

Understanding young onset dementia



Dementia is an umbrella term for a range of progressive conditions that affect the brain. It damages the nerve cells in the brain so messages cannot pass between them effectively. This stops the brain 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 many different types of dementia. The most common forms 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 type, 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 a genetic mutation. 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 p17.

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. Dementia is often associated with memory loss, but this is less likely to be an early symptom in younger people. 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
- 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

Please see Sources of support on p16 for information on the different symptoms of young onset dementia.

Getting a diagnosis

Whatever their age, if someone is experiencing changes that may indicate dementia, make an appointment to see the GP as soon as possible. Many other conditions can have similar symptoms, such as infections, thyroid problems, stress, depression, perimenopause/ menopause and dietary deficiencies. These may be treatable, so it is important to visit the GP early.

It is a good idea to keep a record of the changes and symptoms that are causing concern, such as:

- what they are
- when they happen (date/time)
- any possible triggers
- whether they are getting better or worse



You can show this to the GP and other professionals involved in the dementia assessment process.

The GP will ask questions about the changes you have noticed and the impact they are having. They may do some basic memory tests, but because younger people may not experience difficulties with memory in the early stages of dementia, these may not be helpful. The GP may also request investigations such as blood tests and X-rays to check for underlying conditions.

If possible, a family member or friend should go to all appointments with the person. They can share any changes they have noticed and help the person communicate with the professional and understand and remember what was said.

If the GP rules out other causes, they may refer the person for further investigation and assessment. This could be with a specialist memory service, or a cognitive disorders or neurology clinic.

At this stage, the health professional should take a detailed medical and family history, including asking about the issues that are causing concern, and carry out 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 is life-changing and can be very difficult to accept. Although people may live with dementia for many years after diagnosis, it is considered life-limiting due to its progressive nature. People with young onset dementia will experience increasing care needs over time, and their life expectancy will be shorter than people without dementia.

It is natural for the person with young onset dementia and those close to them to experience a range of feelings including anger, grief, depression or anxiety. It is important to access support with coming to terms with the diagnosis. You can speak to the GP about NHS counselling or psychology, refer yourself, or find an accredited private therapist – please see Sources of support on p18-19.

Our dementia specialist Admiral Nurses can offer support with any aspect of young onset dementia – please see Sources of support on



p16-17. We also have specialist Consultant Admiral Nurse services for young onset dementia; for information, please contact our Helpline.

Medication for dementia

Currently, there is no cure for dementia, but some people may be prescribed medication. These medications cannot reverse dementia or stop it progressing, but they may slow it down and reduce the symptoms. However, some people find that they make no difference, or that the side effects are intolerable.

Four main medications 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 vascular or frontotemporal dementia as they can make the symptoms worse.

Some people with frontotemporal dementia are prescribed antidepressants called selective serotonin reuptake inhibitors (SSRIs) to help control loss of inhibitions, overeating and compulsive behaviour.

People with vascular dementia – which is linked to problems affecting the blood supply to the brain, for example, strokes and transient ischaemic attacks (TIAs or ‘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 symptoms. Some types of dementia affect how people experience emotions, which could cause distress for the person with the diagnosis and those around them – for example, if they become irritable or emotional more easily than they used to.

The person with dementia may not have insight into their condition or realise that they are behaving in ways that others find upsetting. They might not be aware of the changes in themselves, which can lead to arguments, for example if they resist people’s attempts to offer support.

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.

Younger people with 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 p17 for information on supporting children and teenagers. Our Consultant Admiral Nurse for Children and Young People can also offer support; for more information, please contact our Helpline.

Employment

Younger people are more likely to be working when they are diagnosed with dementia. Over time, their dementia symptoms will have an increasing impact on their ability to work, which may result in them leaving their job or retiring earlier than planned.

Dementia is classed 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 disciplinary action or dismissal due to their diagnosis.

When a person is diagnosed with dementia, it is advisable to let their employer know so reasonable adjustments can be made when necessary to enable them to continue working 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 having difficulties at 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.

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 p16 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 they may have financially dependent children. It is natural to worry about the financial impact of their diagnosis, especially if they

give up work. 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

You can find information on benefits at gov.uk/browse/benefits, and in our guidance on finance and young onset dementia: please see Sources of support on p17.

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. If they do not, their policy may be invalidated, and the insurer may refuse to settle the claim if the person has an accident.

Giving up driving can be very hard. Driving Mobility Centres provide ‘driver retirement support’ for people who have stopped driving, helping them manage this difficult transition and giving advice on other transport options.

Please see Sources of support on p16 for 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
- follow a healthy, balanced diet
- drink plenty of water and other fluids to prevent dehydration, which can increase confusion
- stop smoking
- limit alcohol intake or avoid it altogether
- stay mentally active by continuing with activities they enjoy or taking up new ones, adapting them over time to suit their changing abilities



- establish good sleep habits that help them settle at bedtime and sleep through the night

Connecting with others

Staying socially active helps 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. Our website has a database where you can search for young onset dementia support groups: please see Sources of support on p17.

Taking part in groups and activities that are not specifically for people with dementia – such as singing, exercise, sports, craft and volunteering groups – can also provide connection and enjoyment 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 may not feel necessary if a person is younger at the time of diagnosis, but because the progression of dementia is unpredictable, it is best to put plans in place as soon as possible. These discussions and decisions can be upsetting, but will help the person and their family and friends feel prepared.

Planning for the future should include making:

- **an advance care plan:** this sets out the person's wishes for future treatment and care so they can be respected if they become unable to make decisions in the future
- **a lasting power of attorney (or power of attorney in Scotland, and enduring power of attorney in Northern Ireland):** a legal document that appoints someone to make financial, health and care decisions on their behalf if they lose capacity to do so
- **a Will:** this will ensure their wishes are respected after their death

For more information on advance care plans and LPA, please see Sources of support on p16-17.



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](https://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](mailto: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](https://dementiauk.org/book)

Dementia UK resources

Young onset dementia section

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

Advance care planning

[▶ dementiauk.org/advance-care-planning](https://dementiauk.org/advance-care-planning)

After a diagnosis of young onset dementia: next steps

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

Dementia at work: a guide for employees and carers

[▶ dementiauk.org/daw-employees](https://dementiauk.org/daw-employees)

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

Finance and young onset dementia

- dementiauk.org/finance-and-young-onset-dementia

Find young onset dementia support groups and services

- 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

Lasting power of attorney

- dementiauk.org/lasting-power-of-attorney

Learning disabilities and dementia

- dementiauk.org/learning-disabilities

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

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

The online community for everyone living with, working with or interested in young onset dementia, 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)

**British Association for Counselling and Psychology:
find a therapist**

➤ bacp.co.uk/search/Therapists

British Psychological Society: find a psychologist

➤ bps.org.uk/find-psychologist

**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

Driving Mobility Centres

➤ drivingmobility.org.uk

Find NHS talking therapies services

➤ nhs.uk/nhs-services/mental-health-services/find-nhs-talking-therapies-for-anxiety-and-depression

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**

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.



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