

# Caring for a person with dementia

## A practical guide



**Alzheimer's  
Society**

Together we are help & hope  
for everyone living with dementia

# About this guide

If you are supporting someone with dementia, this guide is for you. It will tell you more about their condition and how it can affect them over time. It is here to support you to care for the person and to look after yourself.

You may not think of yourself as the person's 'carer', especially if you are supporting someone close to you. This could be a partner, friend or family member. You are considered a carer if you give any unpaid support to someone who could not manage without your help. Every situation is different, and how you care for the person will depend on what they need and what you are able to offer.

When someone close to you is diagnosed with dementia, it can bring lots of different emotions. It might make you feel sad, fearful, angry or helpless. Or you may feel some relief that you now have an explanation for the person's symptoms. All of these feelings are natural.

You are not alone. Support is available and there are things you can do to help you cope. It can be daunting to think about what's ahead, but it can help to be prepared. Things will change – but support from friends and family can make a huge difference in helping the person live well with their condition.

This guide gives a general overview of a range of topics. The amount of information might feel overwhelming, but you don't need to read it all at once. You might want to refer back to it when you need to.

# Getting support

Caring for someone with dementia can be a rewarding experience. It gives you opportunities to help someone who is important to you and learn new skills. But we know that it can also be very challenging.

Support is available every step of the way, from individuals and organisations. This includes practical information and advice, and support with how you're feeling and coping.

- Talk to friends or family members you trust.
- There are many professionals who can help. Often the GP is the first person you should see and can refer you to other professionals. These may include, for example, a counsellor or psychotherapist, or an occupational therapist. You can read more about services and support available on pages 106–125, 'Support and care services'.

See page 160 for more information on Alzheimer's Society support services that can help you navigate some of the hardest and most challenging times.





# Foreword

## Louise Yates

My mum, Marion, was 70 when she was diagnosed with Lewy body dementia. I felt numb but not surprised. I had suspected something for quite a while.

This time was extremely difficult for both Mum and me as my dad had just died. Due to Covid, we struggled to access professional help. Eventually I phoned Alzheimer's Society. They are a lifeline – their knowledge and reassurance help take the pressure away.

Everybody's dementia journey is different. But being prepared can help you recognise and act upon things when they happen. This guide offers information, understanding and ideas to support you with this. Some of Mum's symptoms have been very challenging for us both, but it's helped to learn about different ways that people can communicate and express needs.

Other types of support make a huge difference too. Caring can feel lonely. But as well as providing information and advice online and over the phone, Alzheimer's Society has connected me with other carers. Through local groups and Singing for the Brain®, I've made friends I know I can contact to vent, listen or exchange advice.

Dementia affects everyone who is close to a person with a diagnosis. It's so important to find the time to look after yourself too, even though that can be hard. The advice in this guide can help.

## More information

Throughout the guide, you will see suggestions for other Alzheimer's Society publications that give more information on particular topics.

As well as understanding dementia yourself, you may be trying to help the person understand their diagnosis. They may find it helpful to read booklet 872 **The dementia guide**.

Helpsheets are also available. These are short, one-page summaries of key information about dementia.

To get these and other Alzheimer's Society publications:



go to **alzheimers.org.uk/publications**



call **0300 303 5933**



or email **orders@alzheimers.org.uk**

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# About dementia

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# What is dementia?

Knowing more about dementia can help you better support a person with the condition. It can help you come to accept their diagnosis and changes they may go through.

Dementia is a group of symptoms. It's caused by different diseases that damage the brain. The symptoms get worse over time and include:

- memory loss
- confusion and needing help with daily tasks
- problems with language and understanding
- changes in behaviour.

Dementia isn't a natural part of getting older. The diseases affect the brain in different ways, resulting in different types of dementia.

Living well is still possible when you're caring for someone with dementia, but things will change over time.

You may not need a lot of the information in this booklet to begin with, but you may find it useful to refer to in the future.



# Types of dementia

The most common types of dementia are summarised in this section.

## Alzheimer's disease

Alzheimer's disease is the most common type of dementia. It is caused when proteins that are not formed properly build up inside the brain. These proteins join together into structures called 'plaques' and 'tangles' which stop the brain working properly.

Alzheimer's disease causes common symptoms including:

- **memory loss** – such as quickly forgetting things that have recently happened
- **trouble concentrating, planning or organising** – for example, struggling to follow the steps needed to make a meal, or figuring out the correct change to give when buying something in a shop
- **getting confused about time and place** – such as losing track of time and getting lost in familiar places
- **language and communication problems** – for example, difficulty finding the right word for something
- **misunderstanding what is being seen** – such as misjudging distances or misinterpreting patterns.



For more information, see factsheet 401  
**What is Alzheimer's disease?**



Call our Dementia Support Line on **0333 150 3456**

## Vascular dementia

Vascular dementia is the second most common type of dementia. It is the result of the brain not receiving enough blood to work properly. There are different types of vascular dementia.

The main ones are:

- **stroke-related dementia** – caused by a large stroke or a series of small strokes
- **subcortical vascular dementia** – caused by poor blood supply to the deep parts of the brain over a long period of time.

Memory loss doesn't always happen in the early stage of vascular dementia. Symptoms are more likely to include:

- difficulty planning, thinking quickly or concentrating
- getting confused easily
- difficulty walking and keeping balance
- becoming anxious, depressed or more easily irritated.



For more information, see factsheet 402

**What is vascular dementia?**



## Dementia with Lewy bodies (DLB)

Dementia with Lewy bodies (DLB) is caused by Lewy body disease. Lewy bodies are tiny clumps of protein that develop in the brain and stop it working properly. Symptoms of DLB can include problems with:

- **varying levels of alertness and thinking** – this can change from minute to minute or hour to hour. At times the person may appear to ‘switch off’ or suddenly become confused
- **sleep** – such as sleeping for long periods during the day and disturbed sleep at night, including physically acting out dreams
- **attention, planning, organising and reasoning**
- **hallucinations and delusions**
- **judging distances and seeing objects clearly.**

Dementia with Lewy bodies is closely related to Parkinson’s disease and often has similar symptoms. These include difficulty with movement and balance, and problems with how the body works, such as constipation and losing some sense of smell and/or taste.

Memory problems are common in the early stage of DLB, but tend to be much less severe than they are in Alzheimer’s disease.



For more information, see factsheet 403

**What is dementia with Lewy bodies (DLB)?**



Call our Dementia Support Line on **0333 150 3456**

## Frontotemporal dementia (FTD)

Frontotemporal dementia (FTD) is caused by damage from clumps of protein that stop the front and side parts of the brain from working properly. These are the parts of the brain that control behaviour, planning, problem-solving, emotional responses and language skills.

There are two broad types of FTD with different symptoms.

- **Behavioural variant FTD** – changes in personality and behaviour often appear first. These include behaving impulsively, withdrawing from hobbies or interests, making careless or risky decisions, seeming to care less about the feelings of other people, and becoming easily distracted.
- **Primary progressive aphasia (PPA)** – language problems appear first. Depending on which areas of the brain are damaged, the person may gradually lose the meaning of words over time or have difficulties getting their words out.



For more information, see factsheet 404

**What is frontotemporal dementia (FTD)?**





## Mixed dementia

Some people have more than one type of dementia. The most common combination is Alzheimer's disease and vascular dementia.

Someone with mixed dementia is likely to experience a mixture of symptoms of their different types of dementia. For example, a person with Alzheimer's disease and vascular dementia might have problems with their memory (Alzheimer's disease) as well as difficulty thinking quickly (vascular dementia).

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### Young-onset dementia

Around 1 in 20 people with dementia are younger than 65. This is often called 'young-onset dementia' or 'early-onset dementia'. A person under 65 is more likely to have a less common type of dementia, such as frontotemporal dementia or another dementia with a genetic cause.

Younger people with dementia often face different challenges and need different kinds of support to older people.



For more information, see booklet 688  
**Understanding young-onset dementia.**



Call our Dementia Support Line on **0333 150 3456**

## Rarer causes of dementia

A wide range of less common conditions can lead to dementia. Together these account for only about 1 in every 20 people who have dementia.

Someone with a rarer type of dementia may benefit from specialist help, for example, from Rare Dementia Support (for more details, see 'Other useful organisations' on pages 164–172).

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



### Supporting someone with dementia and a learning disability

People with a learning disability, especially Down's syndrome, are more likely to develop dementia at a younger age. This is because the genetic changes that cause Down's syndrome can also increase the risk of getting Alzheimer's disease.



For information about how dementia can affect someone with a learning disability, see factsheet 430 **Learning disabilities and dementia.**



For more information visit **alzheimerers.org.uk**

# Who gets dementia?

The risk of developing dementia increases with age, and one in six people over 80 are living with the condition. However, dementia is not a natural part of getting older.

The overall risk of getting dementia depends on a combination of factors that we can't change, such as age and genes, along with ones we can, such as physical inactivity, smoking and drinking too much alcohol.



For more information on the risks associated with developing dementia, see booklet 35 **Dementia: Reducing your risk.**

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**I know what the future entails, but you can't change it, so you just have to make the most of what you've got and live in the here and now.**

Carer for a person with dementia

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Call our Dementia Support Line on **0333 150 3456**

## Is dementia hereditary?

Most types of dementia are not passed down (inherited) from a parent to a child. There are a few genes that will definitely cause dementia if they are passed down, but these are rare.

There are also genes (known as 'risk genes') that can increase a person's chances of developing dementia. These genes are more common. However, risk genes do not always cause a person to develop dementia. Most risk genes only make a person slightly more likely to develop dementia.

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For more information, see factsheet 405  
**Genetics of dementia.**



# The progression of dementia

It can be difficult thinking about the person's dementia getting worse. But understanding how dementia develops and what may happen in the future can help you adjust, support the person better and plan ahead.

All types of dementia are progressive. This is why it can be helpful to think of the way that dementia progresses as a series of stages – the early, middle and later stages.

## What affects the progression of dementia?

It's not possible to predict exactly how dementia will affect someone as it progresses. Everyone's experience will be different, depending partly on how the disease spreads through different parts of their brain.

Not everyone will experience all symptoms. Their personality, life experience, support and surroundings will also affect how they deal with symptoms and, in turn, their wellbeing.

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**I tell [people], ‘I’m no different to two minutes ago before I told you [I have dementia]’.**

Person with dementia

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Call our Dementia Support Line on **0333 150 3456**



The rate of progression can be influenced by:

- **the type of dementia** – people with Alzheimer’s disease can generally expect to live longer than those with other types of dementia
- **a person’s age** – Alzheimer’s disease generally progresses more slowly in older people (over 65) than in younger people (under 65)
- **other long-term health problems** – dementia tends to get worse faster if the person is living with other conditions, such as heart disease, diabetes or high blood pressure, particularly if these are not well-managed
- **delirium** – this is a medical condition that causes a person’s mental state to change quickly and has a wide range of causes. Long or severe periods of delirium can speed up the progression of dementia (see ‘Delirium’ on page 75).



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



## The early stage of dementia

When someone is at the early stage of dementia, their symptoms might be mistaken for stress, depression or just getting older. The onset of dementia is often gradual, and it is usually very difficult to pinpoint exactly when it starts.

Early symptoms depend on the type of dementia that the person has. Common problems include:

- forgetting recent events
- finding it difficult to adapt to change
- finding it harder to make decisions or plans
- taking longer to process information
- having difficulties with communication, such as struggling to find words, repeating things or not following a conversation
- showing changes in personality, behaviour or mood
- losing motivation or interest in people or things they previously enjoyed (becoming apathetic)
- becoming upset or easily annoyed at finding it harder to do things.



## The middle stage of dementia

In the middle stage, the person's symptoms have a bigger impact on their daily life. Depending on their individual circumstances and symptoms, most people with dementia will benefit from extra support with daily living at this stage.

They may:

- have very poor memory of recent events, for example, saying they've washed or eaten when they haven't. Or they may insist they haven't done these activities when they have (but still remember things from long ago, even if they confuse some details)
- do things that may be unsafe, such as leaving a gas cooker on
- be confused about the time and place
- become lost in familiar places
- forget names of friends or family, or mistake one family member for another
- walk about – often with a purpose that isn't obvious to those around them (this could be inside or outside, during the day or night)
- behave in ways that may seem odd – for example, putting items in strange places
- become angry, upset or distressed very quickly.

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## The later stage of dementia

By this stage, symptoms are more severe and the person will need much more support. This can be provided by care at home but is more often given in a care home setting. The person is also more likely to need to go into hospital, for example, from an infection or fall.

The person is likely to:

- become more frail, find it harder to walk and be more at risk of falling
- become tired more easily
- sleep a lot during the day, which can mean they are more active or need support during the night
- become distressed more easily – sometimes for reasons that are hard to identify
- have a lot of difficulty with eating and drinking
- find it much harder to communicate or understand what's being said to them.



For more information, see ‘Supporting a person in the later stage of dementia’ on pages 136–149 and factsheet 417 **Supporting a person in the later stage of dementia.**



Each time a person with advanced dementia has an illness or accident that needs treatment, it can take them longer to recover and the risk of complications increases. This is the main reason why dementia is a life-shortening condition. It causes the person to become frail and less able to cope with further health problems. For more information, see 'Dementia and the end of life' on page 152.

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**We concentrate on what we can do rather than what we can't. He can get very frustrated with struggling to find the right words and his ability to read and write are reduced, but we still have lots of lovely days and enjoy each other's company.**

Wife of a person with dementia

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# Treatment and support

There is no cure for dementia yet. However, the right treatments and support can make a big difference in living as well as possible with the condition.

These include:

- structured therapies, such as cognitive stimulation therapy (CST) or cognitive rehabilitation
- medicines to improve thinking and memory
- managing other health conditions that can make dementia symptoms worse – for example, hearing and sight loss
- reducing side effects from medicines for other health conditions – some can affect a person's memory and thinking
- helpful changes to the person's everyday routine and lifestyle.

Supporting the person with dementia to stay active is good for their wellbeing. Encouraging them to meet and connect with other people also helps them keep using their language and memory skills.

Different activities, including everyday tasks, can help to preserve the person's self-esteem, improve sleep and help prevent depression. For more information, see 'Activities' on page 95.



The person may find the following treatments and activity ideas helpful.

- **Talking therapies, such as counselling** – these can help someone to come to terms with their diagnosis or discuss their feelings.
- **Cognitive stimulation therapy (CST)** – this is a popular way to help keep someone's mind active. It involves doing themed activity sessions over several weeks.
- **Cognitive rehabilitation** – this is skills training tailored to a person's needs and abilities. It can enable the person to keep their skills, meet their goals and cope better.
- **Life story work** – this is where the person is encouraged to record their life experiences and memories. Knowing about a person's life experiences may help others to provide person-centred care for them.
- **Reminiscence** – this involves talking about the person's past with the help of things like photos, familiar objects or music.

Not all of these will work for everyone. It will depend on the individual, and on the type and stage of their dementia. Speak to the memory clinic, GP or a dementia adviser to discuss what treatments may be best for the person you care for.

Find out what other practical support and advice is available in your area for both you and the person you care for. Go to **[alzheimerers.org.uk/dementiadirectory](https://alzheimerers.org.uk/dementiadirectory)**





## Treatments with medicines

There are medicines that can help some people, depending on the type of dementia they have. These can help with the symptoms or stop them getting worse for a while.

### Medicines for Alzheimer's disease and DLB

Treatments with medicines are available for people with Alzheimer's disease and those with dementia with Lewy bodies (DLB). They may ease some of the symptoms for a while by helping the person to think more clearly.

These medicines don't cure dementia, or stop or reverse the damage to the brain. As with all medicines there are possible side effects, in which case a different medicine could be more suitable.

A person with DLB may also be given other medicines for distressing hallucinations, delusions or agitation.

If the movement problems caused by DLB become very distressing, the doctor may prescribe a low dose of a medicine used to treat Parkinson's disease, called levodopa. However, levodopa can raise the person's chances of having delusions and hallucinations.



### Medicines for vascular dementia

People with vascular dementia will often be given medicines to control their blood pressure or other conditions that can contribute to vascular dementia. Those at risk of stroke will often be prescribed medicines (including low-dose aspirin) to thin the blood, which can prevent further blood clots forming.

### New treatments

Every day, researchers are working on new treatments for dementia. To find out more about how you can support research, go to **[alzheimers.org.uk/research](https://alzheimers.org.uk/research)**



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



**I want to give back to her some of what she gave to me.**

Carer for a person with dementia



Call our Dementia Support Line on **0333 150 3456**

# Taking on the caring role

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## Support for you

You may already have help from health or social care professionals with some aspects of caring for the person. Or you may need help at some point in the future. There is lots of support available to help you. Don't be afraid to ask for this when you need it.

### Talk to your GP

It's a good idea to tell your GP that you're now caring for someone with dementia. This means you can register as a 'carer', which may be useful for a number of reasons. For example, the GP can:

- give you helpful information and let you know where you can get support. For example, they can refer you to health and social care professionals, or for a carer's assessment (see page 113)
- sometimes arrange appointments at times that are more suitable for you
- offer you free annual health checks and vaccinations, such as the flu jab
- provide supporting letters and information if you apply for benefits.

If you have the same GP as the person you support, they may ask the person's permission to share information with you.

It's also a good idea to arrange for regular check-ups for the person with dementia as soon as possible after their diagnosis.





There are longer waiting times at some surgeries so bear this in mind when booking an appointment.

## A network of support

You can read more about different forms of support in this handbook, including:

- professionals who can help you (see ‘Health and social care professionals’ on page 109)
- your local authority, housing and care services (see ‘Support and care services’ on pages 106–125)
- financial support (see ‘Money and work’ on pages 126–135).

For more about people who can support you, see ‘Getting support’ on page 1.

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### The word ‘carer’

You may or may not see yourself as the person’s ‘carer’. You might first and foremost think of yourself as their partner, spouse, family member or friend. Many people feel this way, and it’s your choice whether you use the term ‘carer’.

Many of the services that can support you, including health and social care services and financial support, may refer to you as a ‘carer’. Even if you don’t welcome or identify with this term, it can help you to access the right support when talking to professionals.



Call our Dementia Support Line on **0333 150 3456**

# The impact of dementia on your daily life

Taking on the role of supporting a person with dementia is likely to have a big impact on your life. It can be positive and rewarding, but will bring challenges and affect how you're feeling in many different ways.

If you find things difficult, support is available – and everyone needs this from time to time. The right help will help you carry out the important role of supporting the person, for as long as you choose to keep doing so.

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It's likely that you know the person well, perhaps better than anyone else, and that especially may help you to understand their individual needs. This includes any cultural, religious, spiritual and personal needs they may have that others may not be aware of.

As the person's dementia progresses they will need more support. This may be hard for you to adjust to. You may also not know where or how to find services that would be most appropriate for the person.

This guide includes information on coping with changes and what help is available to you. You can find suggestions for dealing with the effect of dementia on:

- your relationship with the person you are caring for
- your feelings
- your physical and mental health
- your daily life
- your finances
- your responsibilities, such as work or study.



# When the person doesn't accept they have dementia

It can be hard to accept a diagnosis of dementia. Some people might say their memory loss is just because they're getting older. They may avoid talking about their condition by changing the subject whenever someone mentions it.

Denial is a very common and natural reaction to a recent diagnosis. However, it can be frustrating or distressing for you and others who want to help the person to live better with dementia. For example, the person may not take their medicine or accept other treatment they need. They may also carry on doing things on their own when you think they need help.

Some types of dementia cause a person to no longer recognise changes in their behaviour and emotions. This is known as 'lack of insight'. Unlike denial, which sometimes improves over time, lack of insight tends to get worse as dementia progresses.

If you're feeling frustrated or finding the person's denial or lack of insight difficult, it may help to talk to other people in a similar situation. See 'Getting support' on page 1.



**For more information, see factsheet 533  
Understanding denial and lack of insight.**



Call our Dementia Support Line on **0333 150 3456**

# The impact of dementia on your feelings and relationships

When someone close to you has dementia, their condition is likely to affect your relationship over time. As you provide more support for the person, this can bring a range of feelings and it might be hard for you both to adjust. Remind yourself that you are doing the best you can.

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### Your roles in the relationship

As the person's dementia progresses and they need more support from you, your roles in the relationship are likely to change.

You may struggle with caring tasks and adjustments you have to make. Think about how your relationship has worked up to now. Some aspects of this may provide you with comfort and support. You might also find you are able to talk about many of the same things you used to, or enjoy the same activities together.

If you need to start helping the person with tasks that they used to do without support – such as paying the bills, driving or cooking – you might find this difficult to accept or get used to. Talk to others about how you're feeling (see 'Getting support' on page 1).



## Sexual feelings

If you're caring for a partner with dementia, your sexual relationship is likely to change as their condition progresses.

Some people find it hard to enjoy a sexual relationship with the person they are caring for when many other aspects of their relationship have changed. However, many couples do enjoy a physical relationship and sometimes discover new ways of sharing closeness and intimacy.

Some people with dementia lose interest in sex or are unable to be sexually active. If you still want a sexual relationship, this can be very difficult for you. Sometimes, you might even feel guilty for this – though it's natural to continue to want intimacy.

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Alternatively, the person's desire for sex may increase. Some people can behave in challenging or aggressive ways.

Whatever the situation, both partners must consent to any sexual activity. If you ever feel threatened or afraid, it is important to seek help immediately and call the police if necessary.

If you have any questions, it can help to get support and advice, and to talk about how you are feeling. See 'Getting support' on page 1.



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

## Other feelings

Many people have mixed feelings about being in a caring role. The relationship between you and the person you're caring for might be complex. At times, you might be surprised by your feelings and how strong they can be – especially if you feel anger, guilt or sadness.

Remember that intense feelings could be because your relationship with the person is very important to you, and you're supporting them in what may be very difficult circumstances.



## Positive feelings

Caring for someone with dementia can bring positive feelings. For example, your relationship with the person may have always been strong so you feel determined to stay close and support them. You may feel pleased that you're able to cope with the challenges that caring brings. You may learn new things about yourself and the person.

Some carers say that they enjoy providing care and even feel closer to the person they are caring for. Others say they are still able to enjoy spending time with the person even though there are lots of changes. Some people feel pleased because they are giving something back to a person who has given a lot to them in the past.

The pressures of caring can change from day to day. But remembering why you're doing it can help you keep positive and able to support the person.

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**Talking to others is helpful and often mutually beneficial.**

Carer for a person with dementia

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## **If your relationship was difficult before dementia**

Not all relationships are easy. Your relationship with the person you're now caring for may have been difficult before they developed dementia. For example, you or the other person might have had problems with alcohol or other drugs, or with mental illness. Your relationship may even have been abusive at times.

A dementia diagnosis won't make other problems go away. Negative feelings from the past can make it hard for some people to want to take on a caring role. You may be less tolerant of the person or find that distressing memories or events from the past are affecting you now.

If you've had a difficult past relationship with the person, try to get help to develop a healthy and safe relationship with them now. It is important to look after your own mental and emotional wellbeing.

If your relationship has been abusive and you don't feel safe, it's important to tell someone you trust as soon as possible.

Consider whether you want to care for the person yourself. If you do, this should be your decision and you should not feel that it's something you have to do, especially if you feel uncomfortable or unsafe. Talk about these issues with someone (see 'Getting support' on page 1).





## Difficult emotions

As the person's dementia progresses, you're likely to go through a range of emotions. This could be because you feel overwhelmed or don't know which way to turn.

You may find it hard to accept that the future will be different to the one you'd both planned. You might also feel isolated because you aren't able to go out and spend as much time with friends. Or it may be because of changes in the person's behaviour.

Your feelings might include:

- guilt
- grief
- anger
- loneliness
- embarrassment.

These are feelings many carers experience. If you don't find ways of managing them, this can lead to you feeling more exhausted over time. Things may become more difficult and affect your physical and mental health. Understanding your feelings and what's causing them can help you to focus better on ways of coping.



For more information, see factsheets 417 **Supporting a person in the later stage of dementia**, 523 **Carers – looking after yourself** and 525 **Changes in behaviour**.



Call our Dementia Support Line on **0333 150 3456**



## Your relationships with other people

Caring for someone with dementia may affect your relationships with other people. For example, support from family members or friends can have a positive impact on your relationships with them.

At the same time, you may find that others react negatively, don't offer you the support you need, or become distant. This can leave you feeling isolated.

Negative reactions from others can be for a number of reasons – for example:

- they find it hard to accept that the person has dementia and don't know how to talk about it
- they are worried about what other people will think
- it's difficult to talk about dementia in your culture or community
- they don't understand the challenges you are facing or know how to support a person with dementia. You could suggest they read factsheet 524 **Understanding and supporting a person with dementia** or this guide.

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## Talking to children and young people

If you have children, grandchildren or young relatives, you may be wondering whether to talk to them about dementia. Children and young people often sense when something has changed, even when they haven't been told the facts. It can be reassuring for them to understand what the cause is, especially if they are close to the person with dementia.



When talking to them about dementia, bear in mind their age, personality and level of understanding. Try to get a sense of how much detail they can cope with. It can also help to let their school know.



For more information, see factsheet 515  
**Supporting children and young people when  
a person has dementia.**

## 2



### **Carer's cards**

It's a good idea to think about what would happen to the person if something happens to you – for example, if you have an accident or suddenly become ill.

In England, some local authorities offer 'carer's cards'. These are cards you carry to let emergency workers and others know that someone relies on you as a carer. In Northern Ireland and Wales, cards are available from Carers NI and Carers Wales – both are part of Carers UK (see 'Other useful organisations' on pages 164–172).



For more information visit **[alzheimers.org.uk](https://www.alzheimers.org.uk)**

# Looking after yourself

The challenges of caring can mean you don't have time to do all the things you need to do. Making time for yourself can feel impossible. However, looking after yourself is important both for your own health and wellbeing and to help you carry on caring.

It is very important to find the right support and ways of taking care of your own needs. As a first step, it's best to talk to other people you trust. Doing this can help you to feel less isolated and stressed. For ideas of who to talk to, see 'Getting support' on page 1.

## Involving other people

2

Involving family and friends can help to give you a break and reduce some of your stress.

It's a good idea to let people know you need some support. Even if they can't offer help with day-to-day caring, you could ask them to help with certain things (such as paying bills or picking up medicines). They may also be able to support the person from time to time so that you can have a break.

Carers UK has an app called Jointly, which helps you to coordinate caring with other people. See 'Other useful organisations' on pages 164–172.

If you do not have family and friends who can help, there may be voluntary agencies that can offer support. Speak to your GP or social services for more information.



## Taking breaks

Taking regular breaks from caring is important for your wellbeing, whether this is for an hour or two, or for days or weeks. Getting respite and making time for yourself can mean you are better able to support the person you are caring for.

Try to make time to do something you enjoy every day, whether it is on your own or with the person you are caring for.

To take a break, ask if a friend or family member can spend some time with the person. Or see whether there are services that can help with caring, such as a day centre or short-term residential care. See 'Respite care' on page 119 for more information.

## Looking after your own health

Caring can have a big impact on your mental and physical health and wellbeing. The following tips will help you to look after yourself so you can go on caring.

- **Eat balanced meals** – try to have at least five portions of fruits and vegetables per day, as well as protein and starchy foods. Consider preparing larger amounts and freezing portions to reheat later, or using meal delivery services.



- **Keep hydrated** – drink 6–8 glasses of liquid per day.
- **Try to spend time outside and get fresh air** – being outside, even for only short periods of time, can help to reduce stress and improve sleep.
- **Make time for your hobbies and interests** – even if it's just for a short time. You could do these with the person you are caring for too.
- **Keep physically and mentally active** – for example, by going for walks, gardening, or at a gym or exercise class. Mental activities could include reading, learning a language, or doing puzzles or crosswords. Socialising is also very important for your wellbeing. Find things that work for you.
- **Look after your own spiritual or religious needs** – for example, continue with any meditation or prayer. If you usually attend a place of worship, try to keep doing this or watch services online.
- **Try to get enough sleep** – avoid alcohol and caffeine in the evening if you can. Talk to your GP if you think you might need help.
- **Make time to relax** – find exercises and techniques that help reduce stress. Ask your GP, look online (for example, on the NHS website), or visit your local library or bookshop (look in the 'wellbeing' or 'self-help' section). There are also relaxation apps that you can download to your smartphone or tablet.

If you feel anxious or depressed, it can be helpful to talk to a professional, such as a counsellor. Your GP can refer you.



# Looking ahead: putting plans in place

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# Practical arrangements

It can be difficult to think about the future and arrangements you will have to make because of changes caused by the progression of the person's dementia.

As soon as you both feel able to, it's a good idea for you and the person you're supporting to start thinking ahead. It can help you both to prepare for a time when they may not be able to make some decisions for themselves.

Talking about this gives them a chance to make their wishes for the future clear and choose who they want to make those decisions for them when this time comes.

## 3 Driving and dementia

If the person drives, a diagnosis of dementia is not in itself a reason to stop straightaway. The most important thing is whether the person can still drive safely. As their condition progresses, a time will come when they must stop driving.

By law, when a person is diagnosed with dementia and has a driving licence, they must tell their licensing agency straightaway. This is the Driver and Vehicle Licensing Agency (DVLA) in England and Wales, or the Driver and Vehicle Agency (DVA) in Northern Ireland (see 'Other useful organisations' on pages 164–172).



The agency will ask about the person's medical information and decide if they are safe to drive. The person may need to take a driving assessment.

A person who receives a diagnosis of dementia must also immediately tell their car insurance company. If they don't do this, their policy may be invalid.

Many people with dementia will decide for themselves to stop driving. They might begin to find driving stressful or become less confident. For others, however, it can be very difficult to adjust to, and they may need support and understanding.

It may also be hard for you to adjust. You might not drive or, if you do, you may start to do much more driving for the person. You may find that the person struggles with you driving, or feels frustrated or resentful about it.

If you're finding it difficult, consider looking for other transport options in your area or changes to the way you're doing things currently. For example, look into getting shopping delivered rather than driving to the supermarket.



**For more information, see factsheet 439  
Driving and dementia.**

**3**

Call our Dementia Support Line on **0333 150 3456**

## If the person with dementia is working

If the person with dementia is still working, their diagnosis doesn't automatically mean they have to stop. Many people with dementia continue working, although they may need some support.

It is a good idea for the person to tell their employer about their diagnosis (sometimes the person will legally have to). Under equalities law, their employer must make reasonable adjustments to working arrangements to try to enable the person to continue working.

Encourage the person to get some expert advice. This could be from their trade union, local Citizens Advice or from a disability employment adviser at their local Jobcentre Plus. It might sometimes be appropriate to ask for advice from a solicitor.



For more information, the person may find it helpful to look at booklet 1509 **Work and dementia**.







# Legal and financial matters

As part of your practical arrangements, it's also helpful for both you and the person with dementia to think about your finances.

This section is about the legal and financial affairs of the person with dementia. For information about the financial aspects of caring for a person with dementia, see 'Money and work' on pages 126–135.

Try to encourage the person you're supporting to get any legal and financial paperwork in order. You may want to offer to help them with the specific things that are useful for the person to think about.

## 3

### Bank accounts

A person's bank, building society or credit union may be able to support them with managing their accounts. For example, the person may want to set up standing orders or direct debits for making payments.

The person may hold accounts jointly with you or someone else. This may be helpful to the person in the early stage of their condition as it allows the other account holder to provide some support – for example, with paying bills.

However, as their condition progresses and they find managing money more difficult, the person may not be able to give their consent to payments and withdrawals.



Some banks will ‘freeze’ a joint account if one of the account holders loses the ability (known as ‘mental capacity’) to make financial decisions for themselves. This means both account holders are unable to access their money.

The bank will unfreeze the account when someone with appropriate legal power (such as a Lasting power of attorney) can handle it on the person’s behalf.

Think about what will happen to any joint accounts. You may want to encourage the person to discuss this with their bank.



For more information, the person with dementia may find it helpful to look at booklet 1501 **Managing your money.**

3



**I now have all my accounts in order, all paperwork is up to date and filed and easy to get to.**

Carer for a person with dementia



## Lasting power of attorney (LPA)

A person with dementia will eventually lose the ability (or ‘mental capacity’) to make some decisions for themselves.

While the person has mental capacity to do so, they can choose someone who they want (known as an ‘attorney’) to make decisions on their behalf when the time comes. This should be someone they trust.

The person with dementia can give this power using a document called a Lasting power of attorney (LPA). There are two types:

- **an LPA for decisions about health and welfare** – this covers the treatment and care they receive and where they should live
- **an LPA for decisions about property and financial affairs** – this covers their bank accounts, bills, tax, pensions and deciding what happens to their home.

It’s a good idea for the person to make both types of LPA. Different attorneys can be appointed to make different kinds of decisions, and there can be more than one attorney. This may be helpful if one is a spouse of similar age or has health problems of their own.





Making an LPA involves filling out forms that then have to be registered with the Office of the Public Guardian (OPG) to be used. There is a fee for this. See ‘Other useful organisations’ on pages 164–172.



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

Alzheimer’s Society offers an LPA digital assistance service to help people create and register LPAs using the OPG’s online tool. To find out more, the person with dementia can call us on **0333 150 3456**. This service does not offer legal advice.

In Northern Ireland, the process of giving legal authority is currently through an Enduring power of attorney (EPA). It is only possible to do this for property and financial affairs.



For more information, see factsheets NI472  
**Enduring power of attorney and controllership**  
and NI467 **Financial and legal tips in Northern Ireland**  
– these are specific to Northern Ireland.

3



Call our Dementia Support Line on **0333 150 3456**

## What happens if there is no LPA or EPA?

If the person with dementia becomes unable to make these decisions and has not already made an LPA (or EPA), you or someone else can apply to the Court of Protection to become the person's 'deputy'. A deputy can legally make decisions on the person's behalf and manage their finances.

LPAs enable the person to choose themselves who will make decisions for them. This is also cheaper and faster than the process for someone becoming a deputy.



For more information, see factsheet 530 **Deputyship**.

In Northern Ireland, you can apply for a 'controllership' rather than a deputyship.



For more information, see factsheet NI472  
**Enduring power of attorney and controllership**  
– this is specific to Northern Ireland.

If the person has no property or savings and their only income is from state benefits, you can apply to become their 'appointee' to receive and manage those benefits on their behalf. This is instead of a deputyship. For more information, go to **gov.uk** in England and Wales, or **www.nidirect.gov.uk** in Northern Ireland.



For more information visit **alzheimers.org.uk**

## Making a will

Everyone should make a will. A will allows someone to pass on what they own to the people they want to receive it, after their death.

Someone can also express preferences about funeral arrangements and whether they want to be buried or cremated in their will.

If the person doesn't make a will, the law will decide who inherits what they own. This may not be who they want or would expect.

It's not necessary to use a solicitor to make a will but it's often a good idea. Alzheimer's Society can put people in touch with a solicitor through our Will to Remember scheme. Go to **[alzheimers.org.uk/willtoremember](https://alzheimers.org.uk/willtoremember)** for details.



## Planning for future care

It can be very helpful for the person to think about making plans for the care they want to receive later on, when they may not be able to decide for themselves. This is known as ‘advance care planning’.

As well as an LPA for health and welfare, advance care planning can include a written:

- advance decision to refuse treatment
- advance statement.

Even if someone decides not to write out either of these documents formally, discussing them can be a good way to talk about what they want for the future. Discussions you have about these can be shared with health and social care professionals. These can then be recorded in the person’s medical records and care plan.

It can be difficult to know how to start these discussions. Think about what you already know about the person, and gently encourage them to talk about the things that matter to them.

“

**If you haven’t already done things such as getting Lasting power of attorney in place, now is the time to get it sorted.**

Carer for a person with dementia

”



## Advance decisions and advance statements

Advance decisions to refuse treatment allow someone to state which medical treatments they don't want to receive in the future. These documents can make sure that the person is not forced to receive treatment they don't want at a time when they are unable to make this decision themselves.

Advance decisions are legally binding as long as they meet certain conditions. This means that health professionals must follow them. A person's GP can help them understand the advantages and disadvantages of refusing medical treatment in advance. A solicitor can also provide advice.

In Northern Ireland, these are sometimes called 'advance directives' instead of advance decisions. The law is slightly different and, although advance decisions (or directives) are not legally binding in the same way here, it is likely that they would be followed if properly made.

Advance statements are similar to advance decisions, but are not the same thing. An advance statement gives the person the option to make broader general statements about their wishes and preferences for the future, rather than just refusing certain treatments.

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For example, an advance statement might include information about how the person wants their religious beliefs to be taken into account in their care, or preferences such as whether they prefer to shower or have a bath.

An advance statement, unlike an advance decision, is not legally binding. Health professionals do not have to follow it. However, they should take the statement into account when making decisions about the person's care and treatment.



**3** For more information and a template form for drafting an advance decision, see factsheet 463 **Advance decisions and advance statements.**

For information relating to Northern Ireland, see factsheet NI467 **Financial and legal tips in Northern Ireland.**

For more information and a template form for an advance statement, the person with dementia may want to look at booklet 1510 **Planning ahead.**



# Your rights

As the person's dementia progresses, you may both need more practical and financial support. Making sure the person is getting everything they are entitled to may also help you.

As a carer, you also have legal rights of your own. Your rights and those of the person with dementia include:

- being involved in decisions about what is in the person's best interests when the person is unable to make a particular decision for themselves (see page 54)
- getting a carer's assessment from your local authority (see page 113), which may lead to you getting some support from them
- getting a needs assessment for the person with dementia, which may result in them getting some support. This can include respite care to allow you to take breaks (see page 119)
- financial support for you and the person with dementia. This may be subject to means-testing (see page 130)
- making complaints if you are unhappy about the care the person has received (see page 125)
- requesting flexible working arrangements from your employer and the person with dementia's employer (see page 134).

3



# Understanding changes and symptoms of dementia

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# Understanding the person with dementia

Living with dementia can have a big impact on a person – emotionally, socially, psychologically and practically. Many people with dementia describe these impacts as a series of losses. Adjusting to them can be challenging.

It can be hard to imagine what it's like to have dementia. For example, having problems with memory, thinking, senses and emotions can affect the person's self-esteem, independence and relationships.

The person may also gradually lose the ability to do their favourite activities, or everyday tasks. However, they may keep some abilities for a long time and be able to continue doing the things they have always done, even if the activities need to be adapted.

Where possible, support the person to make choices and do things for themselves. This helps them maintain skills and independence.

For more about how dementia will affect the person in the later stage, see 'Supporting a person in the later stage of dementia' on pages 136–149.

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# Communicating with the person in the early and middle stages

From the early stage of dementia people often have problems communicating.

## Language problems in dementia

When a person has dementia, the parts of the brain that control their ability to understand language are damaged.

They may:

- not be able to follow a conversation or respond appropriately
- forget words or confuse one word with another (for example, 'book' instead of 'newspaper')
- repeat themselves or ask the same questions over and over again
- have problems expressing how they're feeling
- use the first language they learned as a child.  
For example, if they learned English as a second language, they may forget how to speak it.

In the later stage of dementia, problems with language and communication become much more severe.  
For more information, see 'Communicating in the later stage' on page 142.



## Communicating – tips

- **Include the person in conversations.** Continuing to communicate with the person is very important. People can become isolated if they start to lose confidence and avoid talking to others or socialising. Give them time to speak and try not to talk on their behalf. Ask others to communicate directly with the person too.
- **Listen to the person closely.** Remove distractions, such as background noise from the television or radio.
- **Adjust your style of speaking.** Speak clearly and a little more slowly, and use simple words and sentences. However, don't talk to the person as you would to a child. Consider using pictures or objects as prompts – for example, holding up a teacup when offering them tea.
- **Make sure they wear their hearing aid or glasses,** if they have them, and that they are working properly. Hearing or vision difficulties can make it harder to understand what someone is saying.
- **Try to maintain eye contact** – as long as it feels appropriate to help the person focus on you.
- **Stay calm, and be as kind and as patient as you can.**

4





- Try to sit or stand at eye-level with the person, rather than standing over them. Make sure there is enough light so that the person can see your facial expressions and body language.
- Avoid asking too many open questions, such as 'What do you want to do today?' Choice is important, but too many options can be confusing. Try giving a short list of options, or ask questions that need a 'yes' or 'no' answer.



For more information on communicating with a person with dementia, see factsheet 500 **Communicating**.



## Managing symptoms

Everyone experiences dementia differently, and symptoms vary from person to person. This section describes and suggests ways of managing some of the symptoms people with dementia and carers often find difficult. These include:

- memory loss
- delusions (mistaken thoughts)
- hallucinations (especially for someone with dementia with Lewy bodies)
- apathy, depression or anxiety.

There is information on changes in behaviour on page 78. For more information on symptoms in the later stage of dementia, see 'Supporting a person in the later stage of dementia' on pages 136–149.

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**My husband sings or hums, doesn't remember the words. Sometimes people stand and stare. I say my husband isn't drunk, he just has Alzheimer's, then they feel embarrassed. I tell them, 'Don't worry, it's not catching'.**

Wife of a person with dementia

”



## Memory loss

Memory loss affects most people with dementia. It can be frustrating and distressing both for the person and those, like you, who are important to them.

Problems can include:

- forgetting appointments and recent conversations or events
- losing or misplacing items
- difficulties with day-to-day tasks
- getting lost in places they know well, or on familiar journeys
- difficulty recognising faces.

Below are some tips you can try.

- **If the person repeats a question, give simple answers and repeat as needed.** You can also write the answer down so the person has a note of it. Telling them they have heard the information before won't help.
- **Mark a calendar with the date** (or use an electronic calendar that automatically changes the day and the date).
- **Use reminders**, such as sticky notes or a wall calendar. Or use a mobile phone calendar, diary, or reminders on a mobile phone or tablet app.





- **Set up more permanent reminders** for regular tasks – for example, put up a sign by the front door to remind the person to take their keys and wallet when they leave the house. Keep important things like money, keys and glasses in the same place.
- **Use visual clues to explain where items go**, such as pictures or photos on cupboard doors to show what goes inside them.
- **Encourage visitors to write the time and purpose of their visit in a book.** Professionals can record their visits in booklet 923 **My appointments**.

As dementia progresses, a person loses more of their memories. This can change how they experience what's going on around them and can cause confusion. For example, someone might talk about wanting to see a family member who died a long time ago, or they may think they need to go to work.

Instead of trying to correct the person, think about their needs or feelings. For example, if they are talking about needing to 'go home', they may be feeling uncomfortable or distressed. Reassure them that they are safe, and try to work out what would help them feel more comfortable.



For more information, see factsheets 526 **Supporting a person with memory loss** and 527 **Changes in perception**.



## Assistive technology for memory problems

There are lots of devices that may help with memory problems. These include calendar clocks to remind people of the day and date, or phones where buttons are replaced with photos of people.

A wide range of devices are available on our online shop. Go to **[shop.alzheimers.org.uk](https://shop.alzheimers.org.uk)**



For more information, see factsheet 437

**Using technology to help with everyday life.**



### Supporting an LGBTQ+ person with memory loss

If the person you're supporting is a member of the LGBTQ+ community, memory loss and other dementia symptoms may affect them in particular ways. This can relate to revealing their sexual orientation or gender identity, for example.



For more information, see factsheet 480

**Supporting an LGBTQ+ person with dementia.**

**4**

Call our Dementia Support Line on **0333 150 3456**

## Delusions

Sometimes, people with dementia strongly believe things that aren't true. These thoughts are known as 'delusions'. They may also be referred to as 'incorrect beliefs'. Even though the delusions are not true, they will feel very real to the person.

Symptoms of dementia can cause delusions. For example, if the person doesn't remember moving their keys and can't find them, it might make sense to them that someone else has stolen them.

The person is trying to make sense of the world around them as well as they can. The person's surroundings, other health conditions and medicines may also contribute to delusions.

Sometimes, delusions are made worse by hallucinations. See the information in the following section.

It's important not to dismiss what the person says or feels just because they have dementia. Try to find out whether what they're saying is true.

If it is a delusion, trying to convince them that they're wrong is unlikely to help and can make both of you feel more frustrated and distressed. Instead, try to stay calm, acknowledge how they are feeling and reassure the person that you are taking their concerns seriously.

4



## Hallucinations

Some people with dementia have hallucinations (where they experience something that isn't there). It is possible to have hallucinations with any of the five senses. A person may be more likely to have visual hallucinations (seeing things) if they have dementia with Lewy bodies or Parkinson's disease dementia.

However, people with dementia can be thought to be hallucinating when in fact they are simply mistaken about what they have experienced. For example, the person might hear voices on the radio and think there are people in the room. These are known as 'misperceptions'.

Hallucinations or misperceptions can be very frightening and will feel real to the person with dementia.

If someone with dementia appears to be seeing or hearing something that you can't and you feel they are frightened or anxious, you can try the following tips.

- **Acknowledge their feelings.** Tell them that what they are sensing is not clear to you, and ask them to describe their hallucination.
- **Stay with the person and offer them reassurance.** Explain what is happening calmly and in a supportive tone. Avoid arguing with them or telling them that they're wrong.
- **Try to gently distract them** – for example, by turning their attention to an activity, talking to them or playing calming music.

4



There are different ways you can support a person to manage hallucinations and misperceptions.

- Make sure the person's surroundings are well lit, and reduce any items that may cause visual confusion, such as mirrors and patterned carpets or wallpaper.
- Check for noises that the person could confuse with someone speaking, such as air conditioning or the TV.
- Make sure the person has had recent hearing and sight tests. Any glasses or hearing aids should be in good condition and working well.
- If the person's hallucinations involve multiple senses, get immediate medical advice. Also talk to the GP if their hallucinations last several weeks, happen over and over again, or are causing them a lot of distress.



For more information, see factsheet 527  
**Changes in perception.**



**A few months ago Mum was confusing real life with TV programmes. She does not do it as much now, but her sentences are not connected – it's like she has all these different thoughts and threads in her head and it all comes out in one conversation.**

Carer for a person with dementia



For more information visit **[alzheimers.org.uk](https://www.alzheimers.org.uk)**

## Delirium

Delirium is a change in a person's mental state that starts suddenly in someone who is unwell. A person with delirium may be more confused than normal, unusually sleepy or agitated, easily distracted, or have hallucinations.

Delirium is much more common in older people, especially those with dementia. If the person you're caring for suddenly develops any of these symptoms, they should see the GP as soon as possible.

The GP will review the person's medicines and stop any drugs linked to delirium. They will also make sure the person is free from pain, has enough fluids and enough oxygen in their blood.

Delirium will usually improve if its cause is found and treated, although this can take some time.

To help a person recover from delirium, their environment should be calm and supportive. For example, there should be no unnecessary noise at night, and the person should wear any hearing aids or glasses properly. They should also be supported to eat and drink regularly. A 24-hour clock and calendar that they can see clearly may also help.

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## Apathy, depression and anxiety

Apathy, depression or anxiety are much more common in people living with dementia. It can also be harder to find the right treatment that works for the person. Talk to the person's GP if you think they have apathy, depression or anxiety.

### Apathy

A person who has apathy will be less motivated to do things. They may rely on other people to suggest and organise activities, or seem not to care about their own problems or about news and personal events.

Try to find tasks and activities the person will enjoy and find meaningful, even if they only engage with them for a short time. A daily routine may help.

**4**

Sometimes, a person may seem apathetic when they are just finding it difficult to start an activity. Try to help the person by starting it first or breaking it down into chunks, as they may then be able to carry on with it.

If you feel frustrated, try to stay calm and don't blame the person. They are not being lazy, unhelpful or uncaring – the apathy is not their choice.

### Depression

Most people feel low or sad from time to time. However, depression is a medical condition that can last for several weeks, months or longer. It can involve feeling sad or hopeless, disturbed sleep, and having little or no energy.





The person may benefit from regular physical exercise (see page 96). A daily routine and regular contact with other people can also help.

### Anxiety

Anxiety involves feeling very worried, tired, uneasy and irritable. It can have physical symptoms, including fast or irregular heartbeats (palpitations), sweating, dizziness or nausea. In some cases, it can cause panic attacks.

A person with dementia who has anxiety may also have changes in their behaviour, such as agitation or closely following you or another person around.

There are several things that can help a person with anxiety, such as regular physical exercise. The GP may also offer medicine.



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



**Person-centred care is paramount to meeting  
someone's complex and cultural needs,  
so never lose sight of the person who is living  
with dementia.**

Carer for a person with dementia



Call our Dementia Support Line on **0333 150 3456**

# Changes in behaviour

As a person's dementia progresses, they may begin to behave in ways that other people find hard to understand. This can be one of the most difficult aspects of dementia, for the person, for you and for others around you.

These behaviours usually happen when the person is feeling confused, uncomfortable or distressed and trying to make sense of what is happening, or when they are trying to communicate a need. Looking at the causes of the behaviour and identifying the person's needs can help to reduce them and support the person.

Some of the most common changes in behaviour in people with dementia are:

- repetition of questions or actions
- aggression
- agitation, including restlessness
- hiding, hoarding and losing things
- trailing, following and checking
- walking about
- losing inhibitions
- shouting and screaming
- sleep disturbance and waking up at night.

4



These behaviours are sometimes known as ‘behaviours that challenge’. This is because they can bring challenges both for the person with dementia, and for you and others who support them.



For more information, see factsheet 525  
**Changes in behaviour.**



## What causes changes in behaviour?

The way we behave often shows how we are feeling. Some types of dementia can cause behaviour that challenges early on. With other types, these behaviours develop later, or don't develop at all.

A person's behaviour is not always a symptom of their dementia. Thinking about what else could be causing the behaviour can help you understand how to help.

People with dementia may be less able to recognise their own needs and feelings, know how to meet them, or communicate them. Their behaviour could be because of the following needs:

- **physical needs** – for example, the person may be in pain or discomfort, hungry or thirsty, or need to use the toilet
- **psychological needs** – for example, the person may be feeling overwhelmed, anxious, depressed or frustrated about not being able to do the things they used to
- **social needs** – for example, the person may be feeling lonely and not interact much with others.

4



## Aggression

If a person with dementia behaves aggressively, it can be very challenging for them and those who support them.

Aggression can be:

- **verbal** – such as swearing or screaming
- **physical** – such as hitting, scratching or biting.

The causes of aggressive behaviour are likely to be similar to those of other changes in behaviour (see page 78).

If someone is behaving aggressively towards you, it's important that you put your own safety and wellbeing first. If your safety is at risk, step away from the situation as soon as possible and call for help.



For more information, see factsheet 509  
**Aggressive behaviour.**

**4**

Call our Dementia Support Line on **0333 150 3456**

## Sleep problems

Dementia can affect sleep patterns (separately from normal sleep difficulties that come with getting older). The person may keep getting up during the night, become disorientated, get dressed or try to go out. This can be stressful for you. Help the person to:

- treat underlying health conditions and check side effects of medicine – talk to the GP about these
- keep to a routine during the day. Make time to relax at bedtime – soothing music may help
- get plenty of daylight and reduce screen time towards the end of the day
- avoid cigarettes, alcohol and caffeine
- keep their bedroom quiet, dark and cool with a clock showing whether it's day or night next to the bed.

## 4

### Sundowning

Some people with dementia become confused or distressed towards the late afternoon or early evening. This is known as 'sundowning'.

It can be caused by overstimulation during the day, tiredness or disturbance to the person's body clock. Better sleep can help reduce sundowning. Relaxing and enjoyable activities in the late afternoon or early evening may also help.



For more information, see factsheet 534  
**Understanding sleep problems, night-time disturbance and dementia.**



For more information visit [alzheimers.org.uk](https://www.alzheimers.org.uk)

## Walking about

If the person you're supporting walks about, it can be challenging for you and them, especially if they leave home and you don't know where they are. Walking isn't a problem in itself – but it can be worrying for carers and may at times put the person in danger.

Like many behaviours, walking about can have a range of causes. Identifying these can help to meet the person's needs. Reasons why they may walk about include:

- continuing a habit or interest (if they previously walked a lot)
- relieving boredom
- pain or discomfort
- feeling unsettled or confused
- feeling as though they need to get somewhere specific – such as work or picking up children from school.

You may feel that the person doesn't have a purpose for walking. Try to remember that it does for the person in that moment, even if they can't communicate it to you.

It's usually best to let the person walk if it's safe to do so. It may help to build a regular walk with the person into their daily routine.





Some carers consider locking the front door if the person is at risk of walking about. However, a person with dementia should never be locked in if they are on their own, as this would be very dangerous if there was a fire or accident. If there is another adult in the house with the person, you may want to lock the doors, only if all of the following apply.

- They are unable to make this decision themselves.
- It is in their best interests.
- It is the least restrictive option.

If the person goes missing when walking about, you will naturally feel distressed. Try to be calm, contact the local police and think about where they might have gone.

Technology can help limit the risk of this happening. Many smartphones can have tracking enabled, and there are tracking devices which a person can carry or wear. The person would need to agree to this.

You may feel that you can no longer care for the person at home or that it is too unsafe. These are natural reactions and it's important to think about what is best for the person. If you haven't had them already, this might encourage you to ask for a care needs assessment for the person and a carer's assessment for you from the local authority – see page 113.



**For more information, see factsheet 501  
Walking and dementia.**



For more information visit **[alzheimerers.org.uk](https://alzheimerers.org.uk)**

# Ways to support the person

Always try to see things from the person's perspective. People with dementia can sometimes find it hard to understand what is going on around them. This can be confusing and frightening for them.

Ways to support the person, meet their needs and reduce behaviours that challenge include:

- **helping them stay in touch with other people and including them in conversations with others**
- **encouraging the person to do things they enjoy or find useful.** These may need to be adapted to match the person's abilities – see 'Activities' on page 95
- **making changes to their environment if necessary –** for example, reduce noise and improve the lighting, or play music that the person finds calming
- **keeping familiar, comforting or personal items close to them,** such as a favourite jumper or photo album
- **keeping their sleeping environment comfortable –** for example, making sure it is quiet, dark and cool
- **being aware of the person's beliefs and thoughts, and trying not to argue with them.** For example, if they believe they need to go and collect their children from school, don't tell them they're wrong. Instead, ask them to tell you more about their children and their feelings, then gently move their focus onto an activity
- **trying therapies with professionals,** such as cognitive stimulation therapy. Talk to the GP about whether these might be suited to the person.

4



## Tips for managing changes in behaviour

- **Look for triggers for the behaviour.** Does it always happen at the same time or in the same place? Could something in the environment or the way someone does something be causing the person to react a certain way?
- **Consider whether the behaviour is really a problem.** If it is disrupting a particular activity, such as washing or dressing, ask yourself if you could come back to it later. Sometimes, it's best to leave the person to do things how they want to, as long as this will not cause any harm. It could be that they need time to themselves.
- **Ask the person's GP to check for any possible physical causes,** including pain or an infection, and advise on any treatments.
- **Try to remember that the person is not behaving this way on purpose.** They may be experiencing a different reality to you, and are responding to their needs.
- **Think about what you know about the person and their life.** For example, if you know someone used to work night shifts, it might explain why they now want to stay awake or go out at night.
- **Focus on their feelings.** Even though a person with dementia may not be able to fully remember people, places or facts, they still feel and respond to emotions. It may help to respond directly to how the person is feeling (for example, by saying, 'I can see that this is difficult for you').

4



- **Offer the person gentle reassurance.** Try not to show any frustration as it may make things worse.
- **Support the person to do as much as they can for themselves.** The behaviour may be a response to feeling they can't contribute or are not valued by others. If you think they are bored, support them to find things to do that are engaging and mean something to them.

## Coping with changes in behaviour

Changes in the person's behaviour can be challenging, frustrating and often very upsetting for you. They may affect your relationship with the person you're caring for. You may also worry that people are judging them or you, or that they don't understand the challenges you face and expect too much of you.

If the situation feels too intense, step away if it's safe to do so. This can give you and the person time and space to calm down.

Do seek help if you need it. See 'Getting support' on page 1.



**For more information on managing changes in behaviour, see factsheet 525 [Changes in behaviour](#).**



Call our Dementia Support Line on **0333 150 3456**

# Personal care and staying well

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# Supporting a person to stay healthy and active

Having dementia does not mean that the person should feel unwell. There are lots of things you can do to support them to live safely and healthily, and to continue doing the things that they enjoy.

## Keeping safe

Making changes to the person's home can help them to maintain their independence and to stay safe. For example, you could:

- improve lighting levels and make the most of natural light
- remove anything that may cause the person to trip or fall – such as worn carpets or trailing cables
- use plain furniture and unpatterned towels, cushions and other soft furnishings that contrast with the walls and floors
- keep important items where they're easy to find – for example, keep the keys by the door
- leave the bathroom door open and a light on at night
- consider using sensor lights if the person gets up during the night.



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







## Technology

Different types of technology can support the person, such as easy-to-use clocks and virtual assistants like Apple's Siri or Amazon's Alexa. Any technology should always be used with the person's consent or in their best interests, to help maintain their independence and keep them safe.



For more information, see factsheet 437  
**Using technology to help with everyday life.**





## Sight and hearing loss

Many people have some sight or hearing loss as they get older. If you think the person you support cannot hear you, you may need to arrange a hearing test.

The following can also help.

- If the person hears better with one ear, ask people to speak clearly towards that one.
- Make sure you are where the person can see your face, and speak clearly and slightly more slowly.
- Use a laptop or tablet device to type what you're saying.

The person should also have regular sight tests. These can be arranged at home if travelling is difficult for them. If the person needs glasses, check that they are wearing them and that they are clean. If they have more than one type, make sure they wear the correct ones.

You can also support someone with sight problems by:

- making sure there is enough light in the room. Their eyesight may be better at a certain distance, so bear this in mind when considering where other people will sit
- introducing yourself and getting the person's attention before starting or ending a conversation. If you don't, they may become confused about who is talking, or if they are being spoken to.



For more information, see factsheet 500  
**Communicating.**



For more information visit [alzheimers.org.uk](https://www.alzheimers.org.uk)

## Eating and drinking

Eating a healthy balanced diet with plenty of liquids will help someone to stay well. If a person with dementia isn't eating enough, it can make them frailer and less able to recover from infections. It can also make them more confused.

If the person you are caring for isn't eating a balanced diet, the GP can suggest ways to help or may prescribe vitamins or supplements.

People with dementia often have problems with eating and drinking, due to:

- poor appetite
- not recognising food and drink
- not remembering how to use cutlery
- problems sensing that they are hungry or thirsty.

If a person seems to have a poor appetite, talk to their GP. It may be caused by something that can be treated, such as depression, pain or constipation.

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There are other ways to help a person if they lose interest in eating.

- Try different foods as the person's tastes may change.
- Find other opportunities for the person to eat – for example, snacks during activities or during the night if they're awake.
- Present food in different ways – for example, try smoothies as a way for the person to have fruit and vegetables.
- Offer foods that don't need utensils like forks or chopsticks.
- Encourage the person to get involved at mealtimes – for example, setting the table or helping you prepare food.
- Choose contrasting, plain colours for the food, plate and table (for example, a green tablecloth, a red plate and mashed potato).
- Leave healthy snacks within reach for the person to eat when they want to.

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Encourage the person to drink throughout the day. It can help to offer different types of drink and use a clear glass so the person can see what's inside. Jelly Drops® are sweets that can help people with dementia to get more water into their diet. For more information, go to **[www.jellydrops.com](http://www.jellydrops.com)**



For more information, see factsheet 511  
**Eating and drinking.**



For more information visit **[alzheimers.org.uk](http://alzheimers.org.uk)**

## Activities

Staying involved and active can have powerful physical and mental benefits for the wellbeing of a person with dementia. Activities, whether they are hobbies or everyday tasks, can also be a chance for you to do things together and connect with each other.

The person may gradually need more support with taking part in activities. It can help to adapt activities so that the person can still do them. For example, if the person no longer uses the washing machine, they could still help to fold and put clothes into piles.

There may be times when the person becomes upset or frustrated that they can't do things as well as before. Acknowledge these feelings and look for ways to support them. This could include doing things together. Be careful not to take over or undermine them.

You can help make activities easier and more comfortable for the person by:

- breaking tasks down into smaller steps
- giving the person plenty of time
- focusing on progressing with the activity, not the result
- removing or minimising any distractions.



For more information and ideas, see booklet **77AC The activities handbook**.



Call our Dementia Support Line on **0333 150 3456**



## Exercise

Being physically active can have many benefits for people with dementia and carers. It can improve the health of the heart and blood vessels, mobility and physical fitness. And it can help with daily living abilities, emotions and sleep too. Spending time outside also has many health benefits.

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Whether you exercise together or separately, finding activities you and the person enjoy doing will help you keep doing it regularly. You may enjoy walking, swimming or tai chi, but any everyday activities that get you moving, like gardening or dancing together, can have great benefits.

Seated, chair-based exercises are also a good option, especially if the person has limited mobility.



For more information, see factsheet 529  
**Physical activity, movement and exercise.**



For more information visit [alzheimers.org.uk](https://www.alzheimers.org.uk)

## Holidays

Going on holiday may still be an option even as the person's dementia progresses. There are more things to consider when planning a holiday with or for a person with dementia, but there are ways to adapt the trip so that it can be relaxing and fun.

If you decide to go away, it helps to:

- plan well ahead of time
- look into suitable travel insurance – some providers will cover people with dementia
- think about how you can help the person adjust to a new environment, such as leaving the bathroom door open and the light on at night
- talk to staff where you're staying about the person's needs and what would help – such as ground floor accommodation or accessible lifts
- consider going with an extra person, to offer both you and the person with dementia some support
- use a holiday provider that specialises in holidays for people affected by dementia.

External factors can affect travel arrangements. Consider how you may need to change plans and how the person with dementia would cope.



For more information, see factsheet 474  
**Going on holiday when a person has dementia.**



Call our Dementia Support Line on **0333 150 3456**

## Other tips for staying healthy

- Make sure the person has regular check-ups with their GP.
- Support the person to get a good night's sleep. For more information, see 'Sleep problems' on page 82.
- If the person smokes, try to support them to stop. This can be challenging, but there are resources that can help, such as the NHS website (see 'Other useful organisations' on pages 164–172).
- If the weather is very cold, make sure they are wearing enough clothing and that the room temperature is comfortable.
- If the weather is very hot, try to keep the person from overheating by providing lots of drinks and making sure they are dressed appropriately.
- Keeping bones healthy is important. Strong bones help prevent damage from falls, which are a risk for people with dementia. Calcium and vitamin D are important for bone health. Find out more from the NHS website – see 'Other useful organisations' on pages 164–172.
- Keep feet clean and dry with toenails cut short. See a podiatrist or chiropodist for any foot care problems. Make sure shoes and slippers fit well.

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**While no one can change the outcome of dementia, with the right support I think you can change the journey.**

Person with dementia

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## Managing medicines

The person you're supporting may start to need help with managing different medicines, whether they're for dementia or other conditions.

Make sure you know the names and doses of any medicine they take. It can help to keep a recent prescriptions list with all this information, or use the NHS app. Look at the leaflets for any side effects and what happens if the person misses a dose or takes too much.

Ask the pharmacist about a medication reminder box (sometimes known as a 'dosette box'). The box has compartments for different days and, sometimes, times of the day. This can help you and the person keep track of whether they have taken their medicine.

Ask the pharmacist if they offer a free medication review or check-up. This involves a private appointment to discuss any medicines, including how they should be used and any issues that come up.

If the person won't take their medicine, speak to the GP about other options. For example, they may suggest liquids or a patch worn on the skin instead of tablets.



**For more information, see factsheet 407  
Medicines to help memory and thinking.**

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Call our Dementia Support Line on **0333 150 3456**



## Personal care

As the person's dementia progresses, they will need more help with daily personal care, such as washing, getting dressed, shaving and looking after their teeth and gums. At first, this might be difficult for both of you to adjust to.

### Washing, shaving and dressing

If the person still washes themselves, help them maintain their independence for as long as possible. For example, lay out toiletries and towels. Using a non-slip mat and installing a bath rail may help the person to stay safe.

If you help the person with washing and bathing, consider their feelings. They might feel very distressed or threatened being washed by someone else. But their hygiene is essential and can affect their health and how they feel about themselves, as well as affecting how others treat them. The following tips may help.

- If they seem shy, embarrassed or reluctant, try uncovering only the part of their body that you are washing. A towel or robe can be useful for this.
- Make the experience as pleasant and relaxed as possible. Make sure the room is warm and try nice-smelling bubble bath or relaxing music.

Helping someone to shave may be easier with an electric razor, as long as the noise does not frighten them. Razors designed for sensitive skin can also be helpful to avoid cuts or skin irritation.

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Support the person to get dressed by making sure they are as comfortable as possible and have privacy. Offer help gently and sensitively. Let the person choose what they wear and how they look. Too many options can be confusing, so you could offer them the choice between two items of clothing at a time.

It can help to lay out clothes on a non-patterned background in the order the person will put them on. If they need prompting, remind them which item comes next or hand them the one that they need.

Ask if they would like to use the toilet before getting dressed. Once they are dressed, check for any signs of discomfort – the person may not be able to tell you if they're too hot or cold, for example.



For more information, see factsheet 504  
**Supporting a person with washing and dressing.**



## Dental and mouth care

A person's teeth and gums should be cleaned twice a day. Poor oral health can lead to pain and tooth loss. It can affect the person's self-esteem and their ability to eat, laugh and smile.

Make things simpler by offering the person a toothbrush with the toothpaste already on it. If they have dentures, encourage the person to wear them and offer help with putting them in as required. They should also see their dentist every six months.

If you need to clean the person's teeth for them, a community nurse or a dental hygienist at your local dental surgery can advise you on how to do this.



For more information, see factsheet 448  
**Dental and mouth care.**



**These are still people with feelings, maybe even heightened feelings, so don't ignore them or cut them off.**

Carer for a person with dementia



# Managing toilet problems and incontinence

As dementia progresses, some people find it harder to use the toilet. They may have accidents or incontinence – the accidental leakage of pee (urine), poo (faeces) or both. Causes can include:

- medical problems – urinary tract infections (UTIs), prostate gland problems or other gut conditions, such as irritable bowel syndrome
- not reacting quickly enough to the sensation of needing to use the toilet
- not being able to find, recognise or use the toilet
- not being able to do the things they need to, such as undoing clothing.

Supporting someone with incontinence can be difficult for you both. Finding out the reasons for the person's incontinence will help you to manage and get any support you need. The GP can help with information and referrals to specialists.

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## Reducing continence accidents

Try the following tips to reduce accidents.

- Help the person to identify where the toilet is. A sign on the door, including both words and a picture, may help.
- Keep the way to the toilet well lit and clear of any furniture or trip hazards.
- Use contrasting colours to make the toilet easier to see (for example, a black seat on a white base).
- Install handrails and a raised toilet seat.
- Choose clothes that the person can undo easily. You can find 'adaptive clothing' with Velcro fastenings at our online shop – go to **shop.alzheimers.org.uk**
- Ask the person regularly whether they need to use the toilet. Look for any signs they want to go, such as fidgeting, pacing or pulling at their clothes.
- Make sure the person's last drink of the evening is at least two hours before bed, to reduce the chance of urinary incontinence at night.

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Radar keys (sold by Disability Rights UK) can give the person access to accessible toilets. Just Can't Wait cards can help explain that the person needs urgent access to a toilet. They are available from Bladder & Bowel Community. See 'Other useful organisations' on pages 164–172.



## Managing continence accidents

If the person has an accident, it's important to remember that it's not their fault. Try to avoid appearing angry or upset. This can be difficult, and you may find it helpful to talk things through with the GP, a community nurse or a continence adviser (a specialist nurse or therapist).

The following tips may also help.

- If someone has an accident, they should wash as soon as possible with mild soap and warm water. Then they should dry carefully and put on clean clothes.
- When out, make sure you know where the accessible toilets are. Carry spare clothing, wipes and pads, as well as a bag for soiled items.
- The person may want to wear incontinence pads or pull-up pants to soak up pee.
- Try to approach any accidents with understanding, a practical attitude and, when appropriate, some humour.



For more information and advice, see factsheet 502 **Continence and using the toilet.**



# Support and care services

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## Support services

You may be able to manage without much support from others for some time. However, we all need extra help at times. Ask for this when you need it (or even before you think you need it). It may make it easier for you to go on caring for longer.

This section tells you about the different sources of support available from health and social care professionals and other services, including care and housing options.

The support that you need may change through your time as a carer. Be as honest as you can with those close to you about what support would be most useful for you.

Dementia advice and support services are available from many local authorities (or councils) – see page 113 for information on assessments for carers as well as people living with dementia. See ‘Alzheimer’s Society support services’ on pages 160–163 for details of available online, phone and face-to-face support.

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**The community mental health nurse put us in touch with an occupational therapist, who was an absolute godsend. She gave Mum respect and didn’t treat her like she was ill.**

Carer for a person with dementia

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# Health and social care professionals

Health and social care professionals provide important support, both to enable the person with dementia to live well and to help you to care for them. They include doctors (such as GPs and consultants), different types of nurses and other specialists (such as social care workers).

Seeing lots of professionals and having to repeat what you say can be frustrating. If you have a meeting, several professionals may sometimes be able to come at once but this isn't always possible.

You might like to keep a note of who these professionals are and what they do or say. You can help the person you care for to keep track of who they're seeing and when by filling in booklet 923 **My appointments**. This helps people living with dementia keep a record of the appointments they have. To download it, go to **[alzheimers.org.uk/myappointments](https://alzheimers.org.uk/myappointments)** or to order, call **0300 303 5933**.



Different professionals can help with a range of other health problems. If you think one of the professionals listed here may be able to help, ask the person's GP to refer them. In some instances, you may be able to contact them yourself. However, there may be waiting lists.

<b>Problem</b>	<b>Who can help?</b>
communication, eating, drinking and swallowing	speech and language therapist
maintaining skills and independence	occupational therapist or adult social care/telecare team
exercising and moving around	physiotherapist
foot care	podiatrist/chiroprapist
eyesight and vision	optometrist
hearing	audiologist
behaviours that challenge (such as aggression), anxiety and restlessness	clinical psychologist or a specialist, such as a music therapist
relationship and emotional problems	counsellor or clinical psychologist
nutrition	dietitian
toilet and continence problems	continence adviser



## Doctors

The person's GP surgery should be the first contact for any concerns about their health. Try speaking to their specific GP if they have one. The GP can discuss the person's symptoms and medicines. They can also refer them to other professionals (such as nurses) and services. The person may also see a specialist medical consultant, such as a psychiatrist, a geriatrician or a neurologist.



For more information, see factsheet 425

**How the GP can support a person with dementia.**

Speak to your GP as soon as possible if you have any concerns about your own wellbeing, including your mental health. This is just as important as the health of the person you are supporting, and staying well will enable you to carry on supporting them.



## Nurses

Different types of nurses support people with dementia and those who care for them. These include:

- community mental health nurses (also known as ‘community psychiatric nurses’ or CPNs) who work with people living with dementia and those with mental health problems
- dementia nurse specialists or Admiral Nurses (see Dementia UK in ‘Other useful organisations’ on pages 164–172)
- your GP or local health centre’s practice nurse and district or community nurses.

## Social care professionals

These professionals can help with non-medical support.

- Social workers work for local authorities or councils. They assess the person’s needs and advise on support for them and you. This may include equipment and adaptations (see page 118). This can also be done by an occupational therapist or community care assessor.
- Social care workers (including paid domiciliary or homecare workers) help with practical things, like washing, dressing and meal preparation – see ‘Help at home’ on page 116. They can also help with providing carers with a short break and social stimulation. If the person is employing someone to support them through a direct payment (using money from the local authority or their own money), the person they employ is sometimes called a ‘personal assistant’.



# Help from the local authority

Local authorities (councils) have a legal duty to see what help is needed for people with care and support needs. This includes many people living with dementia and their carers, if they are asked to do so. They will carry out assessments by talking to the person you are caring for and to you to find out what support is needed.

## Care needs assessments and carer's assessments

To get a care needs assessment for the person, contact your local authority. You can find the contact details on your local authority/council website. If you can't access the internet, your GP surgery or local library should be able to help.

If the assessment shows that the person with dementia needs care and support that meets the criteria, the local authority may carry out a financial assessment to work out how their care will be paid for – see 'Paying for care' on page 115.

If the person you care for has needs that the local authority agrees to meet, be as clear as possible which parts of their care you are happy to help with and which needs the local authority should meet. You have no legal duty to meet the person's care needs yourself. Once it is agreed, you will get a care and support plan that sets out how the person's needs will be met.

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You can also ask for a carer's assessment to look at your needs. These assessments can be carried out separately, or at the same time, if you prefer.

You can still get a carer's assessment even if the person you care for doesn't want an assessment for themselves. Before the assessment, think about what parts of your caring role you find difficult and what support would help you.

These assessments are important to get you and the person you care for the support you both need. You may not be familiar with the processes or the words they use, so ask for more information if there is something you don't understand. If English isn't your first language and you would benefit from having an interpreter at the assessment, the local authority can arrange this.



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



## Paying for care

If the person is found to need care, the local authority will look at their finances to decide how much they will have to contribute towards the cost of their care.

In England, if the local authority is helping to fund the person's care, they set a 'personal budget'. This is the amount of money allocated to meet the person's needs. If the care is provided in the person's home, a personal budget can be received as a direct payment. This means they give the person (or someone else on their behalf) money to organise and pay for care services themselves. The local authority can also manage the budget.

Direct payments are also available in Wales and Northern Ireland, but there are different systems in place with no managed personal budgets.

Carers who receive financial support after a carer's assessment may also receive a direct payment.



For more information, see our **Paying for care and support** factsheets 532 (England), NI532 (Northern Ireland) and W532 (Wales). See also factsheets 473 **Personal budgets** (England and Wales) and NI431 **Direct payments** (Northern Ireland).



## Help at home

As the person's dementia progresses, you, as their carer, may reach a stage when you need more help at home. This could be with practical things, like washing or dressing, or taking the person out so you get a break. Accepting you need this kind of help can be difficult. However, it can help you both to live better and may help you support the person at home for longer.

If the person's care needs assessment shows that they need care at home and they won't be paying for this themselves, the local authority will usually help to put the care in place. The local authority may have their own team of care workers, but most homecare workers are employed by private companies (homecare agencies) – the local authority may pay them directly to provide care. You should be able to choose which company you would like to use.

Some people decide to have a direct payment instead. This is where the local authority passes the money to the person or their carer and they arrange the care. You can employ someone from an agency or as an individual.

You can also arrange homecare services yourself without involvement from the local authority. You might prefer to do this, or it may be because the person with dementia's income or savings are too high for local authority support. A live-in care worker may be an option for some people. See 'Accommodation with support' on page 147.



When deciding on a care service, you can:

- look at the ratings for care services and agencies. These can be found online from the Care Quality Commission (CQC) in England, Care Inspectorate Wales (CIW) or the Regulation and Quality Improvement Authority (RQIA) in Northern Ireland (see ‘Other useful organisations’ on pages 164–172)
- ask if agencies or care workers are trained in dementia care
- talk to other carers about agencies or individuals they’ve used.

If the person with dementia lives at home and their GP or specialist thinks they need nursing care, they can refer the person to community nursing services. Often, however, homecare workers will do personal care that involves support with skincare, continence and mouth care, sometimes on the advice of a community nurse.

“

**You can also access help from user groups, specialist groups, and other people in your situation that’s for the care and the person who has dementia. There is help out there and treatment is progressing. If you hide away you could get missed.**

Carer for a person with dementia

”



Call our Dementia Support Line on **0333 150 3456**

## Advice on equipment and aids

An occupational therapist, or your local social services assistive technology or telecare team, will be able to offer advice on equipment and adaptations you can make to the home. These can make life easier for the person you care for and support them to stay as independent as possible. You may be able to get help with the cost of large equipment and adaptations to the home.



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



### Living together

If you don't already live with the person you care for, there may come a time when you both feel that it may help to live together. Think about how it will affect both of you and anyone else you live with. This includes how it may affect you both financially.

The person may find the change difficult, especially if they are used to living alone. They may feel a loss of independence and find a new place confusing.

The person with dementia should be supported to make decisions about their care, where they live and who with, if they are still able to do so.



For more information visit [alzheimerers.org.uk](http://alzheimerers.org.uk)

## Respite care

Caring for someone can be tough. It is important that you're able to rest, whether it is a short break for a few hours or a few days away.

A break could help with your wellbeing, and give you the chance to meet friends and do things you like to do. It can stop you from becoming too stressed or tired to cope. It may also give the person with dementia an opportunity to do other activities or meet different people.

Your local authority may be able to arrange and help fund respite care, following a care needs assessment and/or carer's assessment. Only the person with dementia can be financially assessed for respite care – the carer shouldn't be charged.

Alternatively, you could make arrangements privately with a care home or care agency.



For more information on paying for respite care, see our **Paying for care and support** factsheets 532 (England), NI532 (Northern Ireland) and W532 (Wales).

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Call our Dementia Support Line on **0333 150 3456**

Different options for respite care include:

- **day centres** – a good way for the person to take part in activities and meet other people
- **holidays or short breaks** – some holiday providers offer specialist respite care. This includes support with caring and facilities so that you can focus on spending quality time with the person (see ‘Holidays’ on page 97)
- **short stays in care homes** – some care homes have rooms set aside for people requiring respite care. It’s a good idea to check for availability well in advance and perhaps try it out to see if it suits everyone.

With any respite care, it helps if you provide information about the person so that they are supported in a way that acknowledges and respects who they are. If the person has communication difficulties, you could record their needs, preferences, likes and dislikes using our **This is me**® form (see page 123).

The person might take time to settle into their new environment or when they return home. Try not to feel guilty about this – respite care is important for enabling you to carry on caring. Reassure the person that this arrangement is only for a short time.



For more information, see our **Respite care** factsheets 462 (England), NI462 (Northern Ireland) and W462 (Wales).



# Hospital care

A person living with dementia might go into hospital for many reasons. Sometimes, they may need to spend time there for assessment or for treatment for another condition.

## Supporting a person with dementia in hospital

If the person you care for is in hospital, you can still support them. It's helpful to tell hospital staff about the person's dementia. Being with the person in hospital can provide them with comfort and reassurance. You might also be able to help with practical things, such as personal care or eating and drinking.

## Your rights when the person is in hospital

You have an important role in the person's life and this should not change just because the person you support is in hospital. You have rights as a carer.



For more information, see factsheet 477  
**Hospital care.**

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Call our Dementia Support Line on **0333 150 3456**



## Decision-making

If the person with dementia is unable to make certain decisions, such as consenting to treatment, these decisions will be made on their behalf.

- You or someone else may make these if you have legal authority to do so – for example, under a health and welfare Lasting power of attorney (LPA) in England and Wales. The person making these decisions should talk to health and social care professionals. For more information, see page 54.
- If the person you care for doesn't have anyone who has this legal authority, the doctors or clinical team will usually make decisions about their medical care and treatment. They should still involve you where possible.

Any decisions relating to the person being discharged from hospital, including any aftercare, will be made by a combination of the health and social care professionals and those close to the person.

All decisions must be made in the person's best interests. Doctors and professionals should consult you, as someone close to the person, about what is in their best interest.



**This is me®**  
This leaflet will tell you all about who I am, to help you support me.

Name I like to be called \_\_\_\_\_

**This space is for you.**  
You can attach a favourite photo here – of yourself, your family, a pet or a place you've visited.






Or list four things that interest you:

- 1 \_\_\_\_\_
- 2 \_\_\_\_\_
- 3 \_\_\_\_\_
- 4 \_\_\_\_\_

Keep this in a suitable and safe place where anyone caring for you, at home or elsewhere, can refer to it easily. You can also take it with you if you need to go into hospital.




## This is me®

Our **This is me®** form (code 1553 for England, 1553W for Wales) is an easy and practical way of recording information about a person with dementia. It has space for details on aspects of their lives and how best to communicate with them.

The completed form should be kept with the person's medical notes, so that all staff working with them can see and follow it. When you visit, check that the professionals caring for them still have the form and know about the information. This is especially important if the person has been moved to another ward.



To download, go to [alzheimers.org.uk/thisisme](https://alzheimers.org.uk/thisisme) or to order, call **0300 303 5933**.



Call our Dementia Support Line on **0333 150 3456**

## John's campaign

Many hospitals support John's campaign. This is a campaign for those who are important to a person with dementia to have a right to stay with them in hospital outside of normal visiting hours. For more information, go to **[www.johnscampaign.org.uk](http://www.johnscampaign.org.uk)**

## Carer's passport in hospital

Many hospitals have a carer's passport scheme. These give additional rights, such as flexible visiting times and access to refreshments or free parking.

Ask hospital staff about this. If they don't have this scheme, you can still talk about your needs. They may be flexible with things such as visiting hours.

## NHS continuing healthcare

This care is paid for by the NHS and is for people with ongoing and complex healthcare needs. In some cases, this may include a person with dementia. If the person does not qualify for NHS continuing healthcare, they are considered to have social care needs. The local authority, the person or both are responsible for paying for their care (see page 115).



For more information, see booklet 813  
**When does the NHS pay for care?**



For more information visit **[alzheimerers.org.uk](http://alzheimerers.org.uk)**

## Making complaints and giving feedback

If you are unhappy with the care a person has received in any setting, you have a right to raise this. Often, issues can be resolved through discussion and better understanding of the person's needs. The process you should follow is:

### Step 1

Try to resolve the issue directly with the person or organisation if possible (for example, by contacting the manager).

**If the complaint is not resolved, then:**

### Step 2

Lodge an official complaint. If the complaint is about funded care or services, the complaint needs to be made to whoever pays for the care (such as the local authority or the NHS) as well as the provider.

**If the complaint is still not resolved, then:**

### Step 3

Take the complaint to the relevant Ombudsman (see 'Other useful organisations' on pages 164–172). Bear in mind there may be a time limit for when complaints can be raised.

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## Other feedback

If you feel that a health or social care professional is doing their job particularly well, consider passing on your comments or thanks. You could email or phone the department. Some organisations have a feedback form on their website.



# Money and work

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## How your finances may be affected

You may be thinking about how supporting a person with dementia will affect your own financial situation.

There is no legal duty for you to pay for the person with dementia's care. Whether the person can receive financial support from the local authority will depend on their income and savings, not yours.

Some carers choose to contribute to the person's care costs at some stage, if they are able to. For example, they might pay for extra support at home, or pay a 'top up' for a more expensive care home than the local authority will fund. This is optional and the decision is yours.

If this is something that you may want to do, it's worth thinking about this when you're looking ahead to the future and planning your own finances. Consider whether it's something that you'll be able to afford in the long term.

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**I tend to use taxis and cabs quite a bit now for various appointments. Buses and trains are out of the question for my wife because of the crowds and noise.**

Carer for a person with dementia

”



Other things that might affect your own financial position include:

- loss of earnings if you need to take time off work to care for the person, or if you reduce your hours or stop working
- increased travel costs – for example, to visit the person or take them to medical appointments or on trips out
- the costs of equipment or making adaptations to the home (though in many cases these should be free or part-funded)
- increased phone charges if you're calling the person more often
- increased childcare costs if you need extra childcare to allow you to care for the person with dementia
- any extra costs you may have related to caring for the person, such as for heating or more laundry.

If you can, planning ahead for these costs can help. Look into what financial support might be available to you and the person you care for (see 'Financial support' on page 130) and what rights you have at work (see 'Working when you're caring' on page 133).





# Financial support

Caring for someone with dementia can often lead to extra costs for you. You may be able to get benefits or financial support.

Some carers find it hard to ask for financial support, but it can be a big help.

## Claiming benefits

As a carer, you may be entitled to claim a number of benefits.

### Carer's allowance

This can be paid to carers over the age of 16 who regularly spend at least 35 hours a week looking after someone who is receiving one of the following benefits:

- Attendance allowance (AA)
- Personal independence payment (PIP) – daily living component at the enhanced or standard rate
- Disability living allowance (DLA) – care component at the highest or middle rate.

You don't have to be related to or living with the person you care for to receive Carer's allowance. If you have a job and earn over a certain amount, you will not be eligible for it.



Carers who are not eligible for Carer's allowance, but who care for someone for at least 20 hours per week, may be able to claim a Carer's credit. This keeps your National insurance record up to date and protects your state pension.

### Other benefits

Some carers on a low income will be eligible for Universal credit, Housing benefit or Pension credit. This will depend on their income, savings and age.



**For more information, see factsheet 413  
Benefits for people affected by dementia.**

Contact Age UK or Citizens Advice to be put in touch with a benefits adviser who can help check your entitlement and any claims. The Turn2Us website has a free benefits calculator that can show you the benefits you might be entitled to. See 'Other useful organisations' on pages 164–172.

### Grants

Some organisations may be able to offer grants to help people in financial difficulty, including carers. Grants do not have to be repaid. The Turn2Us website has a tool to search for grants – see 'Other useful organisations' on pages 164–172.



## Help with your council tax bill

Council tax is set by local authorities to pay for the services they provide. There is one bill for each property. It is based on the estimated value of the home and the assumption that two adults live there.

A council tax bill might be reduced if:

- only one adult lives at the property
- two adults live at the property, and one has a 'severe mental impairment' (which may include dementia).

People on a low income may qualify for council tax support (previously called 'council tax benefit'). This can be claimed directly from the local authority.

Advice is available from organisations such as Age UK and Citizens Advice (see 'Other useful organisations' on pages 164–172).



For more information, see factsheet 414 **Council tax**.

## Being an appointee for someone's benefits

If the person with dementia is not able to manage their benefits themselves, they can ask that you or someone else they trust receives and manages this money for them. This is called being an 'appointee'.



For more information, see factsheet 413

**Benefits for people affected by dementia.**



For more information visit **alzheimerers.org.uk**

## Working when you're caring

Balancing work with caring responsibilities can be challenging. As well as the practical aspects, you may find that your feelings about work change. For example, work may feel less important than it did before, or it may now feel like an especially important part of your identity outside of your caring role. You may feel guilty about spending time away from the person with dementia. It can also become harder to concentrate at work, or you may find you're making mistakes more often.

You don't have to tell your employer about your caring role, but it might help. You have rights as an employee who is a carer, and your employer may be able to offer some additional support.



## Your rights when you're working

You have rights and protections as an employee, including:

- a right under equalities law not to be discriminated against because of your caring responsibilities
- a right to take a reasonable amount of unpaid time off to deal with an emergency or unforeseen situation involving the person you care for
- a right to request flexible working (though it is not a legal right to be granted it). This could include working from home, flexible hours or job-sharing. Your employer can only refuse your request if they have a good business reason to. You have this right if you've worked for the employer for at least six months.

These are your legal rights, but your employer may offer you more support or flexibility as part of your contract. Look at your contract and talk to your manager or employer to see how they can help. Some organisations have Employee Assistance Programmes, which offer confidential support with practical and emotional issues at work.



If you work for yourself, you won't have these options. However, you may have more control over your own schedule, when you work and what changes you can make, such as taking on temporary or part-time staff.

If you spend a lot of time caring for the person, it's likely that your income will be reduced. The information from page 130 onwards about financial support may help you.

For more information about working while you're caring, contact Carers UK or Carers Trust (see 'Other useful organisations' on pages 164–172).

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**I find that if I don't try to be too rigid with my plans for the day I can relax and to begin to enjoy my life again with [the person with dementia] or on my own.**

Carer for a person with dementia

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# Supporting a person in the later stage of dementia

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## Symptoms in the later stage

A person in the later stage of dementia needs much more support. In turn, you are also likely to need more support in caring for them.

In the later stage of dementia, a person's symptoms will affect them much more than before. These may include:

- severe problems with memory – they may think they are living in a different time period, or be unable to recognise familiar people or objects
- changes in behaviour – see page 78
- needing much more support with activities, including personal care such as washing and getting dressed – see page 100
- problems with continence or recognising when they need to use the toilet – see page 103
- sleep problems and night-time disturbance – see page 82
- becoming more frail.

### Concentration and thinking abilities

A person will often also develop more difficulties with mental abilities in the later stage of dementia, such as concentrating, planning and organising. They may only be able to do simple activities, or be unable to concentrate for long.



The person may also become more disorientated and confused. This may include getting very confused about time and place. They might not recognise where they are living and feel distressed or frustrated.

There are ways to help support the person so they feel less disorientated. Listen to them, acknowledge how they're feeling and try to understand how it is affecting them. Changing the subject or doing something different with them can also be a helpful distraction if they are getting confused about time or place.

Trying to persuade the person of factual details may cause further distress or arguments. Instead, try to reassure them that they are safe and engage them in an activity they enjoy. For more tips and activity ideas for the late stage of dementia, see booklet 77AC

**The activities handbook.**

## Mobility difficulties

The later stage of dementia is likely to have a large physical impact on the person. They may gradually lose their ability to walk, stand or get themselves up from the chair or bed. They are also more likely to have a fall.



The person may stay in one position for a long time (such as sitting in a chair or lying in a bed) and not move around much. Doing this puts them at risk of stiff joints and pressure ulcers (bedsores).

The following can help – speak to the GP, or a community nurse, occupational therapist or physiotherapist for more advice.

- **Try to help the person to change position regularly.**  
This can help to improve blood circulation and relieve pressure on certain areas of their body.
- **Check regularly for any rashes, discolouration of the skin or pressure ulcers.** If you have concerns, speak to the GP or community nurse. If pressure ulcers aren't treated early, they can become painful and infected. Pressure-relieving mattresses and cushions are available.
- **Ensure the person is supported and encouraged to move around as much as they can** – for example, by supporting them to walk or with chair-based exercises. Increasing the person's mobility can lower their risk of infections and blood clots. Equipment and adaptations can help with this.



For more information, see booklet 819 **Making your home dementia friendly** and factsheet 529 **Physical activity, movement and exercise.**



## Eating, drinking and weight loss

In the later stage of dementia, eating and drinking become more difficult for the person. They might lose their appetite, develop swallowing difficulties or not recognise food.

These problems can lead to weight loss and make it hard for the person to fight infections and other illnesses. It can also increase the risk of falls. Contact the GP if you have any concerns. See page 93 for more information on eating and drinking.

## Pain, discomfort and infections

Infections are common at this stage. They can increase confusion. It is important that any infection is quickly diagnosed and treated.

The person may not be able to tell you how they feel. They may behave out of character or avoid what's causing them pain, such as walking or eating.

If the person is unwell and a sudden change in their mental abilities or behaviour lasts several hours, it is often a sign they have delirium (see page 75).

Changes in the person's expression, movements or on their body (such as a rash, swelling or sore) could be a sign of pain or further illness. Speak to the GP if you are worried. They will look at possible causes and treatments with or without medicines (see 'Treatment and support' on page 23).



## Communicating in the later stage

As the person's dementia progresses, they are likely to have problems with communication, particularly speaking and understanding language. They may also have sight or hearing problems, and there may eventually come a time when the person can hardly communicate at all as they usually would.

This can be very distressing and difficult to adjust to, but there are ways you can continue to communicate with the person.

The person is more likely to use body language, gestures, sounds and facial expressions to express themselves and their needs. They may pace around if they are feeling agitated, for example.

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**You've got to cherish moments with the people that you love, because you don't know how dramatically things can change from one moment to the next.**

Carer for a person with dementia

”



There are many ways you can help the person with dementia communicate in the later stage.

- Use positive body language (such as smiling and touching the person's hand).
- Take your time and maintain eye contact (as long as this is appropriate).
- Even if you don't think the person understands or is listening, keep talking to them. They may feel a reassuring connection to your voice. If you don't know what to talk about, use things the person finds interesting or from their past.
- Speak calmly in short and simple sentences.
- Consider responding to the person in the way they respond to you ('mirroring' them, for example with gestures or sounds).
- Use music to connect with the person. People with dementia often remember the tunes or lyrics of favourite songs, and may find communicating this way reassuring.



## Treatment and care in the later stage

By the later stage of dementia, a person is likely to need more care and support from a range of professionals and services. This will usually become a full-time responsibility as their needs increase.

You might find it difficult to rely on more professionals to support the person. You may worry that they won't understand the person or treat them as an individual.

Talk about the person and explain their needs and preferences to everyone involved in their care. This will help professionals provide the best person-centred care.

### Treatment with medicines

The drugs commonly prescribed for the treatment of Alzheimer's disease and Lewy body dementia (dementia with Lewy bodies or Parkinson's disease dementia) are sometimes helpful for people in the later stage of these conditions.

They can slow down the progression of symptoms, including difficulties with everyday activities and confusion. There is some evidence they can also help with symptoms such as delusions, aggression and agitation.

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These drugs are not appropriate for people with frontotemporal dementia, vascular dementia or other types of dementia. However, other drugs, such as antipsychotics and antidepressants, can be prescribed and might be helpful. There are also many ways to treat a person in the later stage that don't involve medicines (see page 23).

## Treatment without medicines

Different types of approaches without medicines can have benefits for people with dementia. These will need to be adapted as the person's abilities change and they need more support in the later stage. These include:

- engaging with musical activities, such as singing
- engaging the different senses, such as using the smell of essential oils or the feel of different textures or fabrics for comfort. Sensory boxes that are created around someone's hobbies or previous work role can be a useful tool
- doll or animal therapy – this can involve the person holding or 'caring for' a doll or a toy animal. This can inspire feelings of love and connection, and help the person feel a sense of purpose and fulfillment.

“

**I kept thinking, 'I can do this by myself. I don't need help from anyone.' But I did.**

Carer for a person with dementia

”

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Call our Dementia Support Line on **0333 150 3456**



The availability of therapies and activities vary by area. To see what's available in your area, go to **[alzheimers.org.uk/dementiadirectory](http://alzheimers.org.uk/dementiadirectory)** or see 'Other useful organisations' on pages 164–172. You may be able to apply to or refer the person to these services yourself. Health and social care professionals can also refer the person to local services.

The person's hobbies, interests and activities can also help them to live as well as possible in the later stage. For a wide range of other activities ideas, see booklet 77AC **The activities handbook**.



# Choosing a new home

As the person's condition progresses and their needs change, you may have to make decisions about the person's care and where they live. There may come a time when you have to consider whether the person needs to move into supported living or a care home.

## Accommodation with support

Supported living can provide flexibility in the way someone receives their care. It can enable someone to stay living in a flat or bungalow instead of moving into a care home – as long as they can access the care and support they need.

Supported living comes in various forms including those described in this section. It's a good idea for you and the person with dementia to visit the place before deciding where they should live. If the local authority (adult social services) are paying for the care, they may need to agree that the person needs this type of accommodation.

- **Sheltered housing** – these are self-contained flats. They may have a warden or manager and a 24-hour emergency alarm system, and some have communal facilities. The level of support will vary depending on the scheme. Sheltered housing schemes usually expect tenants or owners to have a certain level of independence.



- **Extra care housing** – this provides more support than sheltered accommodation, such as assistance with personal care, meals, housework and community activities. These services may be arranged and paid for by social services or funded by the person, depending on their finances.
- **Homeshare and Shared Lives** – for those with lower care needs, Homeshare can be useful. This is where someone moves in with the person to provide companionship and help around the house in exchange for reduced rent. Shared Lives is a scheme where someone who needs care and support goes to live or stay with an approved Shared Lives carer. For more information on both schemes, contact Shared Lives Plus (see ‘Other useful organisations’ on pages 164–172).

For more information, visit Elderly Accommodation Counsel’s Housing Care website (see ‘Other useful organisations’ on pages 164–172).



For more information, see booklet 689 **Care homes and other options: Making the decision.**

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“

**When encouraging my mum to take part in activities at her care home, I did the activity too. I felt a bit weird at first, but it helped her to settle and I got to know everyone.**

Carer for a person with dementia

”



For more information visit **[alzheimers.org.uk](https://www.alzheimers.org.uk)**

## Care homes

Many people with dementia move into a care home as their condition progresses. This can be because of a change in the person's health or circumstances, or those of someone caring for them.

It can be hard to decide that a care home is the best option. From making the decision to choosing the right environment, support is available.

You may have mixed feelings about care homes. Some people feel guilt or grief that this stage in their relationship has ended. Others feel relief that they are no longer caring 24 hours a day and feel that the person will be better cared for. These feelings are natural.

Your support doesn't have to end when the person moves into a care home. You can be involved in the person's care. Speak to staff about how you can do this. For example, some carers help the person at mealtimes or take them out for an afternoon.

If the person has difficulties with communication, it's also a good idea to use our **This is me**® form when they move into a new setting – see page 123.



For more information, see factsheet 480

**Supporting an LGBTQ+ person with dementia,**  
booklet 690 **Choosing a care home for a person**  
**with dementia** and booklet 691 **Supporting a person**  
**with dementia in a care home.**



Call our Dementia Support Line on **0333 150 3456**

# End of life care and support

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## Dementia and the end of life

Approaching the end of their life can be a very difficult and unsettling time for the person with dementia and the people around them. You may feel a range of emotions about it. You and the person may not want to think about this or what may happen in the future.

You can come back to this section later if you don't feel ready to look at it now. However, it's a good idea to plan ahead for this time when you are ready. For more information about planning for the end of life, see 'Looking ahead: putting plans in place' on pages 46–61.

Dementia is a life-shortening condition, but it's difficult to predict exactly how long someone will live with it. A person may die from another condition at any stage of having dementia. Because of this, they may die before their dementia symptoms become very advanced.

Once someone reaches the later stage of dementia (see 'Supporting a person in the later stage of dementia' on pages 136–149) and their symptoms get much worse, they are much more likely to develop other medical problems that can lead to death. These include infections (like pneumonia) or cardiovascular problems (like a blood clot in the brain or lungs).



As they go through these changes, you may worry that they are in pain or distress – it's important that you have support. Health and social care professionals should be able to offer information and reassurance about what is happening.

As someone gets very near to the end of life (within days and hours), they will go through more changes, such as losing consciousness or being unable to swallow. These can be very distressing, but they are normal parts of the dying process. Often the person is unaware of what is happening to them, and end of life medical care will concentrate on ensuring that they aren't in any pain or distress.

If you are concerned, speak to your GP or other professionals about the person's care and whether medicines are appropriate. They should let you know when the person is in this stage and close to the end of their life.

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**Medical staff generally don't want to commit themselves to a timeline [for the end of life], as everyone is different. I just take each day as it comes and try not to think too far ahead.**

Carer for a person with dementia

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## Palliative and end of life care

Palliative care is for anyone diagnosed with a life-shortening condition, including dementia. It focuses on making a person's quality of life as good as possible by relieving discomfort or distress. A person can receive palliative care for any length of time, from a few days to several years.

End of life care supports a person in the later stage of their condition to live as well as possible until they die. It aims to enable the person to die in the way that they would have wanted, giving priority to the things that matter most to them.

For many people, this means:

- being treated with compassion and respect
- being clean, comfortable and free from distressing symptoms
- being in a calm and familiar place surrounded by those close to them.



# Caring for someone at the end of life

Caring for a person with dementia at the end of life is emotionally challenging. But there is a range of things you can do for them and yourself. It can be helpful to talk to a GP or district nurse to get a carer's assessment to support you during this period. Local hospices may also provide support in the person's home.

Care from professionals is important, but you are likely to know the person best. Things you know about the person can help support them at the end of life. Sharing this information with professionals can also help them to understand and support the person better.

It's important that the person's individual spiritual needs are respected. Let professionals know about any objects, symbols or rituals that are important to them. The person may also have wishes about how soon they would like the funeral or whether they wish to be buried or cremated.

It helps if the person's wishes and preferences are recorded in a care plan and advance statement (see page 59 for more information). You may also find it helpful to use our **This is me**<sup>®</sup> form – see page 123.

End of life care should also enable you to meet your own needs. This may include whether you want to be with the person when they're in their final moments.



## Physical care

As the person reaches the end of life, they may be cared for somewhere other than their home. Even if the person is in a care home, hospice or hospital, there are still things you can do to help with their care.

- You may want to help the person eat and drink (even if it's just small amounts). This should be carried on for as long as they show an interest and it's safe to do so.
- When the person is close to death they are likely to stop eating and drinking – this is normal. If you wish, you can still provide care by keeping their lips moist, giving sips of water or juice (if it's safe to do so) and applying a lip balm. You could also use a moisturising mouth gel or spray to help the inside of the person's mouth stay clean and comfortable.
- If you think the person is in pain or distress because of their reactions or non-verbal communication, speak to a professional and explain your concerns.

Many of these may be mentioned in their advance care plan (see 'Looking ahead: putting plans in place' on pages 46–61).

For information about communicating with a person with dementia as they reach the end of life, see 'Communicating in the later stage' on page 142.



**For more information, see factsheet 531  
End of life care.**



For more information visit [alzheimers.org.uk](https://www.alzheimers.org.uk)

# After someone has died

When someone close to you dies, you will go through grief and bereavement in your own way. You are likely to feel many different emotions, some of which may be intense.

As well as allowing yourself to go through the grieving process, there are a few practical things to consider, especially – registering the death, organising the funeral, and changes to financial and legal arrangements and benefits. It's a good idea to plan ahead for this (see 'Looking ahead: putting plans in place' on pages 46–61).

For more information, contact Citizens Advice (see 'Other useful organisations' on pages 164–172).

## Grief and bereavement support

It's important you are supported to grieve as you need and want to. You may feel numb, angry, sad or relieved. Some people feel these, and other emotions, very strongly while others feel they have no strong emotions left.

You may have experienced grief and loss throughout the time you have cared for the person. Having already grieved for these losses and changes, you may feel better able to cope with their death. However, bereavement is often still a painful time.



After the funeral, you may need time to adjust to no longer being a 'carer'. Some carers feel empty after the person dies as they come to terms with the change to their daily routine and having to rebuild relationships. This can lead to feeling isolated and lonely.

When you're grieving, you may think you hear or see the person. This is normal after someone close has died.

Some people find it takes time after the person has died for them to grieve. This is known as 'delayed grief'. This can happen because:

- it takes a while to accept the person has died
- your feelings are overwhelming and you need time to deal with them
- there are so many practical things to do that there isn't time to grieve.

It can be very hard to adjust after caring for a person with dementia. It's important that you take time to address your needs.

You may find that you need more emotional support during this time, but people may not always offer it. If you need support, try to tell people – talk to friends or family members. This can be hard and often people don't realise you need help. If you need more support or feel you are becoming depressed, speak to your GP or contact Cruse Bereavement Support (see 'Other useful organisations' on pages 164–172).



## Readjusting after bereavement

Life does not just go back to being the same after bereavement. In time, you may find that the pain eases and you can cope with life without the person who died. Some carers find readjusting easier than others. How long it takes will vary from person to person, and there is no 'right' length of time.

The following suggestions may help.

- Be kind to yourself. Allow yourself time and space to grieve.
- Try to eat properly and get enough rest (even if you don't manage to sleep).
- Try to do things with other people – you could start doing past interests and hobbies again, or consider starting new ones.
- Look after your spiritual and religious needs. For example, some people find meditation or prayer helpful during bereavement.
- If you feel you want to, talk to friends and family about the person who died.
- Keeping hold of items that belonged to the person may help you feel close to them.



For more information about bereavement, see factsheet 507 **Grief, loss and bereavement.**



# **Alzheimer's Society support services**

**We provide a range of services and resources to support people living with dementia, including carers, families and friends.**





# Dementia Support from Alzheimer's Society

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



## Online

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

You can also connect to others affected by dementia on our Dementia Support Forum (**[forum.alzheimers.org.uk](https://forum.alzheimers.org.uk)**), and search for services in your area using our dementia directory at **[alzheimers.org.uk/dementiadirctory](https://alzheimers.org.uk/dementiadirctory)**



## Phone

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



For more information visit **[alzheimers.org.uk](https://alzheimers.org.uk)**

If you have speech or hearing difficulties and have a textphone or an adapted computer, you can **use Text Relay** to call our English-speaking dementia support line on **18001 0300 222 1122**.



### **Lasting power of attorney digital assistance service**

We offer a Lasting power of attorney digital assistance service to help people living with dementia create LPAs online. If you don't have access to the internet, we can help you to create an LPA through a series of telephone appointments. The service does not provide legal advice. Call us on **0333 150 3456**.



### **Face-to-face services**

Our local dementia advisers and volunteers can meet you to offer further support, advice and information. They can also connect you to other face-to-face services in your area.

These include Singing for the Brain®, activity groups and peer support for people with dementia, and information and support groups for carers.



Call our Dementia Support Line on **0333 150 3456**

## Other useful organisations

### **Age UK**

0800 678 1602 (advice line, 8am–7pm Monday–Sunday)  
[www.ageuk.org.uk](http://www.ageuk.org.uk)

### **Wales – Age Cymru**

0300 303 4498 (advice line, 9am–4pm Monday–Friday)  
[advice@agecymru.org.uk](mailto:advice@agecymru.org.uk)  
[www.ageuk.org.uk/cymru](http://www.ageuk.org.uk/cymru)

### **Northern Ireland – Age NI**

0808 808 7575 (advice service, 9am–5pm Monday–Friday)  
[advice@ageni.org](mailto:advice@ageni.org)  
[www.ageuk.org.uk/northern-ireland](http://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.

### **The Association of Lifetime Lawyers**

020 8234 6186 (9am–5pm Monday–Friday)  
[www.lifetimelawyers.org.uk](http://www.lifetimelawyers.org.uk)

The Association of Lifetime Lawyers (formerly Solicitors for the Elderly) is an independent, national organisation of lawyers who provide legal advice to older people. They can also help you to find a solicitor.

### **Bladder & Bowel Community**

help@bladderandbowel.org

www.bladderandbowel.org

The Bladder & Bowel Community support people in the UK who are living with conditions that affect their bladder or bowel. They can help with RADAR keys and Just Can't Wait cards for urgent access to public toilets.

### **Care Inspectorate Wales (CIW)**

0300 790 0126

ciw@gov.wales

www.careinspectorate.wales

The CIW is the independent regulator of health and social care services in Wales.

### **Care Quality Commission (CQC)**

03000 616161 (8.30am–5.30pm Monday–Friday)

enquiries@cqc.org.uk

www.cqc.org.uk

The CQC is the independent regulator of health and social care services in England.

### **Carers Trust**

0300 772 9600 (England)

0300 772 9702 (Wales)

info@carers.org (England)

wales@carers.org (Wales)

www.carers.org

Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring for a family member or friend.

**Carers UK**

0808 808 7777 (helpline, 9am–6pm Monday–Friday)

[advice@carersuk.org](mailto:advice@carersuk.org)

[www.carersuk.org](http://www.carersuk.org)

Carers UK provides information and advice about caring, alongside practical and emotional support for carers.

**Citizens Advice**

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Citizens Advice offers free, confidential and independent advice on issues including benefits, employment, housing and discrimination.

**Cruse Bereavement Support**

0808 808 1677 (helpline, 9.30am–5pm weekdays, except Tuesday 1pm–8pm)

[www.cruse.org.uk](http://www.cruse.org.uk)

Cruse Bereavement Support is a national charity for bereaved people in England, Wales and Northern Ireland. It offers face-to-face, telephone, email and website support.

**Dementia UK**

0800 888 6678 (9am–9pm Monday–Friday, 9am–5pm Saturday and Sunday)

[helpline@dementiauk.org](mailto:helpline@dementiauk.org)

[www.dementiauk.org](http://www.dementiauk.org)

Dementia UK provides Admiral Nurses, who are mental health nurses specialising in dementia care.

**Disability Rights UK**

0330 995 0400

[enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)

[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)

Disability Rights UK works with disabled people's organisations and government to influence change for better rights, benefits, quality of life and economic opportunities for disabled people.

**Driver & Vehicle Agency (DVA)**

0300 200 7861 (9am–4pm Monday–Friday)

[dva@infrastructure-ni.gov.uk](mailto:dva@infrastructure-ni.gov.uk)

[www.nidirect.gov.uk/contacts/driver-vehicle-agency-driver-licensing](http://www.nidirect.gov.uk/contacts/driver-vehicle-agency-driver-licensing)

DVA is responsible for licensing and testing vehicles and drivers in Northern Ireland.

**Driver and Vehicle Licensing Agency (DVLA)**

0300 790 6806 (for queries about medical conditions, including dementia, 8am–7pm Monday–Friday, 8am–2pm Saturday)

[www.gov.uk/contact-the-dvla](http://www.gov.uk/contact-the-dvla)

DVLA is responsible for licensing and testing vehicles and drivers in Great Britain.

**Elderly Accommodation Counsel (EAC)**

[www.eac.org.uk](http://www.eac.org.uk)

[www.housingcare.org](http://www.housingcare.org)

EAC is a national charity that aims to help older people make informed choices about housing and care.

**Jointly**

[www.jointlyapp.com](http://www.jointlyapp.com)

Jointly is an app that helps you to coordinate care with other people who are supporting the person.

**Living Made Easy**

[www.livingmadeeasy.org.uk](http://www.livingmadeeasy.org.uk)

Living Made Easy (formerly Disabled Living Foundation) provides a wide range of products and services, such as mobility and communication aids, assistive technology and equipment for inside and outside the home.

**Local Government and Social Care Ombudsman**

0300 061 0614 (10am–1pm Monday, Tuesday, Thursday, Friday; 1pm–4pm Wednesday)

[www.lgo.org.uk/how-to-complain](http://www.lgo.org.uk/how-to-complain)

[www.lgo.org.uk](http://www.lgo.org.uk)

The Local Government and Social Care Ombudsman is the final stage for complaints about councils and some other organisations providing local public services, as well as care homes and home care providers.

**Mind**

0300 123 3393 (infoline, 9am–6pm Monday–Friday)

[info@mind.org.uk](mailto:info@mind.org.uk)

[www.mind.org.uk](http://www.mind.org.uk)

Mind is a charity that offers information and advice on all aspects of mental health. It provides a range of support services through local Mind associations.

## **NHS**

[www.nhs.uk](http://www.nhs.uk)

The NHS website is the UK's biggest health website. It provides a comprehensive health information service that aims to help people make the best choices about their health and lifestyle.

## **Northern Ireland Public Services Ombudsman**

0800 34 34 24 (10am–12pm Monday–Friday)

[nipso@nipso.org.uk](mailto:nipso@nipso.org.uk)

[www.nipso.org.uk](http://www.nipso.org.uk)

The Northern Ireland Public Services Ombudsman investigates complaints where local resolution has not been possible.

## **Office of the Public Guardian (OPG)**

0300 456 0300 (9am–5pm weekdays,

except Wednesday 10am–5pm)

[customerservices@publicguardian.gov.uk](mailto:customerservices@publicguardian.gov.uk)

[www.gov.uk/opg](http://www.gov.uk/opg)

The OPG is set up to protect people in England and Wales who lack the mental capacity to make certain decisions for themselves. It is responsible for registering Lasting and Enduring powers of attorney and dealing with complaints about how attorneys are acting.



**Parkinson's UK**

0808 800 0303 (helpline, 9am–6pm Monday–Friday,  
10am–1pm Saturday)  
[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)  
[www.parkinsons.org.uk](http://www.parkinsons.org.uk)

Parkinson's UK is a national charity that provides support to anyone affected by Parkinson's disease.

**Parliamentary and Health Service Ombudsman**

0345 015 4033 (helpline, 9am–4pm  
Monday–Thursday, 8.30am–12pm Friday)  
[www.ombudsman.org.uk](http://www.ombudsman.org.uk)

The Parliamentary and Health Service Ombudsman makes final decisions on complaints that have not been resolved by the NHS in England.

**Public Services Ombudsman for Wales**

0300 790 0203 (10am–12.30pm and 1.30pm–4pm  
Monday–Friday)  
[ask@ombudsman.wales](mailto:ask@ombudsman.wales)  
[www.ombudsman.wales](http://www.ombudsman.wales)

The Public Services Ombudsman for Wales is an independent body. It investigates and considers complaints where they have not been resolved locally.

**Rare Dementia Support**

020 3318 0243 (voicemail)

[contact@raredementiasupport.org](mailto:contact@raredementiasupport.org)

[www.raredementiasupport.org](http://www.raredementiasupport.org)

Rare Dementia Support runs specialist support services for people living with, or affected by, one of seven rarer types or causes of dementia including posterior cortical atrophy (PCA) and familial Alzheimer's disease (FAD).

**Regulation and Quality Improvement Authority (RQIA)**

028 9536 1111 (9am–5pm Monday–Friday)

[info@rqia.org.uk](mailto:info@rqia.org.uk)

[www.rqia.org.uk](http://www.rqia.org.uk)

The RQIA is the independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland.

**Relate**

[www.relate.org.uk](http://www.relate.org.uk)

Relate provides relationship counselling for individuals and couples, family counselling and sex therapy. It also provides phone, email and live chat counselling.

**The Respite Association**

01566 783383 (9.30am–5pm Monday–Friday)

[help@respitassociation.org](mailto:help@respitassociation.org)

[www.respiteassociation.org](http://www.respiteassociation.org)

The Respite Association is a charity that funds short-term respite care for people with long-term health conditions, so that their carer can take a break.

**Shared Lives Plus**

0151 227 3499

[info@sharedlivesplus.org.uk](mailto:info@sharedlivesplus.org.uk)

[www.sharedlivesplus.org.uk](http://www.sharedlivesplus.org.uk)

Shared Livies Plus is a UK network for Shared Lives Plus and Homeshare schemes that can provide support at home.

**Turn2Us**

[www.turn2us.org.uk](http://www.turn2us.org.uk)

[benefits-calculator.turn2us.org.uk](http://benefits-calculator.turn2us.org.uk)

Turn2us is a national charity providing practical help to people who are struggling financially. Their website includes a tool to search for charitable grants as well as a benefits calculator to check entitlement to benefits.

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Reviewed by: Dr Karen Chumbley, Lead for End of Life Care, North East Essex Health and Wellbeing Alliance; Tish Hanifan, Barrister and Joint Chair, Society of Later Life Advisers; Professor Jill Manthorpe, Professor of Social Work and Director of the NIHR Health & Social Care Workforce Research Unit, King's College London; Jessica Peterson, Therapy Co-ordinator, Dementia Team, East Kent Hospitals University NHS Foundation Trust and Dr Emma Vardy, Consultant Geriatrician, Salford Royal NHS Foundation Trust.

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