Young-onset dementia:
Understanding your diagnosis

For more information
alzheimers.org.uk
0300 222 1122
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 – at least 42,000 people in the UK who are under the age of 65 have dementia, and there are around 850,000 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 the Alzheimer’s Society website:

For booklets and helpcards, visit alzheimers.org.uk/publications

For factsheets, visit alzheimers.org.uk/factsheets

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.
There is no ‘right’ or ‘wrong’ way to feel. 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 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 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?’
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. You may need some time and space now that you have a diagnosis, 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 the following ideas:

- finding a support group for people with young-onset dementia – where you can talk to others with a similar experience (See ‘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 445, Talking therapies.

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 helps them to cope with their emotions. Talk to people 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

For advice and support, call the National Dementia Helpline on 0300 222 1122
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 also show them helpcard 1562, I have dementia.

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.
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 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 discussion forum 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 – Alzheimer’s Society’s Dementia Connect. Visit alzheimers.org.uk/dementiaconnect

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.

For more information see factsheet 514, Sex and intimate relationships.

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 Dementia Connect to find out about services in your local area at [alzheimers.org.uk/dementiaconnect](http://alzheimers.org.uk/dementiaconnect)

For more information on how dementia can affect your 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 with dementia
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.

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.

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, and it may 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?’

For more information on the causes of different types of dementia see factsheet 400, What is dementia?
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.
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 been diagnosed with.
Alzheimer’s disease
Memory loss and memory problems (for example, losing things or struggling to find the right word) are often the earliest symptoms in 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 one of these forms, 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 booklet 616, Alzheimer’s disease: Understanding your diagnosis.

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 migraine, repeated strokes and fits.
How does dementia affect younger people?

For more information see booklet 614, Vascular dementia: Understanding your diagnosis.

**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.

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

Younger person 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.

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 booklet 37, Dementia with Lewy bodies: Understanding your diagnosis.

**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.
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.

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 of Alzheimer’s disease and other dementias.

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
How does dementia affect younger people?

- 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’ in section 6, ‘Work, money and legal matters’.

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

You or someone supporting you can find more information on the end of life in factsheet 531, End of life care.
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 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 overnight. 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.

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 be confident, and improve your quality of life. It’s important to find what works for you.

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

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.
- Take regular physical exercise such as walking, swimming or gardening.
- If you smoke, consider stopping.
- 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.
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.

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).

‘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 with dementia
Coping with memory loss

Some younger people with dementia have problems with their memory, which can be very frustrating and distressing, and 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, events and recording what has 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 ‘Services and support’ and booklet 1540, The memory handbook.
Getting involved

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

Research
Alzheimer’s Society and other organisations are funding and supporting research to try and understand the causes of dementia, how to prevent it, how to improve care for people with dementia, and how to cure it.

Research often relies on people with dementia volunteering to take part – either by participating in a research study or clinical trial, or by getting involved in planning and designing research.

You can register your interest in participating in research by contacting Join dementia research. This service helps anyone interested in dementia research to be matched with studies taking place in their area. For more information see www.joindementiaresearch.nihr.ac.uk or contact the National Dementia Helpline.

To find out more about getting involved in planning and designing research, visit 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 contact your local Alzheimer’s Society.

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.youngdementiauk.org/young-dementia-network
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, or mixed dementia where Alzheimer’s disease is the main type, you will usually be prescribed a cholinesterase inhibitor (donepezil, rivastigmine or galantamine) or memantine.

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

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, Drug treatments for Alzheimer’s disease, and 408, Drugs used to relieve behavioural and psychological symptoms in dementia.

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’ in the previous section).
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.

**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, speak to your local Alzheimer’s Society or Young Dementia UK 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 the National Dementia Helpline on 0300 222 1122.**

**Visit Talking Point, our online discussion forum:** [alzheimers.org.uk/talkingpoint](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. Whilst 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.

‘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 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.

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 like where you would like to live in the future, or 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.
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’.

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

Younger person with dementia.
Work, money and legal matters

As well as your care and treatment, there are practical things to think about. It is important 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, not just financial. It may give you independence, a sense of purpose and a community, and may be part of your identity.

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 can help, or moving to a quieter area.

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.

Your employer could look at booklet 939, Creating a dementia-friendly workplace – A practical guide for employers.

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 at this stage to think about the future, but it can help to be prepared.
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.

**Bank account**
There are things you can do to make managing these 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*

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

Younger person with dementia

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For advice and support, call the National Dementia Helpline on **0300 222 1122**
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 and help you to complete the forms (which can be long and detailed).

Try to get help from someone who can complete these forms 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.
Young-onset dementia: Understanding your diagnosis

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. It can also provide some support for paying mortgage interest.

- 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 below).

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.

For more information visit 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. 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). These are based on daily living, care and mobility needs, not on the dementia diagnosis. They aren’t means-tested or based on National insurance contributions. PIP is the new benefit which 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). No new claims for DLA will now be taken. 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 through Council tax discounts. (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.

‘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 with dementia
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.
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 0345 608 4321 or at GOV.UK

For more information see factsheets 413, Benefits and 431, Benefit rates and income/savings thresholds.

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.

‘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 with dementia
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.

For more information see booklet 1504, Driving.

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, 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.

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 National Dementia Helpline on 0300 222 1122. 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.
For more information see factsheet NI472, Enduring Power of Attorney.

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.
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 cafes 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 Alzheimer’s Society, memory clinic or neurology clinic, who can advise on any local services for younger people with dementia
- Young Dementia UK, who have a list of services across the UK for younger people with dementia: [www.youngdementiauk.org/support-across-uk](http://www.youngdementiauk.org/support-across-uk)
- Rare Dementia support groups – support groups available for people with certain forms of dementia that are more rare: [www.raredementiasupport.org](http://www.raredementiasupport.org)

You can search for local services via [alzheimers.org.uk/dementiaconnect](http://alzheimers.org.uk/dementiaconnect)
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 and other 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 in many different ways, including:

- maintaining skills and independence (occupational therapists)
- exercising and moving around (physiotherapists)
- caring for your feet (chiropodists)
- vision (optometrists)
- hearing (audiologists)
- speech, communication, eating, drinking and swallowing (speech and language therapists)
- anxiety and restlessness (music therapists)
- relationship, emotional and behavioural issues (clinical psychologists)
- nutrition (dietitians)
- toilet problems (continence advisers)

**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.

For more information see booklet 1503, Health and social care professionals.
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 advice and support, call the National Dementia Helpline on 0300 222 1122
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 a time when the person with dementia needs more support.

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, your local Alzheimer’s Society 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, Selecting a care home.
Alzheimer’s Society services

Alzheimer’s Society provides a range of services and resources to support people affected by dementia.

National information and support services
These are available wherever you live in England, Wales and Northern Ireland.

National Dementia Helpline – 0300 222 1122
The Helpline is for anyone who is affected by dementia or worried about their memory. Trained advisers provide information, support, guidance and signposting to other appropriate organisations. The Helpline is open 9am–8pm Monday–Wednesday, 9am–5pm Thursday and Friday, and 10am–4pm Saturday and Sunday. You can also contact the Helpline by email at helpline@alzheimers.org.uk

Talking Point online discussion forum
Talking Point is an online support and discussion forum for anyone affected by dementia. It’s a place to ask for advice, share information, join in discussions and feel supported. Talking Point is available 24 hours a day, every day of the year. Visit alzheimers.org.uk/talkingpoint

Printed and online information
You can read and order publications online at alzheimers.org.uk/publications

You can also order printed copies by phoning 0300 303 5933.

You can also view Alzheimer’s Society videos for more information, as well as stories from people affected by dementia. Visit www.youtube.com/AlzheimersSociety
Local services
Alzheimer’s Society (and other organisations) provides a range of local services in England, Wales and Northern Ireland. Please note that not all the services listed below are offered everywhere.

- Dementia Adviser services
- Dementia support services
- Side by Side
- Dementia cafés
- Singing for the Brain® groups
- Community support services (including befriending)
- Support groups for people with dementia
- Support groups for carers
- Carer Information and Support Programme
- Advocacy services for people with dementia
- Day care and support services
- Homecare and support services.

Contact your local Alzheimer's Society office or the National Dementia Helpline for more information about Society services in your area, or visit alzheimers.org.uk/dementiaconnect
Other useful organisations

Citizens Advice
www.citizensadvice.org.uk
03444 111 444 (Advice line – England)
03444 77 20 20 (Advice line – Wales)

Provides free, independent, confidential and impartial advice to everyone on their rights and responsibilities.

Dementia Engagement and Empowerment Project (DEEP)
www.dementiavoices.org.uk

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
www.dementiauk.org

Offers specialist one-to-one support and expert advice for people living with dementia, through specialist dementia nurses known as Admiral nurses.

GOV.UK
www.gov.uk

The website for finding information and services from the UK government, including information about benefits.
Office of the Public Guardian
customerservices@publicguardian.gsi.gov.uk
0300 456 0300

PO Box 16185
Birmingham
B2 2WH

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
www.raredementiasupport.org
contact@raredementiasupport.org
07341 776 317

Queen Square
London

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

Shared Lives Plus
G04 The Cotton Exchange
Old Hall Street
Liverpool
L3 9JR

UK network for family-based and small-scale ways of supporting adults. Members include the Shared Lives scheme.

Young Dementia UK
www.youngdementiauk.org
web@youngdementiauk.org
support@youngdementiauk.org
01993 776295 – general enquiries
01865 794311 – support-related enquiries

Young Dementia UK
PO Box 315
Witney
Oxfordshire
OX28 1ZN

Charity that offers help to people whose lives are affected by young-onset dementia.
Notes
This booklet has been reviewed by people living with young-onset dementia and health and social care professionals.

It can be downloaded from our website at [alzheimers.org.uk/youngonsetdementia](http://alzheimers.org.uk/youngonsetdementia)

A list of sources is available on request.
Alzheimer’s Society is the UK’s leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

If you have any concerns about Alzheimer’s disease or any other form of dementia, visit alzheimers.org.uk or call the Alzheimer’s Society National Dementia Helpline on 0300 222 1122. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)