

Young onset dementia: different symptoms



Dementia is often associated with old age, but it can also occur in younger people. When it develops in people under the age of 65, it is known as ‘young onset dementia’. Over 70,000 people in the UK are estimated to be living with the condition.

Younger people with dementia may experience different symptoms from people who develop the condition later in life. This may make it harder to tell if someone has dementia, and to get an accurate diagnosis.

Symptoms of young onset dementia

The symptoms of dementia differ from person to person, depending on the type of dementia and which parts of the brain it affects. Memory issues are one of the most recognisable symptoms of dementia, and include:

- forgetting conversations and future plans
- becoming repetitive
- getting lost in familiar places
- being unsure of the day or date
- forgetting names and faces

However, these changes may not be obvious in the early stages for younger people, and as a result, the signs of dementia may be missed or mistakenly attributed to other conditions.

More commonly, people with young onset dementia experience early changes in:

- behaviour and personality
- language and communication



- movement and coordination
- social and life skills
- vision and spatial awareness

Changes in behaviour and personality

Dementia causes changes in a person's behaviour and personality. These changes are especially common if there is damage to the frontal and temporal lobes of the brain – for example in frontotemporal dementia, which is a common form of dementia in younger people (please see Sources of support on p12 for more information). Symptoms and changes may include:

Emotional changes

- reduced empathy and emotional engagement, eg the person being unable to express their emotions and read those of others

4 Dementia UK

- lack of awareness of the emotional changes they are showing
- becoming irritable or anxious, sometimes without an apparent cause
- becoming withdrawn, suspicious of the intentions of others or paranoid
- mood changes, eg becoming depressed
- inability to take an overview of a situation
- becoming isolated and less engaged with family life

Personality

- irrational and out of character decision-making
- being secretive or unable to account for themselves or how they have spent their time
- developing new habits or activities that are out of character
- change in sense of humour
- inappropriate comments, eg commenting negatively on someone's appearance; making suggestive remarks
- difficulties coping with change, eg new systems at work, different routines, going on holiday

Behaviour

- apathy or lack of energy
- behaving in a 'jittery' way
- obsessive, compulsive or impulsive behaviour
- changes in libido or sexual disinhibition, eg using inappropriate

language; touching themselves in public; exposing themselves to others

- becoming verbally or physically aggressive
- decline in personal routines and hygiene standards

If a person shows several of these changes, which become more noticeable over time without any clear indication of why they may be happening, it is important for them to see a GP to identify any possible causes and to discuss next steps. These changes may be due to potentially treatable conditions but may also indicate that the person could be developing young onset dementia.

Changes in behaviour and personality in someone with young onset dementia will increase over time, but the person may be unaware of these changes and their consequences. This can be difficult for family members, friends and colleagues to cope with – particularly children, if their parent has changed in ways that cause them embarrassment or make them feel rejected or less loved than before.

To prevent or manage difficult scenarios, it is helpful to think about possible triggers. For example, you may be able to avoid places, situations or people that prompt the person to behave in an inappropriate way.

Sometimes agitated or aggressive behaviour is caused by the person feeling unwell, in pain or unable to express themselves clearly. However, whatever the cause of this behaviour, it is important to ask for help and support if any situation becomes unmanageable or unsafe.

Changes in language and communication

Difficulties with language or speech, known as aphasia, may occur in all forms of dementia. It can be caused by changes in the blood

flow in the brain, eg after a stroke or transient ischaemic attack (TIA), sometimes known as a ‘mini stroke’, or by damage to the brain cells, for example in frontotemporal dementia or primary progressive aphasia.

Signs of aphasia include:

- word-finding difficulties – speaking less fluently; reduced vocabulary
- laboured, hesitant speech – not being able to get the right word out
- vague or overly detailed speech – failing to get to the point; using the wrong words for objects
- slurred speech
- reduced communication – writing, reading or speaking less
- avoiding correspondence such as emails, post or answering the phone
- changes in handwriting – becoming difficult to decipher; writing more slowly

These changes are often first recognised by work colleagues, but they may attribute them to a cause other than dementia.

Communication difficulties can lead to a lack of confidence, connection and interaction with others, so it is important that family, friends and work colleagues are aware of this so the person can be well supported. See Sources of support on p14 for details of our Tips for better communication leaflet.

Speech and language therapy may help to improve a person’s speech or help them and their family find new ways to communicate. The



GP can make a referral, or you can look for a therapist in your area through the Association of Speech and Language Therapists in Independent Practice: please see Sources of support on p14.

Using smartphones, tablets and virtual assistant devices such as an Alexa to call or message friends and family can be useful in the early- to mid-stages of dementia. Assistive technology and apps such as ReadClear, Proloquo2Go and React2 may help the person to read and communicate – see Sources of support on p15 for more information.

Changes in movement and coordination

Over time, dementia may lead to changes in a person's movement and physical skills – particularly in Lewy body dementia and Parkinson's. Common symptoms include:

- changes in gait – shuffling; slower walking speed; shorter strides
- issues with balance – falling, tripping
- clumsiness – bumping into things

- involuntary movement such as hand tremors or fixed eye movements
- loss of dexterity and mobility
- difficulty judging distances, eg when walking down steps or getting on or off an escalator

Younger people with dementia may be physically fit and active. Activities such as walking, running, swimming, cycling or gentler exercise such as Pilates or yoga can help to maintain or improve a person's movement by building their core strength, flexibility and balance.

If a person with dementia is unable to exercise alone, look for a local class or group or ask if a friend or family member can accompany them as their exercise buddy. GPs and social prescribers may refer them to a local gym or leisure centre for an assessment and fitness programme to help maintain their strength and fitness levels.

Physiotherapy may also be useful. You can ask the GP to make a referral or find a local physiotherapist through the Chartered Society of Physiotherapists' website – please see Sources of support on p14.

Making adaptations to the home can make it easier for a person with young onset dementia to move around more safely. You can request a needs assessment via social services to look at equipment and adaptations to make daily living easier. An occupational therapist can also offer advice on this. For more information, please see Sources of support on p13 and p15.

Changes in social and life skills

Over time, dementia will cause a general decline in a person's social and life skills, including:

- problems with literacy, numeracy and other basic skills, eg telling the time; dealing with money; getting dressed; preparing meals
- struggling to complete tasks or meet deadlines at work
- a deterioration in driving ability
- being unable to plan ahead
- impaired judgement, including making unsafe or inappropriate decisions
- being unable to recall things, regardless of their significance
- becoming less willing to socialise or go out

It is important that a person with dementia is helped to maintain their work and social life, carry out everyday tasks and remain independent for as long as possible. Simple adjustments sometimes make a big difference, for example:

- using assistive technology such as a smartphone or speaker (eg Alexa) to set alarms and reminders for appointments, taking medication etc
- shopping using a contactless debit card rather than cash
- listening to audio books and podcasts if reading becomes difficult

If the person works, adjustments in the workplace can make things easier and enable them to continue to work for longer. For more information about dementia at work, see Sources of support on p12.

Changes in visual perception and spatial awareness

Changes in visual perception and spatial awareness are particularly common in some types of dementia, including posterior cortical atrophy (PCA) and Lewy body dementia. These changes are often not related to the eye itself, but to the brain's interpretation of what the eye sees. The person may make repeated visits to the optician but find nothing wrong.

Common symptoms include:

- issues with perception and spatial awareness – mis-reaching for objects in clear view; difficulty perceiving depth and volume
- hallucinations, particularly in Lewy body dementia
- words appearing to float off the page when reading
- difficulties seeing what things are and where
- problems judging distances or seeing objects, particularly when driving

There are steps you can take to help reduce the impact of these symptoms in the home. For more information, see Sources of support on p13.

It is also important for the person with dementia to have regular eye tests, and to wear their prescription glasses if required. It is helpful to have a spare pair in case their usual pair is misplaced or broken.

Preparing for the future

The symptoms of dementia will change and the person's abilities will deteriorate over time. This will lead to changes in your relationship with them. You can prepare for the future by reading up about their particular type of dementia and being aware of possible symptoms and scenarios that may occur.

Sharing the news of the person's dementia diagnosis and the way it affects them with family members, friends, work colleagues and neighbours can help them be more understanding and offer support.

If the person has children, it is important to speak to them in an age-appropriate way about the diagnosis, how the symptoms are affecting their parent and what might happen in the future. While these conversations can be difficult, being open and honest with the child will help avoid misunderstandings and create a sense of openness so they can share any questions or fears. Please see Sources of support on p13 for information on supporting children and adolescents when a parent has young onset dementia.

In some cases, prescription medication such as antidepressants may be beneficial. You can ask the person's GP about this but bear in mind that dementia is a progressive condition – medication may help with some of the symptoms, but it is not a cure and will not prevent further deterioration.

If you have been diagnosed with dementia yourself, it is natural to be fearful about how your condition will affect you in the future. Your symptoms will change and your abilities will decline over time, so it is important that you are well supported. Using the Sunflower lanyard and ID cards when out and about could help you indicate to others that you have a hidden condition and may need assistance – please see Sources of support on p15.

Changes in symptoms or new symptoms are a normal part of the progression of dementia, but if you have any concerns or need support, please speak to your GP or specialist, or contact our specialist dementia nurses – see Sources of support on p12.

Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, ‘Dementia: what next?’ at ➤ dementiauk.org/dementia-what-next

To speak to a dementia specialist Admiral Nurse, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email ➤ helpline@dementiauk.org

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit ➤ dementiauk.org/book

Dementia UK resources

Young onset dementia section

➤ dementiauk.org/young-onset-dementia

Changes in perception

➤ dementiauk.org/changes-in-perception

Dementia at work

➤ dementiauk.org/information-and-support/dementia-at-work

Find support: database of young onset dementia groups and services

➤ dementiauk.org/find-support

Frontotemporal dementia

➤ dementiauk.org/frontotemporal-dementia

Lewy body dementia

➤ dementiauk.org/dementia-with-lewy-bodies



Living aids and assistive technology

➤ dementiauk.org/living-aids-and-assistive-technology

Making the home safe and comfortable

➤ dementiauk.org/making-the-home-safe-and-comfortable

Managing anxiety and depression in dementia

➤ dementiauk.org/managing-anxiety

Posterior cortical atrophy (PCA)

➤ dementiauk.org/posterior-cortical-atrophy-pca

Staying healthy

➤ dementiauk.org/staying-healthy

Supporting children and adolescents when a parent has young onset dementia

➤ dementiauk.org/supporting-children

Tips for better communication

➤ dementiauk.org/tips-for-better-communication

What are the symptoms of dementia?

➤ dementiauk.org/symptoms-of-dementia

Understanding frontotemporal dementia

➤ dementiauk.org/frontotemporal-dementia

Young onset dementia: next steps after diagnosis

➤ dementiauk.org/young-onset-dementia/next-steps

Other resources

AssistiveWare: augmentative and assistive communication products and apps

➤ assistiveware.com

Association of Speech and Language Therapists in Independent Practice: search for a speech and language therapist

➤ asltip.com/find-a-speech-therapist

Chartered Society of Physiotherapists: search for a physiotherapist

➤ csp.org.uk/public-patient/find-physiotherapist

Dementia Carers Count: support courses for people caring for someone with dementia

➤ dementiacarers.org.uk

Dyscover: long-term support and opportunities for people with aphasia and their families

➤ dyscover.org.uk

Getting a care needs assessment

➤ nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment/

Occupational therapy

➤ nhs.uk/conditions/occupational-therapy

Physiotherapy

➤ nhs.uk/conditions/physiotherapy

Proloquo2Go assistive communication app for non-verbal people

➤ assistiveware.com/products/proloquo2go

Rare Dementia Support

➤ raredementiasupport.org

ReadClear app: reading app for people with brain-related visual impairment

➤ makingreadingreal.org

React2 app: speech and language therapy app

➤ react2.com/home-users

Sunflower lanyard

➤ hiddendisabilitiesstore.com

tide – together in dementia everyday: online groups including a monthly young onset dementia carers' group

➤ tide.uk.net

Young Dementia Network ID cards for the person with young onset dementia and their supporters

➤ youngdementianetwork.org/id-cards

**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:

0800 888 6678 or ➔ **helpline@dementiauk.org**

Book a virtual appointment:

➔ **dementiauk.org/book**

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit ➔ **dementiauk.org/donate**
- Scan the QR code

Thank you.



dementiauk.org • info@dementiauk.org

Publication date: May 2025. Review date: May 2028. © Dementia UK 2025

Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC 047429).