



**Alzheimer  
Scotland**  
Action on Dementia

# Coping with dementia

Caring for someone in the mid  
to late stages of dementia





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Scotland**  
Action on Dementia

**Alzheimer Scotland is Scotland's national dementia charity. Our aim is to make sure nobody faces dementia alone. We provide support and information to people with dementia, their carers and families, we campaign for the rights of people with dementia and fund vital dementia research.**

We have Dementia Resource Centres right across Scotland. These Centres provide a safe and friendly environment for people with dementia and their carers to visit and take part in a wide variety of activity groups.

We are also very proud of our 24 hour Freephone Dementia Helpline which provides information and emotional support to people with dementia, carers, families, friends and professionals.

Our National Dementia Advisor Service provides a responsive, high quality information, advice and advocacy service relating to all aspects of brain health and dementia.

We also have a network of support for people living with and caring for someone with dementia in communities across Scotland. For more information on what's going on in your local area, contact our Helpline on **0808 808 3000**.



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## Hello and welcome

**If you are caring for someone with dementia, this guide is for you, and we hope it becomes a valuable resource.**

You may not think of yourself as a carer, particularly if the person with dementia is a partner, parent, or close friend. No matter what the relationship, caring for someone with dementia is rarely straightforward and it can be tricky to navigate the ups and downs, the good days and the bad. But, with the right support, it can be a positive, rewarding and often satisfying experience.

To help, we've pulled together some important information that we hope will be useful. When you're looking after someone else, it can be easy to overlook your own needs but taking care of yourself, physically and mentally, is one of the most important things you can do.

We have a range of further information on our website [www.alzscot.org](http://www.alzscot.org) or you can contact our Helpline or National Dementia Advisor Service.



### **24 hour Freephone Dementia Helpline**

Our 24 hour Freephone Dementia Helpline provides information, signposting and emotional support to people with dementia, their families, friends and professionals. Call **0808 808 3000** or email [helpline@alzscot.org](mailto:helpline@alzscot.org)

### **National Dementia Advisor Service**

Our National Dementia Advisor Service provides a responsive, high quality information, advice and advocacy service relating to all aspects of brain health and dementia. The service is available from 9am – 5pm, Monday to Friday, and can help with a wide range of issues such as accessing health and social care support, help with complaints, power of attorney, guardianship, and money and legal matters. You can call the service on **0300 373 5774** (charged at a local call rate), or email [NDAS@alzscot.org](mailto:NDAS@alzscot.org)

## What is dementia?

**It is estimated that around 90,000 people in Scotland have dementia. Dementia is a condition associated with the progressive loss of the powers of the brain.**

The most common type of dementia is Alzheimer's disease. Other kinds include vascular dementia, Lewy body dementia, frontotemporal dementias (including Pick's disease) and alcohol-related dementias such as Korsakoff's syndrome. It is also possible to have more than one type of dementia, for example Alzheimer's disease and vascular dementia. What all these diseases have in common is that they damage and kill brain cells, so that the brain cannot work as well as it should.

Everything we do is controlled by our brain. It analyses and makes sense of what we see and hear. It helps us to do things like think, move, taste, smell, speak and write. It contains all our memories and determines how we see ourselves in the world. When someone has dementia, some of the brain cells are damaged and dying. This affects how that person can remember, think, and act, and why it is more difficult to manage everyday activities. These changes can be gradual. Although it may become difficult to continue with some of the usual activities, it can be possible to rediscover other things to enjoy – for example painting, walking, or listening to music.

People can live well for many years with dementia, this will vary from person to person and will depend on many things, like the type of dementia and whether they have other health conditions. Every person with dementia will experience it differently and a lot can be done to help cope with the various symptoms.

### Is dementia inherited?

This is a complex question. Most forms of dementia are not inherited, although genetics can play a part. If you have a family history of dementia and would like further information you should discuss this with your GP or consultant.

### How dementia progresses

The progress of the illness varies a lot from one person to another. Some issues are more common early in the illness and others tend to happen later, but it can be variable, and people can live well with a diagnosis for many years.

It is possible for someone to have more than one type of dementia at the same time, and they will gradually need more and more support. Some of the issues you may have faced earlier on will no longer be a problem later in the illness. As time goes on, the person's whole personality may change a great deal, which can be hard to accept and understand.

Most people keep strong physically for a long time. In the later stages of the illness though, people with dementia can become very frail. In the very last stages, even the person's ability to resist simple infections is lost and, sadly, the illness is eventually fatal. However, as it is such a long-lasting illness, and because many people are older when it develops, often people with dementia die of completely unrelated causes.

## Rights for people with dementia and those who care for them

People with dementia and you, as their carer, have the same human and legal rights as every other citizen. It is important that this is recognised and respected. The PANEL principles represent underlying values that are of fundamental importance in applying a human rights-based approach in practice. These are:

**Participation:**

Everyone has the right to participate in decisions that affect them. Participation must be active, free, meaningful and give attention to issues of accessibility, including access to information in a form and a language which is understood

**Accountability:**

Requires effective monitoring of human rights standards as well as effective remedies for human rights breaches

**Non-discrimination and equality:**

A human rights-based approach means that all forms of discrimination in the realisation of rights must be prohibited, prevented, and eliminated

**Empowerment:**

You should understand your rights and be fully supported to participate in the development of policy and practices that affect your life and that of the life of the person you care for

**Legality:**

A human rights-based approach requires the recognition of rights as legally enforceable entitlements and is linked in to national and international human rights law. There are a wide range of legal provisions that are designed to provide rights and protection in Scotland, including a Charter of Rights for people with dementia and their carers. The charter is not law, but it explains your existing rights as set out in human rights law and other legal provisions

For more information, please see [www.alzscot.org/sites/default/files/images/0000/2678/Charter\\_of\\_Rights.pdf](http://www.alzscot.org/sites/default/files/images/0000/2678/Charter_of_Rights.pdf)

## Triangle of Care

The Triangle of Care guide provides a self-assessment tool for dementia services to ensure carers are identified, supported, and involved in the care and treatment of the person with dementia. It can be found on the Carers Trust website at <https://carers.org/> and has been endorsed by the Royal College of Nursing in Scotland. If you care for a person with dementia, you are entitled to an Adult Carer Support Plan (ACSP) or, for a young person, a Young Carers Statement (YCS). You do not need to provide a regular and substantial amount of care to get an ACSP or a YCS drawn up. This entitlement was introduced in April 2018 and replaces the old carer's assessments.

To find carer services near you visit

<https://carers.org/help-for-carers/carer-services-near-you> or call **0300 772 7701**

## Being involved

Along with the person you care for, you should be fully involved in decisions about their care and given as much choice as possible. Any services you are offered should meet the needs of the individual and be appropriate to their culture and lifestyle.

## Advocacy

People with dementia have a right to independent advocacy. This can help make sure their voices are heard and guide them, and you, through complicated health, financial and social service systems. Advocacy can be particularly useful if you don't have a wide support network of friends and family, if there are additional barriers to communication, such as speech or hearing difficulties or if the person you care for doesn't speak English as their first language.



The Scottish Independent Advocacy Alliance (SIAA) can provide information on advocacy, empowering people who need a stronger voice. Call them on **0131 510 9410** or visit [www.siaa.org.uk](http://www.siaa.org.uk)

## Caring for a person with dementia

**Caring for a person with dementia is unlike caring for someone with any other condition due to its complex, unpredictable, and progressive nature.**

One of the things you may find most difficult is managing your own feelings, especially if they are negative at times. It is very common, and not surprising, to experience sadness, guilt and fear.

You might be less prepared to feel frustrated, angry and at times, a bit resentful and experiencing these feelings can cause alarm. You may also experience a sense of loss that your loved one is no longer the same and relies on you more for support and care.

On the other hand, caring can also be very rewarding. For example, some people see it as a chance to return the care they were given as a child. It can bring a sense of accomplishment, personal growth and encourage greater family cohesion.



### **What you can do:**

It helps if you talk about your feelings rather than bottle them up. You may want to do this with a friend or family member, or you may prefer to talk things through with a professional, such as a social worker or community psychiatric nurse. If you are a young carer, it is important that you get as much help as possible.

Seek support from a carer service - there are several throughout Scotland that will be able to provide you with the help and advice you need. The Young Scottish Carers Services Alliance can be found by contacting Carers Trust Scotland on **0300 772 7701**. The Carers Trust can also help you find your nearest carer centre at **[www.carers.org/country/carers-trust-scotland](http://www.carers.org/country/carers-trust-scotland)**.

Call our 24 hour Freephone Dementia Helpline on **0808 808 3000**. Trained volunteers are here to offer emotional support and practical information, whenever you need it.



## Look after yourself

Sometimes you might feel as though you're being selfish if you take time for yourself to do some of the things you like and enjoy. Looking after yourself is not selfish, it's sensible. It's important that you take care of yourself, both physically and emotionally.

Family, friends, local home support services and day care centres can help. Ask for respite breaks to give you time away from your caring responsibilities. Have a think about what you find relaxing – try to make sure you take time every day, even if it's only a few minutes, to do something you find enjoyable.

As time goes on, you may feel less able to manage the demands placed upon you. There is help there to advise further, such as your GP or social worker, and there are other settings, such as residential care homes, that may be able to offer an enhanced level of care.



For more information, go to <https://publichealthscotland.scot/publications/steps-to-deal-with-stress-a-simple-guide-to-stressing-less-and-enjoying-life-more/> where you'll find helpful advice on how to deal with stress.

Breathing Space is a free, confidential service which provides support in times of difficulty. Call **0800 83 85 87** or visit [www.breathingspace.scot](http://www.breathingspace.scot)

NHS Living Life is a telephone service based on cognitive behavioural therapy. They provide help for low mood, mild to moderate depression and symptoms of anxiety. You can reach them on **0800 328 9655**.

The Samaritans helpline is available free on **116 123**.

## Alzheimer Scotland's National Dementia Carers Action Network (NDCAN)

NDCAN is a national, member led campaigning and awareness raising group of current and former dementia carers in Scotland. Formed in 2011, the group exists to make the voices of dementia carers heard and to raise awareness of the issues impacting on carers. It is open to anyone living in Scotland who has experience of caring for someone with dementia. Find out more at [www.alzscot.org/ndcan](http://www.alzscot.org/ndcan).

## You and your family

Looking after someone with dementia can trigger changes in wider family relationships. Children can experience feelings of embarrassment and if the person with dementia lives at home with you, they might not feel comfortable about bringing friends back to the house.



### Here are some tips about talking to family, friends, and especially children, about dementia:

- keep it simple and use everyday words and avoid jargon
- if something isn't understood, try to explain using different words and don't make light of their fears
- be clear that it's OK to ask questions and tell you how they feel
- try to arrange times when the person with dementia is involved with other activities - this might encourage children to invite friends over without feeling uncomfortable
- try not to let caring take over your life - ask for help to give you time off to spend with your family
- if disagreements occur over what is best, it might help to ask someone else to take part in discussions to make sure everyone gets a fair hearing

## Courses for carers

Although caring can be a full-time job, few carers get any training on how to do it - you may feel you're learning by trial and error. Alzheimer Scotland and other carers' organisations arrange courses for carers through their local services. These give you access to accurate information about dementia, the services available to help, financial and legal matters, and how to cope. Research has shown that carers with this sort of training may feel less stressed than others. Call our Helpline on **0808 808 3000** to find out about a course near you.

## Share the care

Looking after someone with dementia can be a round-the-clock job. You might feel that you're in control for now and that you don't need much help but getting to know a support worker earlier on might be more beneficial for the person you care for.

If you can, try to share caring with other members of the family and friends.

Often people don't get help because no one realises they need it, so it's important to ask. Family, friends and neighbours may be willing to help once you explain, and the person with dementia will enjoy having different company too.

# Money and legal matters

## Planning for the future

Often practical arrangements for the future are the last thing you and the person with dementia may want to think about, but it is important to make plans sooner rather than later. To make legal arrangements for the future, the person needs to be mentally capable of making decisions and legally able to sign documents. They should check with their doctor if they or their solicitor are not sure. If the person is still able, they should make important decisions as soon as possible. They should:

### **Choose one or more people (spouse, partner or carer) and grant them power of attorney (PoA).**

#### **There are three types of PoA:**

- 1** Continuing/Financial PoA which gives powers to deal with money and/or property
- 2** Welfare PoA which gives powers to make decisions around health and personal welfare matters
- 3** Combined PoA which gives both continuing and welfare powers

### **Make a will. There are three other documents someone diagnosed with dementia should consider completing. These are:**

- 1 A statement of wishes and values:** an informal document in which someone outlines issues of importance to them and how they would normally deal with them. It is intended to help attorneys and others make appropriate decisions once the person cannot make these themselves.
- 2 An Advance Statement:** this document states, in advance, what is important to the person. They state their preferences about the kind of care, support and treatment they want in the future - when they may not be able to communicate well enough. An Advance Statement can also be a formal document which has legal effect in our mental health law.
- 3 An Advance Directive:** this is a document (sometimes called a living will) in which someone states their treatment preferences in the last stages of their life. Typically, this will state a preference not to receive interventionist treatment when death is imminent.

All these documents are important, and their terms should be communicated to the appropriate parties, including medics and attorneys. Solicitors can prepare them and legal aid can often be obtained. Check with Scottish Legal Aid Board at [www.slab.org.uk](http://www.slab.org.uk) for solicitors in your area who provide legal aid.

The person you are caring for should be supported to consider their future medical care, and whether they have any specific wishes regarding that. These can be written down as an advance directive or living will and both their doctor and the attorney should get a copy. If the person has no bank account, encourage them to open one, while remembering that the bank will need to know about any powers of attorney.

## Everyday money matters

As time goes on, you might notice that the person you're caring for is less able to cope with money. They may lose their understanding of the value of money which can cause a great deal of worry. At this stage, you or someone else may have to take on more of the responsibility for managing the person's money.

### What you can do

- make sure the person always has some cash, even if it is a small amount – this may reassure them and help them keep some independence
- try to agree safeguards, such as making sure they don't have large amounts of money in the house or go outside with large sums of money
- if the person with dementia loses money, gives it away or forgets that they have spent it, they may mistakenly accuse others of taking it – reassure them that they have enough money



In some cases, people may seek to take advantage of someone who is vulnerable because of dementia. If you suspect that someone is stealing from them, you should involve the police and/or the Health and Social Care Partnership.

If you or someone else has a power of attorney for the person covering financial matters, make sure it is registered with the Public Guardian (see link on p.13). Once it is registered, you (or the person named as their attorney) can use it to manage the person's finances.

If you are concerned that someone is misusing the person's money, for example using a power of attorney, the Public Guardian can investigate. If the person has money in a joint bank or building society account, in most cases the other account holder can continue to use the account as usual.

If the person has money in an account in their sole name, and they are no longer able to manage it, you can apply to access the money yourself to spend it on their behalf (but you can't do this if someone has a financial power of attorney, or financial guardian, for the person). You don't need a solicitor to apply. You can get an application form for Authority to Access Funds from the Public Guardian. If you handle the person's money, always keep it separate from your own. Keep a record of what you receive and spend, in case someone asks you to account for it.

## More legal powers to help the person

In some cases, the court may have to give you extra powers to manage the person's affairs. This may happen especially when no one has power of attorney for the person, and he or she is no longer able to make one. Under the Adults with Incapacity Act, there are two ways the court can help. It can appoint a guardian, with financial or welfare powers or both, to look after the person's affairs. Or it can grant an intervention order, normally used for a one-off decision or short series of actions.

### What you can do

- go to [www.alzscot.org](http://www.alzscot.org) or phone our Helpline on **0808 808 3000**
- see a solicitor, who can apply for guardianship or an intervention order for you. Alternatively, you can apply to the court yourself. If you decide to do this, you can get more information and the forms you need from the Scottish Government Justice Department. The person you care for may be entitled to legal aid

The Office of the Public Guardian offers advice on power of attorney, including an indication of costs. Visit [www.publicguardian-scotland.gov.uk/power-of-attorney](http://www.publicguardian-scotland.gov.uk/power-of-attorney)

## Claiming benefits

Caring for a person with dementia at home can be costly. Financial benefits may be available, both for the person with dementia and for you as their carer.

The benefits system is complex and can be daunting. It's a good idea to get help from a benefits advisor who can give you advice about what you are entitled to. Most Health and Social Care Partnerships provide benefits and welfare rights advice.

If the person living with dementia is unable to navigate the benefits system without help, you can apply for the legal right to manage this on their behalf. This is known as becoming their 'appointee'. Find out more at

[www.mygov.scot/acting-on-behalf-of-someone-applying-for-benefits](http://www.mygov.scot/acting-on-behalf-of-someone-applying-for-benefits)

The Citizens Advice Bureau can also help you, visit the Citizens Advice Scotland website at [www.cas.org.uk](http://www.cas.org.uk) or call the Citizens Advice Direct helpline on **0800 028 1456**.

The Department for Work and Pensions (DWP) also offers support to people claiming benefits related to disability (including dementia) and you, as their carer. Visit [www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits) for more information.

## Practical caring

**Every person with dementia will be affected differently by the condition. As much as possible, support the person with dementia to keep doing things for themselves, rather than taking over. This can take patience, but it will help the person to maintain their skills and independence.**

### Physical wellbeing

It is important to make sure the person you're caring for stays as healthy as possible and a healthy diet and enough exercise are important. Problems with sight, hearing, infections or discomfort can make life harder and add to their confusion. It might be difficult for them to tell you if something is wrong so if you notice that they are more irritable or confused than normal, you should arrange for them to see their doctor.

#### What you can do

- try to make sure the person has enough to eat – ask for advice from a dietician or speech and language therapist if the person has swallowing difficulties.
- make sure they drink enough – aim for about six to eight glasses per day.
- physical activity is important and may also help the person sleep better – try to include some exercise every day, even if it is just a walk to the shops.
- if the person has difficulties walking or experiences falls, physiotherapists can help with advice to improve strength and balance.
- physiotherapists can also provide walking aids and can give you advice on the safest way to help the person move.
- if the person becomes ill, has a fall, or appears to be in pain or depressed, seek medical advice.
- if hallucinations develop then a GP should be consulted – delirium can be caused by physical illness so it's important to notice and listen to the person with dementia if they're feeling ill.
- if the person experiences significant unexplained weight loss over a period of 3-6 months, consult a doctor

Don't feel you have to cope on your own. Talk to the person's doctor, community psychiatric nurse or occupational therapist and to other carers. Or call our Helpline on **0808 808 3000** for support and advice.

Allied Health Professionals can help in a variety of ways to improve the quality of life for people who are living with dementia. For more information, visit [www.alzscot.org/ahpdementia](http://www.alzscot.org/ahpdementia)



### Mental stimulation

The person you're caring for will benefit greatly from having things to do – for interest, enjoyment and satisfaction, and to have a good quality of life. Staying as active as possible will help them maintain their abilities for as long as possible and encourage them to be independent. You can help by suggesting activities that you will enjoy together, though don't feel you must provide entertainment and something to do every minute of the day. There's help there to support with this – for example, a day centre can offer enjoyable and stimulating activities for the person, giving you some time for yourself.



### Life story book

This is a collection of reminders of important times in the person's life, such as old photographs, tickets or postcards. It can be enjoyable to make and benefit the person in lots of different ways. Many people can still remember a lot about their past even if their recent memory is poor so making a life story book, digital book or audiobook is an opportunity for them to talk about themselves and their life. It can also help family, friends and support staff learn more about the person and what's important to them. It's your chance to find out things about their life and record their past, so you will have something to remember.



### Spiritual wellbeing

Caring for someone with dementia means caring for their spiritual needs, too. If spirituality has been important to them throughout their life, it's important to help them maintain this otherwise they may feel abandoned, like they've lost their purpose. Try to help them attend religious worship for as long as possible. If this is impossible, perhaps they could continue to take part at home.



## Decline in memory

For mild memory problems and forgetfulness, simple memory aids may be helpful. Later, you will need to give more direct reminders and help. The person you're caring for may become more confused and disorientated – forgetting basic facts like who people are, where they are. At this stage, reassurance becomes very important. The person may be aware that their memory is failing which can be upsetting, frightening and frustrating. Try to respond to the emotions the person shows as well as what they say or do. The following ideas will help you cope – an approach known as 'reality orientation'. It means providing reminders to help the person along.

### What you can do

- keep to a routine as much as possible and try not to change where things are as changes can make confusion worse
- use memory aids - these work best when they are habit so introduce them early
- a large clock with the day and date and a loud tick can help or a tablet-sized digital clock that gives information about the date, and specifies 'morning' or 'afternoon' might help
- putting up a calendar and marking off days can be helpful
- signs on doors (using words or pictures) can help the person find their way around
- if you are not with the person, try reminding them about things by phoning or texting
- try to include basic facts in your conversation, such as times, places and people
- family photographs can help keep a sense of identity - talk about the photographs, especially if their sight is not good



## Repeated questions

Sometimes, people with dementia ask the same question over and over. This is because they don't remember asking or can't remember the answer. This can be difficult to deal with. They may seem afraid to let you out of their sight. This is because they may not be able to remember where you are or when you'll be back.



### What you can do

- keep reminding yourself that they are not doing it deliberately to annoy you
- try to be tactful, for example, it's better to say, 'oh, didn't I mention that we're going to the shops to buy bread and milk?'
- try to be reassuring as the person might be asking because they are worried about something – physical reassurance, like a hug, can be comforting
- try writing the answer to a question in a notebook or on a notice board, then point it out as you answer – if you do this repeatedly, they will get used to looking there for the answer
- remember that even with all your efforts, they may keep repeating questions and sometimes you might have to leave the room to keep your patience

## Conversation and communication

As dementia progresses, communication can become more difficult. Sometimes, it might seem that your loved one can't hear you. Deafness might be the problem – but it is also possible that the person hears you but doesn't understand. This is because dementia slows down people's ability to take things in and make sense of what they hear. Some may have difficulty finding the right words or be unable to understand certain words. They may also begin to lose track of what they're saying in the middle of a sentence. A referral to a speech and language therapist might help with this and it is also important to keep talking and reacting to the person in the same way as you have always done, even if they can't respond.

### What you can do

- make sure that the person's dentures, glasses or hearing aids are clean, in good working order and are the correct prescription – find out more about hearing loss at: <https://rnid.org.uk/>
- speak clearly and slowly but don't shout – make sure the person can see your face
- try using different words if you feel what you've said hasn't been understood
- try to get one idea across at a time
- try saying things slightly differently if you're not initially understood, or you might just need to repeat yourself
- use questions that ask for a simple answer. Instead of asking, 'what would you like to do this afternoon?', you could say, 'do you want to go for a walk, or shall we look at some photographs?'
- allow plenty of time for the person to take in what you say and to reply, and try not to embarrass them by correcting them bluntly
- if the person can't find the right words, ask them to describe what they mean
- a smile, touch or gesture can be just as important in getting the message across – holding the person's hand while you're talking can be very reassuring

## Confused thinking

As dementia progresses, the person's thinking may become more mixed up. They may confuse the past with the present, facts with imaginings. It can also cause difficulty with abstract thought, as well as memory problems – for example, they may find it trickier to pick up on emotions or humour and take things more literally.

### What you can do

- try a flexible approach, depending on the situation
- try diverting them onto another subject until they forget
- respond kindly to their feelings without agreeing to what they're saying

## Daily living

**People with dementia usually find everyday tasks such as dressing or eating harder as time goes on, so they need more help. Try to support the person with dementia to do things rather than doing them yourself. This can take more time, but it helps the person maintain their independence.**

### **Dressing, appearance and personal care**

People with dementia often have problems with dressing. They may lose track of the order of putting on clothes or forget halfway through and start to undress. They may struggle with fastenings and give up easily. The person may need help but not want it. For all these reasons, dressing can take a long time. Eventually, dementia may cause the person you're caring for to forget even the basic tasks of personal care, like brushing their teeth or hair. Some people may lose interest in how they look and may not like to be reminded about personal tasks. But it is important to encourage them to do as much as they can by themselves.

#### **What you can do**

- compliment the person when they look good
- remind the person about cleaning teeth, brushing hair or shaving
- show them what to do if they get mixed up
- keep up regular dental and hair appointments
- encourage men to get used to an electric shaver as early as possible



## Bathing and showering

It may be difficult to persuade the person with dementia to have a bath, especially if they believe they have recently taken one. Bathing can be problematic as people can sometimes forget how to wash themselves. It can also be difficult to provide such intimate care because the person may not like being supervised or, if you are caring for a parent, it can feel very uncomfortable. Try talking it through and reassure the person that you are there to help. It can help to make bath time as pleasant as possible, allowing plenty of time and ensuring the bathroom is warm. Little things like music or bubble bath might make the experience more relaxed. If bathing or showering is becoming problematic from a safety perspective, an occupational therapist may be able to help. Speak to the person's GP about arranging an assessment.

## Managing continence

Some people with dementia may experience urinary or faecal incontinence. Often the person may not be truly incontinent at all. They may have forgotten the way to the toilet, or they may not recognise the feeling of a full bladder. Establishing a regular toilet routine may be necessary. A physiotherapist can often work with the person with dementia if they have urge incontinence as a result of stress and they may be able to provide simple exercises to combat this.

Urinary incontinence may be the result of an infection or some physical problem. For instance, in men it may be caused by an enlarged prostate gland. Infections can be treated, and physical problems can often be put right. You should consult the person's doctor or community nurse if you are concerned.

Sadly, sometimes incontinence is because of the degree of brain failure in dementia. In this case, it cannot be cured and slowly gets worse. In the end the person may need changes of clothes throughout the day and bed-linen at night. Ask the doctor if there is a continence advisor in your area and ask about incontinence aids.

### What you can do

- watch for restlessness or agitation – signs that the person may need to go to the toilet
- take a very matter-of-fact approach and avoid making an issue out of it – remind the person to go to the toilet at regular intervals
- try putting a sign on the toilet door or leave the door open – also leaving a light on at night can help the person find their way
- use velcro if you feel zips or buttons are becoming too awkward to manage
- don't use laxatives unless prescribed by a doctor
- call our Helpline for an information sheet on urinary and faecal incontinence – the person is entitled to incontinence equipment if they have a medical need

## Eating and drinking

People with dementia may have a poor appetite, might seem to lose weight even when they are eating properly or become confused about whether they have eaten or not. Some may want to start on the next meal as soon as they finish one, lose their table manners or become messy in their habits. Some may experience dehydration if they aren't drinking enough fluids, or they may have difficulty swallowing which could stop them from eating properly. A speech and language therapist can help reduce this difficulty. Where possible, try to encourage the person to help with the preparation of food, especially if they have always enjoyed cooking. This can help them maintain an interest in food and take enjoyment in an activity.

### What you can do

- allow plenty of time for eating and try to make sure that mealtimes are relaxed and pleasant experiences
- make sure dentures fit well
- tell the person you care for what meal it is and what they will be eating
- try offering finger foods and snacks if the person is not eating meals
- try having the main meal in the middle of the day as this may help reduce night-time indigestion and discomfort and it may also help the person sleep better
- avoid using patterned plates - the colours of the food, plate and table should be different



## Psychological issues

People with dementia can at times seem to become bored and withdrawn. They may not seem able to keep an interest in anything for more than a few minutes. This can be upsetting if you are used to seeing them busy and happy. Sometimes they may be depressed which can be treated. If you think this is the case, seek medical advice. But even without depression, apathy is common in dementia.

### What you can do

- try to make sure that each day has something of interest - it might be going for a walk, listening to music, a game of cards or gardening
- involve the person with dementia as much as possible in choosing what to do
- help the person with dementia do whatever jobs around the house or garden they can manage as doing these tasks can help the person to feel useful
- try to get other people involved as a chat with friends, perhaps talking about the past, can help to raise the person's spirits

## Hallucinations and delusions

Some people with dementia may hear or see things that are not there (hallucinations). This is especially common for people with Lewy body dementia. Some may believe things that are not true (delusions).

More often, people with dementia may mistake what they hear or see for something else or confuse events. For example, someone may mistake a reflection in the window for someone in the room. In some cases, they may be upsetting or frightening, but in others the person may find them comforting.

### What you can do

- get help from the doctor as it may be caused by a treatable infection or the side effects of medication
- explain what is there and offer reassurance - it may just be a case of opening the curtains or turning a light on
- explain the situation to others, but bear in mind, if the person thinks someone is stealing, first check whether it is true - just because a person has dementia doesn't necessarily mean they are mistaken

## Depression and anxiety

People with dementia may suffer from anxiety or depression. They may seem agitated and keep asking the same questions, becoming depressed because their condition is making them feel isolated and unable to cope. The side effects of drug treatments, physical illness and tiredness can also have an impact. The symptoms of depression and dementia can be similar so it can be hard to distinguish. You might notice them becoming more withdrawn, not sleeping, lacking energy or interest, being more emotional or seeming sad.



### What you can do

- depression and anxiety can be treated, so it is important the person sees their doctor
- try to establish a routine as this can help people feel more secure
- try to alternate activities as some people will enjoy stimulating, social activities but others may find this overwhelming.
- doing things the person enjoys is worthwhile, even if they don't remember afterwards
- say positive things to the person you're caring for, as often as you can.
- try to do any important tasks at the beginning of the day when they're feeling their best

## Keeping connected

At times, you might find the behaviour of the person you care for difficult, but there are a few basic ideas that may help. No solution will work for everyone, but you could try different things until you find what works best for you. Over the next couple of pages, we cover some of the common difficulties faced by people with dementia and their carers, and some possible solutions.

## Walking about

You're not alone if you worry about your loved one walking about. This behaviour is often referred to as wandering, but this term is unhelpful because it suggests aimlessness, whereas walking about often does have a purpose.

Before you start worrying, ask yourself if there is really a problem. If the person goes out, do they find their way home again? Are they able to cross the road safely? Perhaps walking around the house is no problem but going outdoors is a worry. It is important to give the person as much freedom as reasonably possible, even the freedom to take a risk sometimes. If this a concern for you, why not call our Helpline for more information and advice on **0808 808 3000** or visit [www.pathsforall.org.uk/pfa-home](http://www.pathsforall.org.uk/pfa-home).

### What you can do

- don't try to prevent walking about if there is no real risk
- keep a current photograph in case the person gets lost
- be aware of door locks and bolts - locking the door when the person is home alone could make them panic and be dangerous in an emergency
- if they are never alone, a bolt at the bottom of the outside door could stop them going out by themselves
- give the person identification, such as a card, bracelet or pendant showing their name and a contact number - for security reasons, don't include their address
- if the person becomes lost, contact the police immediately
- make sure they are comfortable and warm at night and reassure them.
- try to make the house as safe as possible and enquire about equipment and services, for example GPS technology, adult stair gates and gas shut-off valves

## Needing attention

You might find that the person you care for wants to be with you all the time. They may follow you from room to room and become very distressed if you ever must go out.

### What you can do

- offer plenty of reassurance - it's likely the person is feeling insecure and anxious
- remember that your wellbeing is important too and you will find it easier to cope if you take some time off
- ask family and friends to spend time with the person to give you a break.
- consider enlisting the support of a day care or home support service so that you can have some time to yourself



## Shouting

You may notice that the person with dementia begins to display out-of-character behaviour, like raising their voice or using abusive and hurtful language. This could come as quite a shock – but there are a variety of reasons why it could be happening. Perhaps they are in pain, trying to communicate a feeling or they could be struggling to find the words to tell you something. If this happens, try to keep calm and don't take it personally. If you are concerned, speak to your doctor about what might be causing the problem. It might also be worthwhile getting the person's hearing and sight checked.

## Losing inhibitions

Sometimes, you might become embarrassed by the way the person with dementia is behaving. This could include socially or sexually inappropriate behaviour in public or shouting at visitors. This loss of inhibitions can be caused by different things. For some, it may be the effect of dementia (specific to frontotemporal dementia), they may need to go to the toilet or be too hot, or they could be feeling anxious or frustrated.

### What you can do

- remember that the person doesn't realise that what they are doing is inappropriate and if you explain to people who are there, they will usually understand
- try to deal with the situation as calmly as possible, don't overreact
- if the person tends to lose or hide things, put items in a secure place – it may be a good idea to remove keys from drawers and cupboards

## Sex and intimacy

If you are caring for your partner, you might notice that their attitude to sexual relationships may change. You might want to continue with a sexual relationship but worry if you should. You can usually tell from your partner's behaviour if they also want to, or not.

Any changes to do with sexual behaviour can be confusing and hard to accept, and it can sometimes be a difficult subject to talk about. If you do feel that you need to talk things through with someone, contact a professional you trust. Or you can call our Helpline confidentially and anonymously on **0808 808 3000** for a free information sheet about sexuality and dementia.

### What you can do

- try to remember that the person's attitude to sex and intimacy, and their behaviour, may change because of dementia
- if you need to get things off your chest, have a question or would like information, get in touch with someone you trust or call our Helpline on **0808 808 3000**
- if you can, give the person plenty of physical contact, such as hugs and cuddles

## In the home

As dementia progresses, it may be more difficult for the person with dementia to move around the home, or they may become confused with the layout of the house, which may lead to walking about. Try not to worry, simple changes and alterations to the home may help this.

### For example:

- a downstairs bedroom and bathroom, a wet room, or a ramp instead of steps outside can help with mobility and balance
- clear pictorial signs on doors to the kitchen or toilet may help with navigation
- contrasting tones for areas like door frames, doors and walls, or walls and carpets will help to reduce confusion
- use contrast of colour or tone to make wall switches clear
- reduce clutter on surfaces and leave only essential items on worktops
- repair loose bannister rails and ragged carpet edges and remove rugs so there's less risk of slips and trips
- rearrange furniture and fit electric night lights so there's no risk of bumping into things at night
- install extra lights and stronger bulbs, especially on steps and stairs

The Dementia Services Development Centre (DSDC) at Stirling University has online resources for suggestions on how to create dementia-friendly homes. Visit [www.dementia.stir.ac.uk](http://www.dementia.stir.ac.uk) or ask an occupational therapist for advice.

## Risks and hazards

Dementia increases the chance of accidents, and it can be hard for you to know how far to go when trying to protect your loved one from possible risks. It's worth taking a few simple steps but you can't remove all dangers. If you don't live with the person you care for, safety can be a particular worry. Try to assess what the real risks are. Observe what the person can and can't do, for example can they light a gas hob safely? If there is a burning pan, do they react appropriately? Ask an occupational therapist for help if you are worried.



### What you can do

- check for risks and make repairs as needed.
- fit smoke and gas safety alarms, letting neighbours know this has been done
- make sure lights are bright enough and fit electric night lights
- use fire guards - the large 'nursery' type is best, hooked onto the wall or fireplace
- keep work surfaces clear and make sure bleach, paints and so on are out of reach
- check that the person can use heaters and cookers safely
- get gas appliances checked for leaks - most energy suppliers have a Home Energy Care free Gas Safety Check for people who are disabled or over 60 and living alone or with other people over 60.
- ask an occupational therapist about safety and new technology

## Driving

In general, people with moderate to severe dementia will not be able to continue to drive. If you are not sure if the person is safe to drive, their doctor can refer them to the Scottish Driving Assessment Service to check. You must tell the insurance company and the DVLA about a diagnosis of dementia. Not doing so may invalidate their insurance cover. Driving without insurance is a criminal offence. If a doctor advises against driving for a period of three months or more then the person must surrender their driving licence. If the person is not safe to drive, discuss it with them – they may be ready to give up. It is a difficult issue but don't wait until there is an accident. If you can't persuade them to stop, contact the DVLA.



### What you can do

- encourage the person to get used to other transport, such as buses and trains
  - raise the subject of driving tactfully and point out the benefits of not having a car, for example, walking more and no longer paying for insurance and MOTs
  - if the person does not want to stop driving, ask other carers how they handled the problem
  - the person may find it easier to accept that they must stop driving if someone in authority says so – ask the doctor or the police to help
  - make other arrangements for transport. Some groups, such as the Royal Voluntary Service, may be able to help or visit
- [www.royalvoluntaryservice.org.uk/our-services/getting-out-about/](http://www.royalvoluntaryservice.org.uk/our-services/getting-out-about/)**
- check with the Health and Social Care Partnership, as some have taxi schemes for people with disabilities
  - some taxi firms allow journeys to be paid on account, which can be very useful for independence



### Smoking and alcohol

Having a diagnosis of dementia doesn't mean that the person you care for can't enjoy an alcoholic drink, if they're sensible about it and don't have a condition that is affected by alcohol, such as Korsakoff's syndrome. It is very important that they check with their doctor first though, as some medication can have a negative reaction when mixed with alcohol. Also, remember that alcohol can cause slight loss of mental alertness and for a person with dementia, this could have greater impact. It could increase confusion so some care and supervision may be required.

Smoking damages health generally and adds to the risk of stroke, and people with vascular dementia are at even greater risk. Try to encourage the person to give up – there is plenty of support to help, just ask your community psychiatric nurse for advice or visit [www.nhs.uk/live-well](http://www.nhs.uk/live-well)

#### What you can do

- try to persuade the person with dementia to stop smoking – many people with dementia forget to smoke and then do not miss the habit once it's broken
- keep matches out of reach
- put big ashtrays everywhere
- make sure they do not abandon lit cigarettes or throw them away in wastepaper baskets
- stop the person from smoking in bed if you can
- fit smoke alarms
- bear in mind that a heat detector might be more suitable in the bedroom, if there is a risk that the person may smoke in bed, because it goes off sooner if there is a fire
- ask the doctor whether the person should drink alcohol or not
- don't leave alcohol where the person can drink unsupervised

## Getting help

**Dementia not only affects the person with the illness. You will know that it affects family and friends too. Caring for someone with dementia can impact your social life, work, leisure time, financial situation and family relationships. There are many services that can support you and the person you look after.**

### **The right to support after diagnosis**

The Scottish Government has set out a commitment that everyone diagnosed with dementia from 1 April 2013 will get individual support from a named and trained person – a link worker – for at least one year after diagnosis.

#### **This person's role is to help the person with dementia and carers to:**

- understand the type of dementia, come to terms with the diagnosis and manage any symptoms
- stay connected to community and social networks
- get support from other people with dementia, their families and carers
- plan for future care and support, to make sure it's shaped around individual preferences
- put in place arrangements for future decision-making, such as powers of attorney or advance statements
- develop a personal plan, based on individual wishes, goals, and expectations – this should be complete by the end of the year

People who are newly diagnosed will be allocated a link worker and they will help you navigate through the range of services available. If it has been some time since the person you care for has been diagnosed, this type of support may not be available or appropriate. Ask your doctor, your local Health and Social Care Partnership or contact our Helpline on **0808 808 3000** for information about other services in your area. The local Health and Social Care Partnership is the main route to getting support services in your own home or through services near where you live. It's worth contacting them as soon as possible, either directly, or through your GP or local voluntary organisations, even if you don't feel you need any help just yet.

A social worker can carry out an assessment on the person you are caring for and discuss any questions you may have. They can then advise on what local support might suit you and your family best. They may also be able to help you access welfare benefits and other financial support.

As well as an assessment of the person you are caring for, you can also receive an Adult Carer Support Plan or Young Carer Statement, if you provide substantial and regular unpaid care. This can help you to explore what care you are able to provide and what support you may need.

You can also get help from Alzheimer Scotland and your local carer centre, which provide services all over Scotland, including support groups, carer education, welfare rights advice and one-to-one support.

For more information, visit:

**[www.alzscot.org/pds](http://www.alzscot.org/pds)**

## Help for carers

You can request an assessment of your own needs if you're providing care to someone with dementia.

### You may find it useful to plan:

- what help you could use - it might be beneficial to make a list
- what problems face you and the person you care for?
- what do you want to know?
- what do you and the person with dementia need for practical help and emotional support?

## Help at home

Home care services are available to help you care for your loved one in their own home. For example, help might be available to prepare a meal, get dressed or go out for a walk. This could give you a few hours without worry. Home care services can also help people who live alone to do so as independently as possible, for as long as possible. In some areas, overnight services may be available to enable you get a good night's sleep. If you feel you would benefit from this type of support, ask your local Health and Social Care Partnership or call our Helpline on **0808 808 3000**. Some voluntary organisations provide home support or 'sitter' services with trained care assistants to help look after people with dementia. They can provide stimulating activities or even take them on outings. Private nursing or care agencies can provide care assistants or nurses day or night.



## Support at appointments

You may feel that you would like some emotional or professional support when you go to appointments, as they can be overwhelming. If English is not your first language, or if you are deaf or hearing impaired, you may find it useful to arrange to have an interpreter with you. It is important to contact local minority ethnic or deaf community support groups within your area as they may also be able to refer you to other suitable support.

## Day centres

Day centres offer people with dementia a chance to socialise and enjoy stimulating activities. As well as being beneficial for them, this will also give you some valuable time off. Some of these centres are run by local Health and Social Care Partnerships. Alzheimer Scotland has Centres across Scotland offering friendly, accessible environments. Our Centres offer information, advice and support and are a base for a range of groups and activities.

For more information, visit: [www.alzscot.org/drc](http://www.alzscot.org/drc)

## Short breaks

Both you and the person with dementia may enjoy a holiday, either together or separately. Shared Care Scotland can also provide information and support in this area. Call **01383 622462** or visit [www.sharedcarescotland.org.uk](http://www.sharedcarescotland.org.uk).

Everyone needs time off sometimes. Caring for someone with dementia can be tiring and often stressful. A short break, when the person with dementia goes into short term respite care, or sometimes a hospital, will give you the chance to recharge your batteries. Perhaps you might take a holiday, or maybe just have some time for yourself at home. Don't feel you have to visit the person – this is a time to give yourself a break – ask family if they can visit during this time. In some areas, social workers or health professionals can arrange a programme of regular respite breaks for you.

When the person is on their short break, it might be useful to put familiar items in their room and share their life story book with the staff. It may also be useful to complete and bring along a document called 'Getting to Know Me', which is available from Alzheimer Scotland. This lets staff know their likes and dislikes, as well as a little bit about them, to help them settle in better. The Care Inspectorate offers more information about selecting a care home for respite. For more details, visit

[www.careinspectorate.com/index.php](http://www.careinspectorate.com/index.php)

### There are three routes to respite

- 1** Respite through the Health and Social Care Partnership: If you are assessed as needing respite, the social worker or care manager should arrange a place in a care home for the person. If you haven't been assessed as needing respite, but you need a break, call Health and Social Care Partnership and ask for a new assessment.
- 2** Respite through the health service: In some areas, a GP or hospital specialist can arrange a respite place in hospital. There is no charge for this.
- 3** Private respite: If you arrange respite in a care home privately, you will have to pay the home's fees. Make sure the home you choose is suitable. Visit, preferably with the person you care for, talk to the staff and, if you can, talk to residents and their relatives.



### Meals services

Meals on Wheels and other similar services can provide hot meals or, in some areas, frozen meals, delivered to the person's house. You can ask your Health and Social Care Partnership about this service.

### Laundry service

Some areas have a laundry service for people who have extra washing because of continence problems. Ask your social worker or community nurse for advice.

### If the person does not want the service

You might find that the person you're caring for isn't keen to accept a service for several reasons. Perhaps they think they can cope and don't need help or maybe they're reluctant to have a stranger in the house. They may have negative ideas about day centres or fear being taken away from home. Often this is more problematic earlier on when the person may feel that their independence is being taken away. This may change later and even when someone is initially unwilling, they are quite likely to enjoy and benefit from it once they start – so it's worth persisting.

### Free personal care

Free personal and/or nursing care is available to all adults in Scotland who have been assessed by the local authority as eligible for these services. Personal care includes help with dressing, eating, washing, going to the toilet, simple treatments (such as eye drops), staying safe and support (such as reminders).

### Charges for care services

Whether or not the person gets free personal care, they may still have to pay for some services, such as day care, lunch clubs, Meals on Wheels, community alarms, help with shopping and housework or respite breaks. The amount depends on the income and individual circumstances of the person with dementia.

### Support services from your Health and Social Care Partnership

Depending on how much support your loved one needs, they may be eligible for support from your Health and Social Care Partnership. If they are assessed as needing 'community care services', they (and you) should expect to have some choice over how they receive that support. If you have power of attorney, then you will be able to have your say. If you want, you can ask your social worker or care manager to organise this. You can also help to direct support on behalf of, and with, the person you care for if you have power of attorney. This means you can ensure that they live as independently as possible for as long as possible.



### Directing your own support

Self-directed support is about people making informed choices about their support and having as much control over it as they want. It offers flexibility so they can use their support in the ways, and at the times, that suit them.

#### The Health and Social Care Partnership must offer four options:

- 1** The Health and Social Care Partnership gives you funds to organise and pay for the support of your choice. This is called a Direct Payment.
- 2** The Health and Social Care Partnership or a service provider handles the money but you decide what it is used for.
- 3** You allow the Health and Social Care Partnership to arrange your support.
- 4** Any combination of options **1, 2** or **3**.

### Individual service funds

With an individual service fund, the council tells the person with dementia or you, as their carer, how much money they have for their support. It is then possible to choose who they want to provide the support and when, but they don't have to manage the money. If either a direct payment or individual service fund is chosen, then the funds must be used to meet the care needs, but it is possible to be quite creative about how this is done. For example, some people have used the money for computer software or equipment to keep connected with others, or to pay for support to help them go away on holiday with their family rather than having respite in a care home. For a direct payment or individual service fund, the person with dementia needs to be able to make choices and decisions either on their own or with assistance from other people. If you are appointed power of attorney, you can help the person manage things – but it's important that they are still free to say how they want their funding spent (if this is in line with their assessed needs).

## Health services for people with dementia

### Seeing the doctor

If you are concerned about the health (physical or mental) of the person you care for, you can talk to their family doctor or GP. Early in the condition, the doctor may not be able to tell you about the person's health without their permission because of confidentiality, but your information will help the doctor, especially when the person does not have a clear idea of their own problems. If you have welfare power of attorney you may have the power to access their medical records or make decisions on their behalf about medical treatment.

If you have a lot to discuss, ask for a double appointment or a time at the end of a surgery so that you don't feel rushed. Standard health checks (such as blood pressure, cholesterol, eye tests and dental check-ups) can help them keep fit and well, and better able to cope with symptoms. Discuss with the person beforehand if they'd like you to be with them when they see the doctor.

### Day hospital

The person with dementia may be offered a place at a day hospital to be medically assessed. This may offer services such as occupational therapy assessment, nursing assessment, physiotherapy, bathing or podiatry (chiropody). The person with dementia will be able to take part in stimulating activities but day hospitals do not usually offer longer-term support.

### Assessment units

The doctor may arrange for the person to go into an assessment unit in the hospital. They can be given special diagnostic tests if necessary or the unit may try to help with a particularly troubling problem, such as hallucinations or aggression.

If you are not satisfied with the GP or hospital service, every part of the NHS has a complaints procedure.

### Admission to hospital

If the person you care for needs to go into hospital, either for planned treatment or in an emergency, it can be a confusing and distressing experience. If hospital staff are to provide good person-centred care, it's important that they know as much as possible about the person, including any routines or unusual behaviours the person might have. Alzheimer Scotland and the Scottish Government have developed a document called 'Getting to Know Me', which the person with dementia or you can fill in or be helped by hospital staff to complete. This provides a snapshot of the individual, such as their specific needs, preferences, likes, dislikes, background and interests or even what they prefer to be called. The form is then kept with their hospital notes during their stay so that staff can consult it at any time.

## Care homes

### The decision

Eventually, you may not be able to go on looking after the person with dementia at home. Perhaps they have become so ill they need a team of people to care for them, or perhaps your own health has changed. Not everyone can be a carer and not everyone can go on caring as long as they wish they could. It is important to understand and accept what you can and can't do. Many people with dementia will need to move into a care home in the later stages of their illness. Try not to take this difficult decision on your own. Involve the person as much as you can and consider any wishes expressed in the past, but remember that things change, and sometimes it may be in the person's best interest to move into a home, even if that isn't what they or you would have hoped for. Involve other family members too if you can. But if they disagree, remember that as the carer, you know the person and the situation best. Professionals, such as the social worker, doctor, nurse or staff at services the person uses, can help you. It may also help to talk to other carers who have had to decide about a care home. For further information on care homes call our Helpline on **0808 808 3000**.

### Coping with your feelings

You may find it hard to accept that you can no longer offer the care your loved one needs. You might feel guilty or worry that others will disapprove. You might feel a bit lost, not only will you miss the person with dementia, but you'll also now have a lot more spare time. It's hard to avoid these feelings so it might be beneficial to talk to friends and family if you're experiencing them, or to call our Dementia Helpline. In time you will probably realise that your decision is for the best. It can be a comfort to see

the person settle in and enjoy your visits. Although the home will cope with the day-to-day caring, you can still be involved. Taking the person out for a walk, a trip out in the car or a day at home may still be possible. You may also be able to help with personal care, or at mealtimes, if you want to.

### Moving to a care home

The best way to arrange the move to a care home is to ask your local Health and Social Care Partnership for a community care assessment. This will make sure the person gets the right kind of care to meet their needs. An assessment is essential for the person to be able to get the free personal or nursing care allowance towards the care home fees (see p.37 for more information). It is also important for the person to have an assessment to find out whether he or she needs help paying the fees now or might need help in the future.

You also have the right to an assessment of your own needs, which then forms an Adult Carer Support Plan or Young Carer Statement. This will look at how you are coping, and how able you are to go on caring. To do the assessments, a social worker, care manager or another professional will talk to you and to others involved in the person's care. The assessment may show that moving into a care home is the best option for the person. Or sometimes it may be that there are other services which could help the person cope at home for longer. If the person is assessed as needing long-stay care, the social work department can arrange it, or you can choose to arrange it yourself. The Health and Social Care Partnership can also help you to find a care home place even if you plan to fund it from the person's own money.

## Choosing a home

Most people with dementia who need long-stay care will move into a care home. Care homes may be run by private companies, the Health and Social Care Partnership or voluntary organisations. All care homes must meet National Care Standards and all in Scotland are registered and inspected by the Care Inspectorate. The Care Inspectorate can give you a list of homes in any area and copies of inspection reports for homes you are considering. For more information, visit [www.careinspectorate.com](http://www.careinspectorate.com)

The Health and Social Care Partnership has a maximum amount they will normally pay for home fees. They should offer the person a place in a home that is suitable and equal to or below this maximum. Or they may provide a list of homes for you to choose from. If you can, visit several homes before you decide on which would best suit the person with dementia. Perhaps you and the person can visit together. You can also choose a different home, anywhere in the UK, if it is suitable for the person's needs and doesn't cost more than the Health and Social Care Partnership normally pays. Or, if it costs more, you or someone else can agree to pay the extra, bearing in mind that, if you stop paying for any reason, the person may have to move. It is important to keep the Health and Social Care Partnership informed if you plan on choosing a care home in a different area from where the person usually lives, particularly if you are expecting the person to receive the free personal and nursing care allowance. It may be helpful to involve an independent advocate when you are making these decisions. Call our National Dementia Advisor Service on **0300 373 5774** or the Scottish Independent Advocacy Alliance **0131 510 9410** to find out about advocacy services near you. A few people with dementia who have very complex needs may need hospital-based complex care. This decision is up to the person's hospital consultant.

## Paying the care home fees

### Free personal care

In Scotland, anyone assessed as needing care in a care home and is paying some or all of the fees, is entitled to free personal care. If they are assessed as needing nursing care, they are also entitled to a payment towards nursing care costs. These payments are financial contributions paid by the Health and Social Care Partnership towards the care home costs. They pay the allowance for the personal/nursing care directly to the home. The person then pays the rest of the fees which might include the remaining costs of personal and nursing care, food, accommodation and so on.



### Other help towards the fees

Care home fees can be costly. The Health and Social Care Partnership will carry out a financial assessment to work out how much financial assistance is needed to pay the care home fees. They will look at the person's income and capital. Income and capital are either considered in full, partially disregarded or fully disregarded. Financial assessment is used to work out how much contribution the person will pay towards the care home fees. No one should be left with less than a weekly personal expense allowance which is set each year by the Scottish Government. If the person's income is not enough to pay the full fees, the Health and Social Care Partnership may help to pay the amount over their income. If the person has savings or property worth more than the 'upper limit', they will have to pay the home fees themselves from their savings until the savings reach the 'lower limit'. Between these upper and lower limits, a 'tariff income' is calculated and is added to the person's assessed income to decide the level of contribution. If they have an amount between the upper limit and the lower limit, they may still be entitled to financial help, over and above any free personal and nursing care payments. If they have less than the lower limit, the social work department will pay, up to their maximum amount. Only the income and capital of the person moving to the care home should be considered when calculating any financial contribution towards care home fees (a carer's capital or income is excluded from the financial consideration). More information on care funding can be found at <https://www.agescotland.org.uk/information-advice/information-guides/care-support>

### The house

If the person owns a house, the Health and Social Care Partnership will normally count it as part of their capital if they move into a care home permanently. They can count its value, less any mortgage and less 10% of the house's value to cover selling costs. They must ignore the value of the house for the first 12 weeks of the person's stay in the care home. However, the value of the house must be completely ignored if one of the following people still lives there:

- the person's husband or wife, or civil partner
- a relative who is 60 or over
- a relative who is disabled or incapacitated

The Health and Social Care Partnership can also decide to ignore the value of the house if someone else still lives there, such as a carer or a same-sex partner. Seek advice from our National Dementia Advisor Service or a solicitor if you live with the person with dementia and the Health and Social Care Partnership say they will take the house into account. For any householders, making plans to cover care costs and how to mitigate their effects is very important. For example, it is not always necessary for houses to be sold to pay for care costs, although many families make that decision automatically. Taking professional advice well before care is considered can be very helpful. The financial assessment process is complex, and it is a good idea to get expert advice. If you disagree with the outcome of a financial assessment, you may be able to challenge the decision.

### The move and after

Spending time planning before the person moves can help to make it easier for both of you. You will have to cope with practical issues, as well as with the emotional effect of the change on the person with dementia and on you. Talk to the staff at the home about how to manage the move. The person may find it easier to settle in if there are familiar things in their room, such as some of their own furniture and ornaments. If possible, involve them – help them to choose what they would like to take. Some people with dementia settle in quickly but others may take longer to adjust. Some people find it better not to visit at first, to give the person a chance to settle in – ask the home staff for advice. Ask them how the person is when you are not there – perhaps the visits, while important, are a reminder for them of the change in their life. Give the person lots of reassurance. The home will put together a care plan and you can give them important information about their needs, their likes and dislikes. If they have a life story book make sure they take it to the home with them, so that staff can learn about their life.

### If you are not satisfied with the care home

If you are not satisfied with the person's care at the home, you can make a complaint. All care homes must have a complaints policy and should give you information about it if you ask. First, speak or write to the person in charge of the home. If you are still not satisfied, you can talk to the Health and Social Care Partnership if they arranged the place in the home. Or you can contact the Care Inspectorate.

### Loss and bereavement

You might feel a great sense of loss when the person is admitted to long-stay care. Even when it is obvious that the person needs to move, you may feel guilty about handing over much of the task of caring. Getting used to not being responsible for day-to-day caring can be hard. It may leave a big gap in your life. Talking about this with other carers can help, for example at a carers' support group. Even if you haven't been to a support group before, now might be a good time to join one. When the person with dementia dies, it is normal to feel a mixed range of emotions. Everyone is different and each person reacts to bereavement differently. Some people feel less sad than they feel they 'should', because they have already experienced anticipatory grief. These feelings are quite normal.

It takes time, of course, to come to terms with bereavement. At first most of your memories of the person with dementia may be about the years of the illness. This is when you may appreciate the help of family, friends and other carers. They can help you come to terms with your feelings. Cruse Bereavement Care can help with bereavement counselling. Contact them at [www.cruse.org.uk](http://www.cruse.org.uk)

You may find that feelings of stress and emotional upset stay for quite some time, but eventually you will begin to remember the person before the illness.

## Contact us

We hope you have found this guide useful but if you have any questions or need further advice, you can:

Visit our website at [www.alzscot.org](http://www.alzscot.org)

Call our 24 hour Freephone Dementia Helpline on **0808 808 3000** or email [helpline@alzscot.org](mailto:helpline@alzscot.org)

Or for general enquiries email us at [info@alzscot.org](mailto:info@alzscot.org)

Find us on social [@alzscot](https://www.instagram.com/alzscot)

