

Young onset dementia: next steps after a diagnosis



If you or someone close to you is diagnosed with dementia under the age of 65, it can come as a shock. Many people do not realise that dementia can develop in midlife, and it is natural to feel anxious or uncertain about what the future holds. One specific question may be on your mind: “What happens next?”

This leaflet offers advice on the things you need to know about now and how to prepare for what might be ahead.

What is young onset dementia?

Young onset dementia is any type of dementia where symptoms develop before the age of 65. Many people associate dementia with memory loss, but often, in younger people, memory is not significantly impacted in the early stages. More commonly, people with young onset dementia initially experience:

- changes in behaviour
- personality changes
- difficulties with vision and spatial awareness
- difficulties with language and communication
- changes in relationships and social functioning
- impaired decision-making and problem-solving

The changes in the brain caused by dementia usually progress over several years. There may be periods when the person’s condition seems to have stabilised, but over time, the changes in their personality, behaviour and ability to carry out everyday activities will continue.



What happens next?

After a diagnosis of dementia, there are some matters that should be addressed as soon as possible. Some of these may not seem urgent or relevant; however, it is important to tackle the following issues to minimise stress and worry in the long run.

Financial and legal affairs

Lasting power of attorney (LPA)

Lasting power of attorney is a legal process where someone appoints another person/people (called the attorney) to make decisions for them if they reach the point where they cannot make decisions themselves – this is called losing capacity.

There are two types of LPA:

- health and welfare
- property and financial affairs

LPAs cover big issues, like selling property or moving into a care home, but even smaller decisions like cancelling a mobile phone or digital TV contract cannot be taken on the person's behalf without an LPA in place.

You can set up an LPA yourself online, or with a solicitor.

LPAs are valid in England and Wales. The equivalent of an LPA in Scotland is known as power of attorney; in Northern Ireland, it is called enduring power of attorney. For more information on all three types, please see p16-18.

If a person lacks capacity and has not made an LPA, the person who needs to make decisions on their behalf will need to apply to the Office of the Public Guardian to become their deputy. Sometimes this is unavoidable, but it can be a long and complicated process, so the best option is to set up an LPA while the person with dementia still has the capacity to do so.

For more information on LPA and mental capacity, see Sources of support on p14-15.

Wills

If the person with dementia has not yet made a Will, it is important that they do so as soon as possible to ensure their money and possessions go to the people and causes close to their heart. If they have already made a Will, it is a good idea to check that it still reflects their wishes.

If you are a family member or friend of someone with dementia and are planning to leave them money or possessions in your Will, you may wish to think about whether they will have the capacity to decide how to manage these gifts and whether you need to make any changes to your Will.

For more information on making a Will, including free Will-writing offers from Dementia UK, please see Sources of support on p14 and p17.

Finances

Banks and building societies have systems in place to help people manage their finances, so if you or a family member or friend are diagnosed with dementia, notify them as soon as possible. They can help with financial safeguarding, for example by limiting access to funds or capping daily expenditure to help prevent overspending.

If you need advice on financial planning, such as managing investments or a large estate, or around pension management, early retirement, mortgages and savings, it may be helpful to consult a financial adviser. Always choose a professional who is regulated by the Financial Conduct Authority: you can search online at [fca.org.uk](https://www.fca.org.uk)

For more information on finance and young onset dementia, see Sources of support on p15.

Benefits

A person with dementia may be eligible for benefits such as Personal Independence Payment (PIP) and a reduction in Council Tax. Family members may qualify for Carer's Allowance.

To find out about benefits and eligibility, visit [gov.uk/benefits-calculators](https://www.gov.uk/benefits-calculators). You will also find more information on benefits in our finance and young onset dementia leaflet: see Sources of support on p15.

Employment

If the person with dementia works, it is helpful if they inform their manager and/or Occupational Health Team of their diagnosis as soon as possible. This ensures they are protected under the Disability

Discrimination Act and will help their employer support them to stay in work if they wish to do so.

If the person with dementia is in the military, works in healthcare, or their job involves driving, working with machinery, with chemicals or medicinal products, with precision tools, at height etc, it may be a contractual requirement to inform the employer in case their condition puts them or others at risk.

It can also be helpful for people who care for someone with dementia to inform their own employer/Occupational Health Team of the situation so that they can be supported too, for example by accessing flexible working.

If the person with dementia is struggling at work, their GP may sign them off so they can access the employment support system and benefits like Statutory Sick Pay (SSP). However, this is a short-term measure, with SSP only paid for up to 28 weeks, so it may be necessary to reflect on how the person could be better supported at work, or whether they need to consider leaving employment.

Some people feel they cannot cope at work any longer and leave their job, but this means that they may not be entitled to some benefits or to access 'early retirement on health grounds' and may miss out on significant income.

For more information about employment and young onset dementia see Sources of support on p15.

Driving

Continuing to drive

If the person with dementia drives, they are obliged to inform the DVLA (DVA in Northern Ireland) and their vehicle insurer of their diagnosis. This does not necessarily mean that their licence will be



withdrawn, but they may be issued with a shorter licence (up to five years) with the requirement to be reassessed after that time.

The DVLA/DVA may seek the person's GP or specialist's opinion on their fitness to drive, and may request that the person takes a driving assessment.

If the person with dementia does not inform the DVLA/DVA and their vehicle insurer about their diagnosis, their insurance may not be valid if they have an accident, regardless of who was at fault.

Discussions about driving competency can be sensitive and upsetting, but a family member can inform the DVLA/DVA and insurance company on the person's behalf if needed. For more information on driving and dementia, see Sources of support on p14.

Blue Badge

A Blue Badge entitles people with health conditions or disabilities to use accessible parking, including parking for free in disabled bays on streets and in public car parks, and on yellow lines. Blue Badges are also recognised in many private car parks, although it is essential to check the signage.

People with dementia are eligible to apply for a Blue Badge. For more information, visit [gov.uk/apply-blue-badge](https://www.gov.uk/apply-blue-badge)

Family and friends

Partners and spouses

Dementia can have a big impact on people's roles and relationships. The person's spouse might feel that they are now their carer rather than their partner. They may find it hard to cope with their caring responsibilities, especially if they are working and/or have children at home, and it can impact on their social life and activities.

The person with dementia may not feel that they need to be looked after and feel resentful, or disagree with the decisions that their partner makes on their behalf. There can also be changes in intimacy and sexual relationships.

It is important that both partners have support with the changes in their relationship. You can speak to your GP about how to access help such as counselling or support groups or contact our Helpline to talk to a specialist dementia nurse – see Sources of support on p14.

Children

It is natural for children and teenagers whose parent is diagnosed with dementia to struggle with the changes. Their parent may become less engaged and interested in their school life, hobbies, friends, extracurricular activities and homework. Over time, their ability to look after and support them (for example, by attending school events, cooking, cleaning and driving) may be impaired. It may become harder to go on days out or on holiday.

Children and teenagers may also find their parent's behaviour embarrassing or worrying. They may want to spend less time at home or be reluctant to invite friends over. They may be upset about their declining health and scared about them dying.



It is helpful to have an open and honest discussion with the child about dementia and how it is affecting their parent, using age-appropriate language and acknowledging their feelings. The person's GP or dementia specialist may be able to suggest resources or support with talking to children about dementia, including counselling for young carers.

It is also helpful to keep the child's school or college informed so that practical and emotional support can be put in place.

While inherited forms of dementia are rare, they are more common in younger people, so if the person has been diagnosed with a genetic form of dementia, it is possible that their child will also develop it in the future. It is important to think about if, when and how to discuss this with the child – the person's specialist may be able to refer you to a genetic counselling service for advice.

For more dementia information for children and adolescents, see Sources of support on p15.

Other family members and friends

Sharing the news of the person's dementia diagnosis with friends and family enables them to be understanding and supportive, for example if the person is struggling to recognise them or follow a conversation. They may also be able to offer practical help, such as taking them to appointments or spending time with the person with dementia to give family members a break.

Making life easier

The more straightforward life is, the easier it will be to manage, so it is helpful to try to simplify the person's daily routines, home and work environment, and other responsibilities.

Even small changes could relieve a lot of pressure. For example:

- Could you use a smart device to set reminders for appointments, medication, work commitments and social activities?
- Could family duties and responsibilities be shared more evenly with others?
- Could you create a weekly routine, eg having shopping delivered on a set day?

ID cards and lanyards

It is a good idea for the person with dementia to carry some form of identity that explains their diagnosis in case they need help outside the home – for example an ID card or MedicAlert jewellery. They could also set up medical ID and an emergency contact on their mobile phone – these can be accessed in an emergency even if the phone is locked.

Some people with dementia find it helpful to wear a lanyard indicating that they have a hidden disability, such as the sunflower lanyard – please see Sources of support on p17.



Creating a life story

A life story is a detailed record of the person's past and present life and future wishes that can help people such as health and social care professionals understand and communicate better with them. You may wish to start working on creating a life story soon after the person is diagnosed with dementia. You might like to use our life story template: see Sources of support on p15.

GP services

At some point, the person with dementia may need a family member or friend to help them manage their healthcare. The person's GP can name you as their 'trusted person' which means you can manage their appointments and prescriptions (including online services), be informed about test results, and speak to their health professionals on their behalf.

Please see Sources of support on p15 for our information on online GP services for people with dementia, which explains how to become a trusted person.

If the person has an LPA for health and welfare, this will act in a similar way – but unlike having access as a trusted person, it can only be used if the person has lost capacity to manage their own healthcare decisions.

If you are living with or caring for a person with dementia, you can register with your GP practice as their carer. This will qualify you for additional support such as free flu vaccinations and greater flexibility with appointments.

Carer's card

If you care for a person with dementia, it is advisable to carry a carer's card when away from home. If you are involved in an accident or become unwell, it will alert emergency services that you care for someone with dementia who may be home alone or need help and support. You can request Dementia UK's ID cards via our Helpline: see Sources of support on p14 for details.

Accessing information and support

When a younger person develops dementia, you may feel robbed of your hopes and plans for the future, so it is important to get support, for example from:

- the GP or other health professionals
- specialist dementia services
- a counsellor
- family and friends
- a faith leader
- support groups for people with dementia and/or family carers



With the right support, the person with dementia may be able to continue with their work, hobbies and interests for some time, helping them stay engaged with everyday life and maintain some independence. Keeping up with work, social activities and friendships may also benefit family carers and give them some respite from their caring responsibilities.

Some people living with dementia or caring for someone with the diagnosis prefer not to know what lies ahead – this is natural, and a personal choice. However, being well informed about dementia will help you prepare for the years ahead and feel better equipped to cope with the changes and challenges.

Young onset dementia groups and services across the UK can provide the person with dementia and their family members with information, advice and vital peer and professional support. Dementia UK's website includes a section dedicated to young onset dementia, including a database of specialist support services: please see Sources of support on p14 for information.

Sources of support

To speak to a dementia specialist Admiral Nurse about next steps after a young onset dementia diagnosis or any other aspect of dementia, 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)

You can also register for our free online programme, ‘Dementia: what next?’, for people with dementia and their carers. Visit [▶ dementiauk.org/dementiawhatnext](https://dementiauk.org/dementiawhatnext)

Dementia UK information

Young onset dementia section

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

Capacity and decision-making

[▶ dementiauk.org/capacity-decision-making](https://dementiauk.org/capacity-decision-making)

Changing relationships and roles

[▶ dementiauk.org/changing-relationships-and-roles](https://dementiauk.org/changing-relationships-and-roles)

Dementia UK free Will-writing offers

[▶ dementiauk.org/freewill](https://dementiauk.org/freewill)

Driving and dementia

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

The emotional impact of a dementia diagnosis

[▶ dementiauk.org/emotional-impact-of-a-diagnosis](https://dementiauk.org/emotional-impact-of-a-diagnosis)

Information about dementia for children

- dementiauk.org/get-support/resources/children
- dementiauk.org/dementia-books-for-children

Employment and young onset dementia

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

Finance and young onset dementia

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

Financial and legal sources of support and advice

- dementiauk.org/sources-of-support-and-advice

Lasting power of attorney

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

Life story work

- dementiauk.org/creating-a-life-story

Life story template

- dementiauk.org/life-story-template

Looking after yourself as a carer

- dementiauk.org/looking-after-yourself-when-you-care

Online GP services for people with dementia

- dementiauk.org/gp-online-services

Registering as a carer with your GP

- dementiauk.org/the-importance-of-registering-as-a-carer-with-your-gp

Supporting children and adolescents when a parent has young onset dementia

- dementiauk.org/supporting-children-and-adolescents

Other resources

Age UK

Information, advice and advocacy for people over 50. Includes Age Scotland, Age Cymru and Age NI

➤ ageuk.org.uk

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)

Carers Trust

UK-wide network providing information, replacement care and support for unpaid carers

➤ carers.org

Dementia Carers Count

Information, online learning and face-to-face courses for carers

➤ dementiacarers.org.uk

DVLA (England, Scotland and Wales)

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

DVA (Northern Ireland)

➤ nidirect.gov.uk/contacts/driver-vehicle-agency-dva-northern-ireland

Enduring power of attorney (Northern Ireland)

➤ nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney



Hidden Disabilities Sunflower Scheme

➤ hiddendisabilitiesstore.com

Lasting power of attorney (England and Wales)

➤ gov.uk/power-of-attorney/make-lasting-power

Living with dementia toolkit

Resources for people with dementia and their carers

➤ livingwithdementiatoolkit.org.uk

Making a Will

➤ gov.uk/make-will

MedicAlert

Medical ID jewellery for use in emergencies

➤ medicalert.org.uk

Pathways Through Dementia

Free legal and financial information for people living with dementia

➤ pathwaysthroughdementia.org

Power of attorney (Scotland)

➤ mygov.scot/power-of-attorney

The Law Society

Database of independent professional solicitors

➤ solicitors.lawsociety.org.uk

Young Dementia Network

An online community of people living with young onset dementia, their family and friends, and professionals. For ID cards and other young onset dementia-related resources visit:

➤ youngdementianetwork.org



Checklist

- ☐ Set up lasting power of attorney
- ☐ Write or update your Will
- ☐ Inform your bank of the diagnosis and speak to a financial adviser
- ☐ Find out what benefits you are eligible for and apply
- ☐ Inform your employer and discuss how they can support you
- ☐ Inform the DVLA/DVA and vehicle insurer about the diagnosis
- ☐ Apply for a Blue Badge (you may decide not to do this immediately)
- ☐ Let your child's school or college know about the diagnosis
- ☐ Share news of your diagnosis with family and friends
- ☐ Simplify daily routines at home and work
- ☐ Request an ID card for a person with dementia and a carer's card
- ☐ Ask in major shops, supermarkets or train stations for a free sunflower lanyard or order one online
- ☐ Start to create a life story of the person with the diagnosis
- ☐ If you provide care for the person with dementia, register as a carer at your GP practice
- ☐ Learn more about dementia and look for local support services and groups

**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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