

Young-onset dementia:

Understanding your diagnosis





About this booklet

If you are under 65 years old and have recently been diagnosed with dementia, this booklet is for you. It will help you, and the people who are important to you, to understand more about dementia and how it can affect you. The booklet also covers feelings you might have and suggests ways of staying positive.

In section 2, you can read about what the terms ‘dementia’ and ‘young-onset dementia’ mean. You’ll also find information about different aspects of living with dementia as a younger person. These include how dementia can affect you if you are working or driving, and information about treatment, support and services that are available.

You are not alone – over 42,000 people in the UK who are under the age of 65 have dementia, and there are around 900,000 people in the UK living with dementia. It is possible to live well with dementia as a younger person. Support is available for you and the people who are important to you.

This booklet also tells you about other Alzheimer’s Society publications that can give you more information on particular topics. These can be accessed on our website.



**To see all available publications,
visit [alzheimers.org.uk/publications](https://www.alzheimers.org.uk/publications)**



**You can also call 0300 303 5933
to order publications.**



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Coping with your diagnosis

When you find out you have dementia, you may feel a range of emotions. Give yourself time to think things through.

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There is no 'right' or 'wrong' way to feel when you receive a diagnosis of dementia. Everyone's experience of dementia is individual. However you feel, it is right for you, at this moment. And don't worry if it all seems to be overwhelming at first. There are good and bad times, and with support many people come to terms with their diagnosis.

It may help to talk things over with friends and family, or with a health or social care professional who understands dementia.

Things you might find it helpful to think about after a diagnosis include:

- your emotions and relationships
- treatments and ways to stay active and healthy
- talking to your employer (if you work)
- driving (if you drive)
- finances
- planning ahead
- practical and emotional support – from the NHS, social services, private companies or voluntary organisations.

You don't need to think about all these things straightaway, so take things at your own pace.

'Not talking won't magically make the issue go away – talking enables you to tell loved ones how you're feeling and they in turn should also feel able to talk. If you don't talk how do people know how to help you?'

Younger person living with dementia

Managing your feelings

You may have a number of different feelings after a diagnosis. This is normal and there are ways to cope with them.

- Younger people who are diagnosed with dementia often feel a sense of shock. You may not have thought of dementia as a condition that affects people of your age. You may find it hard to accept that you are having problems or that things have changed.
- It may have taken a long time and lots of appointments for you to receive a diagnosis. You or your family and friends may have noticed changes and wondered what was wrong. Sometimes people feel some relief when they get their diagnosis, as they now know what has been causing the changes, and can do something about it.
- Many people feel a sense of sadness, loss or grief after their diagnosis. You may feel that you will no longer be able to do the things that you enjoy or that you had planned. Having dementia may mean you need to make changes to the way you do things. But with the right information and support, you can carry on doing the things you want to for some time.
- Fear is another very common reaction. You may be afraid of the future, of losing control or of becoming a burden to your family. Talking about this with others can help. It is important not to feel that you are on your own.
- Many people feel frustrated or angry, have a sense that it isn't fair, or ask 'why me?', 'why now?'

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- Sometimes people feel guilty for having dementia and the impact that it is likely to have on the people who are important to them.
- Some people worry that they did something wrong to get dementia, or did not do enough to prevent it. In many cases it is not known why dementia develops. Don't dwell on this. Instead try to keep going with a positive outlook.

After a diagnosis, you may want to talk things over with people you trust. This might be your partner if you are in a relationship, or close family or friends. You may not want to talk about it at all. Now that you have a diagnosis, you may need some time and space before you are ready to find out more. It is important to go at your own pace.

Talking to others with a similar experience can help as well. You could try:

- finding a support group for people with young-onset dementia where you can talk to others with a similar experience (see section 7, 'Services and support')
- joining an online discussion forum (for example Alzheimer's Society's Talking Point, which has a discussion area for younger people with dementia)
- talking with a dementia support worker or dementia adviser (see section 7, 'Services and support')
- seeing a qualified health or social care professional such as a community mental health nurse, psychiatrist or clinical psychologist
- seeing a qualified counsellor or psychotherapist (see section 5, 'Treatment and care').



It takes time to adjust to a diagnosis of young-onset dementia and the impact this has on your future. Try to give yourself the time you need.



For more information see factsheet 444, Supporting a person with dementia who has depression, anxiety or apathy.

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Your relationships

After you have been told you have dementia, you will probably wonder who to tell, and how to tell them. When you're ready, talk to your partner or someone else you trust, and let them know how you are feeling. You may want to talk to them about how to tell others that you have dementia, such as family, friends and work colleagues. Many people find that talking to someone else helps them to cope with their emotions. Do this in a way that works for you both. Communicating can help you find ways to face the future together.

It is important that the people you talk to can also discuss how they're feeling. They may want to talk to you about this, or to a friend or family member. Some may want to talk to a professional like a counsellor, community mental health nurse or clinical psychologist.

Your friends or family may not know much about dementia or have trouble understanding it. They might find it helpful to read about dementia. They could also attend a face-to-face Dementia Friends session (a short session for learning about dementia) or watch the Dementia Friends video.



For more information see factsheet 400, What is dementia? or visit www.dementiafriends.org.uk



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Unfortunately, you are likely to meet some people, including some professionals, who do not understand that younger people can develop dementia. This can be frustrating or upsetting. It may help to ask your GP or consultant for a letter explaining your diagnosis, which you can show to people if it would be helpful.



**You could use one of our helpcards.
Go to alzheimers.org.uk/helpcards**

Talking to children

If you have children, nieces or nephews, or grandchildren, it's important to talk to them, too. It's natural to want to protect them – but it is important to explain to them what's going on. They are often aware something is different. It may comfort them to know that any changes in the things you say and do, or how you do them, are not because of them. They may well find out about your dementia at some point. They will probably appreciate it – and understand it better – if you speak about it with them earlier.

Children and young people will have their own individual reactions, just as adults do. How they react may depend partly on their ages, personalities and levels of maturity. It's important to let children come to terms with your diagnosis in their own time and their own way. It is likely to have a big impact on them, and may affect other areas of their life, such as their relationships with friends.

It's important to let them know they can talk to you and ask questions, if they want to. Children and young people can be very honest and sometimes questions might be difficult. Some may not talk about how they're feeling, so try to show them that you're there to listen when they're ready. It might also help for them to have other people they can talk to.





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Changes in your relationships

The people in your life can often give you support – but dementia can have a big impact on your relationships with the people who are important to you. For example, over time you might find it more difficult to communicate or cope with certain social situations (such as family gatherings). In these situations family and friends will need to find ways to adjust to this.

There are many ways that your relationships with different people will change. Over time, you will come to depend more on the people in your life. This might be difficult for you or them to accept. However, in time you may also find it brings you closer together.

As your dementia progresses, you are likely to need more support from the people who are important to you. Often someone close to you will take on more responsibility and they are likely eventually to become your main carer – although you may not use this term or see things this way.

‘The only difference between the day after and the day before your diagnosis is an explanation for your problems, all else remains the same. Above all else, know there are people there to help and research is finally starting to give real hope for a better future.’

Younger person living with dementia

It is important that someone who is helping you is supported themselves. They could find a local carers' support group, or join an online community such as Alzheimer's Society's Talking Point.

People with dementia and carers can search for support in their local area through our online directory. Go to alzheimers.org.uk/dementiadirectory

If you live alone, you may rely on friends, neighbours, or family who don't live with you for support. You may also have more support from health and social care professionals.

Certain relationships can be affected by dementia in different ways. We look at some of these below.

Intimate relationships

If you have a partner, they might become your carer. This can be very rewarding, but it can also make them feel sad, stressed or tired, for example. They may also find it difficult if they have to give up other responsibilities and things they enjoy such as work or hobbies.

Sometimes, when a person develops dementia, the way that they or their partner feel can change. Some couples may feel closer to one another because they are coping together with the person's dementia. But others may feel less close because of the changes the dementia causes or because of the stress and tiredness that caring might bring.



You may become much more or much less interested in sex. If your partner is caring for you, they may be less interested (especially if they're tired). You may need time and support to adjust to these changes.

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For more information see factsheet 514, Sex, intimacy and dementia.

Changes in your roles within the relationship can also affect how you and your partner feel. It can be hard to give up responsibilities and your partner may struggle with the new expectations placed on them. For example, if you used to manage the household finances but your partner has taken on more of this role, it can take time for both of you to adjust to this.

Wider family

Family members can give you support, but you may have relatives who struggle to accept that you have dementia. Some people find their family members spend less time with them, and this can be difficult. It's important to let people come to terms with your dementia in their own way and time.

If family members spend less time with you, or stop seeing you altogether, try not to dwell on this. It is important to focus on your own needs, coping with your diagnosis and living well, and enjoy spending time with the family who are there to support you. It may help to be specific about the support you need. For example, ask someone to come for a walk with you if this would help.

Friends

Friends can be an important source of support when you have dementia. It can be useful to let people know if there are things they can help with or that you would like them to do (such as going for a coffee together or helping you with the gardening).



Some friends may find it difficult to accept that you have dementia, and they may not know what to do or say. You may find that some stop spending time with you. You may also lose touch with other friends simply because you are no longer doing the things you used to do with them – such as work or social activities. This can be difficult to accept. It is important to remember it is not your fault. It may help to focus on the people who are there for you.

If you want to talk about your relationships, including any changes or problems, you can find help from different services. There are peer support groups, dementia support workers or counsellors. You can ask your GP or search our online directory to find out about services in your local area at alzheimers.org.uk/dementiadirectory



For more information on dementia and relationships see booklet 1507, Your relationships.

‘Often people regard younger people with dementia with disbelief because we do not conform to the stereotypical image of a person affected by the condition. This can make our lives so much harder because we are asked to explain ourselves.’

Younger person living with dementia





2

What is young-onset dementia?

Young-onset dementia is the name given to dementia that is diagnosed in people before they are 65 years old. People who have young-onset dementia are often described as ‘younger people with dementia’.

Young-onset dementia is the term used for people under the age of 65 because people traditionally retired at this age. It isn't for any biological reason.

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What causes dementia in younger people?

Dementia is caused by diseases in the brain. Dementia in younger people tends to be caused by the same range of diseases that cause the condition in people over 65. However, certain kinds of dementia are more common in younger people than in older people (see section 3).

Causes of dementia in younger people include:

Alzheimer's disease

This is caused by proteins building up in the brain to form structures called 'plaques' and 'tangles'. These disrupt the way the brain works and cause brain cells to die. People with Alzheimer's disease also have a shortage of some important chemicals in their brain.

Vascular dementia

This is caused by too little blood getting to the brain, because of blood vessels that have become damaged by disease. Without enough blood, brain cells can't get enough oxygen and eventually die.

Frontotemporal dementia (FTD)

FTD is caused by damage to two areas in the brain: the frontal and temporal lobes. It can cause different problems depending on where the damage is.



Dementia with Lewy bodies

This is caused by the build-up of Lewy bodies, which are tiny clumps of protein that develop in brain cells. Lewy bodies disrupt the way the brain functions and cause brain cells to die. They also cause Parkinson's disease. Some people who have Parkinson's disease go on to develop dementia.

Mixed dementia

This is when a person has more than one type of dementia. It is common for someone to have both Alzheimer's disease and vascular dementia.



For more information see factsheet 440,
What is young-onset dementia?

Alcohol-related brain damage

This is caused by damage to the brain as a result of drinking much more alcohol than the recommended limit. Alcohol damages brain cells and causes brain tissue to shrink.

Less common causes

There are many causes of dementia which are less common, such as Huntington's disease, Creutzfeldt-Jakob disease and corticobasal degeneration.



For more information see factsheet 442,
Rarer causes of dementia.

It is important that you are told about the type of dementia that you have, as this can help explain the type of changes you experience. It may also affect the treatment and support available to you.

For more information on the different types of dementia see section 3, 'How does dementia affect younger people?'



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Is young-onset dementia hereditary?

Young-onset dementia is not usually hereditary (inherited). However, around one in 10 people with young-onset dementia will have inherited it. This figure is much higher than in late-onset dementia.

If you inherited dementia, it may also affect your siblings or any children you have. This might be very difficult for you to accept. People sometimes feel guilty about this and think that they are responsible. It may help to remember that you did not have a dementia diagnosis when you had your children, so you could not have done anything to prevent it being passed down.

It is important to talk about how you're feeling. There are some services that are set up to support people and their families living with a hereditary form of dementia. For more information see 'Other useful organisations'.

If anyone in your family is worried about inheriting dementia, they should talk to their GP first, who can arrange for them to be counselled and tested for certain genes (genetic testing) if this is appropriate. If there are other members of your family that have young-onset dementia (especially Alzheimer's disease or frontotemporal dementia), the GP may refer your sibling or adult children to a regional genetics clinic, where they will be given more information and can discuss their risk of developing dementia.



For more information see factsheet 405, Genetics of dementia.



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How does dementia affect younger people?

Dementia affects people in different ways. The ways in which dementia affects you in the early stages will depend partly on the type of dementia you have.

Alzheimer's disease

Memory loss and memory problems (for example, losing things or struggling to find the right word) are often the earliest symptoms of Alzheimer's disease. However, up to a third of younger people with Alzheimer's disease have an unusual type (known as atypical Alzheimer's disease). Memory loss is not one of the first symptoms of atypical types.

If you have an atypical form of Alzheimer's disease, it is more likely that some of the first changes you develop will be in your vision (posterior cortical atrophy), speech (logopenic aphasia), or planning and decision-making (frontal variant Alzheimer's disease).

For a small number of younger people with Alzheimer's disease there is a clear inheritance of the disease – known as familial Alzheimer's disease. Symptoms usually start when someone is in their 30s, 40s or 50s.



For more information see factsheet 401, What is Alzheimer's disease? and factsheet 442, Rarer causes of dementia.

Vascular dementia

Memory loss is not always an early symptom of vascular dementia. You are more likely to have problems thinking things through as well as a slower speed of thought. If vascular dementia follows a stroke, physical problems (such as weakness in a limb) are more common.

Some younger people may have a rare genetic form of vascular dementia known as CADASIL (cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy). This is more likely to appear in people aged 30–50. Symptoms include migraines, repeated strokes and fits.



For more information see factsheet 402, What is vascular dementia? and factsheet 442, Rarer causes of dementia.



Frontotemporal dementia (FTD)

There are three types of frontotemporal dementia:

- **Behavioural variant FTD:**

The first symptoms for someone with this type of FTD are likely to be changes in personality and behaviour – such as changes in ability to control impulses. It is also common for people to have problems with planning, organising or making decisions.

- **Progressive non-fluent aphasia:**

This type of FTD causes changes to speech, such as slow speech or errors in grammar.

- **Semantic dementia:**

This type of FTD causes a loss of vocabulary and understanding of what objects are, such as trouble finding the right word or recognising common objects.

In all types of frontotemporal dementia, people are less likely to have problems with memory in the early stages.



**For more information see factsheet 404,
What is frontotemporal dementia (FTD)?**

‘At times I think, well I’m 54 and I have dementia! I do try to find my own coping mechanisms.’

Younger person living with dementia

Alcohol-related brain damage

Alcohol-related brain damage (including Korsakoff's syndrome and alcohol-related dementia) can affect people in similar ways to Alzheimer's disease and vascular dementia.

However the symptoms of alcohol-related brain damage can stop progressing – and even reverse – in some people. Appropriate treatment, eating well, and not drinking alcohol can all help.

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**For more information see factsheet 438,
What is alcohol-related brain damage?**

Dementia with Lewy bodies

If you have dementia with Lewy bodies you may have varying levels of alertness and experience hallucinations. You may also have some of the features of Parkinson's disease such as slower movement, stiffness and trembling limbs.



**For more information see factsheet 403,
What is dementia with Lewy bodies (DLB)?**

Other types of dementia

Less common causes of dementia include Huntington's disease, progressive supranuclear palsy, corticobasal degeneration (CBD) and Creutzfeldt-Jakob disease (CJD) which is very rare. These types are all likely to cause problems with movement.



**For more information see factsheet 442,
Rarer causes of dementia.**





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The progression of dementia

Dementia is a progressive and life-limiting condition. This means that, over several years, your symptoms are likely to become worse and you will need more help. Eventually you may need care to support you at the end of life. If you have a diagnosis of CJD this is likely to progress much more rapidly, over just a few months.

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Different factors can affect how quickly a person's dementia progresses – including their genes and their overall health. There is also some evidence that keeping active and involved can help a person keep their mental abilities for longer.

Some people think that dementia progresses at a faster rate in younger people. There is not enough evidence for us to be sure of this.

It's important to remember your experience of dementia will be completely unique to you.



**For more information see factsheet 458,
The progression and stages of dementia.**

Everyone is different, but as dementia progresses, the changes in people with all types of dementia start to overlap.

These can include:

- becoming more confused about the time and place, and having greater problems with reasoning
- having more severe problems with communication and speech



- memory problems becoming worse – forgetting events, names and faces
- delusions (strongly believing things that are not true) and visual hallucinations (seeing things that are not there)
- changes in behaviour – for example, asking the same questions over again or getting agitated
- walking more slowly and less steadily, losing weight and having difficulties with swallowing or eating.

In the later stages of young-onset dementia, someone will generally need full-time care and support. This may be distressing to think about, but it can help to be prepared. You may also want to think about what you want to happen when this time comes and also when you reach the end of life.

Consider where you want to be cared for, and also think about what is important to you – the things that make you feel comfortable, safe or content. They might be certain routines you follow, the way you like things done or your spiritual beliefs. Advance statements and advance decisions can help. See ‘Planning ahead’ on page 61 for more information.



You or someone supporting you may find it helpful to look at factsheet 417, The later stages of dementia and factsheet 531, End of life care.



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Living well

Living with dementia is challenging. You may feel angry or frustrated at times. Your plans for the future might change, but dementia doesn't change who you are – even though it may change aspects of your behaviour and sometimes personality. It may take you some time to adjust to living with dementia.

There are practical things you can do to help you live as well as possible. Dementia doesn't mean you have to change everything you do immediately. It's important to continue doing things you enjoy. Try to keep things as normal as possible, making changes when you need to. It can help to make the most of every day.

Keeping involved and active

You might feel like you no longer want to go out or do the activities you have been doing. However, it's important to keep active to help you stay as healthy and independent as possible.

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Adjustments can be made to help you with certain activities or interests. Focus on the things you want and are able to do. You might want to take up a new hobby or activity. Activities such as swimming, walking, cooking or painting can help you stay independent and provide enjoyment. They can also keep you in touch with other people, help you to feel confident, and improve your quality of life. It's important to find what works for you.



For more information see booklet 1506, Keeping active and involved.

You may also be able to continue being active in ways you are now, like working and driving. For more information see section 6, 'Work, money and legal matters'.

Keep doing things with the people who are important to you, where possible. This will help you to be positive and stay in touch with others.



Staying healthy

Staying healthy is important and can make a big difference to your quality of life. There is a lot you can do to stay healthy (or improve your health) including exercise, eating and drinking well and taking care of your physical health.

Eating and drinking well is important to stay healthy. It is important to eat enough as if you don't you might be more tired and likely to develop infections. Not drinking enough could lead you to become dehydrated and confused.

You might find the following tips useful:

- Try to eat balanced meals and drink plenty of fluids.
- Exercise regularly (you could try walking, swimming or gardening, for example).
- If you smoke, consider stopping.
- Try to get enough sleep.
- Take your medications and tell your doctor about any side effects.
- If you find yourself regularly feeling low, anxious or irritable, see your GP.
- If you are in pain, it is important to tell your doctor or carer.
- If you drink alcohol, you may want to continue drinking sensibly. Some people with dementia find they become more confused after drinking alcohol and choose to stop drinking.

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Connect support line on **0333 150 3456**

Making changes to your home

There are changes you can make to your home to help make daily living easier.

For example:

- improve the lighting (it should be good and evenly distributed)
- reduce clutter
- remove any trip hazards such as loose rugs and carpets
- reduce noise distractions by switching off TVs and radios when they're not being used
- consider equipment, such as grab rails for stairs, or devices such as automatic light sensors or a calendar clock.

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It might help to make some of these changes earlier so that they are in place as your dementia progresses. An occupational therapist (OT) can advise on how to make daily living easier and equipment and adaptations for your home. Ask your GP or consultant, or the local council, about contacting an OT.



For more information see booklet 819, Making your home dementia friendly.



Communicating

Many people with dementia find communication becomes more difficult over time. This can be very frustrating and upsetting, and can cause people to feel less confident.

If you are having problems with communicating or language, there are things that might help:

- Make sure the environment is quiet and there are not lots of distractions (such as the TV on in the background).
- Let people know what works for you (for example, talking slowly and giving you more time).
- Ask your GP or consultant for a referral to a speech and language therapist (SALT).
- Use technology that can help (for example, a tablet computer).

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‘Do not sit at home. Do not let others do for you what you can do for yourself. Use your brain and keep using it, stretch it, make it work, even when it takes so much effort just to figure out what used to be so easy.’

Younger person living with dementia

Coping with memory loss

Some younger people with dementia have problems with their memory, which can be very frustrating and distressing, and can undermine confidence.

If you develop problems with your memory, there are things you can do to help:

- A diary or notebook might be helpful for remembering appointments and events and recording things that have happened.
- Use aids at home. For example, label doors and cupboards with a picture and the name of what's inside them. You could also place useful telephone numbers by the phone, and put a note on the door to remind yourself to lock up at night.
- Ask your pharmacist about putting your pills in a dosette box (a simple box with separate compartments for days of the week and times of day).
- Consider whether any gadgets or pieces of technology might work for you – for example, setting alarms or reminders on a phone or tablet device.

You can also get support to cope with memory loss and any other changes, for example in your behaviour or ability to communicate. See Section 7, 'Services and support' and **booklet 1540, [The memory handbook](#)**.





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Getting involved

Some people with dementia want to get involved in work to understand dementia and support those who are living with the condition.

Sharing your experiences can help research into the cause, cure, care and prevention of dementia. There are two main ways you can do this:

- **Taking part in research** – this could involve completing questionnaires or interviews about your experiences, or trials for new treatments. You can register your interest in this by contacting Join Dementia Research. This service matches anyone interested in dementia research with studies taking place in their area. For more information see www.joindementiaresearch.nihr.ac.uk or contact Alzheimer's Society on **0333 150 3456**.
- **Planning and designing research** – this gives you an opportunity to influence our research at every stage including identifying topics for research. Involving people with dementia helps to make sure that research focuses on benefits for them now and in the future. To find out more about contributing to research go to alzheimers.org.uk/researchnetwork

Other ways to get involved

There are lots of other ways to get involved in the work of organisations that support people living with dementia:

- Alzheimer's Society is keen to hear from people who are living with or affected by dementia for various projects – including reviewing information and publications about dementia, and sharing your experience of dementia with the media. For more information visit www.alzheimers.org.uk/yoursay
- There are also opportunities for people living with dementia to volunteer in different ways. For more information go to www.alzheimers.org.uk/volunteer
- The Dementia Engagement and Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia. For more information visit www.dementiavoices.org.uk
- The Dementia Action Alliance is a network of organisations across England that aim to transform the lives of people with dementia. For more information visit www.dementiaaction.org.uk
- The Young Dementia Network provides opportunities for young people with dementia, their families and friends, and health and social care organisations to share experience, knowledge and to learn from each other. It encourages improved young-onset dementia services across the UK. For more information visit www.dementiauk.org/the-young-dementia-network



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Treatment and care

Although there is no cure for dementia, there is treatment and support available for people living with the condition.

Treatment

With many types of dementia it is likely that you will be offered drug treatment to help with some of the symptoms you experience.

If you have been diagnosed with Alzheimer's disease, dementia with Lewy bodies, or some types of mixed dementia, you may be prescribed one of a group of drugs known as cholinesterase inhibitors (for example, donepezil, rivastigmine or galantamine). Later on, you may also be prescribed a different kind of drug called memantine.

If you have vascular dementia you will be given medication to manage any underlying conditions (such as high blood pressure or diabetes).

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If you have behavioural variant frontotemporal dementia you may be prescribed an anti-depressant to help with some of the symptoms.

If you have dementia with Lewy bodies or Parkinson's disease dementia you may be prescribed a cholinesterase inhibitor if you are experiencing distressing symptoms (such as hallucinations).



For more information about possible drug treatments, see factsheets 407, Medicines to help memory and thinking, and 408, Antipsychotic drugs and other approaches in dementia care.

If you are having difficulties with your medication (for example remembering what medicine to take when) ask your pharmacist about ways to help. For example, you could ask for a dosette box (see 'Coping with memory loss' on page 36).



Other treatments

Drug treatments can be important – but they are only a small part of the care and support you should receive. There are many other kinds of treatment that can be used to support you. Ask your GP or another healthcare professional about any of the following.

Cognitive stimulation therapy

This involves activities and exercises to help improve memory and communication. It often takes place in groups.

Cognitive rehabilitation

This involves a psychologist or occupational therapist working with you and someone close to you to help you achieve an agreed goal. This could be learning to use a mobile phone or re-learning a life skill such as cooking. Cognitive rehabilitation works by getting you to use the parts of your brain that are working to help the parts that are not.

Life story work

This involves working with someone over time to make a personal record of important experiences, people and places in your life. This could be in a book or photo album, or on a computer.

Talking therapies

Talking therapies can help you adjust to the changes you are experiencing. They usually take place with a professional, such as a counsellor, clinical or counselling psychologist, psychotherapist, psychiatrist or nurse.

The professional will encourage you to talk about your thoughts and feelings, and how these affect your mood and the things you do.



Different kinds of talking therapies include:

- **counselling** – this involves talking about your concerns and being listened to without judgement. It can be on your own or in a group. Family counselling is also a possibility – focusing on the whole family and how they have been affected by an issue.
- **psychotherapy** – this involves help to think about how your personality, beliefs, and life experiences affect how you are thinking, feeling and behaving now.
- **Cognitive behavioural therapy (CBT)** – this is a common type of psychotherapy. It involves finding the links between your thoughts, feelings and actions, and focusing on more positive ways to think, feel and act.

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Opportunities to talk

Talking to other people with young-onset dementia can be helpful, as they may be experiencing similar challenges and difficulties. Many people with young-onset dementia find talking to others can provide them with comfort, support and advice. However, it isn't right for everyone. If you feel it would be helpful for you, contact DementiaUK to find out whether there are groups you can attend.

You can also find other ways to talk about what's on your mind or how you're feeling, without any kind of therapy.



**For advice and support, call our Dementia
Connect support line on 0333 150 3456.**

**Visit Talking Point, our online community:
alzheimers.org.uk/talkingpoint**



Planning for your future care

You may already be dealing with changes you didn't expect, especially at this age. It can be even more difficult to think about the future.

However, thinking ahead is a good thing to do. It can help you prepare for a time when it may be difficult to make decisions for yourself – especially about the care and treatment you would like to receive.

Making plans can also help your family and friends. They can act to support your wishes because you have made it clear to them what you would prefer. While you may find talking about these things difficult, it is likely to make things easier for your family and friends later on.

There are different systems for recording your wishes for future care in England, Wales and Northern Ireland.

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'Recognise when you can no longer do something... focus on what you can do and keep striving. Consider volunteering... helping others is uplifting.'

Younger person living with dementia

Advance decisions (England and Wales) and advance directives (Northern Ireland)

An advance decision to refuse treatment (ADRT) in England and Wales, or advance directive in Northern Ireland, sets out your wishes concerning medical treatments that you may not wish to receive in certain situations. For example, you may not want to have a blood transfusion because of your beliefs. It can also include a decision not to be resuscitated if your heart stops.

Health professionals must follow your wishes if you are unable to make a decision for yourself at the time. To make sure they follow these, it's important that your advance decision or directive is recorded in writing and includes certain information.

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For more information and a template advance decision form see factsheet 463, Advance decisions and advance statements, or if you are in Northern Ireland see factsheet NI467, Financial and legal tips.

Advance statements (England and Wales) and living wills (Northern Ireland)

An advance statement in England and Wales, or living will in Northern Ireland, is a document that lists your general wishes and preferences for the future. This could include things such as where you would like to live in the future, or record things about you like your favourite foods, music or films.



Advance statements and living wills are not legally binding but if future decisions are made on your behalf, any advance statement must be taken into account. If a decision is made that goes against an advance statement, there has to be a very good reason for this.



For more information and a template advance statement to use as a starting point see booklet 1510, Planning ahead (in England and Wales). If you are in Northern Ireland see factsheet NI467, Financial and legal tips.

Lasting power of attorney (LPA) for health and welfare (England and Wales)

If you are in England or Wales, you can also appoint someone you trust to make decisions about your care and treatment if you become unable to make these decisions for yourself. This is known as a Lasting power of attorney (LPA) for health and welfare. For more information see the next section, 'Work, money and legal matters'.

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'It is very important to keep active. I'm an Ambassador and Dementia Friends champion for Alzheimer's Society.'

Younger person living with dementia



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Work, money and legal matters

As well as your care and treatment, there are practical things to think about. It is a good idea to make plans for these too.

Talking to your employer

Many younger people say that their first symptoms of dementia appeared while at work. You may have found that you forgot meetings or appointments, or were unable to concentrate and found it difficult to follow conversations.

You don't have to give up work just because you have dementia. Some people work for several years after they receive a diagnosis. However, you may decide that you no longer want to work, or that the type of work you do means it isn't possible to carry on.

This can be a very difficult decision to make and it is important to take the time you need to think this through. Work may be important to you for lots of reasons, which are not just financial. It may give you independence, a sense of purpose and a community, and may be part of your identity.

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It's best to tell your employer about your diagnosis of dementia and let them know whether you want to carry on working.

Not everyone has to do this legally, but check your contract as this does vary. In some jobs, you must tell your employer – for example:

- if you drive as part of your job
- if you are in the armed forces.

By telling your employer you gain certain legal rights. Your employer cannot discriminate against you on the basis of your diagnosis.



You can also ask for ‘reasonable adjustments’ to enable you to carry on working for longer. For example some people may ask to be able to work in a different location, such as an office closer to home, or to work from home. It may be that having more or longer breaks, or moving to a quieter area, can help.

Reasonable adjustments can also include equipment and adaptations. There is a lot of assistive technology that can help people with dementia remain in the workplace. Your employer can only turn your request down if they have a business case for doing so.

Some people ask to take a lower position or a post with less responsibility. It may help to think carefully about your role and what you think will be most helpful for you.

You may find it helpful to let your employer know where they can find out more about how to support people with dementia.



**For more information see booklet 1509,
Employment**

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Managing your money

When you have dementia, managing your money from day to day can be more difficult. You may forget to pay bills, or take money out of the bank and then forget where you’ve put it.

You might also want to start thinking about how you will manage your money in future. At some stage you may need to think about your bank account or ask someone to manage your money on your behalf. It can be hard to think about the future now, but it can help to be prepared.



**For more help and advice call our Dementia
Connect support line on 0333 150 3456**

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There are lots of things you can do to make dealing with money easier:

Ways to pay

Find a way to pay that works best for you. This might be using:

- cash
- a Chip and PIN debit card
- a contactless bank card
- direct debit
- cheque.



For more information on these payment methods see booklet 1501, Managing your money.

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Bank account

There are things you can do to make managing a bank account easier, including:

- using telephone banking, which allows you to access your account and make payments over the phone
- registering for online banking, which allows you to do many of the things you do in your branch. These include viewing your balance and statements, making payments, and managing standing orders and direct debits.



Trusts

If you have property or savings, you might want to think about setting up a trust. This is a legal arrangement that allows someone to hold these things (your assets) on your behalf. It will ensure that your money is managed the way you want from now.

In the future it could be used to pay for care or where you live.

Keeping money safe

After a diagnosis of dementia, there are things you can do to make sure your money is safe in the future. People with dementia can be more vulnerable to financial scams and tricks.

There are things you can do to keep your money safe such as keeping good records of finances. You can also ask your bank to put a limit on how much money can be taken from your account at any one time. If you are employing a carer or people to support you at home, run background and reference checks through a DBS (Disclosure and Barring Service) check.



For more information see [GOV.UK](https://www.gov.uk)

'I went to see a solicitor after being diagnosed and made a power of attorney for my finances.'

Younger person living with dementia



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Financial support – benefits

People with dementia and those supporting them may be entitled to a range of benefits. Some are means-tested so they depend on income or savings. Accessing them can seem complicated but there are people who can advise on what to claim for.

The forms for applying for benefits can be long and detailed. Try to get help from someone who can complete these with you. Help may be available from:

- a social worker
- a local welfare rights service
- Citizens Advice or Age UK
- the GOV.UK website
- the Department for Social Development (in Northern Ireland).

For some benefits, the Department for Work and Pensions (DWP) can arrange for someone to visit you at home.

Types of benefits

Some benefits are for people who are out of work, while others are for people who are employed. There are also a range of benefits that people can be eligible for whether they are working or not. These benefits can be claimed whether you live alone or with other people. If you go into hospital or residential care for a prolonged period, any benefit may be suspended temporarily.



Benefits for people out of work

- **Employment and support allowance (ESA):** this is the main benefit for people of working age who are unable to work due to ill health. Eligibility is based on your ability to carry out particular, work-related tasks. Payment can be based on either a National Insurance record or a means test.
- **Income support:** this is a means-tested benefit paid to certain people, including some carers, who aren't expected to look for work. It's intended to provide for basic living expenses and can be paid on top of other benefits such as Carer's allowance (see page 57).

In-work benefits

- **Working tax credits:** this is a means-tested benefit that can be claimed by some people who are on a low wage. Working tax credit is being phased out and will eventually be replaced by Universal credit.

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For more information visit [GOV.UK](https://www.gov.uk)

- **Statutory sick pay:** this can be paid for up to 28 weeks if someone has a job but has been sick and unable to work. It isn't affected by any savings, but there are certain rules to qualify. This benefit is paid by the employer, who can give you information about claiming.



Benefits for people in or out of work

- **Personal independence payment (PIP)** (or Disability living allowance if you claimed before June 2013). This is based on daily living, care and mobility needs, not on the dementia diagnosis. It's not means-tested or based on National insurance contributions. PIP is the new benefit that people under 65 need to apply for. It has two components, for daily living (for example washing or preparing meals) and mobility (for example difficulty walking outside). There will be gradual transfer to PIP for people who currently receive DLA and were born after 8 April 1948.
- **Housing benefit or Council tax support:** if you are on a low income, you may also be entitled to means-tested Housing benefit (if renting) or Council tax support. The local council can advise. Many people with dementia can also get reductions on their Council tax bill – this isn't affected by income or savings.
- **Cold weather payments:** some people on a low income may also qualify for these during very cold periods.

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Carer's allowance

If someone looks after you for at least 35 hours a week, and you receive certain benefits, that person may be entitled to Carer's allowance. Your carer should seek advice before deciding whether to claim. They can get a claim form by calling the Carer's allowance unit on **0800 731 0297** or at **GOV.UK**



For more information see factsheet 413, Benefits for people affected by dementia and go to alzheimers.org.uk/benefitrates



For more help and advice call our Dementia Connect support line on **0333 150 3456**

Attending a face-to-face assessment for ESA and PIP

As part of the assessment for ESA you will be asked to attend a 'work capability assessment' to see the extent to which your illness or disability affects your ability to work. You are also likely to be asked to attend a face-to-face consultation as part of a PIP assessment. Both of these are undertaken by healthcare professionals.

If there is someone who can support you at the assessment appointments, ask them to go along with you. They won't be able to answer questions on your behalf, unless the healthcare professional cannot understand your speech or you cannot understand their questions. But they will be able to add to what you have to say.

When answering the healthcare professional, tell them about any pain or tiredness you feel and whether you feel you would be able to complete a task to a reasonable standard. Let them know if there would be any risk if you tried to undertake the task, if it would take you a long time to complete it or if you need prompting or encouragement. If your condition varies, it is important that you tell the healthcare assessor this, and explain what you are like on bad days as well as on good days.

Putting someone else in charge of benefits

If you are living with dementia, you can contact the Department for Work and Pensions to appoint someone you trust – an ‘appointee’ – to receive and manage the money you get in benefits. The proposed appointee will have to prove that they are managing your money with your best interests in mind. DWP will monitor the situation.

Driving and getting around

Having a diagnosis of dementia doesn’t always mean you have to stop driving straightaway, though you may have already stopped or be thinking about giving up driving. If you have a driving licence, there are things the law says you must do:

- inform the Driver and Vehicle Licensing Agency (DVLA) in Great Britain, or Driver and Vehicle Agency (DVA) in Northern Ireland, as soon as possible
- follow the advice of your doctor if they say you must stop driving immediately – while DVLA are making a final decision
- inform your car insurance company.

The DVLA or DVA will ask your doctor for a report. They may also ask you to take a driving assessment. They will use these to decide whether you are still able to drive.

The DVLA or DVA may decide you can no longer drive safely – or you may decide to give up driving voluntarily. You might think about giving up driving if you’re feeling less confident, getting more irritated, or if you’re getting lost on roads you know well or struggling to judge distances, for example.



If you do need to give up driving, it can be a difficult experience. Sometimes people feel they have lost their independence or freedom. It can be especially hard if you need to drive for work or have dependent children, as they may rely on you for lifts. You may feel guilty or angry that this is impacting them as well as you.

It can take time to adjust to this. You might find it helpful to think about other ways you (and others) can get around: find out what public transport services are running in your area and when.

Try to focus on the benefits of not driving as well – for example:

- you no longer have to try and remember routes, or find space to park
- you can save money on car insurance, road tax, maintaining your car, and petrol
- if you walk more often, it's a chance to get more exercise.

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For more information see booklet 1504, Driving.

'I think, 'consequences, consequences, consequences'. Hard as it will be for me to give up my driving licence, when I or my husband/friends know I am no longer safe to drive, I will let it go. Better I lose my licence than someone else loses their life. Until that point, I will savour it.'

Younger person living with dementia

Planning ahead

It is important to make plans for the future and make sure your family know what your wishes are and that you are legally protected.

Lasting powers of attorney (LPA) (England and Wales)

A Lasting power of attorney is a legal document that gives an adult the authority to make decisions for another adult. Even if you have not thought of creating an LPA before, it is important to think about how this can help in the future. Having an LPA will make it possible for someone you choose to make certain decisions for you, should the time come when you are not able to make them for yourself.

There are two types of LPA: one covering property and financial affairs (such as bills, bank accounts and selling property) and the other health and welfare (such as day-to-day care and treatment).



For more information on LPAs see factsheet 472, Lasting power of attorney.

You can choose to use a solicitor, but you don't have to. The forms to make an LPA are available on GOV.UK, or you can contact the Office of the Public Guardian and ask for them to be sent to you (see 'Other useful organisations'). The government has also created an online tool to aid people in making their own LPA.



For more help and advice call our Dementia Connect support line on 0333 150 3456

If you don't have access to the internet, Alzheimer's Society offers a Lasting power of attorney Digital Assistance Service to help people create and register Lasting powers of attorney. It is also available to anyone who feels they don't have the skills or confidence to use a computer to complete the forms themselves. A trained volunteer will use an online tool created by the government to complete the form on your behalf. You can access the service by contacting Alzheimer's Society on **0333 150 3456**. The service does not offer legal advice.

Enduring power of attorney (EPA) (Northern Ireland)

In Northern Ireland someone can make an Enduring power of attorney (EPA) to appoint someone they trust to manage their finances and any property if they are unable to do this in the future. Generally people will set this up through a solicitor, but someone can get the forms from legal stationers, or the Office of Care and Protection.

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For more information see factsheet NI472, Enduring power of attorney and controllership.

'Soon after diagnosis, me and my daughters sat down and wrote my Lasting power of attorney. Yes, it was a difficult conversation, but at least I now know my daughters won't have to make those difficult emotional decisions in the future as they're now filed safely away until needed.'

Younger person living with dementia

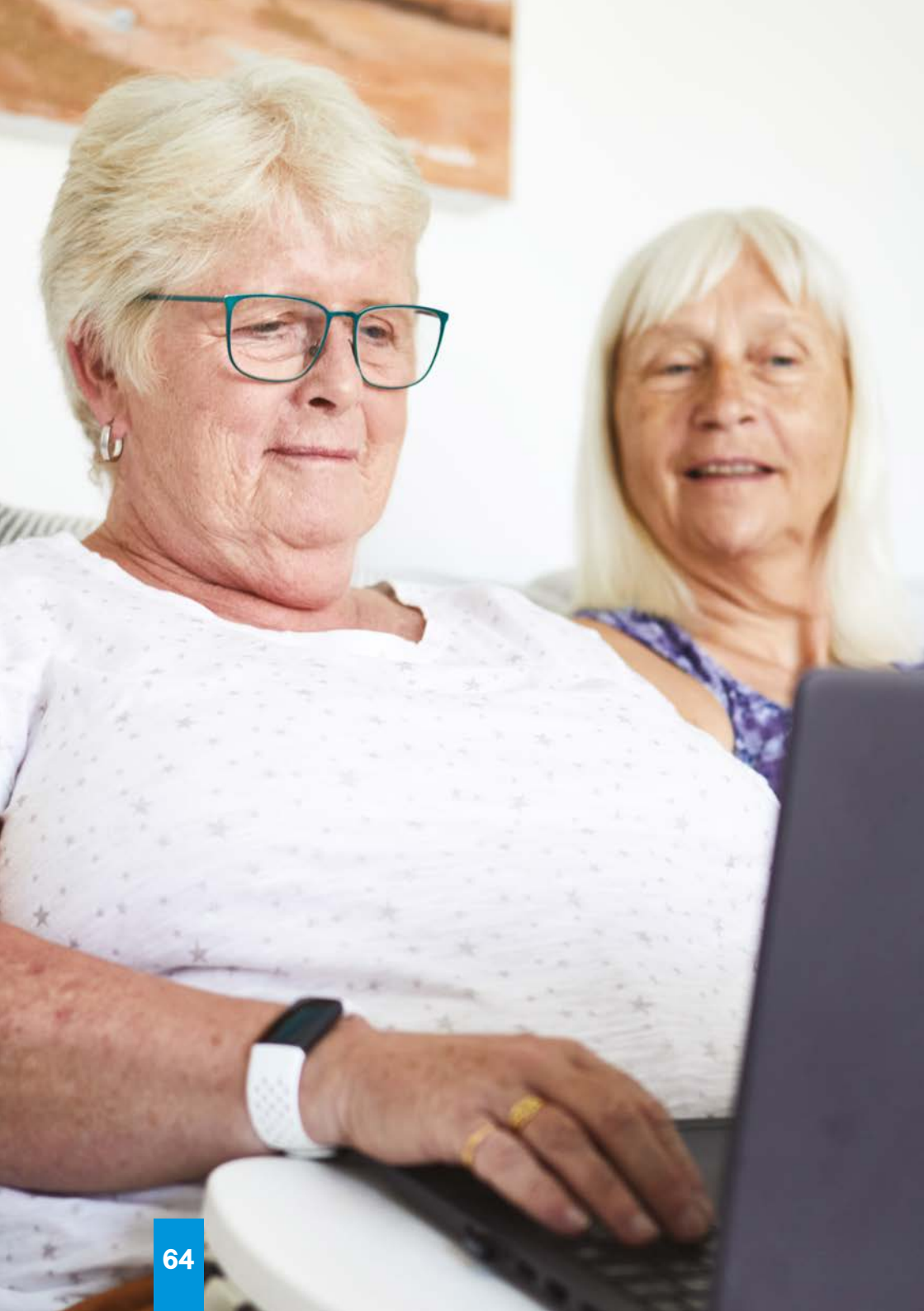
Wills

An important way to prepare for the future is to write a will. A will is a legal document that states who your possessions, property or assets should go to when you die. Speak to a solicitor for more information.

Planning for a funeral

It has become more common for people to plan and even pay for a funeral in advance. The advantages of doing this include being able to plan the funeral that you would like. It can also make it easier for your family and friends to arrange the details. Undertakers or funeral service companies should be able to provide you with more information about funeral planning.





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Services and support

A range of support services are available for people with dementia in many areas of England, Wales and Northern Ireland. These can usually be accessed by people with dementia of any age.

As a younger person with dementia, you will require services that are able to meet your specific needs. Services for younger people with dementia may include specialist support workers or nurses, support groups, dementia cafés and specialist holidays. While some areas have a range of services for younger people with dementia, in other areas there may not be any specialist services.

You can find out more about which services are available by contacting:

- your GP, or the service where you were diagnosed with dementia
- your local memory clinic or neurology clinic, who can advise on any local services for younger people with dementia
- DementiaUK, who have a list of services across the UK for younger people with dementia:
www.dementiauk.org/about-dementia/young-onset-dementia/find-support
- Rare Dementia Support groups – support groups available for people with certain forms of dementia that are more rare: www.raredementiasupport.org

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You can search for local services via alzheimers.org.uk/dementiadirectory



Health and social care professionals

As you come to need more care, many different professionals are likely to be involved. These include doctors, other health professionals, and social care professionals.

Doctors

Your GP can support you in many different ways, including talking to you about your symptoms and medical problems (not just dementia), carrying out a physical examination, arranging further tests with a consultant or hospital specialist, and reviewing whether your drugs are working.

You may also see a number of consultants. These might include a psychiatrist – who can help with dementia as well as mental health problems like depression and anxiety – and a neurologist, who specialises in the brain and nervous system.

Other health professionals

Nurses are also likely to care for you, and the people who support you, in a number of ways. These might include community nurses (including community mental health nurses known as CPNs) who can provide support at home, and Admiral nurses who specialise in dementia care, especially supporting carers.



You can get support from other health professionals to help with many different issues:

Issues	Who can help?
Communication, eating, drinking and swallowing	Speech and language therapist
Maintaining skills and independence	Occupational therapist
Exercising and moving around	Physiotherapist
Caring for your feet	Chiropodist
Eyesight	Optometrist
Hearing	Audiologist
Behaviours, anxiety and restlessness	Music therapist, clinical psychologist (for example)
Relationship and emotional issues	Counsellor or clinical psychologist
Nutrition	Dietitian
Toilet problems	Continence adviser

Social care professionals

Social workers and social care workers can help you in non-medical ways. Social workers assess your needs and advise on the best support for you. Social care workers help with practical things like washing, dressing and eating.

Paying for social care and support

Many people diagnosed with dementia will reach a stage where they need professional care and support at home to help them live well with the condition. Friends and family who care for a person with dementia may also need support.

Some people with dementia and their carers will be entitled (often called 'eligible') to financial support with all or some of the costs of this care. They must meet certain criteria to be eligible.

England

In England, a local authority has a duty to carry out a 'care needs assessment' for anyone with dementia. The assessment is to determine what care needs you have and whether the local authority will contribute towards meeting them.

Wales

In Wales, a local authority has a duty to carry out a 'community care assessment' for anyone with dementia who may require community care. They also have a duty to provide services directly or – more often – make arrangements to meet any needs for which someone is eligible.



Northern Ireland

In Northern Ireland, a local health and social care (HSC) trust has a duty to carry out a 'community care assessment' for anyone with dementia who may be in need of support.

Carer's assessments are also available so that the person who is caring for you can receive support to help them with their caring role.



For more information, see factsheet 418, Assessment for care and support in England, factsheet W418, Assessment for care and support in Wales or factsheet NI418, Assessment for care and support in Northern Ireland.

Support in the later stages of dementia

People with dementia are likely to reach a stage where they need more support. It can be useful to plan ahead for this time.

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Some people may choose to have live-in carers (where a carer lives with them 24 hours a day). There are different options available such as Shared Lives (a scheme where the person lives with a trained Shared Lives carer) and homecare agencies. For more information speak to a professional such as a dementia specialist nurse or social worker.

Sometimes people go into a care home after their dementia progresses. There are a few care homes that specialise in caring for younger people. A professional such as a doctor or social worker, or another voluntary sector organisation may be able to give advice on choosing a care home. At this point, it is likely that someone caring for or supporting you will need to arrange this.



For more information see factsheet 476, Care homes: when is the right time and who decides?





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Alzheimer's Society support services

Alzheimer's Society's Dementia Connect service provides a range of information, advice and support to anyone affected by dementia in England, Wales and Northern Ireland. You can reach us online, on the phone and face-to-face.



Online

Visit [alzheimers.org.uk/get-support](https://www.alzheimers.org.uk/get-support) for online advice and support whenever you need. Here, you'll find information on any aspect of dementia and the option to download or order what you need from our wide range of publications.

You can also connect to others affected by dementia on our online community Talking Point, and search for services in your area using our dementia directory.

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Phone

You can contact our Dementia Connect support line by calling **0333 150 3456** seven days a week. If you speak Welsh, call our Welsh-speaking support line on **03300 947 400**. Our dementia advisers are available to tackle problems, share advice and practical information or simply provide a listening ear. They can send out information that's right for you via email or post and connect you to help in your local area.



Alzheimer's Society offers a Lasting power of attorney digital assistance service to help people with dementia create LPAs online. If you don't have access to the internet, we can help you to create an LPA through a series of telephone appointments. Please note that we do not provide legal advice. Call us on **0333 150 3456**.



Face-to-face services

Our trained staff and volunteers can connect and signpost you to practical advice, support and information in your local area. This includes face-to-face services when these are available. They can make things easier and help you continue doing things that are important to you.

We also oversee support groups that meet in person and sometimes via video or phone. These include Singing for the Brain®, peer support for people with dementia, and information and support groups for carers.

To find out what support is available in your area, call us on **0333 150 3456** or visit [alzheimers.org.uk/dementiadirectory](https://www.alzheimers.org.uk/dementiadirectory)

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For more help and advice call our Dementia Connect support line on **0333 150 3456**

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Other useful organisations

Citizens Advice

0800 144 8848 (for England, 9am–5pm Monday–Friday)

0800 702 2020 (for Wales, 9am–5pm Monday–Friday)

www.citizensadvice.org.uk

Citizens Advice provides free, confidential and impartial advice to everyone on their rights and responsibilities.

Dementia Engagement and Empowerment Project (DEEP)

www.dementiavoices.org.uk

DEEP brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia.

Dementia UK

0800 888 6678 (9am–9pm Monday–Friday,

9am–5pm Saturday–Sunday)

helpline@dementiauk.org

www.dementiauk.org

Dementia UK offers specialist one-to-one support and expert advice for people living with dementia, through specialist dementia nurses known as Admiral nurses. This includes for people with young-onset dementia.

GOV.UK

www.gov.uk

GOV.UK is the website for finding information and services from the UK government, including information about benefits.



Office of the Public Guardian (OPG)

0300 456 0300 (9.30am–5pm Monday, Tuesday,
Thursday, Friday, 10am–5pm Wednesday)
customerservices@publicguardian.gov.uk
www.publicguardian.gov.uk

The OPG supports and promotes decision making for those who lack capacity or would like to plan for their future within the framework of the Mental Capacity Act 2005.

Rare Dementia Support

020 3325 0828
contact@raredementiasupport.org
www.raredementiasupport.org

Rare Dementia Support runs specialist support services for individuals living with, or affected by, one of five rare dementia diagnoses. They support people affected by familial Alzheimer's disease, frontotemporal dementia, familial frontotemporal dementia, posterior cortical atrophy and primary progressive aphasia.

Shared Lives Plus

0151 227 3499
info@sharedlivesplus.org.uk
sharedlivesplus.org.uk

Shared Lives Plus is a UK network for family-based and small-scale ways of supporting adults. This includes the Shared Lives scheme.



Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

This booklet can be downloaded from our website at alzheimers.org.uk/publications

To give feedback on this booklet, or for a list of sources, please email publications@alzheimers.org.uk

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We are Alzheimer's Society. We are a vital source of support and a powerful force for change for everyone affected by dementia. We provide help and hope.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit [alzheimers.org.uk](https://www.alzheimers.org.uk) or call our **Dementia Connect support line** on **0333 150 3456**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)



People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need. To make a single or monthly donation, please call us on **0330 333 0804** or go to [alzheimers.org.uk/donate](https://www.alzheimers.org.uk/donate)



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Code 688

