

Young onset dementia: next steps after diagnosis



If you are under the age of 65 years and have recently been diagnosed with dementia, or you live with or care for someone who has, you may feel shocked about the diagnosis and surprised that dementia can affect someone of working age. You may also 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 how to deal with any issues and how to prepare for what might be ahead – whether you have been diagnosed with dementia yourself or are a family member or friend.

What is young onset dementia?

Young onset dementia is any type of dementia where symptoms develop at or under the age of 65.

Many people consider dementia to be largely about memory loss, but often, in younger people, memory is not significantly impacted in the early stages. More commonly, people with young onset dementia develop difficulties with:

- thinking clearly
- planning ahead

- organising their thoughts and affairs
- behaviour and emotions
- understanding language

The changes in the brain caused by dementia usually progress over several years. There may be periods when it appears that the symptoms have stabilised and the person’s condition is not deteriorating, but these are not sustained and over time, the changes in personality and the decline in mental function and physical wellbeing will continue.

This requires patience and understanding from the people who live with and care for the person with dementia. It may at times cause frustration and challenge strength and resilience.

What happens next?

After a diagnosis of dementia, there are some matters that are best addressed as soon as possible.

Others may appear less urgent, or may not seem to apply to you at all. 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

LPA can only be set up if the person with dementia is able to give consent for someone else to manage these matters. It covers 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.

An LPA can be set up online at gov.uk/power-of-attorney/make-lasting-power or with a solicitor.

If a person reaches the stage where they lack capacity to make a decision but haven't made an LPA, a much more lengthy and costly procedure will be required which involves the Court of Protection/ Office of the Public Guardian taking over the individual's affairs. Sometimes this is unavoidable, but the best option is to set up an LPA while the person with dementia still has capacity to make and communicate their decisions.



Once an LPA is set up, you will have the reassurance of knowing that the right legal processes are in place for the future. For more information on LPA and mental capacity, see Sources of support on p13 or visit gov.uk/power-of-attorney

Wills

If the person with dementia hasn't 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, visit dementiauk.org/freewill or gov.uk/make-will

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 will help with financial safeguarding, for example by limiting access to funds or capping daily expenditure to help prevent overspending.

It may also be useful to consult a qualified financial adviser if you need advice on financial planning, such as managing investments or a large estate, or around pension management, early retirement, mortgages and savings. You should use a financial adviser who is regulated and authorised by the Financial Conduct Authority: you can search for advisers at [fca.org.uk](https://www.fca.org.uk)

For more information on finance and young onset dementia, see Sources of support on p13.

Benefits

The 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 which benefits you or the person you support might be entitled to, visit [gov.uk/benefits-calculators](https://www.gov.uk/benefits-calculators). More information on benefits can be found in

our finance and young onset dementia leaflet: see Sources of support on p13.

Employment

People with dementia are legally protected from discrimination at work, so it is helpful if the person shares their diagnosis with their manager and/or Occupational Health Team as soon as possible. This helps the employer to ensure all legal processes are followed in protecting the employee at work and support them to stay in employment if they wish to do so.

If the person with dementia is in the military or 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 impacts on their work or 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.

If the person with dementia is struggling at work, their GP may issue them with a medical certificate and sign them off in order to activate the employment support system and access benefits.

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 p13.

Driving

Continuing to drive

A person with dementia is obliged to inform the DVLA and their vehicle insurer of their diagnosis. This does not necessarily mean that their licence will be withdrawn – they may be issued with a shorter licence (up to five years) with the requirement to be reassessed after that time.

The DVLA may seek advice from the person's GP or specialist for an opinion on their fitness to drive.

Sometimes the DVLA will request that the person takes a driving assessment to assess this.

The person with dementia may intend to update the DVLA and their vehicle insurer about their diagnosis and provide any necessary paperwork but forget to do so. If the insurance company has not been advised of the diagnosis and the person with dementia is in an accident, their insurance may not be valid regardless of who was at fault.

Discussions about driving competency can be sensitive and upsetting, but a family member can inform the DVLA and insurance company on the person's behalf if needed. For more information on driving and dementia, see Sources of support on p13.

Blue Badge

A Blue Badge allows people with health conditions or disabilities to park on streets (including on yellow lines) and in disabled bays in car parks. On-street parking is free with a Blue Badge, even in areas with meters or pay and display machines, and in many car parks – although it's essential to check the



signage, as some private car parks still charge.

People with dementia are eligible to apply for a Blue Badge. For more information, visit gov.uk/apply-blue-badge

Family and friends

Partners and spouses

The changes that come with dementia can affect the role of the person with the diagnosis and their family members. 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 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 p13.



Children

Some children struggle with the changing behaviour of a parent with dementia, particularly if they become less engaged with things that previously interested them such as the child's school day, hobbies, friends, activities and homework.

Children may also find their parent's behaviour embarrassing or be wary of their changing patterns of behaviour and want to spend less time in their own home.

It's helpful to have an open and honest discussion about dementia and what is happening to their parent using language

appropriate to the child's age, acknowledging any feelings of distress or insecurity. This becomes more relevant if the child themselves is at risk of inheriting the same condition.

Seek advice from people who understand dementia well to support your conversations with children and look for age-appropriate resources. If you have access to a specialist dementia support service, they may have counsellors who can give you advice on talking to children about what is happening in their lives now and what may happen in the future.

It is also helpful to keep the child's school or college up to date so that pastoral and psychological support can be put in place and access given to additional resources to support children who are carers, if available. For more dementia information for children, see Sources of support on p13.

Friends

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

Most friends will want to know how they can support the person with dementia and sharing the situation will make it easier for them to understand how they can help.

Daily living

Making life easier

It can be helpful for the person with dementia to simplify their daily routines, their home and

work environment, relationships and responsibilities. The more straightforward and simple life is, the easier it will be to cope.

Seek the support of others with managing personal and family affairs, your commitments, and your social life and other activities. Can family duties and responsibilities be shared with others? Can commitments be better spaced out? Whether you are the person with dementia or a family member or friend, you may be able to relieve the pressure on yourself if someone else can take on a task that you usually do.

ID card/MedicAlert jewellery

It is a good idea for the person with dementia to carry some form of identity in case they get lost away from home, become separated from a friend, family member or carer, or are struggling to make themselves understood and need help.

An ID card can be kept in the person's wallet or purse or sewn into the lining of a bag or coat.

It should include their name and an emergency contact number, for example a partner/spouse,



relative or friend. It can also include information about their diagnosis.

A MedicAlert bracelet or pendant can also be worn to provide personal information that can be used in an emergency. Emergency services such as the police and ambulance will look for such items if there is an accident, emergency or other occasion where the person is not able to communicate their needs. The information provided will enable them to get the person the most appropriate help as quickly as possible.

MedicAlert jewellery is available from [medicalert.org.uk](https://www.medicalert.org.uk). To print or request the Young Dementia Network's ID card, see Sources of support on p14.

Sunflower lanyard

The Sunflower lanyard indicates to others that the wearer has a hidden disability. It does not specifically indicate dementia but is a signal that the wearer may need a little more time, space or help.

Many shops, supermarkets, train stations and airports issue the lanyards free of charge on request, or they can be purchased online from the Hidden Disabilities website: hiddendisabilitiesstore.com

Creating a Life Story

A Life Story is a detailed record about a person that can help people such as carers and health and social care professionals get to know them, understand more about what is important to them

and communicate better with them. It can also help to educate care professionals about the differing needs that should be considered when supporting a younger person.

It could include information about the person's:

- diagnosis
- medication
- names and status of family members
- likes and dislikes
- dietary requirements and preferences
- health and social care team, including their contact details
- spiritual beliefs and needs
- sexual orientation
- preferred pronouns
- hobbies and interests

These – and any other information that you would like to include – can be compiled into a document such as Dementia UK's Life Story template: see Sources of support on p13.

A Life Story can be prepared at your leisure so that if, for example, the person with dementia goes into hospital or a care setting, their personal information is readily

available to professionals in one handy place. The whole family, including children, can take part in collating the information.

For carers

Your GP practice

If the person with dementia develops a health issue, it can be helpful for a family member or friend to speak to their GP or healthcare professional with them or on their behalf.

If you are living with a person with dementia or providing care for them, you can register with your GP practice as their carer. The person with dementia's GP can name you as their 'trusted person' which means you can manage their appointments and prescriptions, be informed about test results, and speak to professionals on their behalf.

If an LPA for health and welfare is in place, this will act in the same way. It also gives authority for health services to share information with you about any health issues, appointments or treatment plans.

Carer's card

It is advisable that anyone who cares for a person with dementia carries a 'carer's card' when away from home. If there is an emergency involving the carer, it will alert emergency services that there is someone nearby or at home who may need help and support while the carer is ill or incapacitated.

You can request Dementia UK's ID cards via the Admiral Nurse Dementia Helpline: see Sources of support on p13 for details.

Accessing information and support

Dementia brings with it the loss of faculties and abilities for the person affected and changes family life. When dementia occurs in a younger person, you may feel robbed of your hopes and plans for the future.

Some people living with dementia or caring for someone with the diagnosis prefer not to know what lies ahead. This is completely understandable and is a form of self-protection. However, if you don't understand the progression

of the condition, you may be taken by surprise by changes that you had not anticipated. Being well informed about dementia will help you prepare for the years following diagnosis and stay strong in the face of the challenges that ensue.

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

Young onset dementia groups and services across the UK can provide both the person with dementia and their family members with vital peer and professional support. There is information, advice and a database of support services for people affected by young onset dementia on the Dementia UK website: visit dementiauk.org/young-onset-dementia

Remember – you are not alone.

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, please 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

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

Dementia UK information

Young onset dementia section
dementiauk.org/young-onset-dementia

Capacity and decision-making
dementiauk.org/capacity-decision-making

Driving and dementia
dementiauk.org/driving-and-dementia

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

Resources for parents
dementiauk.org/get-support/resources/parents

Life Story work
dementiauk.org/creating-a-life-story

Changing relationships and roles
dementiauk.org/changing-relationships-and-roles

Looking after yourself as a carer dementiauk.org/looking-after-yourself-when-you-care

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

Living with dementia toolkit

Resources for people with dementia and their carers
livingwithdementiatoolkit.org.uk

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

The Law Society

Database of independent professional solicitors
solicitors.lawsociety.org.uk

Young Dementia Network

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

youngdementianetwork.org

Checklist

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

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

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 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

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



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