# Understanding young-onset dementia

Alzheimer's Society

Together we are help & hope
for everyone living with dementia

If you would like to give us any feedback on this booklet, you can email us at **publications@alzheimers.org.uk** or call us on **020 7423 7455**.

# About this booklet

If you have recently been diagnosed with young-onset dementia, this booklet is for you. Family and friends may also find the information useful.

Inside, you will find guidance on handling your emotions, talking to people about your diagnosis, making important decisions and finding support.

## You are not alone

We know facing a dementia diagnosis can feel lonely. That’s why we invited people with young-onset dementia to share their experiences in this booklet. You will find their voices throughout, starting with Vesna on pages 4–5.

Each contribution is different, reflecting the varied experiences, challenges and moments of strength that come with young-onset dementia. We hope they bring you some comfort and reassurance.

If you would like to share your experience, see page 54 for ways you can do this.

## How to use this booklet

The first few days, weeks and months after a diagnosis can be overwhelming. Take the time you need to read this booklet at your own pace.

Remember you can skip sections and come back to them when you feel ready to. You can also write down questions as you go if this would help.

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**Vesna shares her experience of being diagnosed with vascular dementia and how it has affected her life.**

"I was a social worker... out of nowhere, I started experiencing problems with my memory. Computer training wasn't sticking, it was in one ear and out the other.

I eventually saw my doctor and went for a brain scan and that led to a diagnosis of vascular dementia.

I had to leave work. And I couldn't see how I could get any job because I couldn't seem to learn anything new. But I had a mortgage. I had bills.

People with young-onset dementia have totally different pressures than people who are retired.

With the support of other people, you have to make it feel like you have a worth. I still want to do as much as possible. You can find happiness in how you are. That doesn't rely on memory – you're more than your memory.

While I have breath, I'm not going to let dementia define me."

# Coping with your diagnosis

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# Coping with your diagnosis

Being diagnosed with dementia can bring a range of emotions, especially if the news is recent. Some people can feel numb, while others may experience denial. There's no right or wrong way to feel.

However you feel right now, know that you are not alone. There are over 70,800 people in the UK who have young-onset dementia. While every person's experience is unique, there are common emotional and practical challenges that arise. Understanding what to expect and knowing where to turn for support can help bring you more clarity and control during this uncertain time.

**France shares how he felt after being diagnosed. He had previously had a long career as a nurse.**

"When I got the dementia diagnosis, I didn't want to know about it – I was in denial. I knew what the medical people were going to ask, so I could hide it. But there's no point in doing that, you have to accept it and be treated.

People think about dementia and they think about old people. Sometimes I go to a shop in my wheelchair and people talk to my wife and ignore me. Or sometimes people see my colour and assume I can't speak English. I always used to think, if I was in one of my patient's shoes, how would I feel?"

## Understanding your diagnosis

Coming to terms with a dementia diagnosis can take time. But there are some things you can do now that can help.

Learning as much as you can about your diagnosis can make things easier. It helps you know what to expect, what treatment options you have, and how to plan ahead in a way that feels right for you. It also means that you can make the most of any conversations you have with healthcare professionals.

The more you understand, the more you can focus on what really matters to you in the time ahead.

For information about young-onset dementia, go to page 20. If you think of any questions while you are reading this booklet, write them down. There are details on who can answer your questions on pages 12–13.

> **“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 much harder because we are asked to explain ourselves.**
>
> Person with young-onset dementia”

## How we can support you

### Online

Visit **alzheimers.org.uk/get-support** for advice and support. 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 young-onset dementia on our Dementia Support Forum (**forum.alzheimers.org.uk**) and search for services and local support groups using our dementia directory at **alzheimers.org.uk/dementiadirectory**

### Phone

You can call our Dementia Support Line on **0333 150 3456**. It is available seven days a week. If you speak Welsh, call our Welsh-speaking support line on **03300 947 400**. It is open Monday to Friday, from 9.15am to 4pm.

Our dementia advisers are available to help you 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.

## Talking to someone

For many people, talking to friends and family helps them come to terms with their diagnosis. Some people find it easier to talk to someone else, such as a professional. If you don't want to talk about your diagnosis yet, that's ok too. You might find it helpful to write down what you are thinking now for when you are ready to talk.

### Others who can help

- Ask for help from your GP or the memory service that gave you your diagnosis. See pages 12–13 for how each of the different healthcare professionals can help.
- Dementia UK have a list of young-onset dementia services across the UK – visit **www.dementiauk.org/information-and-support/young-onset-dementia/find-support**
- There are support groups for people with rarer forms of dementia – for more information, visit **www.raredementiasupport.org**
- Some people find it helpful to turn to their faith or spirituality.

## Health and care professionals

As you need more support, you will most likely need help from different health and care professionals. Here is a list of some of them and the ways they can help you.

### Doctors

Your GP can support you by:

- explaining your symptoms and helping with your health and any medical problems (not just dementia)
- arranging further tests with a consultant or hospital specialist
- reviewing your medicines.

When visiting the GP, you may want to take someone with you to listen and take notes.

If you are experiencing mental health problems, such as depression and anxiety, you can get a referral from your GP to see a clinical psychologist or psychiatrist.

They can also help if you are struggling with other mental health symptoms of dementia, such as hallucinations (seeing or hearing things that aren’t there).

### Social care professionals

Social workers and carers can help you to adjust to life with dementia. Social workers assess your needs and advise on the best way to support you. Professional carers can help with practical, everyday tasks such as laundry, meals, washing and dressing, and taking medication.

### Other health professionals

These include:

- community nurses, who provide general health support at home
- dementia specialist nurses, including Admiral Nurses
- occupational therapists, who help you to keep your skills and independence for longer
- speech and language therapists, who help with eating and swallowing problems, and can also help with language-led dementias.

**Belle shares her thoughts on young-onset dementia and how her peer support group has helped her.**

"I was diagnosed with frontotemporal dementia. I felt scared and shocked. It took two years. Even now I can't accept it sometimes, I find it hard. You always assume that people are older with dementia.

I feel that when I was told I did have dementia, I thought I was on my own. It was only when I joined a peer group that I feel more positive about it. The peer group was very supportive. I couldn't carry on without them."

## Looking after yourself

As you come to terms with your diagnosis, looking after your physical and mental health can make a big difference. Here are some ways you can do this.

- Try to eat regular meals made from healthy and nutritious foods.
- Drink plenty of fluids, although not too much alcohol as this can make symptoms worse.
- Take care of your body and your mind. See our tips for keeping physically and mentally active on page 52.
- Stay connected to the people and things that matter most to you.
- If you smoke, consider stopping or switching to a nicotine substitute.
- Try to get enough sleep at night, and try not to sleep too much during the day, although a short nap can be helpful.
- Keep doing the things that you enjoy.
- Ask for help to take medication if you're having trouble. Tell your doctor about any side effects.
- If you find yourself regularly feeling low, anxious or irritable, talk to your GP.

It's easy to get caught up in medical appointments and big decisions. Don't forget that the basics of looking after yourself are just as important.

**Graham talks about how his day-to-day has changed and the importance of staying in touch with people.**

"I am unable to read books, which I used to do a lot. Whilst I can read words, looking at a book page with all the words there means I have problems reading them. Also I forget what is happening in a book I was reading.

Then I joined a peer group through Alzheimer's Society. If I hadn't, I'd dread to see what stage I'd been at now. If there's one thing to say, it's if you get diagnosed with young-onset dementia, it's important that you carry on meeting people.

I attend two Zoom meetings each week, walking football, singing sessions and any walking event the Alzheimer's Society organise, such as walking around the RHS garden centre, and coffee meetings.

By attending these events, I get to talk to a lot of people, meet up with them regularly and have made a number of friends, who I see more often."

## Coping with emotions

Receiving a diagnosis of young-onset dementia can bring a lot of emotions. For some, like Tim, the initial impact of a diagnosis can be especially hard to navigate.

**Tim shares his honest thoughts and the raw emotions that came with his diagnosis.**

"I had a review with the GP – 'How was your memory?' If I've got memory problems, how am I going to know? I don't know, I've forgotten them!

Nightmare to get a diagnosis, and then you're abandoned. It feels like you're being told 'we've got you this far, now do this last bit on your own'.

Hardest thing for me was that, pre-diagnosis, things were fixable. After, they were not. I had to figure out why to live. I got a lot of support, but only because I kicked and screamed. I'm still trying to learn why to live, because sometimes I think 'what is the point?'."

Tim's experience reflects that of many people with young-onset dementia. If you are feeling this way and need someone to talk to, you can call our Dementia Support Line on **0333 150 3456** or Samaritans on **116 123**.

It’s important that you give yourself the time and opportunity to express your feelings. Think about what feels comfortable for you. This could be talking to someone, writing in a diary, or finding meaning and purpose in faith.

Remember your emotions can change over time, as you learn more about dementia and find ways to adjust.

If you continue to feel sad, hopeless or anxious, talk to your doctor.

# About young-onset dementia

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# About young-onset dementia

Young-onset dementia refers to any type of dementia that starts before a person is 65 years old. Some people call it 'early-onset dementia'.

## How dementia affects younger people

Dementia is caused by a range of different diseases. This is similar for younger and older people, but there are important differences in how dementia affects younger people.

- A wider range of diseases cause young-onset dementia than other dementias.
- A younger person is more likely to have a less common form of dementia, such as frontotemporal dementia (FTD).
- A younger person is less likely to have memory problems compared with older people. For example, they could mainly have problems with language, vision or behaviour. They may also have problems with movement, balance and coordination.
- Young-onset dementia is more likely to be inherited (passed on through genes). This affects around one in ten younger people with dementia. See pages 22–23 for more on this.

## Types of dementia

Different types of dementia affect the brain differently. Knowing the type of dementia you have will help you understand what to expect and how to manage symptoms in the best way possible.

You can find more information about the following types of dementia on our website (including other print publications):
- Alzheimer's disease
- vascular dementia
- dementia with Lewy bodies
- frontotemporal dementia
- mixed dementia
- other less common types of dementia.

## The progression of dementia

Dementia is a progressive condition, which means symptoms will get worse over time. Eventually, you will need more help and support with daily living.

Lots of different things affect how quickly dementia progresses. Two main things are the type of dementia and any other health conditions you have.

Keeping active and involved may help you keep your mental abilities for longer. See pages 52–54 for advice on how you can do this.

## Can young-onset dementia be inherited?

Some brain diseases that cause young-onset dementia can be inherited. However, in most cases, young-onset dementia is not inherited.

If a family has several members who are closely related and have had dementia, there is a greater chance that it might have been caused by a gene. This is especially the case if they had dementia when they were young.

Around one in ten people with young-onset dementia have a single gene that causes dementia. This is known as ‘familial dementia’ because it runs in families.

If you have been diagnosed with familial dementia, you may be worried about other members of your family getting it too – particularly children. This can be a very difficult subject to think about, so it’s important to ask for help from specialists in genetic diseases.

If anyone in your family is worried about inheriting dementia, they should talk to their GP first. If the GP thinks there is reason to be concerned, they can refer the family member to a local genetics service. Here, they can receive genetic counselling and be tested for certain genes.

Reasons for concern might include:

- having a close relative, such as a mother, father, brother or sister, who has been diagnosed with frontotemporal dementia
- having more than one relative diagnosed with any dementia at 65 or younger, particularly if they developed symptoms at an early age during their 40s or 50s.

If you have children who have inherited a gene from you that causes dementia, remember that it is not your fault. There's no way you could have prevented it being passed on to your children if you didn't know that you had the gene at the time.

For more information about dementia that is inherited, see factsheet 405 **Genetics of dementia**.

# Telling people about your diagnosis

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# Telling people about your diagnosis

After your diagnosis, you may not be sure who to tell, or how to share the news. You might need to take some time for yourself first to come to terms with your diagnosis.

Telling people how you are feeling is helpful because they can then better understand and support you. However, it is natural to wonder how people will react.

Some people may be supportive and understanding. Others may be confused or worried, or they may be uncertain of what to do or say. For some, it can take a while for it to sink in.

Remember that you don't have to talk about everything at once or feel responsible for managing other people's reactions. If your family or friends need support, they can also seek guidance from others, rather than relying solely on you.

Some people might not know much about dementia. They may find it helpful to read about dementia, attend face-to-face Dementia Friends sessions or watch the Dementia Friends video.

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

**Sarah shares her advice for people who have just received a diagnosis of young-onset dementia.**

“I felt that I couldn’t tell people except those closest to me. However, after about six months I felt I wanted to tell everyone.

On a practical side wear a sunflower lanyard [a symbol for hidden disability] at airports and large events or whenever you wish. You will quite often get fast tracked or attract assistance.

Remain positive and enjoy your life to the best of your ability. You will likely make a lot of new friends and enjoy some good new experiences.”

You may meet some people who do not understand that younger people can get dementia. This might even happen with professionals. You can use our helpcards to show people you have dementia.
Go to **alzheimers.org.uk/helpcards**

**I have dementia**
**You can help me by**

**Thank you**

My name

**If I need help, please contact**
Name

Relationship to me

Contact number

Code 1564 Registered charity no. 296645

Alzheimer's Society

## Telling family and friends

Family and friends can be a vital support for you. However, if they aren't familiar with your condition, you may need to be clear about what you need. For example, you could ask for help in getting to the shops, or for someone to go round the shops with you.

Talking about your diagnosis with family and friends can bring you closer together. It lets people understand what you're going through, making it easier for them to support you. Being able to share what's on your mind can make things feel a little less overwhelming.

Some people may struggle to accept that you have dementia. You may need to explain how the condition affects you – especially if your dementia doesn't cause memory problems. Despite this, they may still need time to adjust.

If people spend less time with you, or stop seeing you altogether, focus on your own needs. Remember that this is not your fault. Surrounding yourself with understanding people is important.

Our Dementia Support Forum (**forum.alzheimers.org.uk**) is a welcoming, non-judgmental community for anyone who needs it.

**Paul talks about how he felt after being diagnosed with dementia.**

"My problems started at 46. I got very forgetful with shopping, leaving cooker hob on, leaving toilet light on. And then the final straw was arguing with the satnav.

I was told I had Lewy body dementia. I'd convinced myself I had dementia already. I'm one of these people who think of the worst – most of the shock was from my family. They couldn't accept it. It was very hard for them.

I'm positive. My life started when I got my diagnosis. Everyone thinks that's a weird thing, but otherwise I'd be at work thinking 'I'll do that when I retire'. But now I do it now.

Everything I want to do, I do now, because I know my timeline is going to be short."

## Telling young children

If you have young children, grandchildren or other young people in your life, it's important to talk to them too. It's natural to want to protect them, but they are often more aware of changes than they may let on.

Giving young people information about dementia and what will change allows them to understand and adjust to the new situation. This can be reassuring for them and it can help you feel more understood.

Show that you are open to talk when they are ready. Ask them about their feelings, and allow them time to say how the changes are affecting them.

Our Easy Read booklets use simple words and images to explain dementia. They may be helpful for young children. Go to **alzheimers.org.uk/easy-read**

## Changes in your relationships

It can be difficult for you and the people around you to adjust to your diagnosis.

At first, other people may have a hard time adjusting to some of your symptoms. For example, if you are finding it harder to communicate, they may need help to understand how to best support you.

Dementia can be frustrating, both for you and others who don't fully understand what you're going through. You might struggle with tasks that you used to find easy, or you may need more time to think things through. These changes are common. Try to be patient with yourself, and with those around you.

Over time, most people with dementia will depend more on family, friends and professional carers. This can be hard to accept, especially if you are normally the one who helps other people.

Often, someone close to you will take on more responsibility. They are likely to eventually become your main 'carer' – although you may not want to use this term or see things in this way. This can be difficult to think about. But open conversations now will make things clearer and less stressful for you and those around you in the future. See page 28 for guidance on this.

## Sex and intimate relationships

If you have a partner, they may also become your carer over time. For some people, this can help to bring them closer together. However, it can also be a source of stress and sadness – particularly as the condition progresses.

Your condition may mean that you become much more or much less interested in sex. If your partner is caring for you, they may be less interested in sex, especially if they are tired.

This is not uncommon – many couples go through this. You may need time and support to adjust to these changes.

For many people living with dementia, physical intimacy continues to be a source of comfort, support and pleasure for many years. However, some people may experience sexual difficulties. There is no single 'normal' way of dealing with these. It can be a difficult subject to discuss, but you might find it helpful to talk to someone you trust, such as a good friend or family member.

For more information about adjusting to changes in your relationships, see booklet 1507 **Your relationships**.

# Your treatment and care

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# Your treatment and care

Although there is no cure for dementia, there are treatments and support that can help. These include medicines as well as activities that don't involve medicine.

## Medicines for dementia

For some types of dementia, you may be offered medicines to help with your symptoms.

You may be prescribed donepezil or a similar medicine if you've been diagnosed with:
- Alzheimer's disease
- dementia with Lewy bodies
- Parkinson's disease dementia
- some types of mixed dementia.

Donepezil boosts a chemical in the brain that can help with memory and thinking. Later on, as donepezil becomes less effective, you may be prescribed a medicine called memantine.

If you have **vascular dementia**, you may be given medication to look after your heart or blood circulation. There is not much evidence that this slows down the progression of dementia. However, it may help you feel better and prevent further health problems.

If you have **frontotemporal dementia (FTD)**, you may be prescribed an antidepressant. This can sometimes help with the symptoms.

Some people have difficulties with medicines. For example, they may forget what to take and when. If you experience this, you can ask for help from your pharmacist. You can also request a medication review from your GP. They can help you with a reliable system for taking medicines which works for you.

For more information on medicines, see factsheet 407 **Medicines to help memory and thinking** and factsheet 408 **Antipsychotic drugs and other approaches in dementia care**.

## New medicines for dementia

Now is an exciting time for dementia research. New medicines that can potentially slow down Alzheimer's disease in the brain are being developed. Hopefully, these will be able to help people with Alzheimer's to stay active and involved for longer.

It's hoped that with more research these medicines will become more and more effective, as well as safer and easier to take. However, we're still very much at the beginning of this journey.

For the latest information on these new medicines, visit our website **alzheimers.org.uk** or call our Dementia Support Line on **0333 150 3456**.

Unfortunately, we still don't have any new medicines for other types of dementia, such as vascular dementia or Lewy body dementia. We are continuing to fund research to find new treatments and we know that, in time, they will come.

For more about taking part in research, ask your local memory service or see the Join Dementia Research website at **joindementiaresearch.nihr.ac.uk**

## Non-medicine treatments

Medicines are only a small part of the care you should receive when you have dementia. You may also want to ask your GP or memory service about the treatments described on this page to page 41.

### Cognitive stimulation therapy (CST)

CST involves activities and exercises to help improve memory and communication. It often takes place in groups. At least one course of CST should be offered by an NHS local memory service to anyone with a recent diagnosis of dementia.

### Life story work

Life story work involves working with someone to make a personal record of your life. It's a way of telling people who you are, what's important to you, and holding on to your identity. This could be in a book, photo album or on a computer.

### Talking therapies

Talking therapies can help you to cope emotionally with the impact of a diagnosis. It can give you a way to deal with the changes that happen around this time.

Talking therapy usually takes place with a clinical psychologist or other mental health professional. They will encourage you to talk about your thoughts and feelings, and how these affect your mood and the things you do.

There are different types of talking therapies.

- **Counselling** – this involves talking about your concerns without having to worry about upsetting people close to you. It can be done on your own, with a partner or in a group.
- **Psychotherapy** – this involves working out how difficult feelings, thoughts and behaviour might be affected by your personality, beliefs and life experiences.
- **Cognitive behavioural therapy (CBT)** – this involves finding positive ways to think, feel and act.

See ‘Other useful organisations’ on pages 72–76 for professional bodies that can help you find a counsellor. You can also ask the memory service that gave you your diagnosis.

### Cognitive rehabilitation

Cognitive rehabilitation helps you use other parts of your brain to make up for the parts that are struggling. It involves working with someone else to agree a goal that makes a big difference to your daily life. This could be learning to use a mobile phone, reading more effectively or relearning how to cook.

Ideally, cognitive rehabilitation is provided by a health professional, such as an occupational therapist or a psychologist. However, this type of therapy is still not widely available through the NHS. Instead, some people develop their own goals and are supported by friends and family to achieve them.

My Life, My Goals is a self-help cognitive rehabilitation tool that can help maintain everyday skills. It was developed by the organisation Innovations in Dementia. For more information, see ‘Other useful organisations’ on pages 72–76.

# Living with young-onset dementia

## In this section

# Living with young-onset dementia

To help you adjust to living with young-onset dementia, think about what's important to you in your everyday life. Finding ways to keep doing the things that matter to you can make life more enjoyable and fulfilling.

This section includes advice about adapting when you have dementia. You will find information about driving and working, as well as practical suggestions for communicating and coping with memory loss.

## Driving and dementia

Having a diagnosis of dementia doesn't always mean you have to stop driving straight away. However, if you have a driving licence, there are a few things you must do.

- Inform the Driver and Vehicle Licencing Agency (DVLA) in England and Wales, or the 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. This is just until the DVLA or DVA make a final decision.
- Inform your car insurance company straight away.

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

## Stopping driving

Some people decide for themselves to stop driving. You might be thinking of giving up driving, especially if you're:

- feeling less confident
- getting more irritated
- struggling to judge distances
- getting lost on roads you know well.

It can take time to adjust to giving up driving. You might find it helpful to think about other ways to get around, such as public transport.

It can also help to focus on the benefits of not driving.

- You no longer have to worry about remembering the way.
- You no longer have to find spaces to park.
- You can save money on the costs of keeping a car.
- If you walk more often, it's a chance to get more exercise and stay healthy.

For more information, see booklet 1504 **Driving**.

**Eamonn talks about having to stop driving after his diagnosis.**

"I was a multi-drop driver. After my diagnosis, my licence was revoked, and I couldn't work no more. As someone who has worked all their life since 16 years old, I was lost. I didn't know who to turn to.

All of a sudden you are on benefits and you feel like you've been abandoned. It is soul destroying. I had a motorcycle and a job, and within seven days I had to get rid of all of them."

## Work and dementia

You don't normally have to give up working straight away when you have dementia. Some people continue working after their diagnosis – sometimes for many years.

You may want to keep working for as long as you can. Aside from the money, work may also give a sense of purpose. It can raise confidence and provide a community. For some people it can even feel part of their identity.

This isn't the case for everybody, though. Some people decide to spend their time doing other things, particularly if they can retire early. Others may have to give up work because their symptoms are too severe.

## Talking to your employer

If you want to carry on working, it's generally best to tell your employer about your diagnosis. Not everyone has to do this legally, but you should check your employment contract.

You will need to tell your employer if your job has an impact on the health and safety of other people. This includes work that involves driving or operating machinery.

By telling your employer, you gain certain legal rights. Your employer cannot discriminate against you because of your diagnosis. This is because dementia is classed as a disability under the law.

Dementia can make some jobs difficult to do. As a result, you might need to talk to your employer about having a less demanding role.

## Reasonable adjustments

You can ask for 'reasonable adjustments' to help, like:

- working in a different place – this may be in a building closer to you, or you might be able to work from home
- having longer breaks
- working in a quieter area
- using equipment and adaptations.

Your employer can only turn down your request if they have a 'business case' for doing so. This could be because they can't afford the adjustment.

**This person who has young-onset dementia shares their experiences of working after their diagnosis.**

"My day-to-day routine changed straight away, as I finished work. I was a Production Manager in an oil refinery. I continued to work as I had been with the same employer for 35–40 years. But then after my diagnosis I was offered a new role as a trainer due to my experience training new members.

I left work as I kept forgetting to reply to emails. I had to take them into meetings so I would remember to reply to them. My company was very good to me and paid me till I took out my works pension at 65."

For more information, see booklet 1509 **Work and dementia.**

### Unfair dismissal

If you feel you've been unfairly dismissed, you may be able to make a complaint against your employer. There are organisations that can provide advice and support, such as:

- the Advisory, Conciliation and Arbitration Service (ACAS)
- the Equality Advisory and Support Service (EASS)
- the Equality Commission for Northern Ireland (ECNI).

For contact details, see 'Other Useful Organisations' on pages 72–76.

> **We felt my wife's employer kept putting problems in the way after her diagnosis and not supporting her. They hoped she would resign her role as a GP which she did due to this situation. We are still left fighting for her pension which she is entitled to.**
>
> Partner of a person with young-onset dementia

**Sally talks about how her life has changed without her job.**

“For me, it’s loss of friendships and work colleagues. From six in the morning to six in the evening, that’s your life, work. I think that has been the hardest thing I’ve found, just not knowing where I am at.

I used to be with people and help people – used to facilitate neuropsychologists, GPs, social workers. I found it quite humiliating to contact these people to ask, ‘What do I do?’. I’d dealt with these people on a professional level.

None of them are in my life now.”

## Keeping active and involved

After a diagnosis of young-onset dementia, it's important to keep doing the things you love, if you can.

It's often possible to adapt hobbies and activities to make them easier to do when you have dementia. You don't have to do this straight away, but it can be helpful to make the changes in advance, before you suddenly need them.

You might find there are some things you have to stop doing with dementia. However, there may be opportunities to try something new, for example, being creative or getting outdoors more.

You could also ask a family member or friend to attend a class with you, or try Singing for the Brain. These are regular sessions we run for people to sing together.
For more information, see
**alzheimers.org.uk/dementiadirectory**

Anything that keeps you in touch with other people can help, and can stop you from feeling lonely.

> **"I walk my dogs and have a tracker to help as I can get lost and confused and I can contact my wife through this. I also keep busy on my allotment."**
>
> Person with dementia

**Sarah talks about changes in her life, and hobbies and activities she still enjoys.**

“I no longer go to work. I stopped driving immediately so need lifts or public transport to get around. Gradually my husband took over tasks such as cooking and shopping.

I have however started some new activities. I do Pilates twice a week, go to a sewing and knitting group weekly and do regular talks for an educational group about young-onset dementia.

I love knitting which I find very relaxing although I now knit simple squares rather than complicated patterns.

My husband and I walk whenever possible and at least once a day and I enjoy this very much.

I like watching my regular favourite TV programmes, and I particularly like quizzes. I can’t ‘take part’ due to being unable to read or recognise pictures but still really enjoy watching these quizzes.”

## Getting involved

Some people with dementia want to get involved in work that supports those who are living with the condition. Sharing your experiences can help researchers to find new treatments and develop better ways to care for people with dementia. There are lots of ways you can do this.

To find out how you can get involved with our events and volunteering, visit **alzheimers.org.uk/get-involved**

## Benefits of staying active

Whatever you choose to do, the most important thing is that it makes you feel good. Staying active can:

- make you feel more positive, and less anxious or depressed
- raise your self-esteem and increase your confidence in your abilities
- maintain your physical, mental and social skills
- give you a chance to express your feelings and connect with others
- share your experiences with other people who are affected by dementia.

## Making changes at home

You may need or want to make changes to your home to make it safer and easier to live in. Here are some things to think about.

- Improve lighting levels – it shouldn't be too dark or have shadows.
- Reduce clutter – make it easier to find things by keeping items that are regularly used in view and putting away those that aren't.
- Remove any trip hazards – for example, loose rugs or power leads.
- Reduce noise distractions – switch off TVs and radios when they're not being used.
- Use equipment and technology if it helps – for example, automatic light sensors, calendar clocks or smart devices.

Having a safe, comfortable and easy-to-navigate home is important. Start a list of anything that you find difficult around your home. You can use this list to have conversations with your family, GP or anyone who helps you. Together, you can find changes that will work for you.

An occupational therapist can advise on equipment and adaptations to make your home safer and easier.

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

## Communicating

Many people find that communicating gets more difficult over time. This can make it very challenging to tell people what you need. It can also knock your confidence.

If you are having problems with communication, these tips may help.
- Go to a quiet place or turn off distractions, such as the TV or radio. This makes it much easier to understand what you hear.
- Tell people what works best for you – for example, talking more slowly, using shorter sentences, or just giving you more time to think and respond.
- If you have problems with language, ask your GP or consultant for a referral to a speech and language therapist.
- Take someone with you when you see your GP or consultant. They may be able to make notes of what is said. You can also ask to record these conversations on your phone.

We have guidance to help people communicate in the best way possible with people with dementia. Your family and friends may find factsheet 500 **Communicating** helpful.

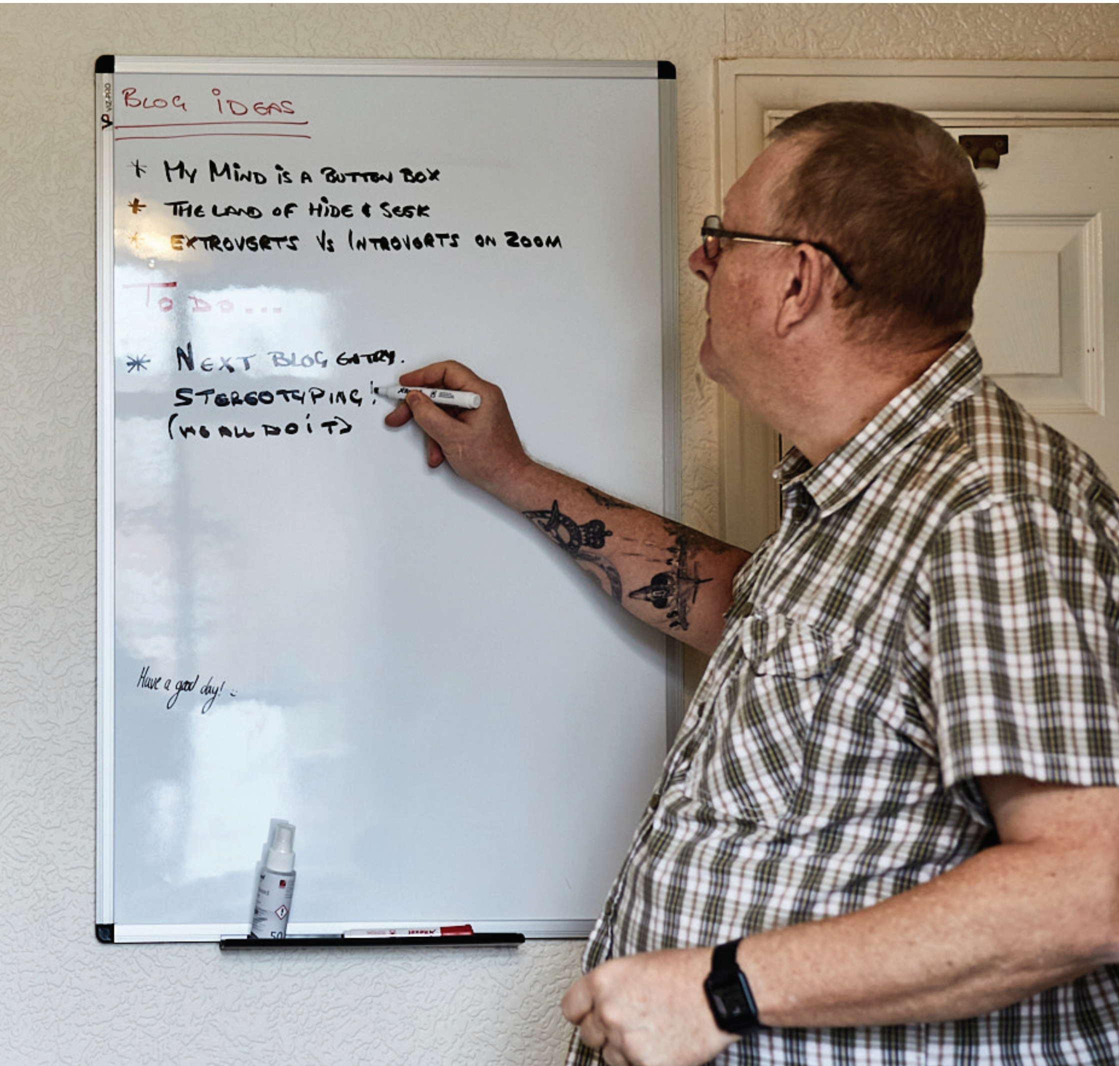
## Coping with memory loss

You may experience memory problems, such as forgetting appointments, recent conversations or where you put something. It can also mean you are less able to keep a thought in your head for long enough before it's lost.

If you have memory problems, the following suggestions may help.
- Keep a diary for remembering appointments or recording events.
- Consider whether technology might help. This could be setting alarms or reminders on phones or other smart devices around the home.
- Use memory aids around the home. For example, some people put labels on doors and cupboards with a picture and the name of what's inside.
- Try to keep important everyday items in the same place. For example, keep keys near the front door or in a large bowl.
- Put medicines in a pill box with compartments for each day of the week. Keep a checklist so you can write down when you've taken them.

For more ideas and information, see booklet 1540 **The memory handbook.**

> **I need to write my appointments down on the calendar in the kitchen.**
>
> Person with young-onset dementia



# Making decisions and managing money

## In this section

# Making decisions and managing money

Making your own decisions and managing your money are important parts of keeping independent. If you have problems with memory, thinking and concentration, these can affect aspects of daily life now and in the future. However, there are ways to help you.

## Why plan ahead?

If you have recently been diagnosed with dementia, you might find it difficult to think about the future. Your priority may be to look after yourself and take time to adjust. For some people this takes a few weeks. Others might need more time.

When you are ready, it is a good idea to think ahead and sort out some practical things. Many people feel better after doing this.

By planning ahead now, you'll be prepared for a time when it might be difficult to make decisions for yourself. This is especially true about the care and treatment you would like to receive in the future.

Planning ahead can also solve practical, everyday problems that might come up later on. It may help avoid complicated and expensive processes.

Making plans also means your family and friends know how best to support you in the future. While it can be difficult to talk about, things may be easier once it is done.

There are legal tools you can use to make sure your preferences and opinions are considered.

For more information about these tools, see booklets 1510 **Planning ahead** and 1501 **Managing your money**. If you live in England or Wales, see also factsheet 463 **Advance decisions and advance statements**.

## Power of attorney

Because dementia gets worse over time, eventually some decisions will be too hard for you to make.

### Lasting power of attorney (LPA) – England and Wales

A lasting power of attorney (LPA) is a legal document in England and Wales. It gives someone you trust, such as a family member or friend, the power to make decisions for you. You can choose anyone you want to be your attorney, as long as they are 18 or over.

There are two types of LPA.

- One covers **property and money matters**. This includes bills, bank accounts and selling property.
- The other covers **health and welfare**. This may involve day-to-day care and treatment options.

You might not have thought about creating an LPA before. However, it might help in the future.

You can choose to use a solicitor to create an LPA, but you don't have to. Most people complete the relevant forms themselves with help from family and friends.

The forms are available on the government website (**gov.uk**), along with an online tool to help you through the process. Alternatively, you can contact the Office of the Public Guardian and ask for the forms to be sent to you. See 'Other Useful Organisations' on pages 72–76.

We offer a Lasting power of attorney digital assistance service to help people create and register LPAs. It is done over the phone. This service is for people who do not have access to the internet or who do not feel confident using computers to complete the forms. To use this service, call us on **0333 150 3456**. This service does not offer legal advice.

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

### Enduring power of attorney (EPA) – Northern Ireland

An enduring power of attorney (EPA) is a legal document in Northern Ireland. It allows you to appoint someone to manage your finances and property if you are unable to do so yourself.

Many people set this up through a solicitor. However, you can get the forms you need from the Office of Care and Protection, or from legal stationers. See ‘Other useful organisations’ on pages 72–76 for details.

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.**
>
> Person with dementia

## Managing your money

If you have problems with your memory, this might affect the way you manage your money. You may forget to pay your bills, or you may buy the same thing many times. It can also be easy to forget your PIN or where you've put your cash.

Some people may struggle to control the impulse to buy things they wouldn't usually buy, or they may buy things they cannot afford. This can get very expensive.

The following are ways to manage money safely and effectively when you have dementia.

### Choosing ways to pay

Find a way to pay that's best for you. This might be using:
- cash
- a chip and PIN debit card
- a contactless bank card
- direct debit
- cheque.

Sibstar is a flexible and secure debit card and app that can help you manage your money safely. It has been designed for people with dementia, and allows you to buy everyday items up to a limit that you set yourself. You can also choose if you want it to work online, over the phone or as a cashpoint card. For more information, visit **www.sibstar.co.uk**

## Managing your bank account

Here are some ways to make managing a bank account easier.

- Speak to your bank. Most banks have different ways they can support you to manage your money.
- Register for online banking. You can view your balance and statements, make payments, and manage direct debits and standing orders.
- Use telephone banking. This allows you to access your account and make payments over the phone.

## Keeping money safe

Sadly, there are organisations and individuals who use scams and tricks to get money illegally. People with dementia can be more vulnerable to the methods they use. Here are some ideas on how to keep your money safe.

- Keep good records of your finances and transactions.
- Ask your bank to put a limit on how much money can be taken out of your account at one time.
- If you are employing a carer at home, run background and reference checks through a DBS (Disclosure and Barring Service) check. For more information, see the government website (**gov.uk**).

## Financial support and benefits

If you have a dementia diagnosis, you may be entitled to a range of benefits. Some of these are means tested, which means the amount you receive depends on your income and savings.

Other non-means tested benefits may be based on your needs or how much national insurance you have paid during your working life.

### Types of benefits

Some benefits are for people who are out of work or unable to work. Examples of these benefits include Universal credit or Employment and support allowance.

Other benefits can be claimed whether people are working or not, for example, Personal independence payment.

Someone who looks after you may also be able to receive carer's benefits. It's a good idea to check with someone who knows the rules before claiming any benefits. For advice, talk to:

- a local welfare rights service
- Citizens advice or Age UK
- Make the call (for people in Northern Ireland).

The Department for Work and Pensions (DWP) may be able to arrange for someone to visit you at home. This is usually for those who need help with forms who are unable to access support elsewhere.

See 'Other useful organisations' on pages 72–76 for contact details for the organisations listed on these pages.

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

If you live in England and Wales, it is also worth contacting your local authority about council tax. You may be able to get support. If you live in Northern Ireland, you can contact the Land and Property Service helpline on **0300 200 7801**.

For more information, go to **gov.uk** or see factsheet 414 **Council tax.**

## Paying for social care and support

Many people with dementia will reach a stage where they need professional care and support. If you live in England and Wales, this is provided by your local authority. In Northern Ireland, it is a health and social care trust (HSCT). They can arrange an assessment to understand your needs and how to meet them.

For more information, see our **Assessment for care and support** factsheets 418 (England), NI418 (Northern Ireland) and W418 (Wales).

Some people with dementia and their carers can get financial support with the costs of care. For more information, see our **Paying for care and support** factsheets 532 (England), NI532 (Northern Ireland) and W532 (Wales).


Alzheimer's

# Other useful organisations

**Advisory, Conciliation and Arbitration Service (ACAS)**
0300 123 1100 (helpline, 8am–6pm Monday–Friday)
www.acas.org.uk

ACAS can give you advice about workplace situations. Its website has guidance and publications, or you can phone the helpline for information and advice.

**Age UK**
0800 678 1602 (advice line, 8am–7pm Monday–Sunday)
www.ageuk.org.uk

**Wales – Age Cymru**
0300 303 4498 (advice line, 9am–4pm Monday–Friday)
advice@agecymru.org.uk
www.ageuk.org.uk/cymru

**Northern Ireland – Age NI**
0808 808 7575 (advice service, 9am–5pm Monday–Friday)
advice@ageni.org
www.ageuk.org.uk/northern-ireland

Age UK, Age Cymru and Age NI aim to improve later life for everyone through information and advice, services, campaigns, products, training and research.

**British Association for Counselling and Psychotherapy (BACP)**
01455 883300 (10am–4pm Monday–Friday)
bacp@bacp.co.uk
www.bacp.co.uk

BACP is the professional association for members of the counselling professions in the UK. You can search for accredited therapists in your area.

**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 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.

### Department for Work and Pensions (DWP)
www.gov.uk/government/organisations/department-for-work-pensions

DWP is the government department that looks after employment and social security in England and Wales.

### Equality Advisory and Support Service (EASS)
0808 800 0082 (helpline, 9am–7pm Monday–Friday, 10am–2pm Saturday)
www.equalityadvisoryservice.com

The EASS helpline can give you free advice and support.

### Equality Commission for Northern Ireland (ECNI)
028 90 500 600
information@equalityni.org
www.equalityni.org

ECNI has a helpline where you can get free advice and support.

### Innovations in Dementia
01392 420076
ideas@myid.org.uk
www.innovationsindementia.org.uk

Innovations in Dementia provides training and consulting to help others engage with people with dementia.

### Make the Call

**0800 232 1271 (9am–5pm Monday–Friday)**

Make the Call is a benefit enquiry line providing information and advice on benefits for people in Northern Ireland.

### NI Direct

**www.nidirect.gov.uk**

The website of the Northern Ireland government, which includes information about benefits available in Northern Ireland and how to contact the Driver and Vehicle Agency (DVA).

### Office of Care and Protection (OCP)

**0300 200 7812 (9am–1pm Monday–Thursday)**
**OCP@courtsni.gov.uk**
**www.justice-ni.gov.uk/topics/office-care-and-protection-patients-section**

The OCP manages the registration of Enduring powers of attorney (EPAs).

### Office of the Public Guardian (OPG)

**0300 456 0300 (9am–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.

**UK Council for Psychotherapy (UKCP)**
020 7014 9955
www.psychotherapy.org.uk

The UK Council for Psychotherapy regulates psychotherapists in the UK and promotes access to psychotherapy for all. It holds the UK's national register of psychotherapists.

**Young Dementia Network**
info@youngdementianetwork.org
www.youngdementianetwork.org

The Young Dementia Network provides opportunities for young people with dementia, and their families and friends, to share experience, knowledge and to learn from each other.

Last reviewed: March 2025
Next review due: March 2028

Reviewed by: Dr Zumer Jawaid, Consultant Psychiatrist, Leeds and York Partnership NHS Foundation Trust and Dr Rumana Chowdhury, Consultant Neurologist, Leeds Teaching Hospital NHS Trust.

This booklet has been reviewed by people living with dementia. To give feedback on this booklet, or for a list of sources, please contact **publications@alzheimers.org.uk**

With the exception of one person, Vesna, the people who have shared their stories are not pictured.

Registered charity no. 296645. A company limited by guarantee and registered in England no. 2115499. Alzheimer's Society operates in England, Wales and Northern Ireland.

At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information **About dementia**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**

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Together we are help & hope
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Alzheimer's Society
43–44 Crutched Friars
London EC3N 2AE

**0330 333 0804**
**enquiries@alzheimers.org.uk**
**alzheimers.org.uk**

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