

# Caring for a person with dementia

A practical guide

For more information  
[alzheimers.org.uk](http://alzheimers.org.uk)  
0300 222 1122



# About this guide

**If you are the main person 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.**

You may be supporting a partner, friend or family member. You may or may not see yourself as ‘caring for’ them, or think of yourself as their ‘carer’.

Supporting someone with dementia can be a rewarding experience, giving you an opportunity to help someone who is important to you and learn new skills. But we also know that it may be very challenging at times. The information in this booklet is here to support you to care for the person and to look after yourself.

You don’t need to read all of this information at once. You may want to come back to some of the sections later on.

As well as understanding it yourself, you may be trying to help the person understand their diagnosis. They may wish to read our other resources, such as booklet 872, **The dementia guide: Living well after diagnosis**.

We refer to these and other publications throughout this guide. These include booklets and factsheets, each of which has a number code. To access any of these:



**go to [alzheimers.org.uk/publications](https://www.alzheimers.org.uk/publications)**



**call 0300 593 5933**



**or email [orders@alzheimers.org.uk](mailto:orders@alzheimers.org.uk)**

# Getting support

**Caring for someone with dementia can be challenging at times and it's very important to get support. This includes practical information and advice, and support with how you're feeling and coping.**

There are a number of ways to get support from the people around you, including professionals:

- Talk to friends or family members you trust. You will know who you feel most comfortable talking to.
- 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 in section 5, 'Services, support and housing'.

Alzheimer's Society also offers a number of services that can help you:

- You can call the National Dementia Helpline on **0300 222 1122**
- Talk to other carers in our online community, Talking Point – go to **[alzheimers.org.uk/talkingpoint](https://alzheimers.org.uk/talkingpoint)**
- Find out what services are available in your area – search our online directory at **[alzheimers.org.uk/dementiaconnect](https://alzheimers.org.uk/dementiaconnect)**



**For more information on these services see section 9 on page 151.**



**For advice and support call the National Dementia Helpline on 0300 222 1122**



**‘Chris and I have had invaluable advice  
and support from Alzheimer’s Society.’**

Heather Ritchie  
Carer for a person with dementia

# Foreword

## Heather Ritchie

**My name is Heather and I care for my partner Chris. She was diagnosed with young-onset vascular dementia at the age of 60.**

This was a great shock as we hadn't realised that younger people can develop dementia. However it also brought relief because it showed there was a reason for the things Chris had been doing that seemed strange to us.

Caring for someone with dementia doesn't have to be the end of life as you know it – it's just a different way of living your life together. There can be many positives – we joke and laugh and sing our way through this journey.

But caring does have challenges too, so it is really important to get support. This guide is a great place to start – it contains lots of information about dementia, its symptoms, treatments and the care and support available. It also includes advice about managing symptoms and planning for the future.

However, we all need support in different ways. Chris and I have had invaluable advice and support from Alzheimer's Society. Apart from this guide, the Society's National Dementia Helpline and Talking Point online community are there for you and the person you care for. Health and social care professionals can support you too. You're not alone on this journey.

As a carer you support and care for others, but always remember 'you' too. It's really important to look after yourself and there's also advice on how to do this in the guide.



For advice and support call the National  
Dementia Helpline on **0300 222 1122**



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# 1

## Understanding the person's diagnosis

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# 1

## What is dementia?

If the person you're supporting has been recently diagnosed with dementia, you may want to know more about their condition. Understanding more about dementia can help you to come to terms with their diagnosis and the changes they may go through.

The word 'dementia' describes a group of symptoms that may include memory loss, difficulties with thinking, problem solving or language, and often changes in mood, perception or behaviour. These changes are usually small to start with, but for someone with dementia they have become bad enough to affect daily life.

Dementia isn't a natural part of ageing. It occurs when the brain is affected by a disease. There are many different diseases that cause dementia. The most common causes of dementia are Alzheimer's disease and the diseases that cause vascular dementia.

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

Person living with dementia

# Types of dementia

# 1

There are many different types of dementia. They are all caused by diseases in the brain which damage the brain cells and cause them to die.

The most common types of dementia are summarised below. Alzheimer's Society produces a wide range of publications that provide more information on these.

## Alzheimer's disease

This type of dementia is named after Alois Alzheimer, the German doctor who first described it. It is the most common type of dementia.

The brain is made up of billions of nerve cells that communicate with each other. In the brain of a person with Alzheimer's disease, structures called 'tangles' form inside these cells, and 'plaques' form outside them. These structures stop the cells communicating with each other and so eventually they stop working and die. Over time, the brain is left with fewer cells to do all its functions – this leads to problems with memory, thinking or reasoning.

There is also a shortage of some important chemicals in the brain of someone with Alzheimer's disease. This means that messages don't travel around the brain as well as they should.



# 1

Common early symptoms of Alzheimer's disease include:

- memory loss – for example, forgetting recent events or planned appointments
- problems with planning and organising
- struggling with language (for example, repeating things)
- becoming confused or losing track of the day or date.



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

## Is Alzheimer's disease genetic?

Genes determine how characteristics are passed down through families. There are more than 20 genes known to increase a person's risk of developing dementia. There are also a few genes that directly cause dementia, but these are very rare.

Having a close relative (parent or sibling) with Alzheimer's disease increases a person's chances of developing the disease very slightly compared to someone with no family history. However, it does not mean that dementia is inevitable.

## Vascular dementia

The second most common form of dementia is vascular dementia. It is caused by problems in the blood vessels, which carry blood around the body (the vascular system). When these vessels become damaged by disease, such as when arteries become 'hard' over time, they cannot carry enough blood to the brain. The brain needs the oxygen in blood to function properly, so when brain cells don't get enough blood they eventually die.

This leads to early changes such as:

- problems with planning and organising
- taking longer to process thoughts
- memory loss – for example, forgetting recent events or planned appointments
- struggling to follow a series of steps – for example, when cooking a meal.



**For more information see factsheet 402,  
What is vascular dementia?**

**'I was relieved [to get my diagnosis] –  
I knew something wasn't right.'**

Person living with dementia

# 1

## Dementia with Lewy bodies (DLB)

Lewy bodies are tiny clumps of protein that develop inside the nerve cells, and disrupt the way the brain functions. They reduce the level of chemical messengers and cause nerve cells to die. This causes early difficulties with planning ahead, reasoning and solving problems.

At least two-thirds of people who have DLB experience problems with movement, as well as changes in their mental abilities. People with the condition are likely to have symptoms such as:

- varying attention and alertness from day to day (and sometimes from minute to minute)
- problems judging distances (such as when using stairs)
- visual hallucinations (seeing things that aren't there)
- delusions (strongly believing things that aren't true)
- problems with movement or balance.

Lewy bodies are also found in people with Parkinson's disease. A person with Parkinson's disease is at high risk of going on to develop dementia as their condition progresses. This is known as Parkinson's disease dementia.



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



## Frontotemporal dementia (FTD)

The term frontotemporal dementia covers a range of different conditions. It includes Pick's disease and is sometimes called frontal lobe dementia.

FTD is caused by the brain's frontal and temporal lobes being damaged. Clumps of abnormal proteins collect within nerve cells in these lobes and cause the cells to die. Important chemicals that carry messages around the brain are also affected. This affects behaviour, emotional responses and language skills.

There are three types of FTD and they lead to different early changes:

- **Behavioural variant FTD** – this can cause people to lose motivation or interest in people or things (apathy) and to lose inhibitions or say things they wouldn't normally say.
- **Progressive non-fluent aphasia** – this can cause a person's speech to become slow or take a lot of effort. They may also leave out small words in sentences like 'the' and 'to'.
- **Semantic dementia** – this can cause a person to ask the meaning of familiar words – for example, 'What is a "fork?"' – or have difficulty recognising familiar people or objects.



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



**For advice and support call the National Dementia Helpline on 0300 222 1122**

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## Mixed dementia

Some people have more than one type of dementia – this is known as mixed dementia. The most common combination is Alzheimer's disease and vascular dementia, although people can have other combinations. If someone has mixed dementia they are likely to experience a mixture of symptoms of the different types of dementia they have.

### Dementia in younger people (young-onset dementia)

Over 42,000 people in the UK have been diagnosed with dementia under the age of 65. This is known as 'young-onset dementia', but is sometimes called 'early-onset dementia' or 'working age dementia'.

People under 65 can develop any type of dementia. However, they are more likely to have a type of dementia that is less common in people over 65 (such as frontotemporal dementia).

The symptoms of young-onset dementia are similar to those in people over 65. However, there will be unique challenges and a younger person is likely to need different types of support than an older person. It can be especially difficult if the person has young children, is working or has a mortgage.



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

# 1

## Rarer forms of dementia

Around 5% of people with dementia in the UK have one of the rarer forms. However, they are more common in younger people. These rarer causes include corticobasal degeneration (CBD), HIV-associated neurocognitive disorder (HAND), Huntington's disease, posterior cortical atrophy (PCA) and progressive supranuclear palsy (PSP).



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

## Who can get 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 ageing.

Younger people can also develop dementia – see 'Dementia in younger people (young-onset dementia)' on page 15.

The causes of dementia are still being researched. Dementia generally depends on a combination of risk factors that we can't change, such as age and genes, along with ones we can, such as too little exercise, smoking and drinking too much alcohol.



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



## The progression of dementia

Understanding how dementia develops and what may happen in the future can help you and the person with dementia to plan ahead. It can be helpful to think of the way that dementia progresses as a series of stages – the early, middle and later stages.

However, everyone experiences dementia differently – some people will have certain symptoms earlier or later, or not at all.

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### 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.



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

# 1

## What affects the progression of dementia?

It is not easy to predict the progression of dementia. Some of the factors that can influence it are listed below.

- Each type of dementia has a different pattern of progression. For example, people with vascular dementia that follows a stroke may find that their symptoms remain steady for a while and then suddenly get worse. In people with Alzheimer's disease the progression may be more gradual.
- The person's physical health may play a large role in how they change over time. An infection, stroke or fall may lead to a sudden deterioration, for example.
- A person's personality and life experience will affect how they cope with dementia.
- The person may also respond to changes in their environment or surroundings. They may be badly affected if they move to somewhere unfamiliar or if their routine is disrupted.



**For more information see factsheet 458,  
The progression of Alzheimer's disease and  
other dementias.**



## The early stages of dementia

When someone is in the early stages of dementia, their symptoms might be put down to other causes such as stress or depression or generally getting older. The onset of dementia is often very gradual and it is usually impossible to identify exactly when it starts. The person may:

- forget details of recent events
- mislay items around the house
- find adapting to change difficult
- become less good at making decisions or plans
- take longer to understand complex ideas
- have difficulties with conversation, such as struggling to find words, repeating themselves or losing the thread of what they're saying
- show personality or mood changes
- lose motivation or interest in people or things (become apathetic)
- become upset or easily annoyed at finding it harder to do things.



# 1

## The middle stages of dementia

In the middle stages, the person's problems will have a bigger impact on their daily life. They may:

- be very forgetful of recent events (but still remember things from long ago, even if they confuse some details)
- do things that may be unsafe (due to confusion or memory loss), such as leaving a gas cooker on
- be confused about the time and place
- become lost in places that aren't familiar
- forget names of friends or family, or mistake one family member for another
- walk around (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
- say they've washed or eaten when they haven't or vice versa
- become angry, upset or distressed very quickly.



## The later stages of dementia

In the later stages symptoms are more severe and the person will need much more support. The person is likely to be more frail, find it harder to walk and be more at risk of falls. They may also show changes in their behaviour that may be distressing (such as being agitated), become disturbed at night-time, and find it much harder to communicate or understand what's being said to them.



**For more information on symptoms in the later stages of dementia, and how to support someone, see section 7 of this guide, and factsheet 417, The later stages of dementia.**

**'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

# 1

## Treatments for dementia

Currently, there is no cure for dementia. However, treatments are available that can help with symptoms. With the right combination of these, it is possible to live well with dementia. These treatments include:

- treatments that don't involve drugs
- drug treatments
- treatments for managing other medical conditions
- changes to the person's lifestyle.

Supporting the person with dementia to stay active is good for their wellbeing. You might also encourage them to meet and connect with other people and so keep some of their skills and memory. Different activities, including everyday tasks, can boost the person's self-esteem, improve sleep, and help avoid depression. For more information about activities, see page 81.

Find out what other practical support and advice is available in your area for both you and the person you care for. It makes sense find out about help as early as possible. For more information see section 5, 'Services, support and housing'.





You may find the following treatments and ideas for activities helpful.

- **Talking therapies, such as counselling** – these might help the person to come to terms with their diagnosis, or help with depression or anxiety.
- **Cognitive stimulation therapy (CST)** – this involves a series of activity sessions in small groups to help improve mental abilities by keeping the person's brain active.
- **Life story work** – using a scrapbook, photo album or app to remember and record details of the person's life (such as their experiences, values or beliefs).
- **Reminiscence** – this involves talking about a theme from the person's past such as school days or holidays (often using prompts). It can help with their mood as well as memory.
- **Cognitive rehabilitation** – this involves support to achieve their own practical goals (for example, handling money confidently or learning to use a mobile phone).

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



# 1

## Drug treatments

There are drugs 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.

### Drugs for Alzheimer's disease

The main drug treatments available for people with dementia are used to treat Alzheimer's disease. For many people, this may ease some of their symptoms for a while.

These drugs don't cure, reverse or even slow the physical damage being done by Alzheimer's disease to the brain. However, they can slow down the progression of symptoms, such as difficulties with carrying out daily activities. Other benefits can include better memory and concentration. However as with all drugs there are possible side effects.



**For more detailed information about these treatments and what to ask the GP see factsheet 407, Drug treatments for Alzheimer's disease.**

### Drugs for dementia with Lewy bodies (DLB)

A person with dementia with Lewy bodies may be given drugs, especially if they have distressing hallucinations, delusions, or agitation.

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



## Drugs for vascular dementia

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

## New treatments

Some people with dementia are interested in taking part in clinical trials and research into new treatments.



**For more information on treatments go to [alzheimers.org.uk/treatments](https://alzheimers.org.uk/treatments)**

**'I've always been able to second guess [my wife], knowing what she is going to say. But now I am really struggling... I try to think of the good times.'**

Husband of a person with dementia

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# 2

## Taking on the caring role

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## The impact of dementia on your daily life

### 2

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 it can also present challenges and is likely to affect how you're feeling.

For many people, there are good and bad times when caring for someone with dementia. If you find things difficult at times, or feel unsure, help is available. Everyone needs support from time to time and it will enable you to carry out the important role of supporting the person. It's likely that you know the person well, perhaps better than anyone else, and that especially may help you to look after their individual needs.

There are a number of things it's worth thinking about early on. As the person's dementia progresses, it will increasingly affect your daily life, as well as theirs. Over time, they will need more support, and this may be hard for you to adjust to. In this guide there is more information and advice on coping with these changes and the help that's available to you. This includes advice on how dementia may affect:

- your relationship with the person you are caring for
- your feelings
- your health
- your daily life and work (if you're working)
- your finances
- your responsibilities.



## The word 'carer'

You may or may not see yourself as the person's 'carer'. To you, the person is first and foremost your partner or spouse, family member or friend.

Many people feel this way and it's your choice whether you use the term 'carer'. It's also worth bearing in mind that many of the services that can support you, including health and social care services and financial support, may refer to you as a 'carer'. Although you may not identify with this term, it can be a good idea to use it when you're talking to a professional as it can help you to access the right support.

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

Carer for a person with dementia

## Support for you

# 2

Although caring for a person with dementia can be very rewarding, it can also be very challenging. There is lots of support available to help you. Ask for this whenever you need to.

### 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 more support.
- They may be able to arrange appointments at times that are more suitable for you.
- They can offer you free annual health checks and flu vaccinations. 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.





## A network of support

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

- professionals who can help you (see section 5 on page 89)
- local authority, housing and care services (see section 5 on page 89)
- financial support (see section 6 on page 107).

For more about people who can support you see 'Getting support' on page 1.

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**'My husband is with me in person as he has been for the last 46 years, but I know he has already left me and I am grieving for my loss. Sad, angry, heartbroken, jealous, furious, inadequate, frightened – I'm experiencing all of this every day, and there are no answers.'**

Carer for a person with dementia

## The impact of dementia on your feelings and relationships

### 2

When someone close to you has dementia, their condition is likely to affect your relationship over time. As you increasingly provide more support for the person, this may affect different aspects of your relationship with them, as well as your own feelings. Some of these might be hard for you both to adjust to. If so, remind yourself that you are doing the best you can at this moment.

### Your roles in the relationship

As the person's dementia progresses and you provide them with more support, your roles in the relationship are likely to change. This may occur whether you are starting to care for a parent, partner or someone else you are close to.

You may struggle with 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 and you may be able to talk about many of the same things you used to.

If you need to start doing tasks that the person with dementia used to do – 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 difficult or impossible to continue to enjoy a sexual relationship with the person they are caring for when so many other aspects of their relationship have changed. However, many couples do enjoy a physical relationship and sometimes develop new ways of sharing closeness and intimacy.

Some people with dementia seem to lose interest in a sexual relationship and may become quite withdrawn at an early stage. Alternatively, the person's desire for sex may increase. Some people start to make demands that can seem unreasonable.

Sometimes, the person with dementia may be unable or unwilling to be sexually active. If this happens, but you still want a sexual relationship, it can be very difficult for you. Sometimes you might even feel guilty for this – though it's natural to continue to want intimacy.

Although you may not be able to have these needs met in the same way, looking after your own wellbeing and getting support for yourself is important. It's a good idea to talk about these issues with someone. (See 'Getting support' on page 1).



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



**For advice and support call the National Dementia Helpline on 0300 222 1122**

## Other feelings

# 2

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 anger, guilt or sadness. Try to remember that, if you're having strong feelings, it means your relationship with the person is very important to you.

### Positive feelings

Caring for someone with dementia can lead to positive as well as negative feelings. For instance, your relationship with the person may have always been strong so you feel determined to stay close and support them. You may develop feelings of satisfaction and self-esteem from being able to cope with the challenges that caring brings.

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

When you're coping with the changing day-to-day pressures of the caring role, remembering why you're doing it can help to keep you feeling positive and able to carry on providing support.



## Difficult emotions

As the person's dementia progresses you're likely to feel a range of different emotions. This could be because you feel overwhelmed or lonely, or don't know which way to turn. Or it may be because of the person's behaviour. Your feelings might include:

- guilt
- grief
- anger
- embarrassment.

These are all common feelings many carers experience but, if you don't find ways of managing them, things may become more difficult and affect your health. Recognise the way you feel and try to work out what is making you feel the way you do. By understanding this you will be able to focus better on ways of coping.

Alzheimer's Society provides a range of information including factsheets that provide emotional and practical support. These include tips on looking after yourself and ways of managing things you're finding difficult.



**For more information see factsheets 417, The later stages of dementia, 507, Grief, loss and bereavement, 523, Carers – looking after yourself, and 525, Changes in behaviour.**



For advice and support call the National Dementia Helpline on **0300 222 1122**

## 2

### **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.

Any problems are not likely to go away just because the person has dementia. This can make it hard for some people to want to take on a caring role. You may have negative feelings from the past, which can affect how you feel now. You may be less tolerant of the person.

If you've had a difficult relationship with the person in the past, try to get help to develop a healthy and safe relationship with them now.

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

If you've had a difficult relationship, consider whether you want to care for the person. If you do care for the person, 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).

## Your relationships with other people

Caring for someone with dementia may affect your relationships with other people. You may find that support from family members or friends has a positive impact on your relationship. At the same time, you may find that others react negatively or don't offer you the support you need. This can be for a number of reasons – for example:

- they may find it hard to accept that the person has dementia
- they may be worried about what other people will think
- they (and you) may be part of a community where it's difficult to talk about dementia
- they may not know how to support a person with dementia – suggest they read factsheet 524, **Understanding and supporting a person with dementia** or this guide.

### Talking to children and young people

If you have children, grandchildren, nieces or nephews, you may be wondering whether to talk to them about dementia. Children and young people are usually very aware of what is going on, but they may not always understand it the way adults do. Try to be as honest and clear as you can.

When talking to them about dementia, adapt what you say and how you say it as you would with any topic. Consider their age, personality, how much they understand, and how they usually react to difficult or upsetting news. If the children are close to the person with dementia, it's usually a good idea to tell them eventually. It may also help to mention it to their school or college.



**For more information see factsheet 515, Explaining dementia to children and young people.**



**For advice and support call the National Dementia Helpline on 0300 222 1122**

## 2

## Looking after yourself

The challenges of caring can mean that you may not have time to do all the things you need to. You might feel that it's not always possible to make time for yourself, but it's 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, and to put things in perspective.

For ideas of who to talk to, see 'Getting support' on page 1. As well as talking to others, important steps include: involving other people in the caring role, taking regular breaks and looking after your own health.

### Involving other people

You may find involving family members and friends helps to give you a break and reduce some of your stress. If you haven't had much support from friends or family members so far, there may be different reasons for this. For example, they may not have realised what you're going through, or they may be struggling to accept that the person has dementia.

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 medication). They may also agree to support the person from time to time so that you can have a break.





## Taking breaks

You will need to take regular breaks from caring. You may be looking after children and want some time to focus on them. Whatever your circumstances, short breaks (for example, taking an afternoon off while someone else supports the person) can help you to go on caring. Maybe you could take a weekend or a week or two away on your own.

Consider what helps you relax. See 'How to relax and reduce stress' on page 41 for more information. Make time for the things you enjoy and that help you to feel you have a purpose other than caring.

Some services can help with caring, such as a day centre or short-term residential care. See Replacement (respite) care on page 98 for information on how to access these services in your local area. As a carer you are entitled to an assessment of your own needs.

## 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 that have several different types of food in – for example, meat or pulses, starchy foods, eggs or cheese and at least five portions of fruits and vegetables per day. Drink 6–8 glasses of liquid per day such as water, tea, coffee and milk.



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- Keep physically and mentally active – for example by going for walks, gardening, joining a gym or exercise class. Mental activity could include reading, learning a language, or doing puzzles or crosswords. Find things that work for you.
- Make time for your own hobbies, interests, or things you find engaging – it's good for your physical and mental health.
- Try to get enough sleep. You may find it helps to sleep when the person with dementia is sleeping. Sometimes, taking a short 'power nap' for about 20–30 minutes can help you to be more alert again. If you're struggling to get enough sleep, try to avoid alcohol and caffeine in the evening. Talk to your GP if you think you might need help.

**'Do not neglect yourself, care for the carer too.'**

Carer for a person with dementia

## How to relax and reduce stress

Making time to relax is important for your health. There are many different exercises and techniques you can practise to help you relax and reduce stress. Some popular ones are listed below – try some of these and see what works for you. You may wish to combine them.

- **Diaphragmatic or belly breathing** – sit or lie down with one hand on your chest and one on your belly, and breathe in and out smoothly, slowly and deeply. Your belly (rather than your chest) should rise and fall as you breathe.
- **Mindful breathing** – sit with your eyes closed and just focus on breathing in and out, and how this feels. When your mind wanders, bring your focus back to your breathing.
- **Progressive muscle relaxation** – lie down and then tense, hold and relax different muscle groups in your body in turn (hands, arms, neck etc).
- **Guided imagery** – visualise yourself being somewhere safe and restful, and imagine experiencing all the sights, sounds and smells.
- **Listening to relaxing music or sounds** – you can get a relaxation CD from your library, a shop or online. You can also download relaxation music to a mobile phone or tablet.

You will need instructions to learn most of these exercises. Ask at the doctor's, look online (for example the NHS website) or visit your local library or bookshop (often in the 'wellbeing' or 'self help' section). You can get specific apps for your mobile phone or tablet to help with relaxation, or try searching for videos online.

## When the person doesn't accept they have dementia

### 2

Some people with a diagnosis of dementia may struggle to accept it fully. For example, they may say their memory loss is just because they're getting older, or they may avoid talking about it by changing the subject or becoming defensive whenever it's mentioned.

Denial can have different causes but for many people it is an unconscious response to their diagnosis. By avoiding having to deal with the negative thoughts and emotions related to their diagnosis, the person protects themselves from feeling overwhelmed by it. You may need to be patient and understanding over a long period while the person with dementia comes to terms with their condition.

Denial is a very common and normal reaction to a recent diagnosis, but it can be frustrating or distressing for you and others who want to help them to live better with dementia.

It can affect you both in different ways – for example, the person may not accept medication or other treatment they need. They may also carry on doing things on their own when you think they need help.

### Will the person accept they have dementia?

Over time, the person with dementia may start to accept that they may have a serious problem – especially as their condition gets worse. They may gradually begin to talk about it with people they trust, though they may change their minds about whether they have a problem. Eventually people may come to accept they have dementia.



However, some kinds of dementia cause a person to lose their ability to process and remember new thoughts and feelings about themselves. This is known as a 'lack of insight'. It can be a very challenging cause of the person not being able to accept their diagnosis, as it may not improve much over time.

It may help to show the person some evidence of their symptoms. It's important to try and do this in a way that involves them and that they find supportive. Avoid comments such as 'you're always forgetting things' or 'you never remember people's names anymore' as these can be frustrating and distressing. Instead, you may want to point out that they need help with some tasks and you're there to support them.

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.

**'It's so important to keep yourself fit to enable you to continue caring for the person with dementia.'**

Carer for a person with dementia

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# 3

## Looking ahead: putting plans in place

### **In this section**

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## Practical arrangements

When someone has been diagnosed with dementia they may be adjusting to changes that they did not expect. It can be difficult to think about practical arrangements for changes they may experience in the future as well.

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However, it's a good idea for you and the person you're supporting to start thinking ahead as soon as they feel able to. It can help you both to prepare for a time when they may not be able to make some decisions for themselves. It will enable them to make their wishes for the future clear and choose who they want to make those decisions for them when this time comes.

### Driving and dementia

If the person you are supporting drives, a diagnosis of dementia is not in itself automatically a reason to stop driving. Many people with dementia drive safely for some time. However there will come a time when they will have to stop driving for their own safety and that of any passengers, as well as other road users.

By law, when a person is diagnosed with dementia and has a driving licence, they must inform the Driver and Vehicle Licensing Agency (DVLA) in England or Wales or the Driver and Vehicle Agency (DVA) in Northern Ireland (see Other useful organisations on page 154).





DVLA or DVA will seek permission to obtain medical reports from the person's GP or specialist. Based on the medical information it receives, DVLA or DVA will make a decision as to whether the person can continue to drive. The person may need to take a driving assessment.

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

Many people diagnosed with dementia will decide for themselves that they wish 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 – try not to take it personally. If you're finding it difficult, try to find out what other transport is available in your area.



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

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**For advice and support call the National  
Dementia Helpline on 0300 222 1122**

## 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.

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It is a good idea for the person to tell their employer about their diagnosis (and sometimes the person might be legally obliged to do so). Under equalities law their employer must make reasonable adjustments in the workplace 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 the disability employment adviser at their local Jobcentre Plus, for example. It might sometimes be appropriate to ask for advice from a solicitor.



**For more information the person may wish to look at booklet 1503, Employment.**





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## Your rights

As the person's dementia progresses you may need more practical and financial support. Making sure the person is getting everything they are entitled to may also help you and, as a carer, you have a number of legal rights of your own. It's helpful for you to bear in mind both your own rights and those of the person with dementia. These include rights relating to:

### 3

- 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 52)
- getting a carer's assessment from your local authority (see page 94) 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 may include respite or replacement care to allow you to take breaks (see page 98)
- financial support for you and the person with dementia – which may be subject to means testing (see page 94)
- making complaints if you are unhappy about the care the person has received (see page 105)
- requesting flexible working arrangements from your employer (see page 114).



## 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. For more about the financial aspects of dementia and caring see Section 6, 'Managing your finances'.

Try to encourage the person you're caring for to get any paperwork they have about their legal and financial affairs in order. You may want to offer to help them with this. Specific things that are useful for the person to think about are covered below.

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### Bank accounts

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

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

**'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

# 3

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. Also, many banks will freeze a joint account if one of the account holders loses the ability to make financial decisions for themselves (known as lacking 'mental capacity'). They will unfreeze it when someone with an appropriate legal power (such as a Lasting power of attorney) can handle the account 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.



**If the person with dementia wants information on this they may wish to look at booklet 1501, *Managing your money*.**

## Lasting power of attorney

A person with dementia may eventually lose the ability (or mental capacity) to make some decisions for themselves. While the person has capacity, they can choose someone who they want to make those decisions on their behalf when the time comes (known as an 'attorney' in England and Wales).

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 (such as the treatment and care they receive)
- an LPA for decisions about property and financial affairs (such as their bills, tax and pensions).



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 very helpful if one is a spouse or has health problems of their own.)

Making an LPA involves filling out a number of 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 section 10, 'Other useful organisations'.



**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 online. To find out more the person with dementia can call the National Dementia Helpline (see below). This service does not offer legal advice.

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



**For more information see Northern Ireland factsheets NI472, Enduring power of attorney and controllership, and NI467, Financial and legal tips.**



**For advice and support call the National Dementia Helpline on 0300 222 1122**

## 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) it will probably be necessary for you or someone else to apply to the Court of Protection to become their 'deputy'. A deputy can legally make decisions on the person's behalf and access their finances.

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It's usually best for the person to make an LPA where possible, to enable them to choose 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 Northern Ireland factsheet NI472, Enduring power of attorney and controllership.**

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](http://gov.uk) in England and Wales, or [www.nidirect.gov.uk](http://www.nidirect.gov.uk) in Northern Ireland.





## Making a will

Making a will is something everyone should think about. A will allows a person to pass on what they own to the people they want to receive it after their death. It can save many problems later on and may include thinking about inheritance tax liabilities.

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

It is 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 an approved solicitor through our Will to Remember scheme. Go to [alzheimers.org.uk/willtoremember](https://alzheimers.org.uk/willtoremember) for details.

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**‘Set up a Lasting power of attorney as soon as you can.’**

Carer for a person with dementia

## Planning for future care

It can be helpful for the person to think about making plans for their needs and wishes for the care they want to receive later on. This is known as 'advance care planning'.

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

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- 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 the person wants for the future. Discussions you've had 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.

### Advance decisions and advance statements

Advance decisions to refuse treatments allow the person with dementia to state which forms of medical treatment they don't want to receive in the future. Their purpose is to ensure that the person is not forced to receive treatment they don't want at a time when they are unable to decide whether to have the treatment 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 procedures in advance. A solicitor can also provide advice.



In Northern Ireland there are advance directives instead of advance decisions. The law is slightly different and, although advance directives are not legally binding in the same way, it is likely that an advance directive would be followed if it is 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 general statements about their wishes and preferences for the future, rather than refusing certain treatments.

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

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**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.**



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



**For advice and support call the National Dementia Helpline on 0300 222 1122**

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# 4

## Understanding and supporting the person with dementia

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## Understanding the person with dementia

Living with a diagnosis of 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.

### 4

It can be hard to imagine what it's like to have dementia. The changes caused by dementia, to a person's memory, thinking, senses and emotions for example, can affect their self-esteem, independence and relationships.

The person may also gradually lose the ability to do their favourite activities, hobbies or everyday skills. However, they will still keep some for a long time and, where possible, you and others should support the person to do things for themselves. This helps them maintain skills and independence.

For more about how dementia will affect the person in the later stages, see section 7, 'Supporting a person in the later stages of dementia'.



## Communicating with the person in the early and middle stages

People in the early and middle stages of dementia often have problems communicating. For example, they may struggle to find the right word, not follow a conversation or repeat themselves. If they have hearing difficulties this might make it harder to understand what someone is saying. Continuing to communicate with a person is very important as they may become isolated if they start to lose confidence and avoid talking to others. The advice in this section will help you to keep communicating.

The type of dementia a person has may also affect their communication. For example, they are more likely to have difficulties early on if they have a certain type of FTD rather than dementia with Lewy bodies.

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**‘Enable the person you care for by placing labels on the doors of the toilet, bathroom and bedroom.’**

Carer for a person with dementia

## Language problems in dementia

Dementia can affect someone's ability to understand words and language, which can make communication more challenging. Communication can be affected by the areas of the brain most affected by disease, and how much damage has been done to these areas.

A person may:

- lose the thread of a conversation
- forget some words, especially the names of objects, or confuse one word with another (for example 'book' instead of 'newspaper')
- talk for a long time or repeat the same things over and over
- lose or ignore the usual rules people follow in conversation – for instance, they may interrupt people, or not respond when someone talks to them
- have problems expressing how they're feeling, such as not being able to say when they are unhappy or upset, or why.

## Communicating – tips

- Make sure the person is included in conversations. 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 as closely as you can. Remove distractions such as background noise.





- If the person finds verbal communication difficult, speak clearly and a little more slowly than usual (but not too slowly) and use simple words and sentences. You can also express meaning by changing the tone and pitch of your voice – for example, by making your pitch higher at the end of a question. However, it's important not to talk to the person as if they are a child.
- Try to maintain eye contact – as long as there is no cultural reason not to. This will help the person focus on you.
- Stay calm and speak with a kind and patient tone as much as you can.
- Try not to stand too close to or over someone when communicating – it may make them feel intimidated. Sit at the same level as them.
- Avoid asking too many direct open questions, such as 'What do you want to do today?' as these can be harder to process. Instead, try giving a short list of options, or just asking questions that need a 'yes' or 'no' answer.

In the later stages of dementia, problems with language and communication become much more severe. For more information, see page 128.



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



**For advice and support call the National Dementia Helpline on 0300 222 1122**

## Managing symptoms

There are many things you can do to support the person with dementia to manage their symptoms and stay as independent as possible. Everyone experiences dementia differently, but some of the changes people can have include:

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

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A person with dementia will often also have problems with sight or hearing, and may develop delirium.

There is more information about helping the person to manage all these symptoms below.

**‘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 and can be frustrating and distressing both for the person and those, like you, who are important to them.

Problems a person might have include:

- forgetting recent conversations or events
- losing items
- difficulties with day-to-day tasks
- getting lost in familiar surroundings
- forgetting appointments
- difficulty recognising faces.

There are lots of ways you can support the person when they have problems with their memory. For example:

- If they've forgotten something that was recently said to them, avoid telling the person they have already heard it. It won't help and may make the person feel frustrated or distressed.
- Mark a calendar with the date (or try an electronic calendar which automatically changes the day and the date).
- Buy a daily newspaper (or get one delivered) – the date and the day of the week are always on the front page.



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- Consider using visual reminders, such as a wall calendar, weekly planner or a noticeboard in an obvious place. They may want to record reminders in a mobile phone calendar, notebook or diary.
- Consider using more permanent reminders for tasks the person does regularly (such as a note by the door to remember their keys and wallet).
- Use visual clues that explain where items go, such as pictures or photos with words on cupboard doors.
- Keep important things like money, keys and glasses in the same place.
- Put helpful telephone numbers by the phone where the person can see them.
- Encourage visitors (friends, family and professionals) to write the time and purpose of their visit in a book. Professionals could record their visits in booklet 923, **My visitors book**.

As dementia progresses, a person loses more of their memories. This can change how a person experiences reality and lead them to become confused. 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 persuade the person that they are 'wrong', try to think about the feelings they're trying to express. For example, if they are talking about needing to see a parent or to 'go home', they may need support and reassurance. Try to understand the person's feelings and give comfort.





**For more information and tips on supporting the person to cope with memory loss see factsheet 526, Coping with memory loss.**

### **Assistive technology for memory problems**

There are lots of devices that are designed to help with memory problems. These include, for example, calendar clocks to help people know 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 [alheimers.org.uk/shop](https://alheimers.org.uk/shop)



**For more information see factsheet 437, Assistive technology – devices to help with everyday living.**

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## **Supporting an LGB or T person with dementia**

If the person you're supporting is lesbian, gay, bisexual or trans, symptoms of dementia such as memory loss 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 a lesbian, gay, bisexual or trans person with dementia.**

## 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 'mistaken thoughts'. Even though the delusions may not be true, they will feel very real to the person, and you won't be able to change their mind by appealing to reason.

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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. Other things that may contribute to delusions include the environment, other conditions and medication. There are some common examples on the opposite page.

Sometimes these ideas may be made worse by hallucinations. See the advice on hallucinations on page 70.

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 first. If it is a delusion, trying to convince them that they're wrong is unlikely to help and may just make both of you feel more frustrated and distressed. Instead try to stay calm and offer the person reassurance.



## Common delusion examples

Delusion	Possible explanation
People are stealing from them	It may be because the person forgot where they put an item, it not being where they think it should be or they have put the item in an unusual place.
Their partner is having an affair	Their partner may have gone out and the person might not remember where or why they have gone. It may also feel as if the partner has been gone for much longer than they have.
There is a stranger in the house	The person may have heard the sounds of people they don't recognise (for example, a care worker or cleaner), either outside, on the radio or TV, or people inside their home whom they don't recognise (for example, a care worker or cleaner). This can also be associated with auditory hallucinations (hearing things that aren't there) or visual hallucinations (seeing things that aren't there).
Neighbours are spying on them	Their neighbours may be worried and checking in on them, but the person may not remember this or be unsure why it is happening.

## Hallucinations

Some people with dementia have hallucinations (where they experience something that isn't there). They may especially have visual hallucinations if they have dementia with Lewy bodies or Parkinson's disease dementia. It is possible to have hallucinations related to any of the five senses.

However, it is much more common for people to 'misperceive' what is going on around them than to have a true hallucination. For example, the person might hear voices on the radio and think there are people in the room.

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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:

- acknowledge the feelings they are experiencing and try to reassure them by responding in a calm and supportive way
- avoid arguing with them or telling them that they're wrong or 'silly'
- try to gently distract them – for example, by turning their attention to another activity or by talking to them.

There are different ways you can support a person to manage hallucinations. For example:

- Make changes to the room or environment, such as checking the area is well lit, and covering or removing mirrors and patterned carpets or wallpaper that may be confusing the person.





- 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 possible, stay with the person and see how they're coping with their hallucination, especially if they are frightened. Offer them reassurance and try to stay calm. It may help to distract the person to see if that stops the hallucination.

Tell them that what they are sensing is not clear to you, but that you want to know what they are experiencing.

If their hallucinations involve multiple senses get immediate medical advice. Also talk to the GP if the person's hallucinations last several weeks, happen over and over again or are causing them a lot of distress. It will help to give them the following information:

- Accurate notes on what the person describes experiencing, when and where it happened and how long it lasted.
- Current and recent medications (including over-the-counter drugs or herbal remedies, if taken) as well as dosage.
- Recent and past illnesses or health conditions, including alcohol or drug use, history of mental health problems, or overdose.
- Any recent bereavements the person has gone through.
- Details about previous eye conditions and their most recent eye test prescription.



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## Delirium

Delirium is a state of mental confusion that causes a person to become easily distracted and more confused than normal. It starts suddenly in someone who is unwell and is much more common in older people, especially those with dementia.

A person with delirium will show changes such as being more confused than normal, becoming unusually sleepy or agitated, being easily distracted, and having rambling speech and hallucinations.

If the person you're caring for suddenly develops any of these symptoms they should see the GP as soon as possible so that they can find the cause. The GP will review the person's medication and stop any drugs linked to delirium, as well as making sure the person is free from pain, has enough fluids and enough oxygen in their blood.

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 they should wear any hearing aids or glasses properly. A 24-hour clock and calendar that they can clearly see will also help.

# 4



## Apathy, depression and anxiety

People with dementia can be prone to apathy, depression or anxiety. Although people who are not living with dementia can experience these too, they are much more common in those with dementia, and can also be more challenging to treat.

Talk to the person's GP if you think they are apathetic, depressed or anxious. There is more about these symptoms and how you can help below.

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#### Apathy

Apathy is a persistent loss or lack of motivation to do things. A person with apathy may rely on others to structure their daily activities, show a lack of concern about their own problems or seem not to care about news or personal events.

To help the person, try tasks and activities that they can do, enjoy and find meaningful. A daily routine may help. Sometimes a person may seem apathetic when in fact they just have problems getting going. Try to help the person by starting the task first or breaking it down into chunks, as they may then be able to carry on with it.

If you find the person's apathy frustrating, try to stay calm and don't blame them. They're not being lazy, unhelpful or not caring – it's not their choice.

#### Depression

Many people feel low or down from time to time. However, depression involves feeling sad for very long periods of time and having little or no energy. It may include disturbed sleep or feeling hopeless and the person may cry.



They may find it helpful to do regular physical exercise, such as short walks, gardening or tai chi, or other activities they enjoy and are able to do. A daily routine and regular activities with other people can also help.

### **Anxiety**

Anxiety involves feeling very worried, tired, uneasy and irritable. It can also have physical symptoms, including fast or irregular heartbeats (palpitations), excessive sweating, dizziness or nausea. Anxiety can become very strong and last for a long time. In severe cases, it can cause panic attacks.

People with dementia and anxiety may show changes from their normal 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 medication.



**For more information see factsheets 444, Apathy, depression and anxiety, and 445, Talking therapies (including counselling, psychotherapy and CBT).**

**‘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

## Supporting a person to stay healthy and active

Having dementia does not mean that the person should feel ill. There are lots of things you can do to support the person to live safely and well, and to continue doing the things that they enjoy, as well as staying healthy.

### 4

#### Keeping safe

Making changes to the environment can help the person to maintain their independence and 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 rugs or clutter
- use plain furniture and linen that contrasts with the walls and floors
- keep important items in the same place
- leave the bathroom door open and a light on at night
- consider sensor lights if the person gets up during the night.



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



There are also different types of technology that may support the person, from easy-to-use clocks to location devices. 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, Assistive technology – devices to help with everyday living.**

## Sight and hearing

Older people, including those who don't have dementia, often have communication difficulties caused by sight or hearing problems.

If you think the person you support may be unable to hear you, you may need to arrange a hearing test. If they do have hearing difficulties, a hearing aid may help.

The person should also have regular sight tests. Ensure that their prescription for glasses is up to date and, if they have more than one type, that they wear the correct ones. Keep glasses clear by wiping them with a soft cleaning cloth.

There are a number of ways to support a person when they have hearing or sight loss:

- If they hear better with one ear, ask people to speak clearly towards that one.
- If the person has a hearing aid or glasses, make sure that they are wearing these and they are up to date.



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- If the person is having problems with their eyesight, you may have to let them know who they are talking to.
- Make sure there is enough light in the room for someone with poor eyesight to see. The person's eyesight may also be better at a certain distance, so bear this in mind when considering where other people will sit.
- When talking to someone with a sight or hearing impairment, make sure you stand or sit where they can see your face, and speak clearly and slightly more slowly.
- Touch them lightly on the wrist or arm to show them you're there (if appropriate). Do this sensitively as a sudden movement can be frightening.
- If the person is struggling to hear, it may help to use a laptop or tablet device to type what you're saying.

## Eating, drinking and dental care

Eating a healthy balanced diet with plenty of liquids will help keep someone well. If someone eats too little or misses out on essential nutrients, it will reduce their resistance to illness. Not eating well can also make a person with dementia more confused. If the person you are caring for isn't eating a balanced diet, the GP may be able to suggest ways to help or may prescribe vitamins or supplements.

People with dementia may have difficulties with eating and drinking and there are many reasons for this. These may include low appetite, not recognising food and drink or problems sensing that they are hungry or thirsty.





If a person seems to have low appetite it's a good idea to see their GP to rule out treatable causes, such as depression, pain or constipation. They should also go to their dentist every six months to maintain good oral hygiene and check for any problems or changes in their mouth, teeth or dentures.

There are a number of other ways to help a person when they have a low appetite. For example:

- Try to make food look, smell and taste appealing, and try different foods as the person's tastes may change.
- Find opportunities for the person to eat – for example, during the night if they're awake.
- Try different types of food and drink – for example, you could try smoothies as a way for the person to eat fruit and vegetables.
- Encourage the person to eat and get involved at meal times – for example, by setting the table or helping you prepare food.
- Make changes to the environment such as making sure the colours of the food, plate and table are contrasting.
- Leave out snacks and foods that are easy to eat during the day as the person may not remember to look in the fridge or cupboards for food.



We all need to drink 6–8 glasses of water or other liquids (including tea, coffee and soft drinks) a day in order for our bodies to work properly and avoid dehydration.

Encourage the person to drink throughout the day. It may help to use a clear glass so the person can see what's inside. Offering different types of drink (including hot and cold) may also help.



**For more information see factsheets 511, Eating and drinking, and 448, Dental care and oral health.**

## 4

### Exercise

Being physically active can help with the health and wellbeing of people with dementia and carers in many ways. This includes improving the health of the heart and blood vessels, mobility and physical fitness, daily living abilities, emotions and sleep.

Look for physical activities that you and the person enjoy and want to do. You may want to do these together or separately. Ideas for exercises include walking, gardening, dancing, swimming or tai chi. As dementia progresses, or if the person has physical problems, it may be better for them to do seated, chair-based exercises.



**For more information see factsheet 529, Exercise and physical activity.**



## Activities

Staying involved and active is important for people with dementia and can support their sense of wellbeing.

The person may gradually need more support with taking part in activities. It can help to adapt activities so that the person is still able to do them. There may be times when they become upset or frustrated that they can't do things as well as they could. Acknowledge these feelings and look for ways to support the person and adapt to changes.

It's important to try different ways of doing things rather than not doing them at all. This could include simplifying the task or doing things with the person. However, be careful not to take over what the person is doing or undermine them.

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

- breaking tasks down into smaller steps
- keeping things simple and allowing the person plenty of time
- focusing on the activity, not the result
- removing or minimising any distractions.



## Ideas for activities

You know the person best so choose activities suitable for them and that they enjoy. Ideas could include:

- reading books, newspapers or magazines. If the person struggles with these you could try audio books or podcasts on a mobile phone or tablet device
- visiting friends or family members, or going on day trips or holidays
- looking at old photographs or souvenirs from past events or holidays, or creating a memory book or photo album
- cooking together – the person may be able to help with tasks such as stirring or peeling vegetables
- puzzles – there are a range of puzzles and other activities specifically designed for people with dementia. For more information go to our online shop – [alzheimers.org.uk/shop](https://alzheimers.org.uk/shop)
- music and singing – these are great ways to stay active and may have a range of benefits for the person with dementia and you. In many places there are singing groups specifically for people with dementia
- activities in the community – such as visiting a dementia-friendly cinema screening or a local group for people with dementia.

Other people can support the person with dementia to take part in activities. This means you can have a break and the person has an opportunity to spend time with other people.





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## Engaging the person's senses

As dementia progresses, activities that stimulate the senses can be really helpful. For example people may find comfort in touching or stroking pieces of fabric or a soft toy or doll, or a fiddle muff – go to [alzheimers.org.uk/shop](https://www.alzheimers.org.uk/shop)

They may find touch and a massage soothing, especially if it is done with herbal oils. They may also enjoy looking out of the window, or having a hanging mobile or a fish tank.

## Holidays

Going on holiday can be possible even as the person's dementia progresses, and some people enjoy the opportunity to do this. It can be a rewarding experience and it can be good to have a change of scene.

You may want to visit friends or family members, or to stay in a hotel or bed and breakfast. If you go away, it may help to:

- look into accessible travel options for a person with dementia
- think about how you can help the person orientate themselves in 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 a downstairs room)
- use a holiday provider that specialises in holidays for people affected by dementia.
- look into suitable travel insurance. Some providers will cover people with dementia who want to go on holiday.



See 'Other useful organisations' on page 154 for details of organisations who provide information.



**For more information see factsheet 474, Travelling and going on holiday.**

## Dressing

It is important to enable a person with dementia to make their own choices about what they wear and how they look for as long as they can and, if they do need assistance, to offer help sensitively.

There are lots of things you can do to help the person to be comfortable and keep some independence. Wherever possible, give the person a choice of what to wear. It may be best to keep this to two options to avoid confusing the person.

Laying out clothes on a non-patterned background in the order the person will put them on may help. Try to keep this in the order the person prefers (for example, starting with underwear and ending with a jumper). If they need help, remind them sensitively which item of clothing comes next or hand it to them.



**For more information see factsheet 510, Dressing.**



## Other tips for staying healthy

There are a number of other important things you can do to help the person with dementia stay healthy.

- Support the person to get a good night's sleep. It may help to limit daytime napping as this can affect a person's ability to sleep at night. They should avoid alcohol and caffeine near bedtime. For more information see 'Sleep problems and night-time disturbance' on page 125.
- If the person enjoys the occasional alcoholic drink, they might want to keep doing it unless their GP advises them not to.
- If the person smokes, try to support them to stop.
- Keep rooms at a suitable temperature and draught free.
- 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 as stronger bones help prevent worse damage from falls, 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'.
- Pay attention to the person's foot care by keeping feet clean and dry with toenails cut short. See a podiatrist or chiropodist for any problems and make sure shoes and slippers fit well.





## Managing medications

The person you're supporting may start to need help with managing different medicines. These may include drugs for dementia and other conditions, such as high blood pressure or diabetes.

Make sure you know all of the drugs they take and the different doses. Look at the leaflets for any side effects and what happens if the person misses a dose or takes too many.

Ask the pharmacist about getting pills in a medication reminder box (sometimes known as a dosette box). The box has compartments for different days and times of the day.

Ask the pharmacist if they offer a free medication review or checkup. This involves a private appointment to discuss any medications, including how they should be used and any issues that may arise.

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# 5

## Services, support and housing

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## Support services

You may find that you're able to manage without much support from others for some time. However, we all need extra help at times, and asking for this when you need it may enable you to go on caring for longer.

This section tells you about the different sources of support available from professionals and other services, including care and housing options. It can also be helpful to let those close to you know early on what support you would like and need with caring. This gives you and others time to prepare.

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**'I have the services of carers, nurses, the hospital and doctors, and the support of Alzheimer's Society which I must admit is superb. All of these have been brilliant. Had I been alone I would not have known where to start.'**

Carer for a person with dementia

## Health and social care professionals

There are a number of health and social care professionals who can provide support, both for you and the person with dementia. This includes doctors and consultants, different types of nurses and other specialists. It may sometimes seem like you're interacting with lots of professionals and have to repeat what you say. Remember that their role is to provide important support for you both, to enable the person to live well with dementia and help you to care for them.

### Doctors

The GP is the first point of call for any concerns about the person's health, as well as yours. The GP can discuss the person's symptoms and medication, and refer them to other professionals (such as nurses) and services.



**For more information see factsheet 425, How the GP can support a person with dementia.**

Also speak to the GP as soon as possible about your 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.

The person may also be supported by medical consultants including a psychiatrist, geriatrician or neurologist.



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Different health professionals can help with a range of other health problems. If you think one of the professionals listed below may be able to help, ask the person's GP to refer them.

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

## Nurses

Different types of nurses support people with dementia and those who care for them, in a variety of roles. These include:

- community mental health nurses (also known as community psychiatric nurses or CPNs) who support people with dementia as well as mental health problems
- dementia nurse specialists or Admiral nurses (see Dementia UK in ‘Other useful organisations’)
- your local health centre’s practice nurse and district or community nurses.

## Social care professionals

Social workers and social care workers can help in ‘non-medical’ ways. These include practical help with personal care as well as equipment and adaptations at home. Social workers assess the person’s needs and advise on the best support for them and their carer (see below). Social care workers (including paid domiciliary carers) help with practical things like washing, dressing and meal preparation – see ‘Help at home’ on page 95.



**For more information you and the person with dementia may wish to see booklet 1503, Health and social care professionals.**



**For advice and support call the National Dementia Helpline on 0300 222 1122**

## Help from the local authority

Local authorities have a legal duty to assess the needs of people with dementia and their carers if they are asked to do so. If this assessment shows that the person with dementia needs care and support, the local authority may carry out a financial assessment to determine how their care will be paid for. For more information on this see 'Paying for care' on page 112.

To get an assessment, contact your local social services. You can find the contact details on your local authority website or at your local library.

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Social services will carry out a care needs assessment for the person with dementia. You can also ask for a carer's assessment to look at your needs. These assessments can be carried out separately, or jointly if you wish. If the person you care for refuses their needs assessment you are still entitled to a carer's assessment.

Part of the process involves writing care and support plans to record your needs. After the needs assessments have been completed, social services will carry out a financial assessment.

These assessments are important for you and the person you care for. You may not be familiar with the processes or the language and so ask for more information if there is something you don't understand.



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





## 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 them shopping or on a day trip. Some carers find it difficult to accept they need this kind of help. However it can help you both to live better and may help you support the person at home for longer.

Some social care workers can provide support in people's homes. You can arrange this through home care services, sometimes referred to as 'domiciliary care'.

Most care workers come from private companies – the local authority may pay them directly to provide care. You should be able to choose which company you would like to use.

You can also arrange home care services yourself by employing someone directly, using benefits or other income received by the person you are supporting. Depending upon a financial assessment, you may have a right to a direct payment (where you get the money to spend on care) or personal budget from the local authority. You can employ someone from an agency or as an individual. Some people employ live-in care workers too.

Make sure agencies or care workers are trained in dementia care and have a good reputation. You can ask your local social services for help with finding care workers. It's also a good idea to look at ratings of care services online from the Care Quality Commission (CQC) in England, Care Inspectorate Wales or the Regulation and Quality Improvement Authority (RQIA) in Northern Ireland (see 'Other useful organisations' on page 154).

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For advice and support call the National Dementia Helpline on **0300 222 1122**

You could also ask 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 put you in touch with the community nursing services.

## 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 mobile. This may include adaptations to a bathroom or fitting grab rails, for example. You may be able to get help with the cost of larger equipment and adaptations to the home.

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**For more information see factsheet 429,  
Using equipment and making adaptations at home.**



## Living together

If you are not already living with the person you care for, there may come a time when you both feel that it may help to live together (in your home, theirs or another home). This is likely to be a big decision for both of you. Think about how it will affect both of you and anyone else you live with.

The person may find it very difficult to move out (or have you move in), especially if they have been used to living alone. They may feel that they are losing their independence and they may find the new environment confusing.

The person with dementia should always be able to make decisions about their care, where they will live and who with, if they are still able to do so. It's important to support them and to respect their decisions.

## Care and support in the community

### Replacement (respite) care

Everyone needs a break from time to time. It is important that you're able to have a rest, whether it is a short break to do things you need to, meet friends or spend some time away.

A break will help with your health and wellbeing, and may give the person with dementia an opportunity to do other activities or meet different people.

You may have a family member or friend who can come and live in your home for a short time to allow you to take a break. Or you may use a private company that provides temporary live-in care workers.

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Different options for replacement care include:

- **Day centres** – these can provide a range of support for a person with dementia, including activities and social interaction.
- **Holidays or short breaks** – some holiday providers provide specialist support that means carers can have a break and focus on their caring role (see page 84).
- **Short stays in care homes** – some care homes have beds set aside for people requiring replacement care. However, these may not always be available when a person requires it. This type of break will usually have to be paid for but a local authority must not charge you for care provided to the person with dementia.



Whatever the type of replacement 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 102).



**For more information on paying for replacement care see factsheets 532, Paying for care and support in England, W532, Paying for care and support in Wales, or NI532, Paying for care and support in Northern Ireland.**

You may both need to adjust to putting replacement care in place. If this involves the person with dementia going into a care home for a short stay, they may take some time to settle into their new environment or when they return home. Try not to feel guilty about this – replacement care is very important for enabling you to carry on caring. Reassure the person when they go into replacement care that it's only for a short time.



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



## Hospital care

There are a number of reasons why a person living with dementia might be admitted to hospital. Sometimes they may need to spend time there for assessment or treatment for another condition and this might involve a slightly longer hospital stay.

### Supporting a person with dementia in hospital

If the person you care for is in hospital you can still support them if you would like to. This may involve telling hospital staff about the person, including making sure that all staff know they have dementia. Being with the person in hospital can provide the person with comfort and reassurance and you might also be able to help with practical things such as personal care or eating and drinking.

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### 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 certain rights as a carer.

#### 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). The person making these decisions should liaise with health and social care professionals. For more information see page 52.



If the person you care for doesn't have any attorneys and can't make some decisions for themselves, the doctors will usually make decisions about their care and treatment. Any decisions relating to the person being discharged from hospital, including any after-care, will be made by the health and social care professionals. All decisions must be in the person's best interests. As someone close to the person, you have a legal right to be consulted if decisions are made on their behalf.

## John's campaign

Some 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  
[johnscampaign.org.uk](http://johnscampaign.org.uk)

## Carer's passport in hospital

Many hospitals run a carer's passport scheme. A carer's passport is a card given to carers listing any additional rights they have as a carer in that hospital setting. For example, many hospitals allow carers to visit outside of visiting hours. Some even provide discounted or free parking or for a person's carer to be included on refreshment rounds.

Ask hospital staff about this. If the hospital does not operate this scheme, it's still a good idea to talk to staff about your needs. They may be flexible with things such as visiting hours if you ask and explain your reasons. If you are visiting regularly or over a long time you may be able to get reduced or free car parking.

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**For more information on what you can do to support someone in hospital see factsheet 477, Hospital care.**

## This is me

Our This is me form is an easy and practical way of recording more information about a person with dementia. It includes space to include important details on aspects of their lives and how best to communicate with them.

The completed form should be placed with their medical notes so that all staff working with the person 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.



## Housing options

As the person's needs change and they reach the later stages of dementia you may have decisions to make about the person's care and where they live. There may also come a point 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 their own 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 listed below. It's a good idea for you and the person with dementia to visit the location before deciding where they should live.

- **Sheltered housing** – these are self-contained flats. They may have a warden and a 24-hour emergency alarm system, and some may have communal facilities. The level of support will vary depending on the scheme. Sheltered housing schemes usually expect residents to have a certain level of independence.
- **Extra care housing** – this is similar to sheltered accommodation but it provides extra support, such as assistance with personal care, meals, domestic support and community activities.

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For advice and support call the National Dementia Helpline on **0300 222 1122**

- **Shared lives** – this is a scheme where someone who needs care and support moves in with, or is supported by, an approved Shared Lives carer.

For more information visit Elderly Accommodation Counsel's Housing Care website (see 'Other useful organisations' on page 154).

## Care homes

Many people with dementia move into a care home as their condition progresses. Deciding that this is the best way forward can be very hard. Knowing when the time is right and who should make the decision if the person cannot make it themselves is especially difficult. Alzheimer's Society produces a number of resources with more information about care homes, from making the decision to choosing the right environment.

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**For more information see factsheets 476, Care homes: When is the right time and who decides?, and 480, Supporting a lesbian, gay, bisexual or trans person with dementia and booklet 690, Selecting and moving into a care home.**

You are likely to have mixed feelings if the person goes into residential care. Some people feel guilt or grief that this stage in their relationship has ended. Some people feel relief, however, that they are no longer caring 24 hours a day.

Your role in supporting the person has not ended just because you no longer do the practical day-to-day tasks. A care home should involve you in the person's care as much as you want and are able to be involved. Some carers visit to help the person at meal times, 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 such as a care home. See page 102.

## Making complaints

If you are unhappy with the care a person has received in any setting, you have a right to raise your issue and attempt to get it resolved. 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 – most organisations have a complaints department or person responsible for handling complaints. If the complaint is about funded care or services then the complaint needs to be made to those that pay for the care (such as the local authority or the NHS).

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

### Step 3

Take the complaint to the relevant Ombudsman (see 'Other useful organisations'). Please bear in mind that there may be a time limit for when complaints can be raised.



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# 6

## Managing your finances

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## How your finances may be affected

Caring for a person with dementia can affect your finances in different ways. However, there is financial support available too.

You may be thinking about how supporting a person with dementia will affect your own financial situation. For example, you might be wondering whether you will have to pay for the person's care, or about other costs you may incur.

You don't have a legal duty to pay for the care of the person with dementia yourself. However, you might choose to contribute to their care costs at some stage. You might, for example, want to pay for care that the person themselves can't afford and that the local authority won't provide. It's worth thinking about this possibility when you're looking ahead to the future and planning your own finances.

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Whether or not you decide to contribute towards the cost of the person's care, there are some other things that might affect your own financial position, such as:

- loss of earnings if you need to take time off work to care for the person, or if you reduce your hours or can't work at all
- increased travel costs – for example, if you visit the person or take them to medical appointments or on trips out
- the possible costs of making adaptations to your own home (if you decide and are able to do this). For more information see factsheet 429, **Using equipment and making adaptations at home.**



- 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 associated with care and support you may need, such as extra heating or washing.

It's worth trying to think about these in advance, and planning for them if you can. This may involve adjusting your budget and setting aside money for future costs. You can also look into what financial support might be available to you (see 'Financial support' on the next page) and what rights you have at work (see 'Working when you're caring' on page 114).

**'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

## Financial support

Although your finances are likely to be affected, there are a number of different types of financial support available. It's important to find out whether either of you are entitled to this support.

Some people find it hard to ask for financial support, but extra help to manage finances is important to enable you to care for someone living with dementia.

### Claiming benefits

There are a number of benefits which, as a carer, you may be entitled to claim.

#### Carer's allowance

This benefit can be paid to carers over the age of 16 who regularly spend at least 35 hours a week looking after someone 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 care for at least 20 hours per week and who are not eligible for Carer's allowance may still be able to claim a Carer's credit to keep their national insurance record up to date and protect their state pension.





For details on the income and savings thresholds for claiming benefits, go to [alzheimers.org.uk/benefitrates](https://www.alzheimers.org.uk/benefitrates)

Contact Age UK or Citizens Advice to be put in touch with a benefits adviser who can help with checking your entitlement and any claims (see 'Other useful organisations').

### 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 dwelling based on the estimated value of the home and the assumption that two adults live there.

There are a number of ways that a council tax bill might be reduced. For example, this may apply if only one adult lives at the property. If there are only two adults living at the property and one has a 'severe mental impairment' (which may include dementia), that person may be 'disregarded' for council tax purposes. Neither of these reductions is means tested.

People on a low income may qualify for council tax support, previously called council tax benefit. This is means tested and the amount of the benefit will depend on income and savings and the amount of council tax they are due to pay. Council tax support can be claimed directly from the local authority.

Council tax support, discounts and disregards are complex, and it is usually worth getting advice from an organisation such as Age UK or Citizens Advice.



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

**For more information on benefits for people with dementia see factsheet 413, Benefits.**



**For advice and support call the National Dementia Helpline on 0300 222 1122**

## Paying for care

Local authority social services departments have a duty to assess a person's need for care and support. If the person is assessed as needing care, the local authority will assess them financially to decide how much they will have to contribute towards the cost of their care.

If a financial assessment shows that the local authority should fund the person's care, it allocates an amount of money to ensure that the person's needs can be met. This is referred to as a 'personal budget'. A personal budget can be used to organise the care directly, or the local authority can be asked to arrange the care.



**For more information on assessment for care and support see factsheets 418, Assessment for care and support in England, W418, Assessment for care and support in Wales, or for Northern Ireland NI418, Community care assessment.**



**For more information on paying for care see factsheets 532, Paying for care and support in England, W532, Paying for care and support in Wales, NI532, Paying for care and support in Northern Ireland, and 473, Personal budgets.**



## Being an appointee for someone's benefits

If at some point in the future the person with dementia is not able to manage their benefits, they can appoint you or someone else they trust to receive and manage this money for them. This is called being an appointee.



**For more information see factsheet 413, Benefits.**

## NHS continuing healthcare

Occasionally the NHS provides free continuing healthcare for people with long-term conditions. This care can be provided in any setting, including at home, but it is usually in a nursing or residential care home. Determining whether someone is entitled to free NHS continuing healthcare is complicated. It will depend on what care they need. If the NHS does not consider the person has what they call a 'primary healthcare need' then they are deemed to have social care needs and the local authority or the person themselves are responsible for their care.



**For more information about NHS continuing healthcare (and NHS-funded nursing care) see booklet 813, When does the NHS pay for care?**

## Working when you're caring

Trying to combine work with caring responsibilities can be challenging. It's useful to know what rights you have so that you can consider all the options.

If you are in employment, you don't have to tell your employer about your caring role but it might help. You have some 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

It's important to know your legal rights as an employee – especially:

- 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. This applies if they are your spouse or civil partner, a parent or child, or if they are living with you as part of your family. In some cases it can apply to someone else who relies on you for help.
- A right to request flexible working (though it is not a legal right to be granted it). Your employer must deal with your request in a reasonable way and can only refuse it where they have a good business reason to. You have this right if you've worked for the employer for at least six months. You should make any request in writing.



These are your legal rights but your employer may offer you more support or flexibility as part of your contract. It's a good idea to look at your contract or talk to your employer to see how they can help.

If you work for yourself you won't have these options, although you may have more control over your own schedule and when you work.

While these options might help you to juggle your caring responsibilities with work, they won't help you financially. Whether you are employed or self-employed, if you spend a lot of time caring for the person it's likely that your income will be reduced. The information earlier in this section about financial support may help you.



**For more information about working while you're caring it may help to contact a carers' organisation such as Carers UK or Carers Trust (see 'Other useful organisations' on page 154).**

**'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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# 7

## Supporting a person in the later stages of dementia

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## Symptoms in the later stages

When a person is in the later stages of dementia, they will need much more support. This section tells you more about the symptoms a person may have in these later stages and how you can support them.

In the later stages of dementia a person's symptoms will affect them much more than before. You can read more about some of these changes and how to manage them in this section. They may include:

- problems with memory – they may be unable to remember what they did a few minutes ago, or recognise familiar people or objects
- problems with communication – see page 128
- changes in behaviour – see page 119
- needing much more support with personal care activities such as washing and getting dressed – see page 132
- problems with continence or recognising when they need to use the toilet – see page 135
- problems finding their way around or with walking and being more likely to fall
- sleep problems and night-time disturbance – see page 125
- becoming more frail.





## 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 them, you and 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 or make them easier to manage.

Some of the most common changes in behaviour in people with dementia that carers find difficult are:

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



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

## What causes changes in behaviour?

Often if a person’s behaviour changes, other people think this is just a symptom of their dementia. This can lead to the person’s needs not being met, extra stress and other people saying that the person is being ‘difficult’ or ‘challenging’. It’s important to look beyond the behaviour and think about what might be causing it.

Everyone has different types of needs. People with dementia may be less able to recognise their needs, know how to meet them, or communicate them. They may be trying to communicate or meet one or more of these with their behaviour. The different types of needs include:

- **physical needs** – for example, the person may be in pain or discomfort
- **psychological and emotional needs** – for example, the person may be 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.

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## Ways to support the person

Always try and see things from the person's perspective. They are likely to struggle to understand what is going on around them at times, and they may find the world confusing, frightening and disorientating.

There are things that you can do to support the person to meet their needs and reduce behaviours that challenge. These include:

- helping them stay in touch with other people
- encouraging the person to do things they enjoy or find useful
- making changes to their environment if necessary. For example, reducing noise and improving the lighting
- keeping familiar, comforting or personal items close to them, such as a favourite jumper
- keeping their sleeping environment comfortable – for example, making sure it isn't too hot or cold
- 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 try asking them to tell you more about their children or how they are feeling
- psychological therapies with professionals, such as cognitive stimulation therapy. Talk to the person's GP about these.



## General tips for managing changes in behaviour

- Ask the person's GP to check for any possible physical causes, including pain, and advise on any treatments.
- Consider whether the behaviour is really a problem. If it is disrupting a particular activity such as washing or dressing, ask yourself if this task really needs to be done right now or if you could come back to it later. Sometimes it's best to leave the person to do what they want (so long as the environment is safe).
- Try to remember that the person is not behaving this way on purpose. Try not to take it personally. Their sense of reality may be very different from yours and they are responding to their own 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 want to stay awake or go out at night.
- Even though a person with dementia may have problems with their memory, 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').
- Offer the person gentle reassurance. If you need to, try stepping away from the situation to give you both time to calm down. Try not to show feelings of frustration as it may make things worse.
- Support the person to do as much as they can for themselves. The behaviour may be their response to the feeling that they are not able to 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.

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## Coping with changes in behaviour

Changes in behaviour can be very difficult for you. They may make you feel frustrated or distressed and affect your relationship with the person you're caring for. You may also worry that people are judging you or expecting too much of you, or that they don't understand the challenges you face.

Talking to others can help you to manage your feelings and any challenges. See 'Getting support' on page 1.



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

## Aggression

If a person with dementia behaves in an aggressive way it can bring a number of challenges for them and those who support them. Aggression can be verbal (such as swearing or screaming) or physical (such as hitting, scratching or biting). The causes of aggressive behaviour are likely to be similar to other changes in behaviour (see page 120).

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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 try to make sure the person isn't going to harm themselves, take yourself out of the situation as soon as possible and call for help.



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



## Sleep problems and night-time disturbance

Sleep disturbances are common for people with dementia. Dementia can affect a person's sleep patterns (separately from normal sleep difficulties that come with getting older). They may keep getting up during the night and may become disorientated, get dressed or try to go out. This can be very stressful for you.

It may help to:

- make sure the person has plenty of daylight and things to do during the day
- consider having a clock next to the bed that shows whether it's day or night
- try gently reminding them that it's night time if the person wakes up at night.

Sometimes changes in a person's behaviour are more common in the late afternoon or early evening. This is often referred to as 'sundowning'. It may be caused by the disturbance to their sleep patterns, or by changes to medication or the environment (such as lots of noise, or too much or too little light). Helping the person to sleep may help with this. It may also help to support the person to do things they find relaxing and enjoyable in the late afternoon or early evening.

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## Walking about

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

Like many behaviours, walking about may have a range of causes and, if you can identify this, it can help to meet the person's needs. Some reasons why the person may walk about include:

- continuing a habit or occupation (if they previously walked a lot)
- relieving boredom
- pain or discomfort
- feeling unsettled
- confusion about where they are or what the time is.

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

If the person you care for walks about it can be hard to know how to manage it. You probably want to keep them safe and may be worried about them.

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 think that they should lock the person in if they are at risk of walking about. You should never lock the person in if they are at home alone, as this could be very dangerous if there was a fire or accident. You should only ever lock the person in when they are with someone else, if all of the following apply:

- they are unable to make the decision themselves
- it is in their best interests
- it is the least restrictive option.



**For more information see factsheet 484, Making decisions and managing difficult situations.**

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

You may feel that you can no longer care for them at home or that it is too unsafe. These are natural reactions and it's important to think about what is best for you and the person. If you haven't had one already, this might encourage you to ask for a needs assessment and a carer's assessment from the local authority – see page 94.



**For more information see factsheet 501, Walking about.**



## Communicating in the later stages

As the person's dementia progresses, it is likely that they will find it more difficult to speak. They may reach a stage where they are no longer able to talk at all. This can be very distressing and difficult to adjust to, but there are many ways you can continue to communicate with the person.

The person you are caring for may also lose their ability to understand the words you use. However, they are likely to understand your non-verbal communication including gestures, facial expressions and body language.

Use the person's non-verbal communication to understand how they're feeling or if they are trying to communicate. They may pace around if they are feeling agitated, for example.

### Tips for communicating

There are many ways you can help the person with dementia communicate in the later stages. For example:

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- keep eye contact when communicating
- use positive body language (such as smiling, touching the person's hand and facial expressions)
- don't rush – allow plenty of time and look for non-verbal clues from the person
- even if you don't think the person can follow what you're saying, continue talking to them clearly as they may find this reassuring
- consider responding to them in the way they respond to you ('mirroring' them, for example, with gestures or sounds).



## Supporting the person during grief and bereavement

Like anyone, people with dementia may respond to grief, losses and bereavements in a range of ways. They may go through grief as their dementia progresses, for the abilities, independence or imagined future that they've lost because of their dementia.

If somebody close to the person dies, they may find it harder to communicate their feelings of grief especially if they are in the later stages of their condition.

### Tips for supporting the person during grief

- Support them to express how they're feeling (if they want to). They may not be able to communicate this verbally but look for other ways to support them such as music or creative activities.
- Give them time to express how they're feeling and reassure them when they're feeling distressed. Support them to keep doing the things they want to and enjoy. You could also help them find new things to do, such as a hobby or getting involved in their local community.
- Think about any religious or spiritual needs they may have (such as meditation, prayer or attending a service) and how these can help the person to cope with their feelings.
- They may find it helpful to talk to a professional (such as a dementia support worker or counsellor) about how they are feeling.

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## Talking to the person when someone has died

When someone close to the person dies, you may wonder whether to tell them. You may also question how much detail to give, especially if finding out how the person died could be distressing.

When making the decision, think about what is in the person's best interests. If the person is not told about the death it may prevent them from grieving or may confuse them when they no longer see the person who has died. However, telling the person may lead to unnecessary distress and they may be unable to process the information.



**For more information on how to approach decisions like these see factsheet 484, Making decisions and managing difficult situations.**

### Tips for telling the person about a death

- Explain what has happened clearly and simply. Don't use euphemisms like 'losing' someone or saying they have 'gone to sleep', as they can be misunderstood.
- Use body language and physical contact if appropriate.
- Try not to give too much information at once.
- Allow plenty of time for the conversation and be supportive. Be prepared to repeat information and try to be patient.



- If the person becomes very distressed, offer them reassurance (for example, by holding their hand). It may help to try a different approach later on when the person is no longer distressed.
- Make sure that you are supported as well.

## Forgetting that someone has died

A person with dementia may forget that someone has died. They may ask about them often, come up with reasons for their absence (such as being away or having left them), or report them as missing. This can be very difficult for the person with dementia, as well as you and any family members and friends coming to terms with a death.

When deciding how to respond, think about what is in the person's best interests. If the person is in the later stages of dementia, trying to remind them repeatedly that the person has died is unlikely to work and may be very distressing because it can come as new to them every time.

Recognising and focusing on how the person is feeling at the time can make knowing what to say easier. If someone is becoming very upset it may be best not to try and remind them.



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

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**For advice and support call the National Dementia Helpline on 0300 222 1122**

## 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

It is important to try to encourage the person to continue with their personal care routines for as long as possible. If the person wants and is able to continue washing themselves, help them maintain their independence. For example, lay out toiletries and make towels easily accessible. Using a rubber mat and installing a bath rail may help the person to stay safe in the bath or shower.

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

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- If the person seems embarrassed by being helped, protect their dignity by covering up one part of their body at a time. Using towels warmed on a radiator can be very comforting.
- Try to make the experience as pleasant and relaxed as possible. Make sure the room is warm enough and try nice-smelling bubble bath or relaxing music.



**For more information see factsheet 504, Washing and bathing.**





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## Shaving

Helping someone to shave may be easier with an electric razor, as long as the noise does not frighten them.

## Dental care

It's important that a person's teeth and gums are cleaned every day, to keep them as healthy as possible. Poor oral health can lead to pain and tooth loss, and can worsen the person's self-esteem and their ability to eat, laugh and smile.

Try offering the person with dementia the brush with the toothpaste already on it. If the person wears dentures, they should be encouraged to wear them and offered help with putting them in as required.

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

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

## Dressing

When you're supporting the person to get dressed, try to make sure they are as comfortable as possible and have privacy. It's also a good idea to ask if they would like to use the toilet before getting 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 510, Dressing.**





## Managing toilet problems and incontinence

As dementia progresses some people find it harder to use the toilet and may experience accidents or incontinence. This could be urinary incontinence (urine leaking by accident), faecal incontinence (faeces leaking by accident) or both.

Incontinence and any accidents can be very distressing, both for the person with dementia and for you. However, toilet problems are common and there is support available. There are many possible reasons for incontinence, such as:

- medical problems – the person may have a urinary tract infection (UTI), prostate gland trouble, constipation, or other gut conditions such as irritable bowel syndrome
- not being able to react quickly enough to the sensation of needing to use the toilet
- not being able to do the things they need to when using the toilet, such as undoing clothing and personal hygiene.

Try to find out the reasons for the person's incontinence. This will help you to manage the situation and get any support you need.

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## Reducing accidents

There are lots of things you can do to try and reduce accidents. For example:

- put a sign on the toilet or bathroom door, with words and a picture, to help the person identify where the toilet is
- make it easier for the person to find their way to the toilet by removing any furniture that's in the way and keeping the route to the toilet well lit
- install hand rails and a raised toilet seat
- choose clothes with fastenings that the person can undo easily when using the toilet. You can find some on our online shop – go to [alzheimers.org.uk/shop](https://alzheimers.org.uk/shop)
- ask the person regularly whether they need to use the toilet and look for any signs they want to go to the toilet, 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 during the night
- put a contrasting coloured toilet seat (black, for example) on the toilet to make it easier to see.

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## Managing 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 of course be difficult – if you need support, talk to the GP, a community nurse or a continence adviser (a nurse with specialist training in managing incontinence).

The following tips may help you.

- Ensure good personal hygiene. If someone has become wet or soiled, they should wash afterwards with mild soap and warm water. They should then dry carefully before putting on clean clothes and fresh pads.
- When you're out with the person, find out where the accessible toilets are and carry spare clothing, wipes, and pads, as well as a bag for soiled items.
- You may want to buy a RADAR key so that the person can access disabled toilets. For more information see 'Radar Key Company' on page 160.
- The person may want to wear incontinence pads and pull-up pants, which draw fluids away from the skin. The person can wear these during the day and night, or night only.



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

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For advice and support call the National Dementia Helpline on **0300 222 1122**



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# 8

## End of life care and support

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## Dementia and the end of life

It can be very difficult to think of someone reaching the end of life. 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 might decide to come back to this section later on if you don't feel ready to look at it now. However, it's a good idea to read this information at some point and plan ahead for this time. If you have had conversations with the person about what they want at the end of their life it can help you to meet their needs and wishes when this time comes. For more information about planning for the end of life see section 3, 'Looking ahead: putting plans in place'.

Dementia is a life-limiting condition, but it's difficult to know exactly how long someone will live with dementia. If someone has another life-limiting condition (such as cancer) it can be easier to know how quickly their condition will get worse.

If someone is in the later stages of dementia, their symptoms will get worse over many months (although it may be less time for some people). This can be difficult for them and those around them to accept.



As they approach the end of life they will gradually:

- become more frail
- sleep more
- eat and talk less
- move less
- have more frequent falls or infections.

It may seem as if the person is close to death, but they may go on to live for many months. As they go through these changes you may be worried that they are in pain or distress – it's important that you have support with any worries like this. 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, and they shouldn't be in any pain or distress.

If you are concerned, speak to the professionals about the person's care and whether medication is appropriate. Healthcare professionals should let you know when the person is in this stage and that the person is close to the end of their life.



## Caring for someone at the end of life

Caring for a person with dementia at the end of life can be difficult and is likely to be very emotional. You may not be sure how to support the person, but there are a range of things you can do for them and yourself.

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

### Communication

As the person with dementia reaches this stage they are likely to have problems with verbal communication. They are more likely to use body language, gestures, sounds and facial expressions to express themselves and their needs. The following tips may help you communicate with the person at the end of life.

- Use non-verbal communication such as gestures, facial expressions, body language and touch (such as holding a hand) to communicate with the person.
- 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 connection to your voice.
- If you don't know what to talk about, use things the person finds interesting or from their past. Speak in a calm and reassuring way.

**‘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

## Physical care

As dementia progresses and the person reaches the end of life, they may be cared for somewhere other than their home. Even though the person may be in a care home, hospice or hospital, there are still things you can do to help with their care. Some of these are listed below.

- 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 wet cotton bud or similar to help the inside of the person's mouth stay clean and fresh.
- If you think the person might be in pain because of how they are reacting or their non-verbal communication, speak to a professional and explain your concerns.

Many of these may be mentioned in their advance care plan (see section 3, 'Looking ahead: putting plans in place').

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## Psychological, cultural, religious and spiritual needs

The person's psychological, cultural, religious and spiritual needs are an important part of their care, especially at the end of life. These include things like how the person is feeling and their beliefs. Your knowledge of the person can help to make sure that these needs are met and the person is comfortable.



It helps if their wishes and preferences are recorded in a care plan and advance statement (see page 56 for more information). You may also find it helpful to use our **This is me** form. See page 102.

The tips below can help.

- Where possible the person should be in a calm and familiar environment.
- Sensory stimulation through music, smells and touch can help them to feel engaged.
- You may want to talk to the professionals caring for the person about any cultural needs and wishes they have. For instance, they may have wishes about how soon they would like the funeral or whether they wish to be buried or cremated.
- 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.
- You should also take time to meet your own needs. This may include whether you want to be with the person when they're in their final moments.



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



## 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 go through 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
- changes to financial and legal documents and benefits. (It's a good idea to plan ahead for this. See section 3, 'Looking ahead: putting plans in place'.)

For more information contact Age UK or Citizens Advice or your local register office. (See 'Other useful organisations' on page 154).

## 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 find they feel these, and other emotions, very strongly whereas others feel they have no strong emotions left.

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



After the funeral you may need time to adjust to no longer being a 'carer', and to your daily routine no longer being based on caring for the person.

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 it. If you need more support or feel you are becoming depressed, speak to your GP or contact Cruse Bereavement Care (see page 155).

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

- it takes time to accept the person has died
- your feelings are overwhelming and you need time to deal with them
- the practical things take over and you don't have 'time' to grieve until things seem to calm down.

Some carers feel empty after the person dies as they come to terms with the change from their caring role and having to rebuild relationships. This can lead to feeling isolated and lonely. It can be very hard to adjust after caring for a person with dementia and it's important that you take time to address your needs and talk about how you're feeling.



Below are some suggestions for coping after the person has died.

- You may find it helpful to take some time to reflect on your situation. Allow yourself time to process what you've been through and don't rush any decisions.
- When you're grieving you may think you hear or see the person. This is normal after someone close has died.
- Keeping hold of items that belonged to the person may help you feel close to them – for example, a favourite jumper or ornament.
- Ask friends or family members for support or someone to talk to, if you need or want to.
- Don't neglect your spiritual and psychological needs. For example, some people find meditation or prayer helpful during bereavement.
- Stay in touch with your GP and look for specialist support services if you feel your grief is becoming overwhelming.



## Readjusting after bereavement

After bereavement, life won't just go back to how it was before. However, with time and support you will usually feel able to cope with life without the person. How long this takes will depend on the individual. The following suggestions may help.

- Talk about the person, if you feel you want to.
- Try to eat well and get enough rest.
- Allow yourself time and space to grieve.
- Don't compare yourself to others – your experience will be unique to you.
- Ask for help and support if you need it.
- Try doing things to stay involved and in touch with other people – you could take up a hobby, start work or volunteering, or join a sports club or music group, for example.

For more information about support from Alzheimer's Society and other organisations, see the following sections.



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

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For advice and support call the National Dementia Helpline on **0300 222 1122**



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# 9

## **Alzheimer's Society services and support**

## National services

Alzheimer's Society provides a range of services and resources to support people affected by dementia. These are available wherever you live in England, Wales and Northern Ireland.

### National Dementia Helpline – 0300 222 1122

The Alzheimer's Society National Dementia Helpline is for anyone who is affected by dementia or worried about their memory. Trained advisers provide information, support, guidance and signposting to other appropriate organisations.

The Helpline is open:

9am–8pm Monday–Wednesday

9am–5pm Thursday and Friday

10am–4pm Saturday and Sunday.

You can also contact the Helpline by email at

**[helpline@alzheimers.org.uk](mailto:helpline@alzheimers.org.uk)**

### Talking Point online community

Talking Point is our online community for people with dementia, their carers, family and friends. It's a place where people can ask questions, share experiences and get information and practical tips on living with dementia. Being connected with other people going through a similar experience means no one feels alone when living with dementia. Talking Point is available 24 hours a day.

Go to **[alzheimers.org.uk/talkingpoint](https://alzheimers.org.uk/talkingpoint)**

### Information

Alzheimer's Society produces a wide range of information for people with dementia, carers, family and friends.

You can read and order this information at

**[alzheimers.org.uk/publications](https://alzheimers.org.uk/publications)** or call **0300 303 5933**.



## Dementia Services Directory

The Dementia Services Directory is our comprehensive, easy to use online support services directory for anyone affected by dementia in England, Wales and Northern Ireland. Through a simple postcode or place name search, you can find voluntary, statutory and private care and support services that are close and relevant to you. Each listing includes clear, essential information about the support service on offer. Go to [alzheimers.org.uk/dementiaconnect](https://alzheimers.org.uk/dementiaconnect)

## Local services

Alzheimer's Society provides a range of local services in England, Wales and Northern Ireland.

Dementia advisers and dementia support workers provide personalised information, signposting, practical guidance and emotional support for people with dementia and their families.

Side by Side is an Alzheimer's Society service that links people with dementia to volunteers so they can keep doing the things they love. For more information go to [alzheimers.org.uk/sidebyside](https://alzheimers.org.uk/sidebyside)

Alzheimer's Society also supports groups such as Singing for the Brain®, peer support for people with dementia, and information and support groups for carers.

The services that are available can vary from place to place. Contact your local Alzheimer's Society office or the **National Dementia Helpline** on **0300 222 1122** for more information about Society services in your area, or visit [alzheimers.org.uk/dementiaconnect](https://alzheimers.org.uk/dementiaconnect)



# Other useful organisations

## **Age UK**

0800 055 6112 (advice line, 8am–7pm everyday)

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

## **Age Cymru (Wales)**

0800 022 3444 (advice line, 9am–5pm weekdays)

[www.ageuk.org.uk/cymru](http://www.ageuk.org.uk/cymru)

## **Age NI**

0808 808 7575 (8am–7pm everyday)

[www.ageuk.org.uk/northern-ireland](http://www.ageuk.org.uk/northern-ireland)

Age UK, Age Cymru and Age NI provide information and advice to help people know their rights and make the best choices for later life.

## **AT Dementia**

0115 748 4220

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

AT Dementia provides information on assistive technology that can help people with dementia live more independently.

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

0300 061 6161

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

The Care Quality Commission is the independent regulator of health and social care in England.



### **Care Inspectorate Wales**

0300 790 0126

[careinspectorate.wales](http://careinspectorate.wales)

Care Inspectorate Wales registers, inspects and takes action to improve the quality and safety of services for the wellbeing of the people of Wales.

### **Carers Trust**

0300 772 9600

[www.carers.org](http://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, 10am–4pm Monday and Tuesday)

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

Carers UK gives expert advice, information and support to carers.

### **Cruse Bereavement Care**

0808 808 1677 (helpline, 9.30am–5pm Monday and Friday,  
9.30am–8pm Tuesday–Thursday)

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

Cruse offers support, advice and information to children, young people and adults when someone dies and works to enhance society's care of bereaved people.



### **Dementia UK**

0800 888 6678 (9am–9pm Monday–Friday, 9am–5pm  
Saturday and Sunday)  
[www.dementiauk.org](http://www.dementiauk.org)

Dementia UK provides specialist dementia support for families through its Admiral Nurse service.

### **Disability and Carers Service (Northern Ireland)**

0800 587 0912 (9am–5pm Monday–Friday)

Contact the Disability and Carers Service if you are in Northern Ireland to enquire about Disability living allowance, Attendance allowance, Carer's allowance and Carer's credit.

### **Disabled Living Foundation (DLF)**

0300 999 0004 (helpline, 10am–4pm Monday–Friday)  
[www.dlf.org.uk](http://www.dlf.org.uk)

DLF provides impartial advice, information and training on equipment for independent living.

### **Driver and Vehicle Agency (DVA)**

0300 200 7861 (9am–5pm Monday–Friday)  
[www.nidirect.gov.uk/motoring](http://www.nidirect.gov.uk/motoring)

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



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

0300 790 6806 (for enquiries about medical conditions including dementia, 8am–5.30pm Monday–Friday, 8am–1pm Saturday)  
[www.dvla.gov.uk](http://www.dvla.gov.uk)

DVLA maintains the registration and licensing of drivers in Great Britain. Its responsibilities include recording driver endorsements, disqualifications and medical conditions.

### **FirstStop Advice (Elderly Accommodation Counsel)**

0800 377 7070 (advice line)  
[www.firststopadvice.org.uk](http://www.firststopadvice.org.uk)

FirstStop Advice is an independent, impartial and free service offering advice and information to older people, their families and carers about housing and care options in later life.

### **Housing Care (Elderly Accommodation Counsel)**

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

Housing Care is a charity run site providing advice on elderly care, including directories for all types of residential care and supported living across the UK.

### **Local Government and Social Care Ombudsman**

0300 061 0614 (8.30am–12 noon Monday, 8.30am–5pm Tuesday–Friday)  
[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.



For advice and support call the National Dementia Helpline on **0300 222 1122**

### **MedicAlert®**

01908 951 045 (9am–5pm Monday–Friday,  
9am–3pm Saturdays)  
[www.medicalert.org.uk](http://www.medicalert.org.uk)

MedicAlert® supports people with medical conditions and allergies.

### **Mind**

0300 123 3393 (infoline, 9am–6pm Monday–Friday)  
[www.mind.org.uk](http://www.mind.org.uk)

Mind provides advice and support to anyone experiencing a mental health problem. Mind campaigns to improve services, raise awareness and promote understanding.

### **NHS**

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

The UK's biggest health website 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 (9am–5pm Monday–Friday)  
[nipso.org.uk](http://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 Monday, Tuesday, Thursday and Friday, 10am–5pm Wednesday)  
[www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)

The OPG protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as about their health and finance.

### **Parkinson's UK**

0808 800 0303 (helpline, 9am–7pm weekdays, 10am–2pm Saturdays)  
[www.parkinsons.org.uk](http://www.parkinsons.org.uk)

Parkinson's UK provides information and support to help everyone living with Parkinson's.

### **Parliamentary and Health Service Ombudsman (England)**

0345 015 4033 (8.30am–5.30pm Monday–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  
[www.ombudsman.wales](http://www.ombudsman.wales)

The Public Services Ombudsman for Wales is an independent body whose role is to investigate and consider complaints where they have not been resolved locally.



### **RADAR Key Company**

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

UK manufacturer of RADAR keys, which allow people independent access to public toilets under the National Key Scheme.

### **Regulation and Quality Improvement Authority (RQIA) in Northern Ireland**

028 9536 1111

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

### **Revitalise**

0303 303 0145

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

Revitalise provides respite care in a holiday setting for disabled people and carers.

### **Shared Lives Plus**

0151 227 3499

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

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



**Solicitors for the Elderly (SFE)**

0844 567 6173

[sfe.legal](http://sfe.legal)

SFE is a national organisation of lawyers who specialise in helping older and vulnerable people.

**Tourism for All UK**

0845 124 9971

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

Tourism for All helps to make accessible tourism and travel in the UK better.

**YoungDementia UK**

01993 776 295 – (general enquiries)

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

YoungDementia UK offers help to people whose lives are affected by young-onset dementia.



For advice and support call the National  
Dementia Helpline on **0300 222 1122**

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For advice and support call the National  
Dementia Helpline on **0300 222 1122**

This booklet has been reviewed by health and social care professionals and people affected by dementia.

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

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First published: 2002.

Last reviewed: January 2019.

Next review due: January 2022.

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



**Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.**

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

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