

## About 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 can't be sent 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 ethnic minority 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, including conditions that can lead to dementia such as Parkinson's disease, Huntington's disease and Creutzfeldt Jakob disease (CJD).

Younger people are also more likely to have an inherited form of dementia caused by genetic mutations, including familial Alzheimer's disease, familial frontotemporal dementia and familial vascular dementia.

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

Early symptoms for 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

## Getting a diagnosis

If someone is showing signs of dementia, it is important to visit a 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.

At this stage, the health professional should take a detailed medical and family history from

the person and their family member, including asking them 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 young onset dementia, 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 young onset dementia can be very difficult to accept. The person may find it hard to adjust, and experience a range of feelings including anger, grief, depression or anxiety. Family members may be affected by similar emotions.

### Medication for dementia

Sometimes, medications may be prescribed for a person with dementia. They do not stop the progression of dementia, but they may reduce the symptoms. However, they are not suitable for all types of dementia. Some people find that they make no difference, or that the side effects are intolerable.

The four main medications that are used for dementia are 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.

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.

The person may also find it difficult to talk about 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. See **Sources of support on p10** 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 in England, Wales and Scotland as a disability in the Equality Act 2010, 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.

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 so. If they have a company or private pension, 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.

See **Sources of support on p10** for information on employment and young onset dementia.

### Financial benefits

Many people with young onset dementia have financial commitments such as a mortgage, credit card bills and loans, and it's 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

You can find information on benefits at [gov.uk/browse/benefits](https://gov.uk/browse/benefits), and in our information on getting financial help and support: see **Sources of support on p10** for details.

Some people with long-term complex health needs qualify for funding to help with their care needs. This is called NHS continuing healthcare (CHC). You can read more in our leaflet on CHC: visit [dementiauk.org/chc](https://dementiauk.org/chc)

### 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 and mobility aids like mobility scooters.

See **Sources of support on pg** for 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
- 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's 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: visit [dementiauk.org/find-support](https://dementiauk.org/find-support).

Taking part in local non-dementia community groups and activities such as singing, walking, cycling, craft and gardening groups can also provide a valuable source of connection and interest.



## Planning future care

When a person is diagnosed with dementia, it's 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.

It is also advisable for the person to complete a lasting power of attorney (LPA): 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.

See **Sources of support on p10** for details of our leaflets on Advance Care Plans and LPA.

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

## Sources of support

Adjusting to a diagnosis of young onset dementia can be difficult. For support and advice from 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 25<sup>th</sup> December) 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/get-support/closer-to-home](https://dementiauk.org/get-support/closer-to-home).

## Dementia UK information

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

**Dementia UK information on driving and dementia**  
[dementiauk.org/driving-and-dementia](https://dementiauk.org/driving-and-dementia)

**Dementia UK information on employment and young onset dementia**

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

**Dementia UK information on getting financial help and support**

[dementiauk.org/financial-help](https://dementiauk.org/financial-help)

**Dementia UK information on Advance Care Planning**

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

**Dementia UK information on lasting power of attorney**

[dementiauk.org/lasting-power-of-attorney](https://dementiauk.org/lasting-power-of-attorney)

**Dementia UK resources for children and young people**

[dementiauk.org/children-and-young-people](https://dementiauk.org/children-and-young-people)

## Useful organisations

### **Young Dementia Network**

A network of people living with young onset dementia, their families, and professionals in the field collaborating to improve support now and in the future. Hosted by Dementia UK

[youngdementianetwork.org](https://youngdementianetwork.org)

### **DEEP**

A network of around 80 groups to help people with dementia connect with each other

[dementiavoices.org.uk](https://dementiavoices.org.uk)

### **Rare Dementia Support**

Specialist information and support about rare dementias

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

### **tide – together in dementia everyday**

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

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

### **Dementia Carers Count**

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

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

## **Practical resources**

### **Young onset dementia ID cards**

[youngdementianetwork.org/resources/young-onset-id](https://youngdementianetwork.org/resources/young-onset-id)

### **Personal checklist**

A document to record signs and symptoms of young onset dementia

[youngdementianetwork.org/resources/personal-checklist](https://youngdementianetwork.org/resources/personal-checklist)

### **Benefits and grants**

[gov.uk/browse/benefits](https://gov.uk/browse/benefits) (England and Wales)

[mygov.scot/browse/benefits](https://mygov.scot/browse/benefits) (Scotland)

[nidirect.gov.uk/information-and-services/benefits-and-money/benefits-and-financial-support](https://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](https://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](https://nidirect.gov.uk/contacts/driver-vehicle-agency-driver-licensing)

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](mailto: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](https://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](mailto:helpline@dementiauk.org)

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



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

Dementia UK, 7<sup>th</sup> Floor, One Aldgate, London EC3N 1RE  
Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429).