

Understanding young onset dementia



Dementia is an umbrella term for a range of progressive conditions that affect the brain. It damages the nerve cells that communicate with each other, so messages cannot pass between them effectively. This prevents the brain from functioning normally.

Dementia is described as ‘young onset’ when symptoms develop before the age of 65. People from Black and other minority ethnic groups are at greater risk of developing young onset dementia, as are people with a learning disability.

Common types of young onset dementia

There are over 200 subtypes of dementia. The most common forms of dementia in younger people are:

- Alzheimer’s disease
- vascular dementia
- frontotemporal dementia
- alcohol-related brain damage or alcohol-related brain injury
- dementia with Lewy bodies

Around 20% of younger people with dementia have a rarer form of the condition, such as posterior cortical atrophy or primary progressive aphasia. There are also other conditions that can lead to dementia such as Parkinson’s and Huntington’s disease.

Younger people are more likely to have an inherited form of dementia caused by genetic mutations. The most common is familial frontotemporal dementia, which accounts for 30-40% of all cases of frontotemporal dementia and often affects many members of the family.

Other types of inherited dementia are familial Alzheimer’s disease



and CADASIL (a rare form of vascular dementia), but these are very rare: fewer than 1% of people with Alzheimer's disease have the familial form, and CADASIL affects around 1,000 people in the UK.

For more information on types of dementia, including familial dementias, please see Sources of support on p14.

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. People often associate it with memory loss, but this is less likely to be an early symptom of young onset dementia. As a result, the signs of dementia may be missed or mistakenly attributed to other conditions.

Early symptoms of dementia in younger people may include changes in:

- personality and behaviour
- speech and language

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- vision and balance
- social functioning
- relationships with others
- involvement in daily activities
- motivation and mood eg depression, anxiety
- concentration levels
- decision-making and problem-solving

Getting a diagnosis

Whatever their age, if someone is showing signs of dementia, it is important that they visit the GP as soon as possible. There are many other conditions that have similar symptoms, such as infections, thyroid problems, stress, depression, perimenopause/menopause and dietary deficiencies. These may be treatable, so the GP may request investigations such as blood tests and X-rays to check for any underlying conditions.

Once the GP has ruled out other causes, they may refer the person for further investigation and assessment. This may be with a specialist memory service, or a cognitive disorders or neurology clinic. It is a good idea for a family member or friend to go to the assessment with them if possible.

At this stage, the health professional should take a detailed medical and family history, including asking about the issues that are causing concern, and conduct a cognitive assessment. This will assess:

- concentration
- short-term memory

- difficulties with language, word-finding and comprehension
- mood and behaviour changes

After a diagnosis

If someone is diagnosed with dementia before the age of 65, they should be told which type of dementia they have, what the symptoms are, and how it might progress. They should be referred for further assessments and interventions that may help. The person and their family should also be told about any specialist advice and support services, locally and nationally.

A diagnosis of dementia at a younger age can be very difficult to accept. It is natural for the person to experience a range of feelings including anger, grief, depression or anxiety. Family members may be affected by similar emotions. For support, please contact our dementia specialist Admiral Nurses – see Sources of support on p13.

Medication for dementia

At the moment, there is no cure for dementia, but some people may be prescribed medication. These medications do not stop the progression of dementia, but they may reduce the symptoms. However, some people find that they make no difference, or that the side effects are intolerable.

There are currently four main medications that are used for dementia: donepezil, galantamine, memantine and rivastigmine. These are usually used for Alzheimer's disease, but are sometimes prescribed for people with mixed dementia, dementia with Lewy bodies and Parkinson's disease dementia. They are not suitable for people with frontotemporal dementia as they can make the symptoms worse.

For some people with frontotemporal dementia, antidepressants called selective serotonin reuptake inhibitors (SSRIs) may be prescribed to help control loss of inhibitions, overeating and compulsive behaviours.

People living with vascular dementia – which is linked to problems affecting the blood supply to the brain, for example, strokes and ‘mini strokes’ – may be prescribed medication to reduce the risk of further damage to the cells in the brain, such as medication for high blood pressure or high cholesterol.

Relationships with family and friends

Relationships with family and friends can be affected by the changes brought on by the person’s dementia. For example, some types of dementia affect how people experience emotions, which could cause distress for the person with the diagnosis and those around them – eg if they become angry more easily than they used to.

The person may also find it difficult to talk about having young onset dementia. However, sharing the diagnosis can help friends and family understand the condition and offer support.

People with young onset dementia may have children to care for. Explaining dementia to children and teenagers can be difficult, but it is important to talk to them openly and share information that is clear and easy to understand. It is also a good idea to inform their school, as they may be able to provide additional support. Please see Sources of support on p14 for our resources for children and teenagers.

Employment

Younger people are more likely to be working when they are diagnosed with dementia – and depending on their age at the time of diagnosis and their expected retirement date, it may eventually affect their ability to remain in employment.



Dementia is classified as a disability in the Equality Act 2010 in England, Wales and Scotland, and in the Disability Discrimination Act 1995 in Northern Ireland. This means people with dementia are legally protected from discrimination, including being pressured to take early retirement or facing formal dismissal due to their diagnosis.

When a person is diagnosed with dementia, it is advisable to let their employer know as soon as possible. Reasonable adjustments can then be made as and when necessary to allow them to continue in their employment for as long as they are able or wish to.

Some occupations legally require a person with dementia to disclose their diagnosis. These include the armed forces, healthcare professions, and jobs that involve operating dangerous machinery or driving.

If the person is struggling with work, taking early retirement could be an option – although their employer must not put them under pressure to do this. If they have a company or private pension, they should seek advice from the employer or pension provider on how retiring early will affect them.

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If you support someone with young onset dementia, consider telling your own employer in case you need accommodations such as flexible working, unscheduled time off, or emotional support. Please see Sources of support on p13 for information on employment and young onset dementia.

Financial benefits

Many people with young onset dementia have financial commitments such as a mortgage/rent, credit card bills and loans, and it is natural to worry about how they will meet those commitments as their condition progresses. However, they may qualify for benefits including:

- Personal Independence Payment (PIP)
- Adult Disability Payment (Scotland)
- Child Tax Credit
- Council Tax Reduction
- Employment and Support Allowance (ESA)
- Personal Health Budget (NHS)
- Statutory Sick Pay (SSP)
- Universal Credit
- NHS continuing healthcare funding (CHC)

You can find information on benefits at [gov.uk/browse/benefits](https://www.gov.uk/browse/benefits), and in our information on finance and young onset dementia: please see Sources of support on p13 for details.

Driving

When someone is diagnosed with dementia, they are legally



required to tell the Driver and Vehicle Licensing Agency (DVLA) or, in Northern Ireland, the Driver and Vehicle Agency (DVA). It does not automatically mean they will have to give up driving straight away, although this is a possibility.

The DVLA will send the person a questionnaire and may ask their GP or specialist for further information. They may ask the person to have a health check and/or take a driving assessment.

There are four possible outcomes:

- Their driving licence is renewed
- They are issued with a shorter licence, for one, two, three or five years
- They need to adapt their car by fitting special controls (this is more likely for physical disabilities rather than dementia)
- They must stop driving and give up their licence – it is possible to appeal

The person must also notify their insurance company.

Giving up driving can be very upsetting. It can cause frustration, a sense of loss, and a loss of independence. Driving Mobility Centres provide 'driver retirement support' for people who have stopped driving, helping them manage this difficult time and giving advice on other transport options. Please see Sources of support on p13 for details of our information on driving and dementia.

Keeping healthy

To help a person with dementia remain physically and mentally healthy for as long as possible, you could encourage them to:

- take regular physical exercise – this improves health and mood, and may slow down further deterioration
- drink plenty of water and other fluids to prevent dehydration, which can lead to confusion
- stop smoking – this improves circulation to the brain
- limit consumption of alcohol or avoid it altogether
- stay mentally active by continuing with activities they enjoy, or taking up a new hobby or activity
- establish good sleep habits that help them settle at bedtime and sleep through the night

Connecting with others

Staying socially active helps to keep people connected to others and maintain brain activity, so it is important for people with young onset dementia to avoid becoming isolated. Relationships are also vital sources of support and can help them get the most out of life.

Connecting with other people with young onset dementia can be



very helpful. The Dementia UK website has a database where you can search for young onset dementia support groups: please see Sources of support on p13.

Taking part in groups and activities that are not specifically for people with dementia – such as singing, walking, cycling, craft and gardening groups – can also provide a valuable source of connection and interest and give the person a sense of identity beyond their diagnosis.

Planning future care

When a person is diagnosed with dementia, it is important to discuss their future care needs and wishes. This can be upsetting but planning ahead will help them, and their family and friends, to prepare.

One way to do this is to write an advance care plan which sets out the person's wishes for future treatment and care. By doing this in the early stages of dementia, they can have an input into how they will be cared for later.



It is very important for the person to complete a lasting power of attorney (LPA) as soon as possible. This is a legal document that lets them appoint someone to make financial, health and care decisions on their behalf if they are no longer able to do so. This may seem a distant prospect, but dementia is unpredictable and some people deteriorate quickly.

For more information on advance care plans and LPA, please see details of our Finance and young onset dementia leaflet in Sources of support on p14.

In addition, the person should be encouraged to make a Will to ensure their wishes are respected after their death.

Sources of support

To speak to a dementia specialist Admiral Nurse about young onset dementia 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](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video appointment at a time to suit you at [▶ dementiauk.org/book](https://dementiauk.org/book)

Dementia UK resources

Young onset dementia section

[▶ dementiauk.org/young-onset-dementia](https://dementiauk.org/young-onset-dementia)

After a diagnosis of young onset dementia: next steps

[▶ dementiauk.org/young-onset-dementia-next-steps](https://dementiauk.org/young-onset-dementia-next-steps)

Different symptoms of young onset dementia

[▶ dementiauk.org/young-onset-dementia-different-symptoms](https://dementiauk.org/young-onset-dementia-different-symptoms)

Driving and dementia

[▶ dementiauk.org/driving-and-dementia](https://dementiauk.org/driving-and-dementia)

Employment and young onset dementia

[▶ dementiauk.org/employment-young-onset-dementia](https://dementiauk.org/employment-young-onset-dementia)

Finance and young onset dementia

[▶ dementiauk.org/finance-and-young-onset-dementia](https://dementiauk.org/finance-and-young-onset-dementia)

Find young onset dementia support groups and services

[▶ dementiauk.org/find-support](https://dementiauk.org/find-support)

Genetic forms of dementia (familial dementia)

➤ dementiauk.org/genetic-familial-forms-of-dementia

Getting a diagnosis of young onset dementia

➤ dementiauk.org/young-onset-dementia-getting-a-diagnosis

Perimenopause, menopause and young onset dementia

➤ dementiauk.org/perimenopause-and-menopause

Supporting children and adolescents when a parent has young onset dementia

➤ dementiauk.org/supporting-children-young-onset-dementia

Types of dementia

➤ dementiauk.org/types-of-dementia

Useful organisations

Dementia Carers Count

Free support courses for family and friends caring for someone with dementia, including young onset dementia

➤ dementiacarers.org.uk

DEEP

A network of around 80 groups connecting people with dementia

➤ dementiavoices.org.uk

Rare Dementia Support

Specialist information and support about rare dementias

➤ raredementiasupport.org

tide - together in dementia everyday

Information and support for family members, including a young onset dementia carers group

➤ tide.uk.net

Young Dementia Network

An online network of people with young onset dementia, their families, and professionals collaborating to improve support.

Hosted by Dementia UK

➤ youngdementianetwork.org

Practical resources

Benefits and grants

➤ gov.uk/browse/benefits (England and Wales)

➤ mygov.scot/browse/benefits (Scotland)

➤ nidirect.gov.uk/information-and-services/benefits-and-money/benefits-and-financial-support (Northern Ireland)

Driving and Vehicle Licensing Agency (DVLA) – England, Scotland and Wales

➤ gov.uk/government/organisations/driver-and-vehicle-licensing-agency

Driver and Vehicle Agency (DVA) – Northern Ireland

➤ nidirect.gov.uk/contacts/driver-vehicle-agency-driver-licensing

Living with Dementia Toolkit

➤ livingwithdementiatoolkit.org.uk

Personal checklist

A document to record signs of young onset dementia

➤ youngdementianetwork.org/personal-checklist

Young onset dementia ID cards

For use by people with a dementia diagnosis, their family and friends

➤ youngdementianetwork.org/young-onset-id

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

Contact our Helpline:
0800 888 6678 or [👉 helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:
[👉 dementiauk.org/book](https://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](https://dementiauk.org/donate)
- Scan the QR code

Thank you.



DementiaUK
Helping families face dementia



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