



**DementiaUK**  
Helping families face dementia

## 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’. Around 70,800 people in the UK are estimated to be living with the condition.

We have created this leaflet to help you recognise the ways younger people with dementia may experience symptoms and share ideas and resources that may help with managing them.

### 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 to 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 (please see Sources of support on p10 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

- lack of awareness of the emotional changes observed by others
- 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- becoming withdrawn, suspicious of the intentions of others or paranoid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 a lack of filter when speaking to others
- difficulties coping with change, eg new systems at work, different routines, going on holiday

### **Behaviour**

- apathy or lack of energy
- behaving in a 'jittery' fashion
- 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 without any clear indication of why they may be happening, it is important for them to see a GP to identify any potential cause and to discuss on 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), 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 over-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 p10 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. Your 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: visit [asltip.com/find-a-speech-therapist](https://www.asltip.com/find-a-speech-therapist)

Using smart phones, 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 p11 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 disease. 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 can also be useful. To search for a local physiotherapist, visit the Chartered Society of Physiotherapists' website at [csp.org.uk/public-patient/find-physiotherapist](https://www.csp.org.uk/public-patient/find-physiotherapist) or ask your GP to make a referral.

Making adaptations to the home can make it easier for a person with young onset dementia to move around more safely. An occupational therapist can

offer advice on this, or for more information about making a home safe and comfortable for a person with dementia, see Sources of support on p10.

## 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 employment and young onset dementia, see Sources of support on p10.

### 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 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 p10 for details of our Making a home safe and comfortable for a person with dementia leaflet.



It is also important for the person with dementia to have regular eye tests, and to wear their prescription glasses as 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 and the way it affects them with family members, friends, work colleagues and neighbours can help them be more understanding and offer support.

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 decline over time, so it is important that you are well supported. Using the Sunflower lanyard and ID cards when out and about may help you indicate to others that you have a hidden condition and may need assistance.

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 p10.

## Sources of support

To speak to a specialist dementia nurse about the different symptoms of young onset dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

To book a phone or video call appointment with an Admiral Nurse, please visit [dementiauk.org/book-a-clinic-appointment](https://dementiauk.org/book-a-clinic-appointment)

### Dementia UK resources

**Young onset dementia section**  
[dementiauk.org/young-onset-dementia](https://dementiauk.org/young-onset-dementia)

**Changes in perception**  
[dementiauk.org/changes-in-perception](https://dementiauk.org/changes-in-perception)

**Employment and young onset dementia**  
[dementiauk.org/employment-and-young-onset-dementia](https://dementiauk.org/employment-and-young-onset-dementia)

**Lewy body dementia**  
[dementiauk.org/dementia-with-lewy-bodies](https://dementiauk.org/dementia-with-lewy-bodies)

**Making a home safe and comfortable**  
[dementiauk.org/making-home-safe-and-comfortable](https://dementiauk.org/making-home-safe-and-comfortable)

**Managing anxiety and depression in dementia**  
[dementiauk.org/managing-anxiety](https://dementiauk.org/managing-anxiety)

**Staying healthy**  
[dementiauk.org/staying-healthy](https://dementiauk.org/staying-healthy)

**Tips for better communication**  
[dementiauk.org/tips-for-better-communication](https://dementiauk.org/tips-for-better-communication)

**What are the symptoms of dementia?**  
[dementiauk.org/symptoms-of-dementia](https://dementiauk.org/symptoms-of-dementia)

**Understanding frontotemporal dementia**  
[dementiauk.org/frontotemporal-dementia](https://dementiauk.org/frontotemporal-dementia)

**Young onset dementia: next steps after diagnosis**  
[dementiauk.org/young-onset-dementia/next-steps](https://dementiauk.org/young-onset-dementia/next-steps)

## Other resources

### AssistiveWare

Augmentative and assistive communication products and apps

[assistiveware.com](https://www.assistiveware.com)

### Association of Speech and Language Therapists in Independent Practice

Search for a speech and language therapist

[asltip.com/find-a-speech-therapist](https://www.asltip.com/find-a-speech-therapist)

### Chartered Society of Physiotherapists

Search for a physiotherapist

[csp.org.uk/public-patient/find-physiotherapist](https://www.csp.org.uk/public-patient/find-physiotherapist)

### Dementia Carers Count

Support courses for people caring for someone with dementia

[dementiacarers.org.uk](https://www.dementiacarers.org.uk)

### Dyscover

Long-term support and opportunities for people with aphasia and their families

[dyscover.org.uk](https://www.dyscover.org.uk)

### Rare Dementia Support

[raredementiasupport.org](https://www.raredementiasupport.org)

### ReadClear app

Reading app for people with brain-related visual impairment

[makingreadingreal.org/en-gb](https://www.makingreadingreal.org/en-gb)

### React2 app

Speech and language therapy app

[react2.com/home-users](https://www.react2.com/home-users)

### Sunflower lanyard

Can be purchased online

[hiddendisabilitiesstore.com](https://www.hiddendisabilitiesstore.com)

### Talking sense: living with sensory changes and dementia

A book by Agnes Houston MBE and Julie Christie

[hammond.com.au/resource-hub/talking-sense-living-with-sensory-changes-and-dementia-by-agnes-houston](https://www.hammond.com.au/resource-hub/talking-sense-living-with-sensory-changes-and-dementia-by-agnes-houston)

### tide – together in dementia everyday

Online groups including a monthly young onset dementia carers' group

[tide.uk.net](https://www.tide.uk.net)

### Young Dementia Network

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

[youngdementianetwork.org/id-cards](https://www.youngdementianetwork.org/id-cards)

The information in this leaflet is written and reviewed by dementia specialist Admiral Nurses. We hope you find it useful. If you have feedback, please email [feedback@dementiauk.org](mailto:feedback@dementiauk.org)

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To donate: call **0300 365 5500**,  
visit [dementiauk.org/donate-to-support](https://dementiauk.org/donate-to-support)  
or scan the QR code.

Thank you.



If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses.  
Helpline: **0800 888 6678** or [helpline@dementiauk.org](mailto:helpline@dementiauk.org)  
Virtual clinics: [dementiauk.org/book-an-appointment](https://dementiauk.org/book-an-appointment)



[dementiauk.org](https://dementiauk.org) • [info@dementiauk.org](mailto:info@dementiauk.org)

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