admiral Nurse about depression, anxiety or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit **dementiauk.org/closer-to-home**

Dementia UK resources

Types of dementia dementiauk.org/types-of-dementia

Getting the most out of GP and other health appointments dementiauk.org/gp-and-health-appointments

Getting the most out of a remote consultation dementiauk.org/remote-consultation

The emotional impact of a dementia diagnosis dementiauk.org/emotional-impact-of-the-diagnosis

Dementia and sleep dementiauk.org/good-habitsfor-bedtime Staying healthy with dementia dementiauk.org/ staying-healthy

Creating a life story for a person with dementia dementiauk.org/creating-a-life-story

Sundowning dementiauk.org/sundowning

Other resources

NHS talking therapies nhs.uk/mental-health/ talking-therapies-medicinetreatments/talking-therapiesand-counselling/nhs-talkingtherapies

Find an NHS psychological therapies service (IAPT) nhs.uk/service-search/mentalhealth/find-a-psychologicaltherapies-service NHS depression and anxiety self-assessment quiz nhs.uk/mental-health/ self-help/guides-tools-and-activities/depression-anxiety-self-assessment-quiz

NHS alcohol advice nhs.uk/live-well/ alcohol-advice

Mental health support groups and services

Mental Health Foundation mentalhealth.org.uk

Mind (including local support services such as counselling and support groups) mind.org.uk

Rethink Mental Illness rethink.org

Samaritans
24-hour helpline: 116 123
samaritans.org

Relate relationship counselling relate.org.uk

Papyrus (suicide prevention for under 35s) Helpline 0800 068 4141 (gam-midnight every day)

papyrus-uk.org

Every Mind Matters nhs.uk/every-mind-matters

Cruse bereavement support cruse.org.uk

BDA depression and diet fact sheet bda.uk.com/resource/depression-diet.html

Professional bodies for finding registered therapists and counsellors

Counselling Directory counselling-directory.org.uk

British Association for Counselling and Psychotherapy itsgoodtotalk.org.uk/ therapists

British Association for Behavioural and Cognitive Psychotherapies (CBT) cbtregisteruk.com

British Psychological Society bps.org.uk/find-psychologist

UK Council for Psychotherapy psychotherapy.org.uk/find-a-therapist

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support

Dementia UK, please visit

dementiauk.org/donate
or call 0300 365 5500.

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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email **helpline@dementiauk.org**

Open Monday-Friday, 9am-9pm Saturday and Sunday, 9am-5pm



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