

coping with

# dementia

Caring for someone  
in the mid to late  
stages of dementia



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# Introduction

This publication is for you if you care for someone in the **middle to late** stages of dementia.

This publication has been developed in consultation with other carers of people with dementia. They have suggested that you may want to dip in and out of this information, rather than reading it all at once. There are helpful tips and signposts to more advice throughout the book. You may also wish to sit and discuss the information within this booklet with your community psychiatric nurse, dementia link worker or carer support worker. Some of the chapters will cover information that you may not need at your particular stage in the dementia journey. Everyone's experience of dementia is individual and not everyone will experience everything covered in the booklet. There are also tips from other carers about how to live well and look after yourself as a carer.

This book contains information and advice for people who care for someone in the middle to late stages of dementia (**moderate to severe dementia**). It:

- gives you practical advice on caring for someone with a diagnosis of dementia
- provides tips from other carers about how to live well as a carer
- highlights where to go for help and for more information.

The DVD *Coping with dementia – a practical DVD for carers* is also available at the back of this publication.

If you are supporting someone with mild dementia or a recent diagnosis, or if you have had a recent diagnosis yourself, *Living well with dementia* and the accompanying DVD or *Younger people with dementia: living well with your diagnosis* and the accompanying DVD are the suggested publications for you. They are based on the experiences of people with dementia and their carers, using their voices to share experience around how to 'live well' after diagnosis. They are both available free from the Alzheimer Scotland Freephone 24-hour Dementia Helpline on **0808 808 3000** or email [helpline@alzscot.org](mailto:helpline@alzscot.org) for information and support. Some mobile networks charge for this number, so check with your provider. Copies may also be available from local carer services in your area.

If you want to talk about anything you have read in this booklet or other publications, or would like more information or local contacts, you can call the Alzheimer Scotland 24-hour Dementia Helpline above, or contact your local carer service.

Anyone in Scotland receiving a diagnosis of dementia is entitled to a minimum of one year's post-diagnostic support from a named and trained person, called a dementia link worker (or similar job title). The link worker works with the person with dementia and his or her partner and family to help them understand the diagnosis, learn to cope with symptoms and live well with dementia, now and in the future.

You will most likely want to know where you go from here, what others in this situation have found helpful and what support is out there. This publication has been written in discussion with carers. It includes information they felt was helpful or would have been helpful to them.

# Introduction: at a glance

- This publication is for carers of people with moderate to severe dementia.
- It includes information that other carers have found helpful.
- There is an accompanying DVD *Coping with dementia* at the back of this publication.
- You are not alone – there are many people who can, and will, help you according to your individual and cultural needs.
- This publication includes tips from other carers about how to live well and look after yourself.
- If you have a diagnosis of dementia or care for someone in the early stages then the resources *Living well with dementia* or *Younger people with dementia: living well with your diagnosis* are the suggested publications for you.

# About dementia

There are over 100 causes of dementia (most of which are very rare) and it is possible to have more than one kind of dementia at the same time. Different types of dementia can have different symptoms but what they all have in common is that the brain cannot work as well as it should. Up to 90,000 people in Scotland have dementia.

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 of our memories and determines how we see ourselves in the world.

When someone has dementia, it is because some of the brain cells are damaged and dying. This affects how we are able to 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.

Alzheimer's disease is the most common form of dementia overall, but there are rarer types of dementia.


Appendix 1 outlines the most common types of dementia and the possible symptoms and treatment.

People can live 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.

At the moment there is no cure for dementia but a lot can be done to help cope with the various symptoms.





This publication is for carers of people with any type of dementia. More information about the different types of dementia can be found in **Appendix 1** on page 172. Little by little, the person will need more help. Eventually someone with dementia will be unable to manage even basic tasks like eating, dressing and going to the toilet. But this will not happen suddenly. The illness can last many years.

This book is about what can help when caring for someone with dementia and what other carers have suggested has been useful to them.

These days, many people are being diagnosed with dementia quite early on in the illness. Talking to a dementia link worker and community psychiatric nurse and linking with support groups can be helpful. Support groups for the person with dementia and carers, groups for you as a carer can be helpful and fun. Contact your local carers, centre or Alzheimer Scotland for more details.

For people in the early stages, the publication and DVD *Living well with dementia* may be helpful.

# How dementia progresses

The progress of the illness varies a lot from one person to another. This means that no one can give firm answers about what you can expect. Some issues are more common early in the illness and others tend to happen later, but can be variable. People can live well with a diagnosis for many years, enjoying full and varied lives.

The illness may last many years. Refer to **Appendix 1** on page 172, this outlines the most common types of dementia and the possible symptoms and treatment.

You should also bear in mind that symptoms vary from person to person and from day to day. You may prefer to cope with any changes as they occur rather than trying to predict the specific impact of the person's diagnosis.

It is possible for someone to have more than one type of dementia at the same time.

Because of changes the person 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. For example, if the person was frustrated and aggressive, they will probably become calmer. As time goes on, the person's whole personality may change a great deal. Some carers say that the person seems to have become 'a shadow of their former self'. But most people keep fairly strong physically for a long time. In the later stages of the illness, people with dementia become physically very frail.

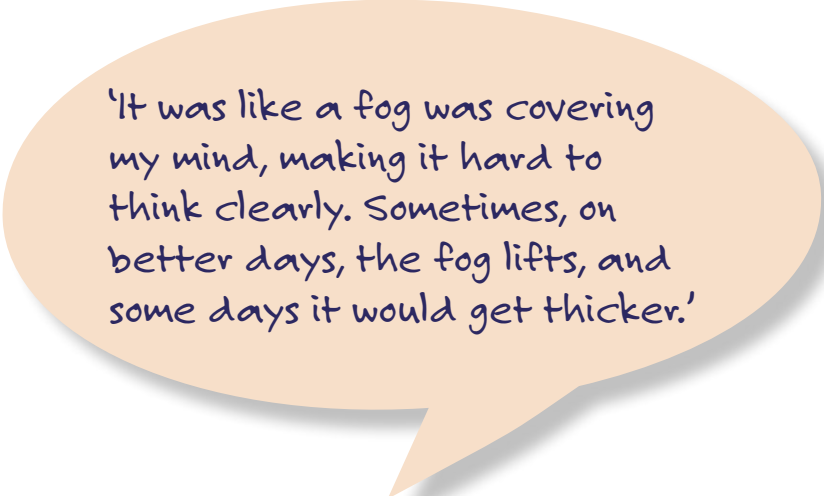
In the very last stages even the person's ability to resist simple infections is lost and, sadly, the illness is eventually fatal. But because it is such a long-lasting illness, and because many people are older when they get it, many people with dementia die of completely unconnected causes.

Looking after a person with dementia can be hard, and it is understandable that many people find it a difficult task. But others find the experience brings out unexpected inner strengths and that caring has its own rewards.

There are suggestions in this book from other carers on what can make life easier and happier for you and the person with dementia.

# How dementia progresses: at a glance

- The progress of dementia varies between different people.
- Early on the person may become forgetful or behave unusually.
- Everyone is different and the person you care for probably won't have all the issues in this book.
- The person will gradually need more support.
- Some of the challenges you faced earlier on may no longer be a problem later in the illness.
- There are many ways of making life easier and happier for both the person with dementia and yourself. You can enjoy life and live well while living and caring for someone with a diagnosis of dementia.



*'It was like a fog was covering my mind, making it hard to think clearly. Sometimes, on better days, the fog lifts, and some days it would get thicker.'*

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

People with dementia and those who care for them have the same human and legal rights as every other citizen. It is important that this is recognised and respected.

There are a wide range of legal provisions which are designed to provide rights and protection in Scotland. Scotland has introduced 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.

**[www.alzscot.org/campaigning/rights\\_based\\_approach](http://www.alzscot.org/campaigning/rights_based_approach)**

There are also Standards of Care for Dementia in Scotland. The standards are based on the Charter of Rights and say that the person you care for has the right to:

- a diagnosis
- be regarded as a unique individual and to be treated with dignity and respect
- access a range of treatments, care and supports
- end-of-life care that respects his or her wishes.

The Charter of Rights also says that carers should be well supported and educated about dementia. The standards apply to everyone with a diagnosis of dementia and their carers in Scotland, regardless of where they live, their age, the support they receive or the severity of the illness. The standards apply wherever the service is being provided – whether it is in your own home and community, or in a care home or hospital.



The Triangle of Care guide provides a self-assessment tool for dementia services to use to ensure carers are identified, supported and involved in care and treatment of the person with dementia. It can be found on the Carers Trust website and has been endorsed by the Royal College of Nursing in Scotland.

People caring for a person with dementia who carry out care on a regular basis will have a right to a Carer's Assessment from the local social work department. New legislation – The Carers (Scotland) Bill – was submitted to the Scottish Parliament in 2015. This will change the Carer's Assessment to an Adult Carer Support Plan or, for a young carer, a Young Carer Statement. Information and advice for carers can be obtained from your local carer centre or from social work departments. To find your local carer centre visit [www.carers.org/local-support](http://www.carers.org/local-support) or call **0300 123 2008**.



## Further information

Alzheimer Scotland's Standards of Care for Dementia in Scotland. A guide for people with dementia and their carers explains what people with dementia's rights are and the quality of care, support and treatment you should receive to stay well, safe and listened to. [www.alzscot.org/campaigning/rights\\_based\\_approach](http://www.alzscot.org/campaigning/rights_based_approach)

Alzheimer Scotland explains what the Charter of Rights for People with Dementia and their Carers in Scotland covers. [www.alzscot.org/campaigning/rights\\_based\\_approach](http://www.alzscot.org/campaigning/rights_based_approach)

Care Information Scotland outlines where you can help with caring. [www.careinfoscotland.co.uk/can-i-get-help-with-caring.aspx](http://www.careinfoscotland.co.uk/can-i-get-help-with-caring.aspx)

Mental Welfare Commission Scotland can advise on your legal rights under mental health and adult incapacity law. Call the advice line on **0800 389 6809** or visit [www.mwscot.org.uk](http://www.mwscot.org.uk)

Carers Scotland's Advice Line can advise on your rights as a carer on **0808 808 7777**. You can also visit [www.carerscotland.org](http://www.carerscotland.org) for more information.

# Being involved

The person with dementia and their family should be involved in decisions about their care and given as much choice as possible. Any services received should meet the needs of the individual and be appropriate to their culture and lifestyle. Carers should be able to say what care they are able and willing to provide and what help they will need to provide care to the person with dementia.

# Advocacy

People with dementia have a right to independent advocacy.

Help from an 'advocate' can be available to make sure the person with dementia and the family's views are heard and to guide them through complicated health, financial and social service systems.

Advocacy can be particularly useful if there is a lack of a support network of friends and family, or additional barriers to communication, such as speech or hearing difficulties or if someone's first language is not English.



## Further information

The Scottish Independent Advocacy Alliance (SIAA) can provide information on independent advocacy, which empowers people who need a stronger voice by enabling them to express their own needs and make their own decisions. Call **0131 556 6443** or visit **[www.siaa.org.uk](http://www.siaa.org.uk)**

# Rights of a person and carer: **at a glance**

- **You have certain legal and human rights following a diagnosis of dementia.**
- **Get involved in decisions about care and choices available.**
- **Consider support from an 'advocate' to assist through complex health, financial and social service systems.**



# Caring for a person with dementia

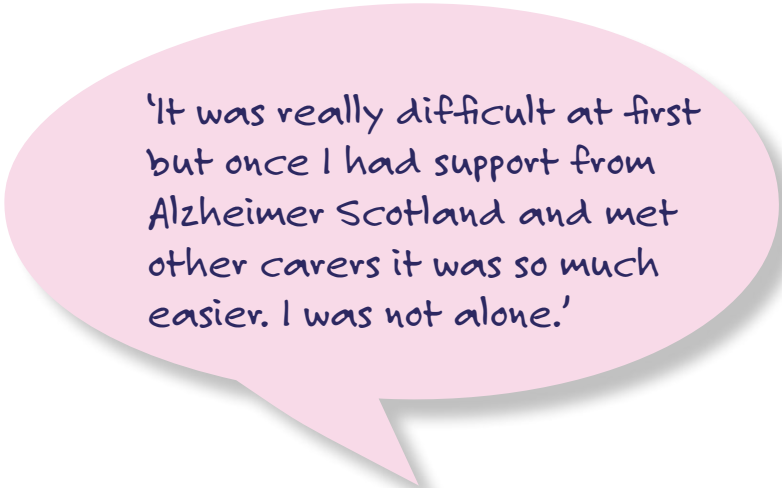
This section provides information and advice from other carers about what is important in order to look after yourself, the carer.

## Emotional reactions

Looking after someone who has dementia can be stressful. One of the things you may find difficult is living with your feelings about caring. It helps to know what these feelings might be.

Most carers experience a variety of emotions. The most common are sadness, guilt, anger and fear. Tiredness and tension are also common. Some of these feelings come as no surprise. You might expect to be sad when you feel you are slowly losing someone you love. Anger can be more of a shock. You may be alarmed at how frustrated and angry you can get. You may find you come to the end of your tether even over quite minor upsets.

If you are a young carer, or young adult carer, you may also experience a sense of loss that the adult person in your life is now not the same and relies on you more for support and care. You may find that you have to take more time away from school or further education and you might experience feelings of resentment.



*'It was really difficult at first but once I had support from Alzheimer Scotland and met other carers it was so much easier. I was not alone.'*



On the other hand, caring can also be rewarding. For example, some people see it as a chance to give back to a parent the care they were given as a child. People with dementia often seem calm and happy despite the illness.

For many carers, there will be both rewarding and stressful times.

Many things can affect your reactions. For instance:

- Your relationship with the person with dementia.
- Someone you depended upon in the past may now be dependent on you. Or there may have been problems in your relationship in the past. Perhaps you are caring for your partner, and so no longer have the support you used to have in your relationship. You may miss things that kept you close, such as sharing problems and talking things out, or a sexual relationship.
- Your reasons for caring.
- People may find themselves looking after a relative because they want to, or from a sense of duty. Some may feel they have little choice, which can add to the strain.
- Particular problems that affect the person you are caring for.
- Interrupted sleep or constant demands for attention can be very stressful.
- Changes in your lifestyle.
- You may have given up a job or moved home to care for someone. You may be managing on less money than you used to have. You may feel isolated.
- How much support you have.
- Do you feel you are the only one looking after the person, or do other people share the care or share the responsibilities?

Other people may not see the changes in the person in the way that you do, as the carer. You know what effect the illness is having on the person, but other people who aren't so close to them may only see them putting a good face on things. This can sometimes make it hard for people to understand what caring is really like for you.

Caring for someone you don't live with brings its own worries too. Many people who care at a distance worry a lot about safety. Some people feel guilty about not being there all the time. Some feel frustrated because they find it hard to know what's going on.

*'I've probably never felt so alone in my life ... suddenly all this world was changing around me, he was changing. I started understanding when I got help, but until that point I was so alone.'*

*'When something goes wrong, I say to myself, "Relax, don't panic. I have coped so far and there is no reason why I won't continue to." It seems to help somehow.'*

## What you can do:

- 1 It helps if you talk about your feelings rather than bottle them up. You may want to do this with a friend or member of your family, or you may want to talk to a professional, such as a social worker or community psychiatric nurse, or both at different times. If you are a young carer looking after someone with dementia it is essential that you get as much help as possible. There are a number of young carer services throughout Scotland who will be able to provide you with the support and advice you need. Information on Scottish Young Carers Services Alliance can be found by contacting Carers Trust Scotland on **0300 123 2008**. Carers Trust can also help adult carers to find their nearest carer centre.
- 2 The Alzheimer Scotland 24-hour Dementia Helpline is available on **0808 808 3000** (freephone). Trained volunteers offer emotional support and information, whenever you want to call.
- 3 Ask your social work department, community psychiatric nurse or allied health professional to arrange an Adult Carer Support Plan or Young Carer Statement (formerly carer's assessment) if you carry out a substantial amount of care on a regular basis.
- 4 In most areas there are carers' support groups. Talking to others in the same situation can be a great help. Even if there is no support group nearby, it is still worth trying to meet with someone else who looks after someone with dementia. Other carers can understand what you are going through. Ask the Dementia Helpline, local carers' services or a dementia link worker about groups in your area or online groups. In many areas there will be regular dementia cafés where carers and people with dementia can meet others in a similar situation.
- 5 Other carers have suggested that you try not to give yourself negative messages like, 'If anything else happens I'll never manage', or 'This is the last straw'. A more helpful approach is, 'I might not be doing a perfect job but I am doing well'. Changing the things you say to yourself can have an amazing effect on how you feel.

# Emotional reactions: at a glance

- Caring can be both rewarding and stressful.
- Many things can affect your reactions.
- Talk about your feelings.
- Call the Alzheimer Scotland 24-hour Dementia Helpline on **0808 808 3000** if you need to talk to someone.
- Contact Carers Trust Scotland on **0300 123 2008** to find out more about young carer services and local carer centres.
- Join a carers' support group.
- Don't hide the fact that a relative has dementia.
- Don't assume that only the person you care for has a particular problem.
- Ask for an Adult Carer Support Plan if you carry out a substantial amount of care on a regular basis.

*'At the beginning just after my husband was diagnosed I found things very hard. But I used to tell myself 'I can cope for today, tomorrow can look after itself.'*

# Look after yourself

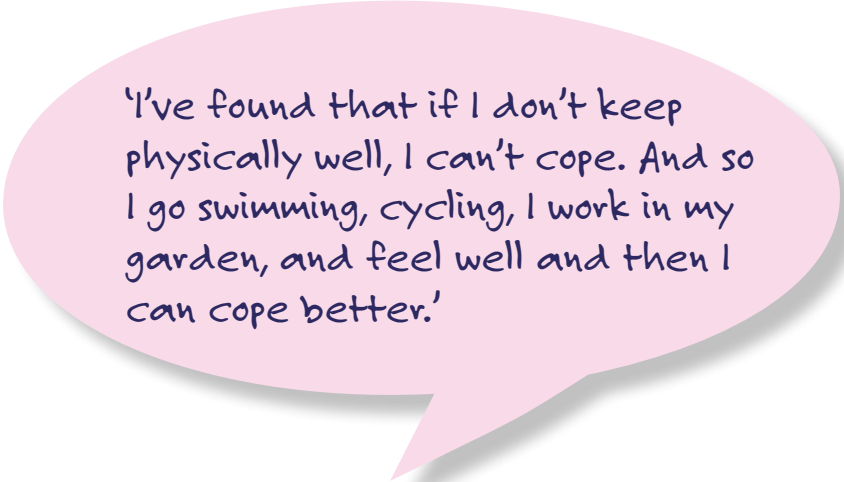
Sometimes carers feel as though they are being selfish if they take time for themselves or do some of the things they like to do. If you feel like that, ask yourself what you would say to someone else in your position.

Looking after yourself is not selfish – it's sensible. You need to look after yourself, physically and emotionally, if you want to be able to go on caring and for your own sake.

## **What other carers have suggested:**

Arrange for regular breaks to make sure you have time off. Family, friends, a local home support service and day centres can help.

- 1 Try not to become isolated from friends and family.
- 2 Ask for an Adult Carer Support Plan or Young Carer Statement.
- 3 Ask for respite breaks to give you a weekend, a week or more away from taking care of the person with dementia. This gives you the chance to recharge your batteries.
- 4 Take time for yourself. Think about what you find relaxing. For example, it might be listening to music, watching television, going for a walk, seeing friends or something else. Try to make sure you get some time each day to relax, even if it's only a few minutes.
- 5 Make sure you look after yourself physically by getting enough sleep, eating well and enjoying some physical activity.



'I've found that if I don't keep physically well, I can't cope. And so I go swimming, cycling, I work in my garden, and feel well and then I can cope better.'



## Further information

Alzheimer Scotland's booklet *Looking after yourself* gives information on how carers can take care of themselves, and why they should.

NHS Health Scotland booklet, *Steps to deal with stress*.

[www.healthscotland.com/documents/5828.aspx](http://www.healthscotland.com/documents/5828.aspx)

Breathing Space is a free, confidential service. They provide a safe and supportive space in times of difficulty by listening and offering advice and information. You can access a British Sign Language service through the website. Call **0800 83 85 87** or visit <http://breathingspace.scot/>

NHS Living Life is a new telephone service based on cognitive behavioural therapy (CBT). They provide help for people suffering from low mood, mild to moderate depression, symptoms of anxiety or a combination of both. Call **0800 328 9655** (Monday to Friday 1 pm to 9 pm).

Many local carer services provide a range of alternative therapies and workshops to help carers enjoy and make time for themselves.

Call the Samaritans helpline free on **116 123** and the Alzheimer Scotland 24-hour Dementia Helpline free on **0808 808 3000** if you need to talk to someone.

Contact Carers Trust on **0300 123 2008** for more information on adult, young carer and young adult carer services in your area.



# Look after yourself: **at a glance**

- Give yourself a break.
- Explain the situation to friends and family.
- Take time for yourself every day.
- Remember, looking after yourself is not selfish – it's sensible.
- Enjoy time to yourself and encourage yourself to discover what helps you to live well while caring for someone with dementia.

*'I go to a carers' group and that has been my lifeline, an absolute lifeline.'*

*'My father used to follow me everywhere. I never had a moment to myself. I took to locking myself in the bathroom with a book for half an hour when things got too much.'*



## You and your family

For many carers, looking after someone with dementia brings changes in family relationships. Perhaps you have children who also have to cope with the person's illness. But the time you spend caring can mean less time looking after them. If the person with dementia lives with you, your children may feel embarrassed to bring their friends to the house.

Tips on talking about dementia to family and friends, especially to children:

- Keep it simple, use everyday words and avoid jargon.
- If something isn't understood, then try to explain it using different words. Don't make light of their fears, especially if they've noticed changes.
- Make it clear that it's OK to ask you questions and to tell you how they feel.
- Try to arrange some times when the person with dementia is out of the house so that children feel more able to bring their friends home.
- Perhaps the person with dementia could go out with a friend or a home support worker sometimes. Try not to let caring take over family life completely. Ask for help to give you time off to spend with your family.
- Talk to the rest of the family. Relatives not involved in day-to-day caring may not realise the demands on you. They may not understand the illness. Perhaps you could have a family discussion about how to care for the person with dementia.
- If there are disagreements on what is best, it may help to ask someone else to take part in discussions, to make sure everyone gets a fair hearing. Perhaps a close friend, a social worker, a religious leader or the doctor could help.



## Further information

NHS Health Scotland. *Understanding dementia: A guide for young people.*

[www.healthscotland.com/documents/3884.aspx](http://www.healthscotland.com/documents/3884.aspx)

The Mental Health Foundation guide *The milk's in the oven* suggests ways to talk to children about dementia.

[www.mentalhealth.org.uk/publications/the-milks-in-the-oven](http://www.mentalhealth.org.uk/publications/the-milks-in-the-oven)

You can ask for a copy of either of these guides from Alzheimer Scotland 24-hour Dementia Helpline on **0808 808 3000** or by emailing [helpline@alzscot.org](mailto:helpline@alzscot.org)

Children may find Carers Trust online communities and local support groups for young carers helpful.

<https://babble.carers.org/>

# You and your family: **at a glance**

- Talk to the whole family about dementia and what helps.
- If the person with dementia lives with you, try to arrange some times when children can bring their friends home.
- Try not to let caring take over family life completely.

'My husband is sometimes very good with our grandchildren, but sometimes he gets angry and they don't see why. So I don't leave him alone with them anymore and I make sure they do something nice together.'

# Getting information

It is easier to deal with caring when you have enough information. You may need information on the illness itself and how it will affect the person. You may need to find out about local services or may want extra help with a particular problem. Or you may want extra help with a particular problem.

## Dementia Helpline

The Alzheimer Scotland 24-hour Dementia Helpline **0808 808 3000** (freephone) can provide information on almost anything to do with dementia. If the person who takes your call can't answer a question, he or she will try to find out. The Dementia Helpline is run by Alzheimer Scotland and has a panel of expert advisers.

## Courses for carers

Although caring can be a full-time job, few carers get any training in how to do it. So you may feel you have to learn by trial and error. Alzheimer Scotland and carers' organisations arrange courses for carers through their local services. A carers course can give you the chance to get accurate information about the illness, services available, financial and legal matters and how to cope. Research has shown that carers with this sort of training may feel less stressed than other carers. Call the Dementia Helpline to find out about a contact near you.

## The National Dementia Carers Action Network (NDCAN)

This is a national campaigning group that aims to represent and raise awareness of the issues encountered by carers of people with dementia. Members have personal experience of caring for a person with dementia. **[www.alzscot.org/ndcan](http://www.alzscot.org/ndcan)**

# Getting information: **at a glance**

- Better information makes caring easier.
- Call the Dementia Helpline on **0808 808 3000**.
- Go on a course for carers.

'I was in a meeting with various professionals talking about my wife's dementia and they all seemed to talk in initials! "CPN" this and "OT" that. Finally I asked them to speak English. They apologised.'

# Share the care

Looking after someone with dementia can be a round-the-clock job. No-one can provide all of the care, all of the time. Don't feel bad about accepting help.

The help you need will change as time goes on. Get help as early on as possible.

You may not feel you need much help now. But the person may find it easier to get to know a home support worker, for example, earlier on in the illness.

## What other carers have found helpful:

- 1 Involve the person with dementia in discussions about their care. Try to make sure their wishes are heard.
- 2 If you can, try to share caring with other members of the family and friends.
- 3 Often people don't get help because no one realises they need it. So it is important to ask. Family, friends and neighbours may be more willing to help than you expect once you explain things to them.
- 4 Regular help with shopping, housework and caring for the person with dementia will allow you time for yourself. The person with dementia will enjoy having different company too.
- 5 Ask the social work department, dementia link worker, community psychiatric nurse or doctor about what services are available. Ask the social work department for a community care assessment and an Adult Carer Support Plan or Young Carer Statement. It is important for both you and the person with dementia that you make full use of these services.
- 6 There may come a time when it is no longer possible to care for the person with dementia at home. They may need to move into a care home. It can be hard to decide when this time has come. You may find it easier to decide if you discuss it with other members of the family or professionals. If the person goes into a care home or hospital, you can still help care for them if you want to (see **Long-stay care**, page 150).



# Share the care: **at a glance**

- Try to share caring with other members of the family and friends.
- Involve the person in discussions about his or her care as much as you can.
- Ask about what services are available.
- If you can no longer care for the person at home, discuss options with other members of the family and health and social care staff.

*'I was struggling to manage work and help mum, but then I asked for help from other members of my family. They have been great and now take mum to the dementia café one day a week so I can get on.'*

# Money and legal matters

## Planning for the future

When you find out that someone you are close to has dementia, it can be upsetting. Often practical arrangements for the future are the last thing you and the person may think about. But if the person with dementia is still able to, it is important to try to make plans sooner rather than later. People in the middle to later stages of dementia are likely not to be able to make legal arrangements any more.

To make legal arrangements for the future, the person needs to be mentally capable of making their own decisions and legally able to sign documents.

They should check with their doctor if they or their solicitor is not sure.

If the person is still able to do so, they should make some important decisions as soon as possible. They should:

- choose one or more people, such as spouse, partner or carer, to look after their financial affairs and welfare decisions if they become unable to, and give them power of attorney. Typically people will appoint their spouse or a close relative (often their carer) as their attorney and that person then has legal authority to act for the benefit of the person appointing them.
- make a will.

There are three other documents someone diagnosed with dementia should at least consider completing. These are:

1) A Statement of Wishes and Values: this is an informal document in which someone simply spells out 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 is a document in which someone states their treatment preferences in advance, contemplating episodes in the future when they may not be able to communicate satisfactorily. This document 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 lives. Typically this will state a preference not to receive interventionist treatment when death is imminent.

All of these documents are important and their terms should be communicated to the appropriate parties, including medics and attorneys.

More information can be found by calling the Dementia Helpline on **0808 808 3000**

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

- 1 Encourage the person to see a solicitor to make powers of attorney covering their financial and welfare matters as soon as possible. That way they can decide who they trust to make important decisions on their behalf in the future, if they become unable to manage. The person will only be able to make a power of attorney if the solicitor is satisfied that they understand what they are doing and is not under pressure from anyone else. They can:
  - choose one or two or more people as joint powers of attorney.
  - choose the same or different people to handle their financial and welfare matters.
  - choose substitutes in case their first choice can't carry on managing their affairs. This can be particularly important where a spouse or partner who is the attorney dies first.
- 2 Encourage the person to make a will, or review an existing will, through their lawyer as soon as possible, so that they can choose what happens to their money, property and possessions. A will is only valid if made when the person is clearly aware of what they are doing, so it is important not to put it off.
- 3 Solicitors can prepare all of these documents. Legal aid can often be obtained if the person feels that they can't afford the legal fees. Check with Scottish Legal Aid Board **[www.slabb.org.uk](http://www.slabb.org.uk)** for solicitors in your area who provide legal aid.

- 4 Encourage the person to think about any wishes about medical care in the future and write these down as an advance directive or 'living will'. Make sure their doctor and the attorney both get a copy.
- 5 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.
- 6 Arrange direct debits so that the bank pays bills automatically. Gas, electricity and telephone companies and other organisations can help with this.

# Planning for the future: at a glance

- Encourage the person to discuss plans for the future.
- Encourage the person to grant powers of attorney.
- Encourage the person to write a will.
- Arrange to pay bills automatically.

*'Taking on financial responsibility had to be worked out. It was important to my dad to have his own bank cards, but I helped set up direct debits and now he is happy for me to check bank accounts with him.'*

# Managing everyday money matters for the person

As time goes on, the person will become less able to cope with money. They may forget to pay bills, pay them twice, or give money away or lose it. They are likely to lose their understanding of the value of money. For many people with dementia financial matters can be a great worry. In time, 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.

- 1 Discuss the situation with the person with dementia as much as possible. Try to agree safeguards, such as making sure they don't have large amounts of money in the house.
- 2 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. This can be distressing, but it is because of the illness. Reassure the person that they have enough money.
- 3 In some cases, unscrupulous people may take advantage of someone who is vulnerable because of dementia, so don't always assume that the person is mistaken if they feel money has been taken. You may need to investigate. If you feel that someone is stealing from them, involve the police and/or the social work department.
- 4 Dementia sufferers are particularly vulnerable to criminal gangs operating scams over the phone or by mail. Depending on the level of dementia displayed and the person's behaviour, carers and attorneys need to consider when it would be sensible to take control of communications to and from the person and their use of bank accounts. Attorneys will have the power to step in and act for the benefit of the person and to prevent their exploitation. If a scam is identified then the police should be informed.

- 5 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 **Further information** on page 46). Once it is registered, you (or the person named as their attorney) can use it to manage the person's finances.
- 6 If you are concerned that someone is misusing the person's money, for example using a power of attorney, the Public Guardian can investigate.
- 7 If the person has money in a joint bank or building society account, for example with their partner, in most cases the other account-holder can continue to use the account as usual.
- 8 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 for the person.) You don't need a solicitor to apply. You can get an application form for Authority to Access Funds from the Dementia Helpline or the Public Guardian (see **Further information** on page 46). On the form you say what you need to spend each week or month on the person's bills, food, clothing and other items. You send it with a small fee to the Public Guardian.
- 9 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.

# Managing everyday money matters for the person: **at a glance**

- Make sure the person has some cash.
- Start using the power of attorney if the person has made one.
- You can apply to access money in the person's bank account on their behalf.
- Keep the person's money separate from your own.

'The benefit I've found from seeing a solicitor about granting the power of attorney is that I can now contact the medical staff and banks about my wife's affairs without any problems.'





IN THE INTEREST OF  
HYGIENE WE ASK  
THAT CUSTOMERS  
DO NOT TOUCH  
UNWRAPPED  
BAKERY GOODS.

# More legal powers to help the person

In some cases, the court may have to give someone 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. Perhaps the person needs someone to look after his or her finances or welfare long term. Or sometimes there may be a power of attorney but it doesn't give enough powers – for example, to sell the person's house.

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, for a one-off decision or action.

## What you can do:

- 1 Call the Dementia Helpline or see the booklet *Dementia: Money and legal matters* for information on guardianship and intervention order.  
Go to **[www.alzscot.org/information\\_and\\_resources](http://www.alzscot.org/information_and_resources)** and search for 'money'.
- 2 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 it yourself, you can get more information and the forms you need from the Scottish Government Justice Department.
- 3 The person with dementia may be entitled to Legal Aid.

# More legal powers to help the person: **at a glance**

- Sometimes you may need more legal powers to make decisions for the person.
- The court can appoint a guardian or grant an intervention order.

*'I delayed getting power of attorney from my husband until too late so I had to go through a long process to apply for guardianship. It was good to get it but I would recommend getting power of attorney as soon as possible.'*

# Financial support and advice

Caring for a person with dementia at home can be quite costly. Your income may have reduced because of your caring responsibilities. And there may be extra costs, such as more heating. Financial benefits, such as attendance allowance, may be available, both for the person with dementia and for you as the carer.

## Claiming benefits

The person with dementia, or the person who cares, may be entitled to financial help from the benefits system, including some if you are still working.

The benefit and tax credit system is complex and can be daunting for anyone. Significant changes are being made to the benefits and tax credits system over the next few years because of new welfare legislation.

It is always a good idea to get help from a benefits adviser who can tell you what benefits you are entitled to and help you with any forms. Benefits advice can be made available in other languages, or you could ask for an interpreter.

Most local authorities also provide benefits and welfare rights advice. You should check how to access this with your local authority. The Citizens Advice Bureau can also help you claim benefits. Contact telephone numbers are listed in the telephone directory or visit Citizens Advice Scotland's website [www.cas.org.uk](http://www.cas.org.uk)

The Department for Work and Pensions (DWP) offers support to people claiming benefits related to disability (including dementia) and their carers. Call the AA helpline on **0345 605 6055** or the Carers Allowance helpline on **0345 608 4321** or visit [www.gov.uk/disability-benefits-helpline](http://www.gov.uk/disability-benefits-helpline)

The person with dementia can appoint someone as a joint account holder or 'permanent agent' to collect benefits from the Post Office for them. Ask for an application form at any Post Office.

It's always worth seeking advice – even if you think you are not entitled. Try the government's online benefit calculator to get an idea of what you're entitled to. [www.gov.uk/benefits-calculators](http://www.gov.uk/benefits-calculators)

## For people under the age of 65 with dementia

### **Employment and support allowance (ESA)**

This is a benefit for people unable to work due to illness or disability who are not entitled to statutory sick pay, income support or jobseekers allowance. You can also claim when statutory sick pay ends.

Visit [www.gov.uk/employment-support-allowance](http://www.gov.uk/employment-support-allowance) to find out about ESA, or call **0800 055 6688** (textphone **0800 023 4888**) to make a claim.

### **Personal independence payments**

From April 2013 (June 2013 in Scotland) personal independence payment (PIP) replaced Disability Living Allowance (DLA) for all new claimants. Over time most DLA claims will be transferred to PIP. If you already get DLA and were under 65 on 8 April 2013, you will eventually get a letter and follow-up phone call asking you to apply for PIP. You should seek advice to help you with this process. If you were 65 or over on 8 April 2013 you will continue to receive DLA.

Personal independence payment is paid according to their daily living and mobility needs, and can be claimed online.

Find out about personal independence payment at [www.gov.uk/pip](http://www.gov.uk/pip) or to make a claim call **0800 917 2222** (textphone **0800 917 7777**). For advice or information about existing claims, call **0845 850 3322** (textphone **0845 601 6677**).

## Universal Credit

During the course of 2013, the government introduced a new benefit called Universal Credit which replaced income support, income-related jobseeker's allowance, income-based employment and support allowance, tax credits and housing benefit. From 2014 to 2017, people who get the old benefits will be moved across to the new system. [www.gov.uk/universal-credit](http://www.gov.uk/universal-credit)

## The Scottish Welfare Fund

The Scottish Welfare Fund is run by local authorities and is split into two parts:

- Crisis Grants to provide a safety net in an emergency when there is an immediate threat to health and safety.
- Community Care Grants to enable independent living or continued independent living, preventing the need for institutional care.

The scheme is for people aged over 65 and does not include loans.

## Help with council tax

If you are aged over 65, have a diagnosis of dementia and receive a benefit, such as Attendance Allowance, Disability Living Allowance, Personal Independence Payment or Employment and Support Allowance, you could be entitled to help with council tax.

If you are on a low income you could be entitled to a council tax reduction.

If you live alone you could be entitled to a council tax exemption.

If other people live in the house you could be entitled to a council tax discount.

Find out more about help with council tax from your local authority or contact your local Citizens Advice Bureau.

## For carers

Carers may also be eligible for financial support.

### Carer's Allowance

A carer over 16 who looks after person with dementia for at least 35 hours a week may be able to receive Carer's Allowance, possibly income support, and National Insurance credits. In some circumstances, Carer's Allowance can affect the benefits the person with dementia receives so it is always a good idea to seek advice before the claim is made.

### Carer's Credit

If the carer is looking after the person with dementia for 20 hours a week or more they can apply for Carer's Credit to protect their state pension. This is a means tested benefit and entitlement depends on how much income and savings you (and your partner) have.

You can collect the person's pension and other benefits if they authorise you to do so. If they can't sign or don't understand what they are signing, ask the Department for Work and Pensions (DWP) to make you (or someone else) their appointee. As appointee, you can apply for and collect all benefits on behalf of the person. You must tell the DWP if the person's situation changes.



### Further information

Find your nearest carers centres to get advice on entitlements.  
[www.carers.org/carers-services/find-your-local-service](http://www.carers.org/carers-services/find-your-local-service)

For information on carer entitlements, contact the Carer's Allowance unit on **0845 608 4321** (textphone **0845 604 5312**).  
[www.gov.uk/carers-allowance](http://www.gov.uk/carers-allowance)

The DWP usually pays the pensions and benefits directly into a bank account. This can be useful, especially if the person's bills are paid by direct debit or standing order. If the person with dementia does not have a bank account he or she may be able to open a Post Office Card Account.

If the person is not able to operate an account, they may have granted someone power of attorney and this person can manage the account. Alternatively, you could apply to the Office of Public Guardian to access the person's funds (see **Further information** below).

If you are unwilling or unable to open an account for payment of your benefit, the DWP will pay you using the Simple Payment service. You will be able to collect your benefit from a PayPoint outlet displaying the Simple Payment sign. You can search for your nearest store on the Paypoint website at **www.paypoint.co.uk**. You will be issued with a card that doesn't need a PIN, and you will need this card, a memorable date and proof of ID in order to collect your cash. The DWP does not need your agreement in order to pay you in this way. Contact the helpline on **0845 600 0046**.



### **Further information**

The Office of the Public Guardian offers advice on power of attorney, including an indication of costs.

**[www.publicguardian-scotland.gov.uk/power-of-attorney](http://www.publicguardian-scotland.gov.uk/power-of-attorney)**



# Welfare benefits: **at a glance**

- You have a right to apply for benefits over the age of 16 years.
- Not all benefits are only available to people on low incomes.
- You can get advice and help filling in forms.

*'I found all the forms daunting and at first put my head in the sand and avoided it. But then with help from my daughter I went to a benefits adviser and it was all sorted out.'*

# Practical caring

Every person with dementia is different, and will be affected differently by the illness. This section looks at some of the challenges you and the person with dementia may face.

Remember, not everything will happen to any one person. Remember too that things will change as the illness progresses. A difficulty which seems impossible to solve may just disappear with time.

There is a great deal that you can do to make things better for yourself and the person with dementia. The 'What you can do' sections list some practical ways of dealing with the changes which people with dementia go through. Finding the best way of coping is often a matter of trial and error. But these ideas have helped other carers.

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.

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 the Alzheimer Scotland 24-hour Dementia Helpline for suggestions on how to approach a challenge.

## Looking after the person

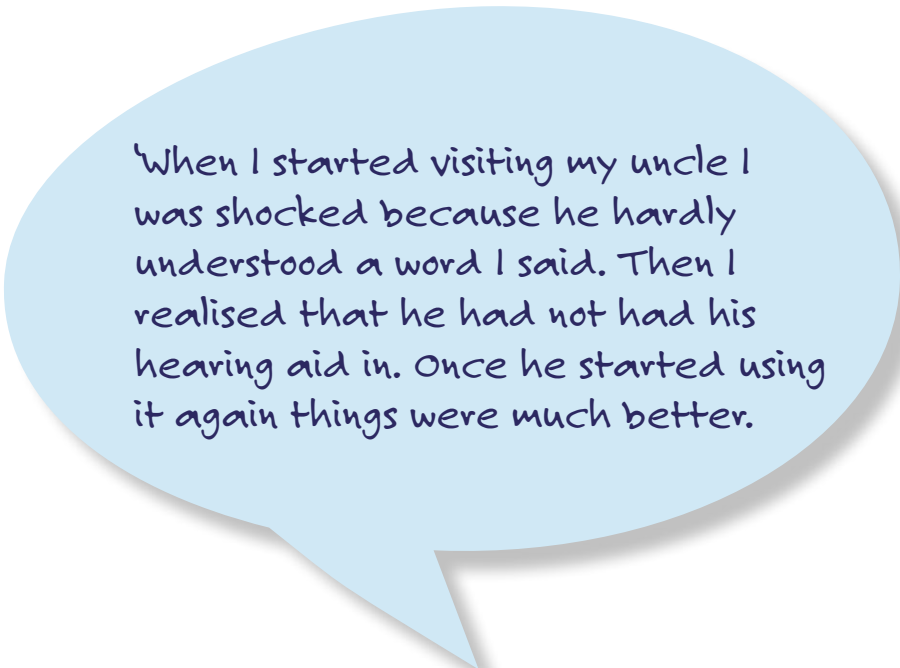
Each person with dementia is an individual and has their own lifestyle and experiences. Try to help the person to carry on with existing interests and social activities as much as possible.

## Physical wellbeing

It is important to make sure the person with dementia stays as healthy as possible. A healthy diet and enough exercise are important for maintaining physical health and can help to avoid illness.

Problems with seeing or hearing can make life extra difficult for someone with dementia. Illnesses such as infections can make the symptoms of dementia worse, and the person may be more confused until the illness is treated. Avoiding constipation is important too, because it can cause discomfort and pain.

It may be difficult for the person with dementia to tell you if there is something wrong. If the person seems irritable, or more confused, it may be because they are uncomfortable or in pain.



'When I started visiting my uncle I was shocked because he hardly understood a word I said. Then I realised that he had not had his hearing aid in. Once he started using it again things were much better.'

## What you can do:

- 1 Try to make sure the person has enough to eat. Ask for advice from a dietitian or speech and language therapist for support if you are worried or if the person has swallowing difficulties.
- 2 Make sure the person with dementia drinks enough. They may not realise they are thirsty, so you may need to keep reminding, or prompting by offering the cup or glass. It is important to avoid dehydration, as this could lead to constipation, exhaustion and more confusion. Aim for about six to eight cups or glasses a day. A few cups of tea and coffee are fine, but try to make sure plenty of water, juice or milk is offered as well.
- 3 Physical activity is important, and may also help the person to sleep better. Try to make sure there is something active every day, even if it's just a walk to the shops.
- 4 People with dementia often have difficulties with walking and some experience falls. Physiotherapists can help by giving advice around exercise to improve strength and balance, by providing walking aids and advice to assist walking and preventing falls. They can also advise carers on the safe way of helping someone to move.
- 5 If the person has problems with his or her eyesight or hearing, talk to a doctor, optician or hearing specialist. It is important that they can see or hear as well as possible.
- 6 Make sure to seek advice from a doctor if the person with dementia is ill (for example with a chest or bladder infection), has a fall, becomes constipated or if appears to be in pain or depressed. Without treatment, they may make the symptoms of dementia worse. The doctor should be consulted if hallucinations (seeing or hearing things which are not there) develop. Acute confusion (sometimes called delirium) can be caused by physical illness so it is important to notice and listen to the person with dementia if they are feeling unwell.
- 7 Consult a doctor if the person has experienced significant weight loss without trying to over the past 3–6 months.

There are a range of allied health professionals who can help, including dietitians, speech and language therapists, occupational therapists, physiotherapists and podiatrists.

# Physical wellbeing: **at a glance**

- Keeping well physically is just as important for someone with dementia as for anyone else.
- Physical illnesses can make dementia symptoms worse.
- Try to make sure the person has a healthy diet, eats enough and enjoys some physical activity.
- Make sure they see the doctor if they become unwell or become more confused.

*'For a while my mother kept losing her purse. She would get very upset and accuse me or her home help of stealing it. But she has become much calmer over the last few months. She doesn't look for her purse at all anymore.'*



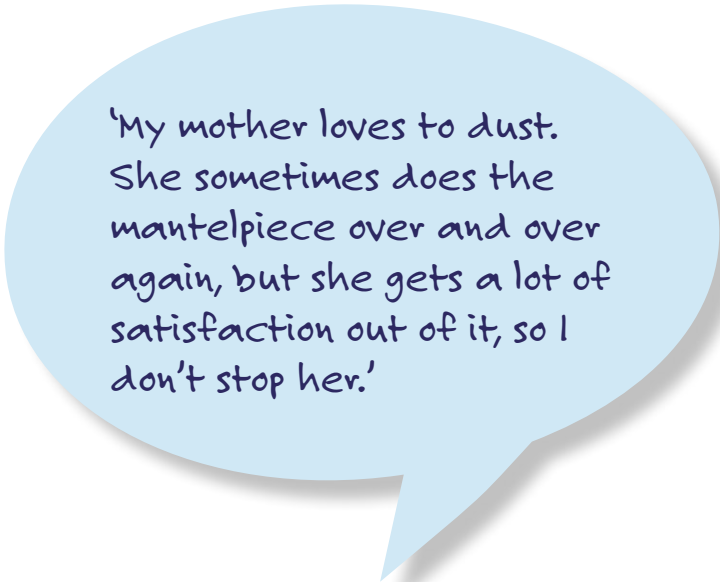
# Mental stimulation

Like anyone else, someone with dementia needs things to do, for interest, enjoyment and satisfaction, and to have a good quality of life. Without enough to do, people can get bored and frustrated. Staying as mentally active as possible can help the person to maintain their abilities and be as independent as they can.

Because of the illness, thinking of what to do, getting started and maintaining concentration all get harder. People may become withdrawn and lose their confidence. They are likely to need a lot more encouragement. You can help by helping the person you care for find activities they will enjoy and things you can enjoy together.

Each person with dementia will enjoy different activities, according to their interests and how the illness affects them.

Don't feel you must provide something to do every minute of the day. Quiet time is important too. Try to find help with caring so that you are under less pressure. A day centre can offer enjoyable and stimulating activities for the person and give you time for yourself. See **Getting help**, on page 122.



*'My mother loves to dust. She sometimes does the mantelpiece over and over again, but she gets a lot of satisfaction out of it, so I don't stop her.'*

## What you can do:

- 1 Think about what the person used to enjoy for ideas on what to try. Help them to keep doing things they used to do. Trying new activities can also be enjoyable for the person with dementia, as long as they are supported and willing to try.
- 2 Involve family and friends – for example, perhaps they would like to accompany the person on outings, help them to stay involved in family life and with community events, play a game or read the paper with them.
- 3 Break down tasks into more manageable steps so that the person can do the parts they are still able to cope with. For example, if they can no longer make a cup of tea, suggest that they get the cups out while you put the kettle on, and so on.
- 4 Many people with dementia can still remember things that happened a long time ago, even if they can't remember more recent events. So they may enjoy activities like looking through old family photographs or copies of old newspapers, for example.
- 5 The person may enjoy walking, knitting, sewing or DIY. Try not to take over, but to help with each stage of an activity as they need it.
- 6 Many people will enjoy listening to familiar music. See [www.playlistforlife.org.uk](http://www.playlistforlife.org.uk)
- 7 Remember that even if the person doesn't remember an activity, it is still worthwhile if they enjoy it at the time.

*'Until she had her first stroke, my sister used to be an avid bridge player. She still loves to play cards, so now we play snap and other simple games.'*



# Mental stimulation: **at a glance**

- People with dementia need interesting and enjoyable things to do.
- The right activities can help the person to maintain abilities and independence.
- Activities need to be suitable for the individual.
- Friends and family can enjoy helping with activities.

'My father used to go down to the bowling club every week. He stopped going for a while because he was worried about his dementia. We agreed that I would explain to his friends and he now has a great time with them at the club.'

# Life story book

A life story book is a collection of reminders of important times in the person's life, such as photographs, tickets, postcards and so on. A life story book can be enjoyable to make and can benefit the person in many ways. Most people can still remember a lot about their past even when their recent memory is very poor. Making a life story book or audio book is an opportunity for the person to talk about themselves and their life, and can enhance and maintain communication with people around them.

The person may enjoy just looking or listening to the audio book later. And the book can help family, friends and staff to get to know the person, their life and what is important to them.

A life story book can be important for carers and families too. It is your chance to find out things about the person's life you may never have known about before, and to record the person's past. When the person can no longer tell you their stories, you will have something to help you remember.

## **What you can do:**

- 1 Use a scrapbook or photograph album or audio recording to make the life story book.
- 2 Help the person look through old photographs, postcards, tickets, music and other reminders of their past to place in the book.
- 3 Label the items together. Put in notes and anecdotes.
- 4 Ask them about things they feel strongly about, from food and drink to music, sports or politics, and put in reminders of these.
- 5 Ask for their permission to show the book to other people, such as family members, friends and staff who are involved in their care.

Remember, it doesn't have to be a book – if it is easier, you could make up a 'digital book' with audio or video stories, or you could have a box of memories, with objects that the person with dementia can rummage through and handle. A lot of people find this enjoyable.

# Life story book: at a glance

- Making a life story book or audio or digital book can be enjoyable, both for the person and for you.
- Looking at the book will help the person reminisce later.
- It can help other people involved in their care learn about their interests and what is important to them.

'My sister had six children and she'd kept locks of their baby hair, so we put them in a memory book with some scraps of cushions from her first house. She now tells lovely stories of the children and that house.'

'Although my aunt doesn't speak any more, she still loves to sing hymns and remembers every word.'

# Spiritual wellbeing


Caring for the person with dementia means caring for spiritual needs too. Most people's spirituality is to do with their ethnic culture, tradition and upbringing. A person's individual awareness of their place and purpose in creation is unique. This is the person's spirituality. People have different personal ways of finding a sense of spiritual wellbeing. If spirituality has been important to someone, it is important to help them to have contact with things that in the past were part of their spiritual wellbeing. Without this, some people may feel abandoned. They may feel a sense of loss of worth and purpose.

## **What you can do:**

- 1 Find out what spiritual or cultural things are important to the person.
- 2 For example, this may include religious worship, meditation, books, songs or chants, symbols, places or other things.
- 3 If the person attended religious worship or groups or festivals, try to help them to keep attending for as long as possible. If this becomes impossible, perhaps they can continue to take part in worship at home.
- 4 Help the person to stay in contact with other people from their place of worship. Encourage visitors.
- 5 Help the person to feel that they still belong, for example by reading newsletters or magazines from the church, mosque, synagogue, temple or other place of worship.
- 6 Ask the person's minister, priest, rabbi, imam or other religious leader or teacher to visit to give pastoral care to the person, and to you if you wish.

# Spiritual wellbeing: **at a glance**

- Find out what is important to the person.
- Try to help them to keep attending religious worship.
- Help the person to stay in contact with other people and newsletters from their place of worship or their community.
- Ask for pastoral care.



*'My husband loved singing and playing hymns, so it's good that the care home has a piano so he can play, and the minister visits and has a service.'*

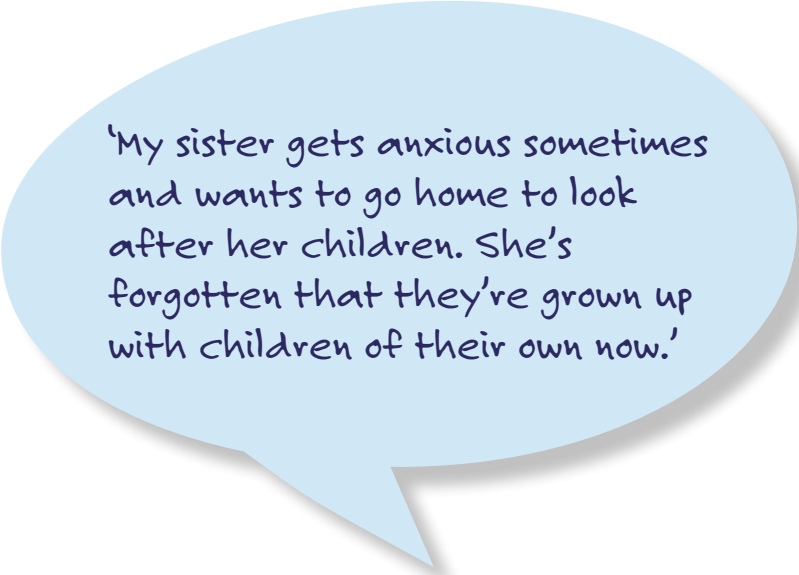
# Decline in memory

## Forgetfulness

Most people with dementia will have memory problems, which become more severe as the illness progresses. For mild memory problems, simple memory aids may be very helpful. Later in the illness memory aids probably won't help. You will need to give more direct reminders and help. The person with dementia may become more confused and 'lost' or disorientated. They may forget basic facts, such as who other people are, where they are and what year it is. They may confuse the past with the present.

Early on in the illness there are simple practical ways to jog the person's memory. The following ideas will help you and the person with dementia cope with forgetfulness. They will help the person keep their mind alert for as long as possible. This approach is known as reality orientation. It means providing reminders to help the person keep an idea of where they are, who people are, what time of day it is, what season it is and so on.

Reassurance is very important. The person may be aware that they now can't remember what they used to. This can be upsetting, frightening and frustrating. Try to be reassuring. Respond to the emotions the person shows as well as to what they actually say or do.



*'My sister gets anxious sometimes and wants to go home to look after her children. She's forgotten that they've grown up with children of their own now.'*



## What you can do:

- 1 Keep to routines as much as you can and try not to change where things are. Being in familiar surroundings helps. Changes can make confusion worse.
- 2 Memory aids work best when the person is in the habit of using them – for example, if they have always used a diary. Try to help them get into the habit as early as you can in the illness. Get other people who visit to write in the diary too. You can use it as a reminder for them of what they have been doing.
- 3 Get a large clock with the day and date. A loud tick helps remind the person with dementia where the clock is. Put up a calendar and mark off the days.
- 4 Put signs in words or pictures on doors to help the person find the way around. Or just leave doors open so that the person can see what's in each room.
- 5 Use a memory board or notice board as a reminder of what is going on. Put it somewhere it is easy to see, such as in the kitchen. You will need to draw the person's attention to memory aids and check that they understand them. The aids alone don't work. Remind them to look at the memory board, calendar, diary and signs. Leave notes where the person will see them if they are still able to understand them.
- 6 If you are not with the person, try reminding them about things by phoning. Or setting their mobile phone alarm or texting them a reminder.
- 7 You may need to provide basic facts in your conversation, such as reminders about times, places and people. Helpful facts might include who you are, where they are, where you are going, what is happening and so on. Be tactful and don't wait for the person to fail.
- 8 Family photographs, including photographs of the person with dementia, can help them keep a sense of identity. Talk about them, particularly if their sight is not good. Named photos of regular visitors (family, friends, home help) may help them to know people when they call.



# Forgetfulness: **at a glance**

- Keep to routines and don't make changes unless you have to.
- Use memory aids and draw attention to them.
- Drop reminders into your conversation.
- Use familiar objects and photographs as reminders.

'Whenever I go out I leave a note for my wife on the door of the fridge to say when I'll be back.'

'Sometimes my dad would mention a visitor he'd had, but he was never sure of who it was. So I put out a "visitor book" and it turned out it was his care worker.'

# Repeated questions

Some people with dementia keep asking the same question over and over again. This is because the person does not remember asking or can't remember the answer. Many carers find this very difficult to deal with. It can be frustrating and irritating, especially if the person follows you around the house asking questions. The person may seem afraid to let you out of their sight. This is because they may not be able to remember where you are or whether you will be back.

## **What you can do:**

- 1 Remind yourself that the person really does forget having asked a question before, or forgets the answer. Remember that they are not doing it deliberately to annoy you.
- 2 Be tactful. For example it is better to say, 'Oh, didn't I mention that we're going to the shops to buy bread and milk.'
- 3 Be reassuring. The person may be asking because they are anxious about something. Try reassuring them physically, perhaps with a hug.
- 4 If the person can still understand written reminders, try writing the answer to the question in a notebook or on a notice board. Point it out as you answer. Try to help the person get used to looking there for the answer.
- 5 Keep the person involved in what is happening. Make eye contact when you talk to them. Remember to include the person with dementia if there is a group conversation. This will help lessen anxiety and may reduce questions.
- 6 Use memory aids.
- 7 Try to divert their attention and involve them in another activity.
- 8 Even with all your efforts they may keep repeating questions. Sometimes you may have to leave the room to keep your patience.

# Repeated questions: **at a glance**

- Remember that repeated questions are not meant to annoy you: they need repeated answers.
- Try to be patient, tactful and reassuring.
- Try other ways of reminding the person of the answer, such as a notebook.
- Try to change the subject gently.
- Keep the person with dementia involved in what is happening.

'The best way I found to keep calm was to see how many different ways I could answer the same question.'

'He used to ask the same thing again and again and it used to frustrate me. So now I try to remind him about things as I talk, and I put reminders on the fridge door.'

# Conversation and communication

As dementia gets worse communication becomes a problem. You may find that the person seems deaf at times. Deafness may be the problem, but it is also likely that the person hears but does not understand.


Dementia slows people down in their ability to take things in and make sense of what they hear. Some people may have difficulty finding the right words for what they want to say. They may also begin to lose track of what they are saying in the middle of a sentence. It becomes harder to hold a conversation. This can be very frustrating for both people with dementia and carers. A referral to a speech and language therapist can often help to improve or maintain their speech and ability to communicate.

It is important to keep talking and reacting to the person with dementia in the same way as you have always done, even if they can't respond.

## **What you can do:**

- 1 Make sure that the person's dentures, glasses or hearing aid are in good working order and are the correct prescription. Poor sight and hearing can make people more confused and conversation difficult.
- 2 Speak clearly, simply and slowly but don't shout. Make sure the person can see your face when you speak.
- 3 Try to get one idea across at a time.
- 4 You may have to repeat yourself. Sometimes it helps if you say things slightly differently the second time: 'Your sister Freda is coming to tea today.' 'We're having a visitor this afternoon. Your sister Freda is coming.'
- 5 Use questions which 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?'
- 6 Allow plenty of time for the person to take in what you say and to reply.

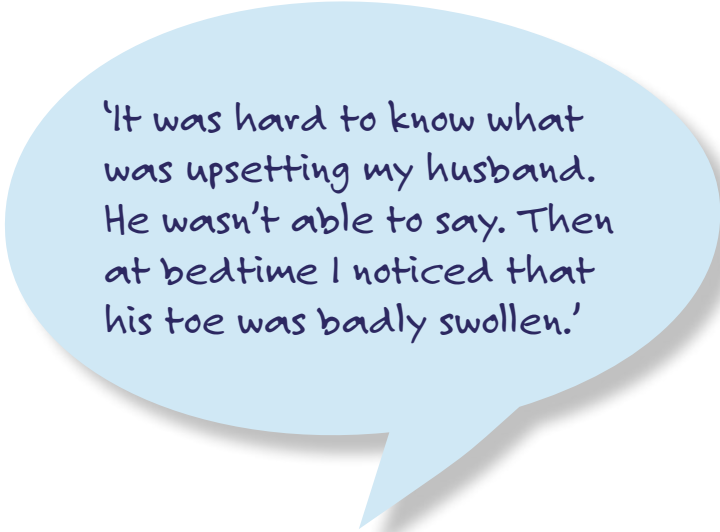
- 7 Try not to confuse or embarrass the person by correcting them bluntly.
- 8 If the person with dementia cannot find the right words, ask them to describe what they mean and suggest a word. But don't get into the habit of providing the right word as soon as they hesitate. If you do, they may become less confident. They might give up trying. Be encouraging but let them know you understand how frustrating it is trying to find the right words.
- 9 A smile, touch or gesture can be just as important in getting the message across and showing that you care. Holding the person's hand when you talk can also be very reassuring.
- 10 Many people with dementia enjoy talking about the past. You may both enjoy reliving some of these memories together. Talking about things which they remember well may help the person to feel secure. Try to make sure that they don't confuse these memories with the present. You can do this by making comparisons with how things were then and now. A life story book can be a useful aid (see page 56).



*'It's really important to try and get communication right. With my mum, the thing I do when I visit her is when she walks up the corridor, I put my arms out and she recognises me and gives me a big hug.'*

# Conversation and communication: **at a glance**

- Check dentures, hearing aids and glasses.
- Face the person, speak clearly and use simple sentences.
- Be patient and allow extra time.
- Help with word-finding problems.
- Use touch and gesture.
- Let the person know that you understand how frustrating it is.
- You may have to repeat yourself slightly differently.
- Use simple questions.
- Try not to embarrass the person.



'It was hard to know what was upsetting my husband. He wasn't able to say. Then at bedtime I noticed that his toe was badly swollen.'

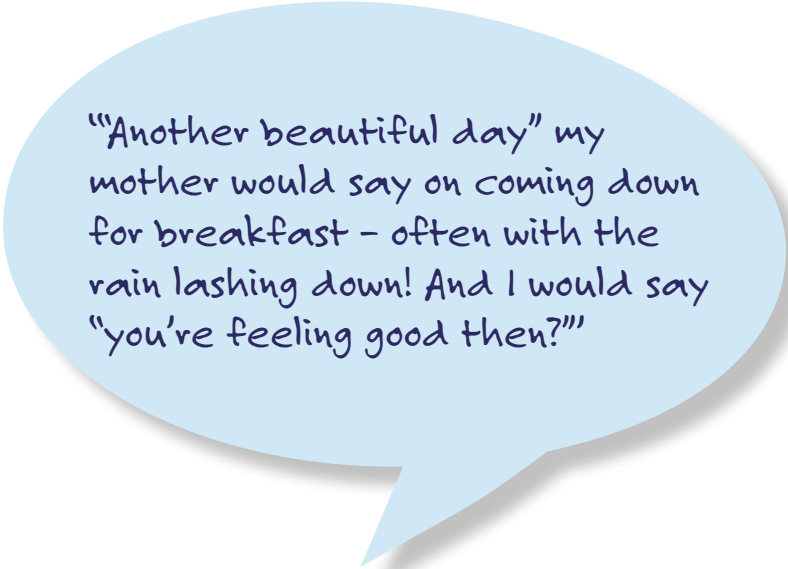
# Confused thinking

As dementia progresses the person's thinking becomes more mixed up. They may confuse memories of the past with the present. They may confuse facts with imaginings. As well as using memory aids, there are some good ways of trying to deal with confused thinking.

Dementia can cause difficulties with abstract thought as well as memory problems. For example, the person may find it harder to understand emotions or humour. They may take things literally. Use a flexible approach, depending on the situation.

## What you can try:

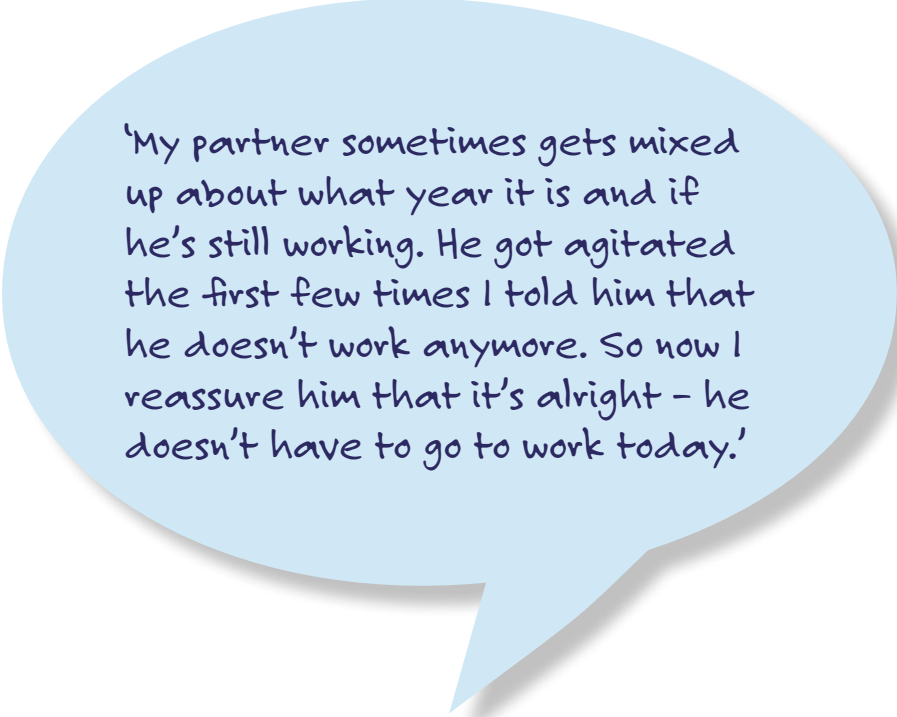
- 1 Try diverting them onto another subject until they forget.
- 2 Respond kindly to the person's feelings without agreeing with what they are saying.



*"Another beautiful day" my mother would say on coming down for breakfast - often with the rain lashing down! And I would say "you're feeling good then?"*

# Confused thinking: at a glance

- Use distraction.
- Talk about feelings the person is showing.



'My partner sometimes gets mixed up about what year it is and if he's still working. He got agitated the first few times I told him that he doesn't work anymore. So now I reassure him that it's alright - he doesn't have to go to work today.'




## Daily living

People with dementia usually find everyday tasks such as dressing or eating harder as time goes on. So they need more help. If you can, try to help the person with dementia to do things rather than doing them yourself. This can take more time, but it helps the person keep as independent as possible. You may have to find a balance between time and effort for you and independence for the person.

### Dressing

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.



'Every time I visited my mum she was wearing the same clothes. We'd argue when I tried to get her to change. So I bought some more clothes the same as the ones she likes and put the clean ones out while she's in bed. We're both more relaxed and happy now.'

## What you can do:

- 1 Allow plenty of time for the person to get dressed. If rushed they may become more confused and upset. Make sure the room is warm and they have used the toilet first.
- 2 As a general rule avoid doing too much for the person. Encourage them to do things for themselves. This will help keep up self-esteem and confidence. Remind the person what to do next if necessary. If that doesn't work, try showing them with actions. Break things down into small steps.
- 3 Allow the person some choice, even if it is limited.
- 4 Lay out clothes in the order they will put them on. If possible, keep to the order that the person was in the habit of using.
- 5 If the person tries to put something on the wrong way, tactfully correct them and give help. Explain what you are doing. The more patient you can be the less likely the person is to become irritable and uncooperative.
- 6 If you have to do most of the dressing for the person, start by putting clothes on either the top or bottom half of their body, then the other half. Don't at any time leave them entirely naked.
- 7 Buttons and hooks may be difficult. You can often replace them with zips or Velcro. Bras are easier to manage if they fasten at the front. Consider self-support stockings or socks.
- 8 If the person is incontinent and needs a great deal of help with dressing, some carers find that track suit tops and trousers can be very useful. They are practical, easy to change, quick to wash and dry and they don't need ironing. But they are not right for everyone – some people with dementia may not feel comfortable or dignified in clothes that are different to what they normally wore. For information about special designs of clothing, contact the Dementia Helpline on **0808 808 3000**.
- 9 The person should only wear slippers for short times. Well-fitting shoes give support and reduce the risk of foot problems.
- 10 Put clothes for washing out of sight so that the person does not put them on again.



# Dressing: at a glance

- Allow plenty of time.
- Don't do too much for the person – encourage independence.
- Lay out clothes in the order the person is used to.
- Allow choice – but you may need to limit it.
- Gently correct any errors in dressing.
- Explain what you are doing when you give help.
- If necessary, alter clothing to make dressing easier.

'When my dad saw all his shirts in the cupboard he just couldn't choose and got confused and upset. So I put most of them in a different place and just left him a couple of his favourites.'

## Appearance and personal care

In time dementia causes the person to forget how to do even basic tasks of personal care. They may forget to clean their teeth or brush their hair. Cutting nails may be a problem and men may have difficulty with shaving. Some people with dementia lose interest in how they look. Of course, many people with dementia do not like to be reminded about these personal tasks. But it is important to encourage the person to do as much as possible for themselves.

- 1 Take notice and compliment the person when they look good. When they need help or prompting, be tactful. Criticism or nagging is likely to upset them.
- 2 Remind the person when necessary about cleaning teeth. It may help if you clean your teeth at the same time to remind them what to do. You may need to clean the person's teeth or dentures as their illness progresses.
- 3 Dental care is vital. Ensure regular check-ups. Ask about the home dental service if visits to the dentist become too difficult. (Contact the Health Board if the person's own dentist is unable to visit.)
- 4 Remember to check finger and toe nails regularly. Cut them or file them if the person can't. Make sure that the person's feet are washed daily and moisturiser applied if their skin is dry. Footwear should be checked for fit, wear and safety. There are films and information available that can help individuals and carers to be confident in providing personal footcare on **[www.lookafteryourfeet.info](http://www.lookafteryourfeet.info)**
- 5 A trip to the hairdressers or a shampoo and set at home may help the person feel good. So can make-up and nail varnish if they use it.
- 6 Men may need to be reminded to shave each morning. Using an electric shaver is safer and may allow the person to shave himself independently for longer. Later in the illness he may find it hard to learn to use a new kind of razor. If he keeps using a traditional razor, you will need to supervise shaving. You may even have to do it for him.

# Appearance and personal care: at a glance

- Compliment the person when they look good.
- Remind the person about cleaning teeth or shaving.
- Show the person what to do if they get mixed up.
- Encourage men to get used to an electric shaver early in the illness.
- Keep up regular dental and hair appointments.

'My mother gets a great boost from her weekly trip to the hairdresser. I try to make sure that she has a touch of make-up and nail varnish. She always used to wear it and I think it makes her feel more self-confident.'

# Bathing

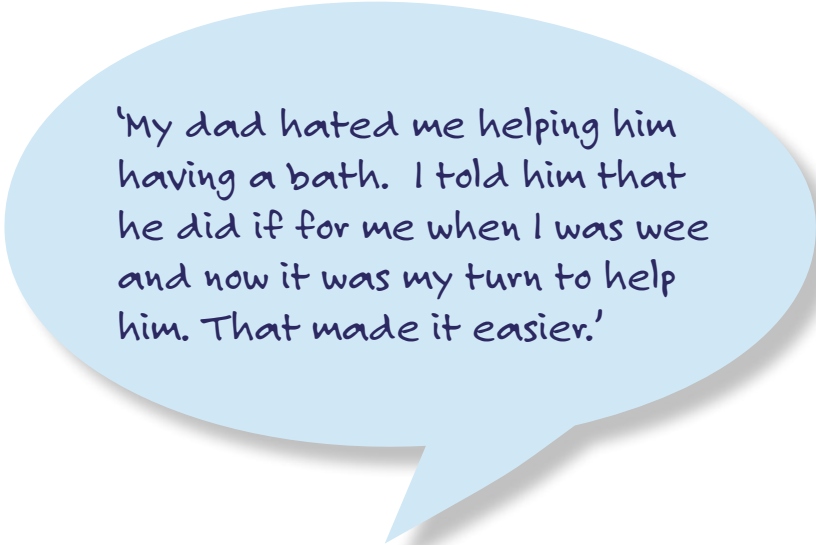
It may be difficult to persuade the person with dementia to have a bath. They may believe that they have recently taken one, when you know they haven't. Bathing itself can have its problems. Some people forget how to wash themselves, wash one area several times and forget others, forget to use soap or forget to rinse off the soap. The person may not like being supervised. Help with such intimate care can be difficult for both you and the person with dementia, especially if you are caring for someone, such as a parent. Try talking about it with the person. Reassure them that you are there to help.

## **What you can do:**

Try to make bath-time as pleasant as possible. Allow plenty of time and ensure that the bathroom is warm. All sorts of little things might help to make bathing more relaxed. Try music or bubble bath, for example. If the person is unwilling to bathe, it may help just to run a bath and offer it to them, rather than ask them about it beforehand.

- 1 Use a non-slip rubber mat in the bath and ensure that the flooring beside the bath is non-slip.
- 2 You may have to help the person in and out of the bath. Various aids may be available. A bath seat might help. Hand rails on the side of the bath make it easier for the person to get in and out. Ask the occupational therapist or nurse.
- 3 Put a chair beside the bath for yourself.
- 4 If the person uses the bathroom alone, make sure the door can't be locked, or that the lock can be opened from outside in an emergency.
- 5 There are many new shower unit designs which some carers find useful.
- 6 Ask the occupational therapist. But a shower may upset the person with dementia if they are not used to them.
- 7 There are products (eg No Rinse) which can be used for personal hygiene in place of conventional shampoos.

- 8 Washing intimate areas of the body is important, but can feel embarrassing. Often this can feel especially awkward if you are helping a parent of the opposite sex. Try giving the person the cloth or sponge and guiding their hand. Some people find it easier to be bathed by someone they don't know, such as a nurse or care assistant.
- 9 If bathing is difficult or distressing, think about whether the person has to have a bath. Is it necessary for hygiene, or would an all-over wash do instead?
- 10 If you cannot deal with bathing or showering, for example if you and the person don't feel comfortable about it, or if you need to lift the person, ask your health visitor, doctor or social worker for advice. Sometimes the district nurse or a home care assistant may be able to call in and help. Different areas have different arrangements for bathing services. People who go to a day hospital may be able to have a bath there if bathing at home is not possible, and some day centres offer baths or showers.

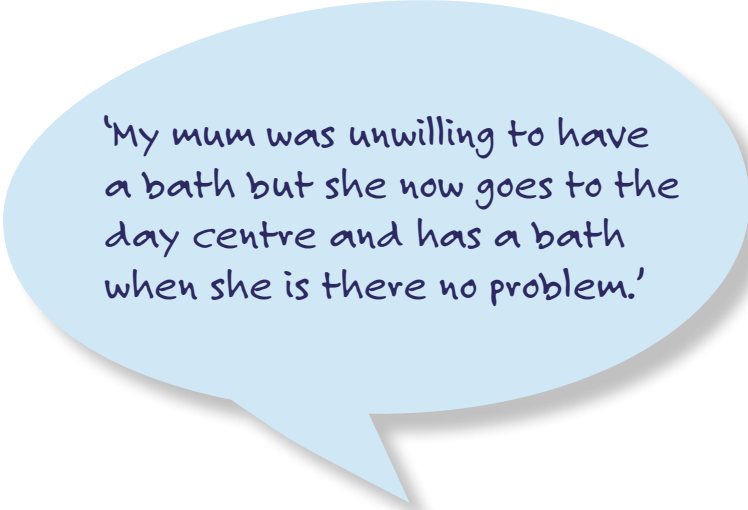


'My dad hated me helping him having a bath. I told him that he did it for me when I was wee and now it was my turn to help him. That made it easier.'



# Bathing: at a glance

- Supervise bathing as required.
- Make bath-time as pleasant as you can and give reassurance.
- Use bath aids to make bathing easier and safer.
- Ask for advice and help.



'My mum was unwilling to have a bath but she now goes to the day centre and has a bath when she is there no problem.'


# Managing continence

Some people with dementia may become incontinent of urine (wet themselves). Bowel incontinence is not common until very late in the illness.

If the person becomes incontinent, don't just accept it as part of the illness. Often the person may not be truly incontinent at all. They may have forgotten the way to the toilet or how to recognise the toilet. Or they may not recognise the feeling of a full bladder. Establishing a regular toilet routine may be necessary if the person is ignoring or not recognising the urge to go to the toilet. A physiotherapist can often work with the person with dementia if the person has urge incontinence as a result of stress, and they may be able to provide simple exercises to combat this.

Incontinence of urine 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. Physical problems can often be put right. Consult the person's doctor or community nurse.

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 through the day and bed-linen at night. Ask the doctor if there is a continence adviser in your area and ask about incontinence aids. Call the Dementia Helpline for an information sheet on continence management.



'My mother would try every door looking for the toilet so I put a notice on the door which said "Ladies" and she had no problem finding it. A picture of a toilet can also help.'

## **What you can do:**

- 1 Consult the doctor about the problem. Ask for an explanation of the cause, after they have examined the person and done tests.
- 2 If the incontinence cannot be treated, ask for an assessment by the community nurse or continence adviser. The nurse or adviser can supply appropriate aids, such as pads, pants and protective bedding.
- 3 Don't just go out and buy your own supplies. The person is entitled to incontinence equipment if they have a medical need.
- 4 Watch for any restlessness or agitation. These may be signs that the person needs to go to the toilet, but they may not realise this.
- 5 To reduce embarrassment, take a very matter-of-fact approach. Avoid making an issue out of the problem.
- 6 It may help if you remind the person to go to the toilet at regular intervals. The timing will vary from person to person. Try keeping a chart of when they need the toilet to help work out a routine.
- 7 It may help to have a sign on the toilet door, or just to leave the door open so that they can see the toilet. Leave a light on at night to help the person find the way.
- 8 Zips or buttons may be too awkward for the person to manage. If this is a problem, clothes with Velcro fastenings might help.
- 9 If the toilet is not easy to get to, it may help to have a commode. Ask the community nurse.
- 10 It is dangerous for anyone who is incontinent to use a standard electric blanket.
- 11 Sometimes soiling is caused by severe constipation. Constipation may be caused by a poor diet. A well-balanced diet with plenty of fibre (roughage), such as fruit, vegetables, whole-wheat bread and cereals helps prevent constipation. Make sure the person has enough to drink. This also helps prevent constipation. Don't use laxatives unless the doctor has prescribed them.
- 12 In some areas there is a laundry service to help with soiled linen. Contact your local social work office.

# Managing continence: at a glance

- See the doctor first of all.
- Don't make a big issue of incontinence.
- Try occasional reminders or regular toileting.
- Agitation may mean that the person needs to go to the toilet.
- If buttons or zips cause problems, replace them with Velcro.
- Ask your community nurse about aids.
- Make sure the person knows how to get to the toilet.
- Avoid constipation with a good diet.
- Get help with laundry if available.
- Don't use an electric blanket for someone who is incontinent.
- Don't use laxatives unless the doctor has prescribed them.

# Eating and drinking

People with dementia may have poor appetite. They may not be very interested in eating. Some people with dementia seem to lose weight even when they are eating properly. They may be confused about whether they have eaten or not.

Some want to start on the next meal as soon as they finish one. They may lose their table manners and become messy in their eating habits. They may have difficulty using cutlery. Eating certain foods can be a problem particularly if someone's dentures don't fit well. Too little to drink causes dehydration. This can cause constipation and make the person exhausted and more confused.

Some people have difficulty swallowing, which may stop them from eating properly. A speech and language therapist can work with the person to reduce this difficulty.

Where possible, try and 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.

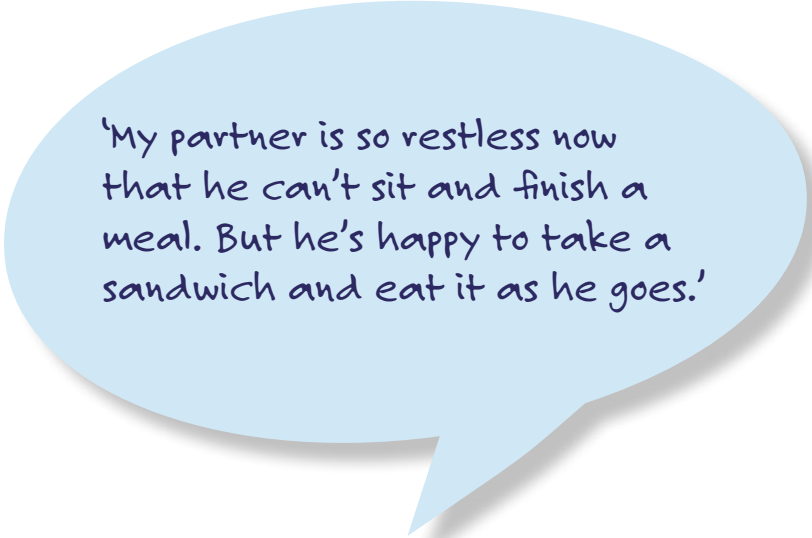
## **What other carers have suggested:**

- 1 Allow plenty of time for meals. Make sure meal times are pleasant and enjoyable.
- 2 Tell the person which meal it is and what there is to eat. You may have to remind the person how to eat by prompting them to pick up the fork or spoon.
- 3 As far as possible avoid feeding someone who has difficulty. This encourages the person to be more dependent than necessary. But sometimes spoon feeding may be needed.
- 4 Try not to worry too much about table manners. Allow the person to feed themselves even if it is messy. Plastic table cloths are very practical.
- 5 If weight loss is a problem put out snacks. If the person is restless, provide tasty finger foods so that they can eat and walk around at the same time.

- 6 See that the person gets enough to drink. They need at least eight cups of fluid a day. This can include soup and fruit juice as well as tea and coffee. Fluid intake should be increased by 1–2 cups when the weather is hot, the person has an infection or if they are sitting for long spells with central heating up high, as this can increase fluid needs.
- 7 If the person has dentures, glasses or a hearing aid check that they are in place and fit properly.
- 8 Make forks and spoons easier to grasp by wrapping the handles to make them thicker. If forks are difficult, the person may be happier using a spoon. If cutlery is confusing, try placing one item such as a spoon or a fork in the person's dominant hand. You may also need to use a spill-proof cup.
- 9 Try having the main meal in the middle of the day. This may help reduce night time indigestion and discomfort. It may also help the person sleep better.
- 10 For people living alone, or alone during the day, try leaving out cold food, such as ham, cheese, sandwiches or flasks of hot food. Don't leave cans and packets that are hard to open. However, the person may not eat food that you leave for them. If this is a problem, perhaps a care assistant could come in at lunch time to make sure the person eats. Remove any unused food on a regular basis to avoid it going off.
- 11 Labelling food and setting mobile phone reminders can be helpful to remind the person to eat.
- 12 If someone loses weight despite eating well, or seems to have lost their appetite, consult the doctor. It may be due to dementia or to another medical problem or require specialist help from a community dietitian.
- 13 Deliberate use of colours can help to support the person. The colours of the food, plate and table should be different. Avoiding patterned plates is important.
- 14 Glass- or perspex-fronted cupboards or fridges can be useful so the person can see the food.

# Eating and drinking: **at a glance**

- Allow plenty of time for eating.
- Make sure dentures fit well.
- Say what meal it is and what they will be eating.
- See that the person gets a balanced diet and enough fluid.
- Use snacks and finger foods.
- Find out about meals on wheels or use reminders about eating.
- Ask the doctor or nurse for advice.
- Refer the person to a dietitian if necessary.



'My partner is so restless now that he can't sit and finish a meal. But he's happy to take a sandwich and eat it as he goes.'

# Psychological issues

## **Apathy and loss of interest**

People with dementia often 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 the person you care for busy and happy.

Some people with dementia may be depressed. This can be treated. If you think the person you care for is depressed, seek medical advice. But even without depression, apathy is common in dementia.

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

- 1 Try to make sure that each day has something of interest for the person with dementia. It might be going for a walk, listening to favourite music, a game of cards or gardening – anything which the person enjoys.
- 2 Involve the person with dementia as far as possible in choosing what to do.
- 3 Help the person with dementia do whatever jobs around the house or garden they can manage. Doing these tasks can help the person to feel useful – even if you have to go over the work again later yourself. Try to get other people involved. A chat with old friends, perhaps talking about the past, can help to raise the person's spirits.
- 4 If you do suggest gardening, remember to store compost in a cool place and open carefully in a well-ventilated area, ideally outdoors. Gardeners should wash their hands immediately after handling compost.





# Apathy and loss of interest: at a glance

- Plan something of interest each day.
- Involve the person with dementia in planning as far as you can.
- Encourage the person to do tasks around the house.
- Get friends to help.

*'Over the last year, my mother has found it difficult to get herself organised to do things. She was sitting in her chair most of the day. But I find that she'll enjoy doing things like sorting out her sewing box as long as I get her started.'*

## Hallucinations and delusions

Some people with dementia may hear or see things which are not there (hallucinations). This is especially common for people with Lewy body dementia. Some may believe things which 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. Or someone may think things have been stolen because they have forgotten putting them away.

These may not be true hallucinations or delusions, but they can still be upsetting or frightening, and the person will need reassurance.

### What you can do:

- 1 If the person starts to get hallucinations, make sure they see the doctor. The problem may be caused by an infection which can be treated. Or it may be a side effect of medicines. Or the doctor may be able to prescribe medicines to stop the hallucinations.
- 2 If the person misunderstands what they see, try explaining what it really is. Or change the source of the problem. There may be a simple solution. For example, turn on a light or close the curtains.
- 3 If the person is really hallucinating, they are experiencing something which is not there. It is pointless to tell them they are imagining it, because it is real to them. Be sympathetic and reassuring. Explain that you cannot see or hear what they can, but that you understand how they feel. Touch and comfort the person in a calm and reassuring way. This may help bring them back to reality.
- 4 If the person thinks someone is stealing, first check whether this is true. It may not be a delusion – just because someone has dementia does not necessarily mean they are mistaken. Someone who lives alone may be very vulnerable to people who take advantage. If you are sure that the person is deluded, talk to children, home support workers and anyone else who they may accuse of stealing.

# Hallucinations and delusions: at a glance

- Get help from the doctor.
- Explain what is really there if this helps.
- Reassure the person.
- Look for practical solutions, such as closing the curtains.
- Explain the situation to others.

*'If my husband addresses remarks to someone he thinks is sitting beside him, I don't laugh or say there's no one there. I take it calmly and say "Are you sure there's someone there? Is it not the pattern on the curtains?"'*

## **Depression and anxiety**

People with dementia may suffer from anxiety or depression. Anxiety is more common earlier in the illness, when the person is more aware that something is wrong. The person may seem agitated and keep asking the same questions.

Someone may become depressed because the dementia is causing problems like isolation and difficulty in coping. The side effects of drug treatments, physical illness and tiredness can also have an effect.

Because the symptoms of depression and dementia can be similar, it can be hard to know if someone with dementia is depressed. But you might notice them becoming more withdrawn, not sleeping well, lacking energy and interest in things, being more emotional or confused than usual or seeming sad.

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

1. Both depression and anxiety can be treated, so it is important the person sees their doctor.
2. Reassure them if they seem anxious.
3. A regular routine can help someone feel more secure.
4. Some people will enjoy stimulating and social activities, but other people may at times feel overwhelmed. Try different things and see what they enjoy.
5. Doing things they enjoy is worthwhile, even if they don't remember them afterwards.
6. Say positive things to the person as often as you can. Try to do any important tasks at times of day when the person feels at their best.

# Depression and anxiety: at a glance

- Make sure the person sees their doctor if they seem anxious or depressed.
- Be reassuring if the person seems anxious.
- Keeping to a routine may help the person.
- Be positive.

'I think the thing that made my Mum feel at her lowest ebb was when she was confronted by the things that she couldn't do any longer. So we concentrated on keeping her involved in things she'd always enjoyed doing, but in a subtly supportive way.'

# Keeping connected

Many carers find changes in the behaviour of the person they care for very difficult to handle. But there are a few basic ideas which may help. The person is more likely to feel better in a familiar environment. Try to help them feel secure.

The next few pages cover some of the common difficulties faced by people with dementia and their carers, and some possible solutions. No solution will work for everyone. Try different things until you find what works best.

## Walking about

Many carers worry about people with dementia walking about. This type of behaviour is often referred to as wandering. However, this term is unhelpful because it suggests aimlessness, whereas walking about often does have a purpose. For example, the person may be looking for the toilet, feel the need for exercise or have another perfectly good reason for walking about.

If you are worried about the person you care for, ask yourself first whether 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 the person is at risk if they go out at night but not during the day? Is it a problem if they walk around the house restlessly? Perhaps walking around the house is no problem but going out is a worry. It is important to give the person as much freedom as reasonably possible – even the freedom to take a risk sometimes.

Call the Dementia Helpline for more information on **0808 808 3000**.





## What you can do:

- 1 Make sure the person gets enough exercise. Try exercise to music or going out for a walk together.
- 2 Keep a current photograph of the person in case they get lost. Try to use an everyday photo rather than one taken at a wedding or party when they are more dressed up than usual.
- 3 If the person is likely to get lost or be at risk outside, you may have to stop them from going out alone. Try fixing a bell to the door (like a shop doorbell) or wind-chimes or an alarm pad under the mat to alert you if they try to go out. Some areas have access to tracking devices which use satellite technology (GPS) to help trace people who are lost. Ask your social worker or community psychiatric nurse.
- 4 Locking or bolting the house door to stop them going out is dangerous if they are in the house alone. If they are never at home alone, a bolt at the bottom of the outside door where they may not look could stop them going out by themselves. But not being able to open the door can make some people with dementia panic or could delay people getting out in an emergency.
- 5 If the person tends to get lost, see that they have identification, such as a card, bracelet or pendant. It should show their name and a contact phone number. For security reasons, do not put their address on it. The person can carry the Helpcard in the back of this booklet and show it to someone if they get confused. The Helpcard also has a space for contact details for emergencies. For more Helpcards, call the Dementia Helpline on **0808 808 3000**.
- 6 If the person is lost or missing, alert the police and provide a photograph.

## Day-time:

- 1 Try to find activities which will hold the person's interest. Walking about is less likely if they have something to do.
- 2 If the person enjoys going for a walk, it is important they can. If they are not safe alone and you can't go along, ask friends or volunteer helpers. Or enquire about tracking devices which use satellite technology (GPS) to help trace someone who is lost. Ask your social worker or community psychiatric nurse.
- 3 If the person with dementia insists on going to see someone who is no longer alive, it is sometimes a good idea to go along too. Gradually divert their attention to things you see or some other topic. Then suggest that it is time to go home. The person may have forgotten the reason for the outing.
- 4 Playlist for Life encourages families and caregivers to create a playlist of meaningful music which can be played on an ipod to the person experiencing dementia. Visit **[www.playlistforlife.org.uk/#2649](http://www.playlistforlife.org.uk/#2649)**

*'My sister used to go out at all hours. I was worried because she's forgotten how to cross the road safely. I put a big notice on the door to remind her not to go out on her own and it seems to work most times.'*

## Night-time:

- 1 If the person is restless or wants to go out at night, it may help if you increase day-time activity and discourage long sleeps during the day.
- 2 Make sure that the person has been to the toilet before going to bed.
- 3 If the person with dementia is restless, make sure they are comfortable and warm. Reassure them about where they are.
- 4 Leave a dim light on in the bedroom or passage to reduce confusion if the person wakes up in the dark.
- 5 Try to make the house as safe as possible so that you don't have to worry about the person walking around at night. For example, the occupational therapist may be able to provide an adult stair gate. Lock the kitchen door at night. Put on safe background heating.
- 6 The occupational therapist may be able to suggest other equipment to help, such as an alarm pad which will tell you if the person gets out of bed, or gas shut-off valves.
- 7 In some areas a night care service may be available. Call the Dementia Helpline on **0808 808 3000** for information, or check with your social work department, Crossroads Caring Scotland, local carers service or Alzheimer Scotland. In certain circumstances the night nursing service may help – ask the doctor about this.
- 8 If the person keeps going out and is not safe, ask the doctor for a specialist assessment. Occasionally medication may help but it should not be the doctor's first thought.

# Walking about: **at a glance**

- Don't try to prevent walking about if there is no real risk.
- Keep a current photograph.
- Make sure the person gets exercise.
- You may have to stop them from going out alone.
- Give the person identification, such as a card, bracelet or pendant.
- If the person is lost, tell the police at once.
- Go along for a walk too and try distraction.
- Make sure they are comfortable and warm at night and reassure them.
- Try to make the house as safe as possible.
- Ask about equipment and services, for example GPS technology.

'When he has gone to a nearby shop, and not come back, I have to go out searching. I keep my cool when I find him. Sometimes he smiles and says "I'm glad to see you, I've had a long walk."

## Needing attention

Some people with dementia want to be with their carer all the time. Someone with dementia may follow their carer from room to room, and get very distressed if the carer goes out.

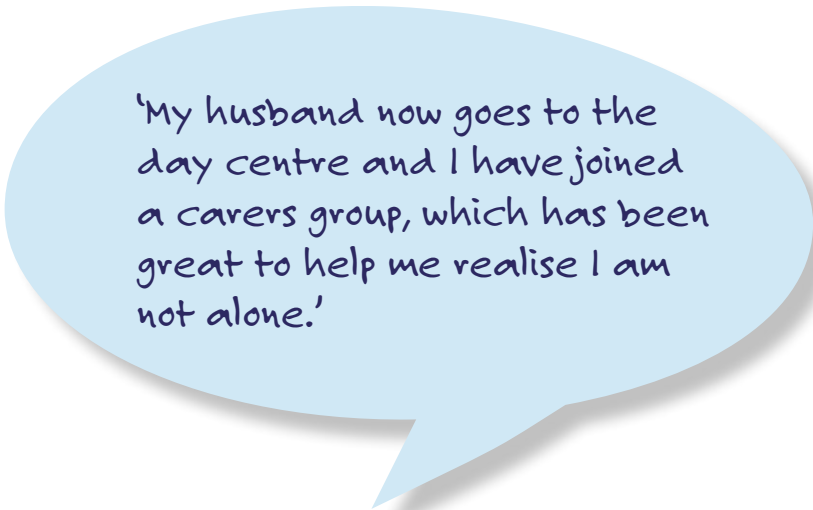
### What you can do:

- 1 Remember that the person is feeling insecure and offer plenty of reassurance.
- 2 Remember that your wellbeing is important too. You will find it easier to cope with the person's need for attention if you get some time off.
- 3 Ask for help from family and friends to spend time with the person to give you a break.
- 4 Consider a day care or home support service (see **Getting help**, page 122) to give you time off.

*There were times when I found it very hard. She would follow me around everywhere, driving my patience to its limits. But now she goes to a day centre, which she loves, and I get two days a week to myself.'*

# Needing attention: **at a glance**

- Reassure the person.
- Arrange for breaks.
- Ask for help from family and friends.



'My husband now goes to the day centre and I have joined a carers group, which has been great to help me realise I am not alone.'

## **Frustration or aggression**

Some people can feel frustration or fear because the situation reminds them of something upsetting from their past.

Verbal abuse is more common than physical aggression. The person may shout or make accusations or threats. It can be quite a shock if a quiet and gentle person starts to be aggressive.

The person may become aggressive because they are frustrated at not being able to do things they used to be able to do. Or they may misunderstand what is going on. Sometimes someone with dementia may overreact to something very minor. The part of the brain that would normally control their reaction may be damaged.

Some people with dementia may be aggressive only to their carers. Perhaps this is because the carer is closest to the person. Many people are more polite to strangers than to people they are close to. This may be very hard to cope with.

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

- 1 Remain calm if you can, though this is easier said than done. Remind yourself that it is not the person's fault, but the illness making them aggressive or angry. Try not to take it personally. The person will probably quickly forget the anger and upset.
- 2 Speak calmly and gently, and try to keep a calm and pleasant expression. Perhaps hold the person's hand. Touching someone can be a good way to help some people feel less isolated, but other people may not like it.
- 3 Remind the person what is going on around them and what will happen next and why. They are less likely to be frightened if they understand what is going on.
- 4 Focus on the things the person does well rather than on mistakes or failures.
- 5 Distract the person's attention away from the situation.
- 6 If the person is gripping you, try not to struggle. Stay calm and try to defuse the situation.

- 7 Try not to get into an argument or get angry yourself. This will only make things worse.
- 8 Afterwards, try to work out what caused the upset and see if there is anything you can change. For example, were they frustrated at failing to do something? If so, perhaps you can make the task easier or avoid it altogether. Explain to other people, such as children or home care workers, that the anger or accusations are caused by the illness.
- 9 Talk to someone you trust, such as a friend, community psychiatric nurse, social worker or the Alzheimer Scotland 24-hour Dementia Helpline.
- 10 Coping with aggression, especially from someone you love, is very stressful. Ask the doctor for a specialist assessment if you are worried.
- 11 Remember, aggression does not last forever. The person you care for will probably change with time and stop being aggressive.



# Frustration or aggression: at a glance

- Keep calm.
- Try to defuse the situation.
- Distract the person.
- Don't get involved in an argument.
- Work out what triggers angry outbursts and try to avoid it.
- Focus on successes.
- Talk about aggression problems with someone you trust.
- Tell the doctor.

# Embarrassing and odd behaviour

Sometimes someone with dementia may do things that are embarrassing to you. The person will not realise that what they are doing is odd. For example, the person may start to use swear words at embarrassing times, or spit or be rude to visitors. They may do things at the wrong time, such as start to undress in public. Some embarrassing or odd behaviour may happen because the person is confused about where they are or forgets what should be done when. For some people, the illness may damage the part of the brain that controls their inhibitions, so that they just don't realise that they should not swear in company, for example. Some things the person does may be irritating rather than embarrassing. For example, they may fidget or start to hide things. Try to think about whether the behaviour really matters, and if so, why. Sometimes you might just be able to learn to live with it.

## **What you can do:**

- 1 Explain what is happening to other people. They will usually understand.
- 2 Don't overreact. For example, if the person starts to undress in company, calmly take them to another room. Make sure that their clothes are comfortable. Check that they are not too hot or wanting to use the toilet.
- 3 If the person fidgets, try finding them something to do, or just try to ignore the habit. If they fidget with clothes, try giving them a handkerchief instead.
- 4 If the person hides things, put important items in a safe place. In time you will get used to where they put things. It may be a good idea to remove keys from drawers and cupboards.
- 5 Remember, it is the illness causing the odd behaviour, not the person doing it on purpose.

# Embarrassing and odd behaviour: **at a glance**

- Remember that it is the illness causing the person to behave in this way, and explain this to other people.
- Deal with the situation in a matter-of-fact way.
- If the person tends to lose or hide things, put important items in a secure place.

'My father sometimes thinks that I'm my mother and climbs into bed with me. The first time I was upset and not sure what to do. But I talked it over with the community psychiatric nurse and now I leave the room and then come back in saying "Hello dad", to remind him who I am.'

## Sex and intimacy

The person's attitude to sex and sexual relationships may change. People with dementia may sometimes lose interest in sex altogether, or want sex more often than before.

If you are caring for your partner, you may feel differently about sex too. Your relationship may have changed now that you are a carer. You may find that dressing and toileting your partner make it hard to have sexual feelings too. Your partner's personality may have changed.

You may want to carry on your sexual relationship but worry about whether you should. Some partners who continue with a sexual relationship worry that they are taking advantage of the person with dementia. You can usually tell from the person's behaviour whether this is so. Continuing a sexual relationship may help both partners feel closer.

Sometimes someone with dementia may make a sexual approach to someone who is not his or her partner. This might be because the illness has damaged the part of the brain which controls inhibitions.

Or the person might have mistaken someone for his or her partner. Or it may just be that the person wants the comfort of touch and closeness.

Any changes to do with sexual behaviour can be confusing and hard to accept. Sex and relationships can be difficult to talk about, but try to discuss the situation with a professional you trust. Or you can call the Dementia Helpline confidentially and anonymously on **0808 808 3000**. They can send you a free information sheet about sexuality and dementia.

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

- 1 If you can, give the person plenty of physical contact. Hold hands, or give a hug or a cuddle.
- 2 If the person approaches the wrong person sexually, stay calm and try to distract and reassure him or her. Remember this is caused by the illness and is not the person's fault.
- 3 Talk to someone about any problems. Your doctor, local marriage or relationship counselling service or Alzheimer Scotland contact may be able to help, or be able to put you in touch with someone who can. They will not be surprised or shocked. Call the Alzheimer Scotland 24-hour Dementia Helpline to talk it over confidentially. You don't need to give your name.

# Sex and intimacy: **at a glance**

- The person's attitude to sex and intimacy, and their behaviour, may change because of the dementia.
- Discuss problems with someone you trust.
- If you can, give the person plenty of physical contact, such as hugs and cuddles.

*'My wife and I had a very close physical relationship, but since she was diagnosed about four years ago she has gradually lost interest. It bothered me a lot at first, but we still share a bed and that helps me feel close to her. It's something I have come to accept.'*

## 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 wandering. 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 problems.
- Clear pictorial signs on doors to the kitchen or toilet may help them find their way around the house.
- Use contrasting tone for things like door frames, doors and walls, or walls and carpets, may be helpful to reduce confusion, as edges can often become difficult to navigate if all the same colour.
- Use contrast of colour or tone to make switches clear.
- Reduce clutter on surfaces and only leave essential items on worktops.
- Repair loose banister 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 you don't bump into things at night.
- Install extra lights and stronger bulbs for good, even lighting, 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

## Safety in the home

Dementia increases the chance of accidents. It is hard for carers to know how far they should go in trying to protect the person with dementia (or others) from possible risks. It is worth taking a few simple steps to prevent accidents. But you cannot remove all dangers. You can't avoid a certain degree of risk if the person is to keep some independence. 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 use a gas fire safely? If there is a danger, such as a burning pan, do they react appropriately or not? Ask an occupational therapist for help if you are worried.

### What you can do:

- 1 Check the home for anything which might cause a fall. Repair or secure any loose banister rails, slippery floor mats and loose carpet edges. Check for badly placed furniture.
- 2 Electrical appliances and plugs need to be checked regularly. Make sure that cables and wires do not trail across floors. If the person is incontinent don't let them use an electric blanket.
- 3 Check that bright enough lights are used throughout the house. Use electric night lights to help the person find the way about at night.
- 4 Fit smoke alarms and make sure neighbours know they are there.
- 5 The lighting of steps and stairs is very important. You can paint the edge of outside steps with a white line to make it easy to see. An extra hand rail on the stairs can be very helpful.
- 6 Have hand rails fitted on the bath and by the toilet and put a nonslip mat in the bath or shower.
- 7 Use a guard in front of any fire. The large 'nursery' type is best, hooked onto the wall or fireplace.

- 8 Get gas appliances checked for leaks. Your gas company should be able to help – for example, British Gas has a Gas Care Register for people who are disabled or over 60 and living alone or with other people over 60. This gives the right to a free safety check every year.
- 9 Keep cleaning fluids, bleach, paints and so on out of reach. Some people with dementia may mistake them for ordinary drinks.
- 10 If the person cooks or lights a fire, make sure they can still do this safely. Put large clear instructions beside the appliance. If the person cannot use appliances safely make sure that they only use them when someone is there. Using only one gas ring lessens the danger. Your gas company can arrange this. An automatic electric kettle may be useful if the person can learn to use it.
- 11 If the person becomes unsafe with a gas fire, it may be better replaced. Some carers recommend an oil filled electric radiator or an electric heater on a timer switch.
- 12 Ask an occupational therapist for help. He or she should be able to tell you about aids and equipment, such as devices to turn off taps if they are left on.
- 13 Ask the social work department about alarm systems. In some areas systems are available which can help someone who lives alone even if they can't sound an alarm themselves. For example, they might alert someone if a tap is left running, or if the person doesn't get out of bed at their usual time. Home fire safety checks are carried out by Scottish Fire and Rescue.

**[www.firescotland.gov.uk/your-safety/for-householders/home-fire-safety-visit.aspx](http://www.firescotland.gov.uk/your-safety/for-householders/home-fire-safety-visit.aspx)**

# Safety in the home: **at a glance**

- Check for risks and make repairs as needed.
- Fit smoke alarms.
- Make sure lights are bright enough.
- Use fire guards.
- Keep bleach, paints and so on out of reach.
- Make sure that the person can use heaters and cookers safely.
- Ask for advice from the gas supplier.
- Remember that you can't prevent all risks. The person needs freedom too.
- Ask an occupational therapist about safety and new technology to support the person with dementia.

*'My father's neighbour was worried about him using his gas cooker because a couple of times he forgot to light it. I talked to the gas board, who fitted a gas isolation tap.'*

## Driving

Generally people with moderate to severe dementia will not be able to drive. However, some people early on in the illness may continue to drive safely for a while. If you are not sure if the person is safe to drive, and they still want to, their doctor can refer them to the Scottish Driving Assessment Service to check if they are still safe to drive. You must tell the insurance company and the DVLA about a diagnosis of dementia. Driving without a valid insurance is a criminal offence.

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. They will check with their doctor and if necessary they can take away the person's licence. Call the Dementia Helpline for an information sheet about driving and dementia.

### What you can do:

- 1 Encourage the person to get used to other transport, such as buses and trains.
- 2 Raise the subject of driving tactfully. Point out the hazards. If possible, also point out the benefits of not having to drive.
- 3 If the person does not want to stop driving, ask other carers how they handled the problem.
- 4 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.
- 5 Make other arrangements for transport. Try to make up a rota of drivers or suggest using buses. Some groups, such as the RVS, may be able to help with transport. Check with the social work department, as some local councils have taxi schemes for people with disabilities.
- 6 Some taxi firms allow journeys to be paid on account, which can be very useful for independence. It can be helpful to point out to people that the savings made on running a car can be used for taxis.

# Driving: at a glance

- Ask the doctor if the person is safe to drive.
- Tell the insurance company and the DVLA of the person's diagnosis.
- Discuss with the person with dementia when driving should stop.
- Consider other ways to travel.

'My mother used to rely on her car and didn't want to stop driving. But I could see that she wasn't safe any more. In the end it was the doctor who told her she'd have to stop.'

'I tried to get my husband to stop driving but he wouldn't. I was worried in the car with him. It was very difficult until the doctor told him to stop driving.'

# Smoking and alcohol

Having a diagnosis does not mean that you can't enjoy an alcoholic drink, as long as you are sensible about it and don't have a condition that is affected by alcohol, such as Korsakoff's syndrome (see **Appendix 1**, page 172). However, it is very important that you check with your doctor first, as some medication can have a negative reaction when mixed with alcohol. Be aware alcohol may cause slight loss of mental alertness and for a person with dementia such a loss has a greater effect. It could increase confusion so some care and supervision may be required.

To reduce the risk of damage to your health, UK Government guidelines recommend that men should not regularly drink more than three to four units of alcohol a day and no more than 21 units a week. Women should not regularly drink more than two to three units a day, and no more than 14 units a week. The guidelines also suggest having at least two days a week without alcohol.

New guidelines published in January 2016 are currently out for consultation. Further information can be found here: [www.gov.uk/government/consultations/health-risks-from-alcohol-new-guidelines](http://www.gov.uk/government/consultations/health-risks-from-alcohol-new-guidelines)

Further support is available locally to provide help and advice around substance craving – ask your clinician or support worker for more information.

Smoking damages your health generally and adds to the risk of stroke, which puts you at higher risk if you smoke when you have vascular dementia. If you can, try to give up – there is plenty of support to help you quit, ask your community psychiatric nurse (CPN).

## What you can do:

- 1 Try to persuade the person with dementia to stop smoking or cut down. Many people with dementia forget to smoke and then do not miss the habit once it is broken. Ask about local smoking cessation support services.
- 2 Some people smoke more when they are bored, so try to make sure the person has plenty of company and stimulation.
- 3 Make sure they do not abandon lighted cigarettes or throw them away in wastepaper baskets. Stop the person from smoking in bed if you can.
- 4 Put big ashtrays everywhere. Put an ashtray at hand height beside the person's favourite chair. Replace wastepaper baskets with metal bins
- 5 Fit smoke alarms in all rooms. 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.
- 6 Keep matches out of reach.
- 7 Buy flame-resistant clothes and furniture.
- 8 If the person is using nicotine patches make sure they do not smoke, as this increases the health risks.
- 9 Don't leave alcohol where the person with dementia can help themselves. The person may not remember how much they have had. You may have to lock alcohol up or hide it.
- 10 Ask the doctor's advice about whether the person can have any alcoholic drink and, if so, how much. This is essential if the person is taking medicines.



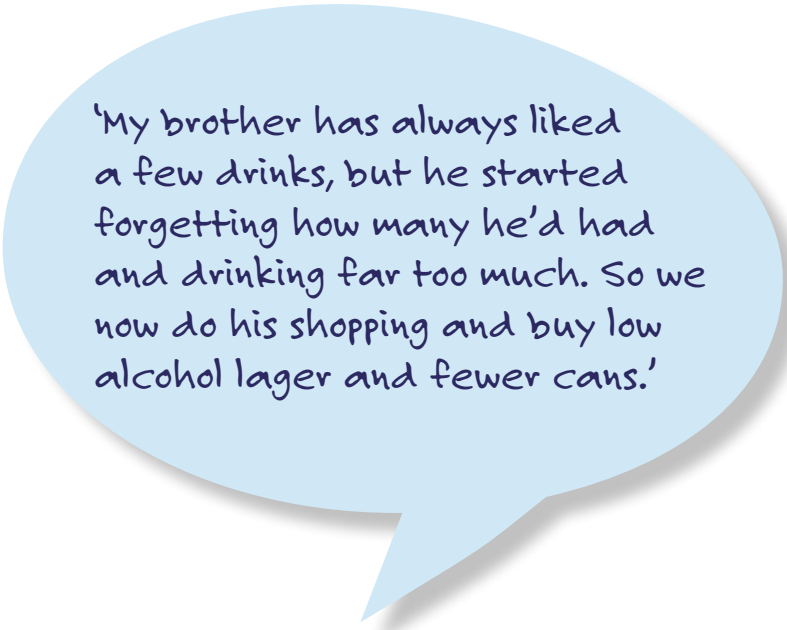
### Further information

Alzheimer Scotland factsheet, *Healthy living with dementia*. Go to [www.alzscot.org](http://www.alzscot.org) or call the dementia helpline on **0808 808 3000**.

For more information about how many units are in a drink. [www.healthscotland.com/documents/5843.aspx](http://www.healthscotland.com/documents/5843.aspx)

# Smoking and alcohol: at a glance

- Try to persuade the person with dementia to stop smoking.
- Keep matches out of reach.
- Put big ashtrays everywhere.
- Fit smoke alarms.
- Don't leave alcohol where the person can drink unsupervised.
- Ask the doctor whether the person should drink alcohol.



*'My brother has always liked a few drinks, but he started forgetting how many he'd had and drinking far too much. So we now do his shopping and buy low alcohol lager and fewer cans.'*



# Medicines

You will have to take special care if the person with dementia is on any sort of medication. They may forget how many tablets they have had. The person with dementia may accidentally take too many or not take them at all. Check with the doctor to make sure the person is only taking what is necessary.

## **What you can do:**

- 1 Ask the doctor or pharmacist if each medicine is really necessary. If it is, ask if the person can take it in a simpler way, such as once a day instead of three times.
- 2 Do not leave it to the person with dementia to manage medication. They are likely to forget or to take too much. It is better if one person is in charge of medicines.
- 3 If you can't supervise medication completely, there are several ideas that might help. You can leave the right daily dose in containers. Ask the pharmacist about special containers with compartments for each dose. You can also get dispensers with an alarm, or which you can set to open at a certain time.
- 4 Keep all medicine bottles clearly labelled and in a locked medicine cupboard.
- 5 Keep a weekly or monthly record sheet on the inside of the medicine cupboard. Note on the sheet which tablets the person should take each day. When you give a tablet, mark the record sheet to show that you have given it. This helps to stop mistakes, especially if more than one person is involved.
- 6 Make sure that you are clear about which medicine to give when. If not, check with the doctor or pharmacist.
- 7 Make sure that both the hospital doctor and the GP know about all the drugs the person is taking. Even medicines bought over the counter, such as laxatives or aspirin, can cause problems when taken with other medicines.
- 8 Make a note of any side effects and let the doctor know.
- 9 Get rid of medicines not in use.

# Medicines: at a glance

- Ask the doctor if medicines are necessary and if they can be given as simply as possible.
- Don't leave the person to take medicines alone.
- Work out a system for making sure that the person takes the right medicine at the right time.
- Watch for side effects and inform the doctor.
- Make sure that the doctor knows about all medicines the person is taking.
- Get rid of medicines not in use.

*'When I looked in my father-in-law's medicine cabinet I found 20 different prescription drugs. Some very old. I took him to his doctor and he's now on three pills a day.'*



# Getting help

Dementia not only affects the person with the illness. It affects family and friends too. Caring for someone with dementia can affect your social life, work, leisure time, financial situation and family relationships. There are many services which can support you and the person you look after.

## Support

### 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 a 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.

At the end of the year, there should be a personal plan developed, based on individual wishes, goals and expectations. So, depending when the diagnosis was made in the dementia journey, you and the person you care for may be able to access this support.

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, the social work department or contact Alzheimer Scotland's Dementia Helpline (**0808 808 3000**) for information about other services in your area.

## Support services

The local council social work department is the main route to getting support services in your own home or through services near where you live.

It's worth contacting the social work department 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 particular 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, carers can also receive a Adult Carer Support Plan or Young Carer Statement, if they provide substantial and regular unpaid care. This can help carers to explore what care they are able to provide and what support they 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.

People newly diagnosed will be allocated a link worker and they will help you navigate through the range of services available.



### Further information

The Alzheimer Scotland 24-hour Dementia Helpline can answer questions about services. Call **0808 808 3000** or email **helpline@alzscot.org**

Alzheimer Scotland factsheet, *Community care and assessments*.

Go to **www.alzscot.org** or call the dementia helpline on **0808 808 3000**.

# Help for carers

Carers can request an assessment of their own needs if they provide care to someone with dementia. Carer groups and carer training may be available in your area.

You may find making a plan helpful:

- Start planning what help you could use, you might find it useful 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?

## Support at appointments

You may feel that you would like some support when you go to appointments, as they can be very overwhelming. You can also ask for professional support at these appointments, such as an advocacy worker.

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 present at appointments. The interpreter will help you understand what is being said and help you to ask any questions you may have. It is important to make contact with local minority ethnic or deaf community support groups within your area, who may be able to refer you to suitable support.



### Further information

Alzheimer Scotland carer training.  
[www.alzscot.org](http://www.alzscot.org) or call the dementia helpline on **0808 808 3000**.

Alzheimer Scotland guide for carers, *Looking after yourself*.  
[www.alzscot.org](http://www.alzscot.org) or call the dementia helpline on **0808 808 3000**.

Carers centres all over Scotland provide training and support.  
[www.careinfoscotland.scot/topics/support-for-carers/carers-centres/](http://www.careinfoscotland.scot/topics/support-for-carers/carers-centres/)

Carers Scotland offers a voice for carers as well as practical help and advice on coping. **[www.carersuk.org/scotland](http://www.carersuk.org/scotland)**

Carers Trust offers information, online training and a discussion forum.

**[www.carers.org/help-directory/alzheimers-and-dementia](http://www.carers.org/help-directory/alzheimers-and-dementia)**

Carers Trust Scotland can provide information on local carer services and young adult carer services. Call **0300 123 2008** or visit **[www.carers.org](http://www.carers.org)**

Alzheimer Scotland factsheet *Dementia and deafness: What you need to know*

**[www.alzscot.org](http://www.alzscot.org)** or phone the dementia helpline on **0808 808 3000**.

Royal National Institute for the Blind (RNIB) offers advice on dementia and sight loss.

**[www.rnib.org.uk/eye-health-sight-loss-other-medical-conditions/dementia-and-sight-loss](http://www.rnib.org.uk/eye-health-sight-loss-other-medical-conditions/dementia-and-sight-loss)**

The *Living well with dementia* and *Younger people with dementia* DVDs have British Sign Language translations.

The *Coping with dementia* DVD at the back of this publication has a British Sign Language translation.

Contact local area health and social care for access to local interpreting services.

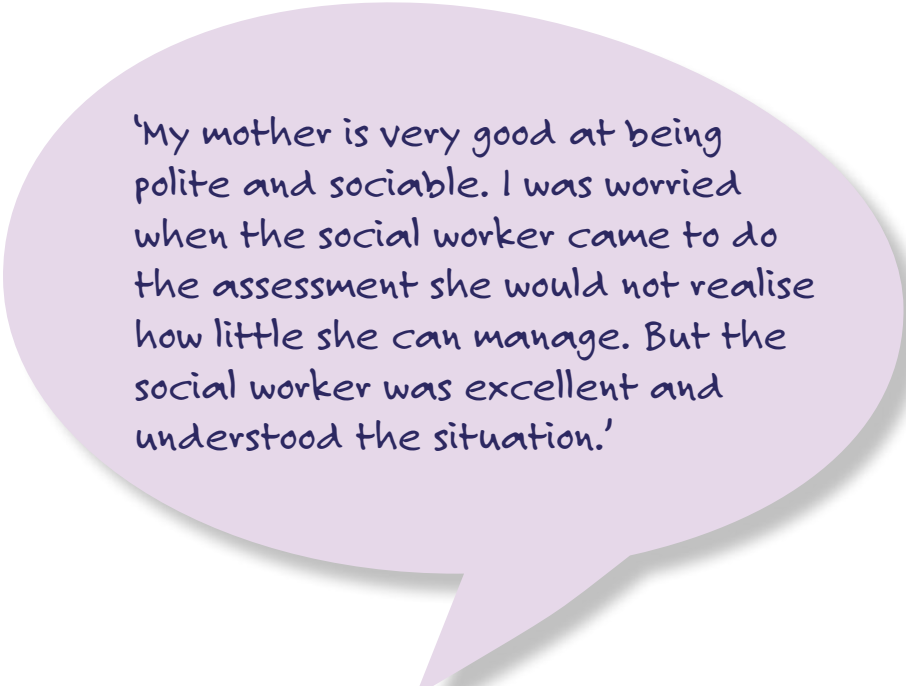
Scottish Council on Deafness. Call **0141 248 2474**, textphone **0141 248 2477**, text **07925417338** or visit **[www.scod.org.uk](http://www.scod.org.uk)**

Action on Hearing Loss. Call **0808 808 0123**, textphone **0808 808 9000**, text **0780 0000 360** or visit **[www.actiononhearingloss.org.uk](http://www.actiononhearingloss.org.uk)**

Deafblind Scotland. Call **0141 777 6111**, email **[info@deafblindscotland.org.uk](mailto:info@deafblindscotland.org.uk)** or visit **[www.deafblindscotland.org.uk](http://www.deafblindscotland.org.uk)**

# Support: at a glance

- The Scottish Government has guaranteed that everyone diagnosed from 1 April 2013 will get individual support from a named and trained person – a dementia link worker – for at least a year after diagnosis.
- Local authority social work departments are the main route to getting support.
- Assessments help you to find out what support might suit you.
- Carers can benefit from an assessment too if you provide care to someone with dementia.
- You are not alone – share experiences with other people with dementia.



'My mother is very good at being polite and sociable. I was worried when the social worker came to do the assessment she would not realise how little she can manage. But the social worker was excellent and understood the situation.'



# Help at home

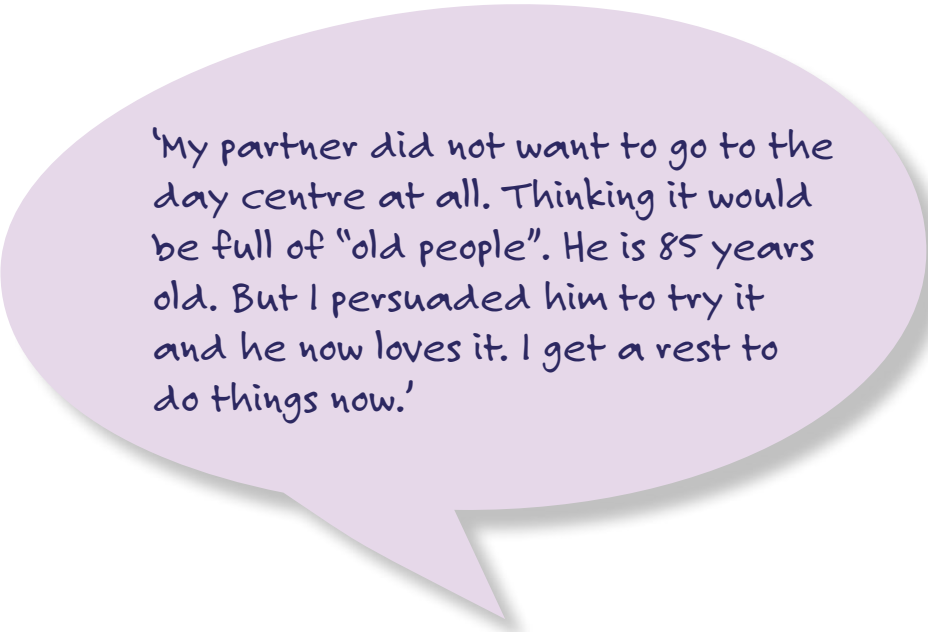
Home care services (sometimes called domiciliary services) can offer care for the person with dementia in their own home, depending on what they need. For example, a home help might help the person to prepare a meal, or a care assistant might help them to get dressed or go out for a walk. For many carers, this gives the freedom of a few hours without worry. Home care services can also help people with dementia who live alone to cope and to live at home safely for as long as possible. In some areas, overnight home care services may be available to enable a carer to get a good night's sleep. Ask the social work department or call the Dementia Helpline for details of services in your area.

## Home support services

Some voluntary organisations provide home support or 'sitter' services. For example, Crossroads and Alzheimer Scotland run schemes in many areas, providing trained care assistants to help look after the person with dementia. They do more than just 'sit' with the person. They can provide stimulating activities or outings, for example. Private nursing or care agencies can also provide care assistants or nurses during the day or at night. You can find them in the local Yellow Pages.

## Day centres

A place at a day centre can give the person with dementia a chance to socialise and to enjoy stimulating activities. It will also give you some time off. Most day centres will arrange transport. Evening and weekend care is also available in some areas. Some day centres are run by the social work department, others by voluntary organisations, such as Alzheimer Scotland. Specialist day centres provide activities suited to the person's abilities. They can often cater even for people whose dementia is quite severe. In some areas there are now day centres particularly for younger people with dementia. But in many areas younger people go to day centres which cater mostly for older people. If you care for a younger person, ask the social work department about services in your area. The NHS Health Scotland publication *Younger people with dementia: living well with your diagnosis* also provides information about younger onset dementia.




'My partner did not want to go to the day centre at all. Thinking it would be full of "old people". He is 85 years old. But I persuaded him to try it and he now loves it. I get a rest to do things now.'

## Short breaks

Both you and the person with dementia may enjoy a holiday, either together or separately. Many people with dementia manage very well in hotels or guest houses, but for information on other places which are suitable for people with dementia, call the Dementia Helpline. 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 a tiring and often stressful job. A short break, when the person with dementia goes into a care home, or sometimes a hospital for a few days or a week or two, 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. Perhaps family and friends could visit rather than you. In some areas social work 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 with the staff their life story book. It may also be useful to complete and bring along a document called *Getting to know me* available from Alzheimer Scotland, which lets staff know the person with dementia's likes and dislikes, as well as a little bit about them, to help them settle in better.



'I felt guilty about my father going into respite care. But I talked it over at the carers group and they pointed out that I must look after myself. He did settle down after a few days and really enjoyed it.'



# There are three routes to respite:

## **Respite through the social work department**

If you are assessed as needing respite, the social worker or care manager should try to arrange a place in a care home for the person. If you haven't been assessed as needing respite, but you feel you need a break, call the social work department and ask for a new assessment. There may be a charge for respite care. The amount depends on where you live and on the person's income and capital.

## **Respite through the health service**

In some areas, the GP or hospital specialist can sometimes arrange a respite place in hospital. There is no charge for this.

## **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. Ask the social work department about the service.

## Laundry service

Some areas have a laundry service for people who have extra washing because of continence problems. Ask the social work department or the community nurse.

### **If the person does not want the service**

Someone with dementia may not want to accept a service for a number of reasons. Perhaps the person thinks they are coping perfectly well, and doesn't realise the need for help. Perhaps they are reluctant to have a stranger in the house. Or they may have negative ideas about day centres. They may not want to go into respite care for fear of being taken away from home. Often this is more of a problem earlier in the illness, when the person may feel that independence is being taken away. Later, they may be less unwilling. Even when someone is initially unwilling to accept a service, they are quite likely to enjoy it and benefit from it once they start. So it is worth persisting.

### **What you can do**

- 1 Talk to the person with dementia about the service you think might help. Try to explain why you think it is a good idea and how the service will help both of you.
- 2 Talk to the social worker, nurse or someone else for advice. Suggest a trial period. The person may well find that they enjoy a day centre, for example. Try going with the person to a day centre for the first few visits, or being there when a home care worker comes. Reassure them that respite is just for a holiday and that they will be coming home.

# Free personal care and charges for care services

## **Free personal care**

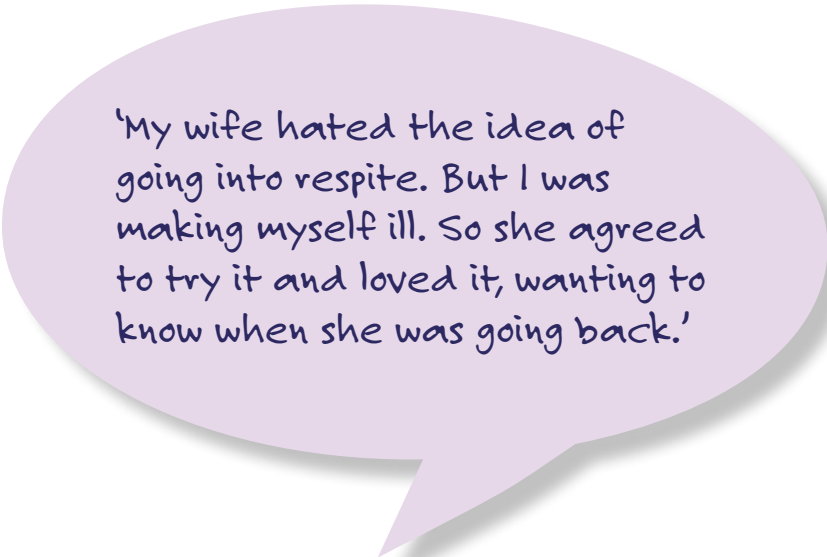
If the person with dementia is over 65 and they are assessed as needing help at home with personal care, they will not have to pay for this help. However, people under 65 still have to pay. Personal care includes, for example, help with dressing, eating, washing, going to the toilet, simple treatments (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. Each social work department has different charges for services. The social worker or care manager will do a financial assessment to work out how much someone can afford to pay. The amount depends on the income and individual circumstances of the person with dementia.

# Free personal care and charges for care services: **at a glance**

- People over 65 can get free personal care at home.
- Nursing care at home is free for people of any age.
- The person may have to pay for some other services.



'My wife hated the idea of going into respite. But I was making myself ill. So she agreed to try it and loved it, wanting to know when she was going back.'



# Support services from your local council

Depending on the level of the person with dementia's needs they may be eligible for services from your local council. If assessed as requiring social care and support or 'community care services', the person with dementia should expect to have some choice over how they receive that support. If the carer has power of attorney then the carer will be able to have a say as well as to support the person with dementia.

If you want, you can ask the social worker or care manager to organise this for the person you care for. They will arrange for services to be provided by the council or by an agency.

You can also help to direct support on behalf of and with the person with dementia if you have power of attorney. By choosing the method of support the person with dementia will receive, you can ensure that they live independently for as long as possible.

## Directing your own support

### **Self-directed support**

Self-directed support includes a range of options to ensure that everyone can exercise choice and control:

- a direct (cash) payment
- funding allocated to a provider of your choice (sometimes called an individual service fund, where the council holds the budget but the person is in charge of how it is spent)
- the council arranges a service for you
- a mix of these options for different types of support.

## Individual service funds

Some councils offer another option – sometimes they will call this an individual service fund or individualised budget. All councils have to offer this way of doing things. This is another way of giving more control over the person with dementia's own support, but without the responsibility of the direct payment where they or their carer (if power of attorney in place) handle the money themselves. With an individual service fund the council tells the person with dementia or 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 actually manage the money itself.

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 your own or with assistance from other people. If a power of attorney is in place (see **Planning for the future** on page 32), the carer or appointed person can help manage things – but it's important that the person with dementia will still be free to say how they want their funding spent (as long as this is in line with their assessed needs).

## Support and information

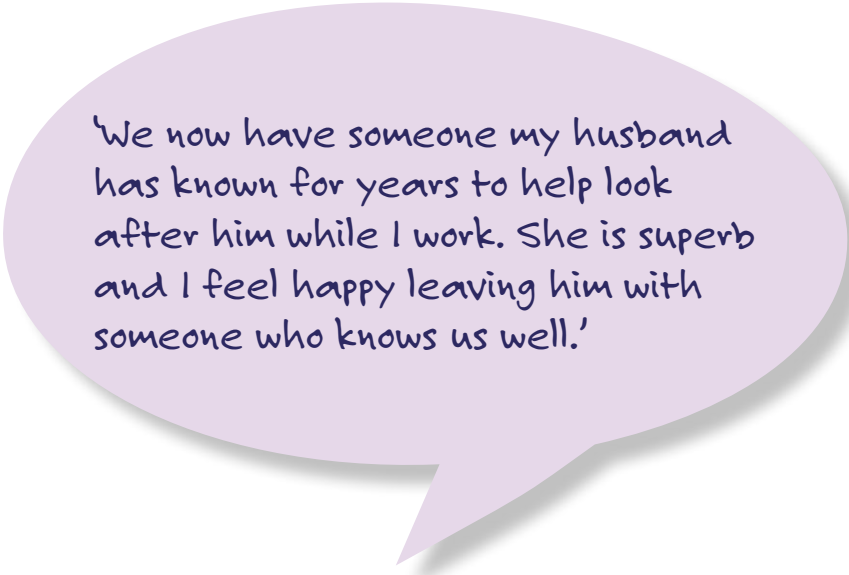
Self-directed support means that the person with dementia and the carer (if power of attorney in place) will have more control but it also means that they have some responsibilities too. If they choose a direct payment they will have to control the money and they might even employ staff. If you would like more information, speak to your care manager if you have one or ask the local social work department. In many areas there is an independent support organisation that can advise you about the options available, including employing a personal assistant.

The Self-Directed Support in Scotland website explains the ways you can choose to receive care funding.

**[www.selfdirectedsupportscotland.org.uk](http://www.selfdirectedsupportscotland.org.uk)**

# Self-directed support: at a glance

- People with dementia can be given more control and choice over how they receive services.
- Direct payments are one way of taking more control.
- You can manage direct payments for someone if you are their attorney or guardian.
- Direct payments mean you can choose and pay for services that meet the person's needs, or employ someone to provide care.



'We now have someone my husband has known for years to help look after him while I work. She is superb and I feel happy leaving him with someone who knows us well.'

# 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 general practitioner (GP). Make an appointment. 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. Make a list before you go so that you remember everything you want to say.

It is important to look after the person's health following a diagnosis of dementia. 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.

Someone with a diagnosis of dementia should have a general health review at least every 15 months, by their GP or practice nurse.

It is important to tell the doctor at once if there is a sudden change. Don't just assume that any change is due to dementia. For example, if the person suddenly seems more confused they may have an infection. If this is treated, the confusion may get better.

If you can, talk to the person you care for before visiting the doctor. If the person agrees, you can be with them when they see the doctor. Early on in the illness, 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 for the person you may have the power to access their medical records or make decisions on their behalf about medical treatment. Later, the doctor will probably feel it is in the person's best interest to discuss their health with you, as their carer.

## Day hospital

The person with dementia may be offered a place at a day hospital where they can be medically assessed. The day hospital may offer services, such as occupational therapy assessment, nursing assessment, physiotherapy, bathing or podiatry (chiropractic). The person with dementia will be able to take part in stimulating activities. 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. The person can be given special diagnostic tests if they are 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 National Health Service has a complaints procedure.

## Admission to hospital

If someone with dementia needs to go into hospital, either for planned treatment like an operation or in an emergency situation, it can be a very 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 a person with dementia or their partner or family member 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 alongside the person's hospital notes during their hospital stay so that staff can consult it at any time.

The *Getting to Know Me* form can be downloaded from the Alzheimer Scotland website, or ask for a copy from the Dementia Helpline on **0808 808 3000**.

# Health services for people with dementia: **at a glance**

- See the GP if you have any concerns about the person's health.
- It is especially important that the person sees the GP if there is a sudden change in their health.
- The GP can refer the person to hospital specialists and other health services.
- The person can get an assessment at a hospital assessment unit or day hospital.
- A copy of the *Getting to Know Me* form can be downloaded from Alzhemier Scotland.

'My husband can get a bit restless at night and often gets up in the early hours but if I give him a glass of warm milk he goes back to bed quite happily. I made sure I told the nurses so they knew what to do if that happens.'

# Information and support

## Dementia Helpline

The Alzheimer Scotland 24-hour Dementia Helpline is **0808 808 3000** or email **helpline@alzscot.org** Calls are free from all landlines and most mobile networks. The Helpline is answered by trained staff and volunteers, many of whom have been carers themselves.

## Carers support groups

A carers' support group gives you the chance to meet other people who also care for someone, for emotional support and good ideas and tips on coping. Many carers support groups also have guest speakers who are a very useful source of information. Some are organised by day care and other services. Ask the local carers' service, Dementia Helpline or the social work department about groups near you.

## Courses for carers

Some organisations run courses for carers. Sometimes these are just for carers of people with dementia and sometimes for all carers. Courses may cover different things. Examples of topics included on a course might be information about dementia, how to cope, what help is available, financial and legal matters and dealing with stress. Ask the Dementia Helpline to put you in touch with your nearest Alzheimer Scotland service or a local carers' organisation.

## Advocacy

Some areas have independent advocacy services. They offer advice and support for people with dementia who need help to make sure their views are represented.

There are also some advocacy services especially for carers. Ask the social work department, the Dementia Helpline or the Scottish Independent Advocacy Alliance (see **Further information** on page 13).

## **Carer's emergency card**

You may be worried about what would happen to the person you look after if you were in an accident or taken ill. If so, carry a note of who to contact in an emergency. Some carer organisations provide a special card you can fill in with details of who you care for and emergency contacts. Call the Dementia Helpline on **0808 808 3000** if you would like one.

## **Voluntary organisations**

Many voluntary organisations can help you care for the person with dementia.

Some, like Alzheimer Scotland, Crossroads or Age Scotland, and many small local organisations, may provide services, such as day care or home support. They may provide information, someone to talk to or carers' groups. See **Useful organisations** on page 166 for more details on individual voluntary organisations.



# Information and support: at a glance

- The Alzheimer Scotland 24-hour Dementia Helpline on (freephone) **0808 808 3000** can provide information and emotional support.
- Try joining a carers' support group.
- Advocacy can help the person with dementia or carer be listened to.
- Your local health promotion department can provide information materials.
- If you are worried what would happen to the person if you were taken ill, carry emergency details.
- Voluntary organisations, such as Alzheimer Scotland and local carers' centres, can provide information and services.

# Care and support glossary

A diagnosis of dementia will bring you into contact with various health and care professionals and services. This is a rough guide to what these can provide. Care and support in your area may not include all of them, or be particularly designed for younger people. Alzheimer Scotland is a good place to start finding out what help is available locally.

## People who can provide treatment, support or advice

### Clinical psychologist

This is a health professional specially trained in diagnosing and assessing dementia and other mental health problems, who can provide a range of psychological treatments to help with symptoms and overall wellbeing.

### Community psychiatric nurse (CPN)

This is a qualified mental health nurse, part of a team reporting to the consultant psychiatrist, who will help the person and his or her carer and family cope with the diagnosis and everyday living.

### Dementia adviser and outreach worker

Dementia advisors or outreach workers (employed by Alzheimer Scotland) provide information and advice to help the person and his or her carer and family find the dementia support they need, connect them to local groups and services, and help local communities to be more dementia friendly.

### Dementia link worker

A named and trained person who works with a person with dementia, their partner and family for at least a year following diagnosis. They help people understand and come to terms with their diagnosis, maintain their existing connections in the community and put them in touch with other people in the same situation. They help people plan for their future care and future decision making. This person may also be called a post-diagnostic link worker or memory clinic link worker.

## **Dentist**

Some dentists will do home visits. Talk to the person's dentist about this or ask your local Health Board about the Community Dental Service.

## **Dietitian**

Registered dietitians are qualified health professionals. They assess, diagnose and treat diet and nutrition problems at an individual level.

It is particularly important to eat well and not become dehydrated when someone has dementia. A dietitian can give you advice on good nutrition, and help if you find your eating habits change because of dementia. A dietitian can work with the person's speech and language therapist to provide advice on different consistency nutritious foods which may be more beneficial, if the person with dementia is having difficulty swallowing.

## **Doctors and nurses at your local practice**

They should be able to advise on treatment and put you in touch with other medical services, and other sorts of care and support locally.

## **Health visitor and district community nurse**

These nurses make home visits if the person with dementia has any general health problems.

## **Occupational therapist**

The occupational therapist (OT) is expert at helping people to continue doing as much as they can in their daily lives, for example with social and practical activities. He or she can recommend the right equipment to help, from bath and toilet equipment to memory equipment. You might be able to borrow equipment to try it out. The occupational therapist can also advise carers how to support someone living with dementia to maintain skills, routines and roles. You can find an OT through the social work department, GP, your local Alzheimer Scotland support organisation or through the community mental health team.



## **Physiotherapist**

People in the moderate to late stages of dementia often have difficulties with walking and some experience falls, or don't feel able to access the activities they used to take part in. Physiotherapists can give advice around exercise to improve strength and balance, provide walking aids and/or advice to assist walking, and provide advice around the prevention of falls. They can also advise carers on the safe way of helping someone to move. Referrals to a physiotherapist are made through the community mental health team or by a GP.

## **Podiatrist**

Podiatrists (the new name for chiropodists) usually work in clinics, but can make home visits. NHS Podiatry services are available free of charge for people who have a foot problem or have a medical need for podiatry treatment. Personal footcare, such as toenail cutting, is not provided by NHS podiatry services.

## **Psychiatrist**

A psychiatrist is a qualified doctor specialising in mental health. Their particular area of interest may be dementia generally, old age, or younger people with dementia. They can prescribe drugs as well as advising on other forms of treatment, like counselling and different types of therapy.

## **Social worker**

Social workers can carry out an assessment of the needs of both the person with dementia and the carer. They can advise on how any support can be provided, including through self-directed support arrangements (see support). They are employed by the local authority.

## **Speech and language therapist**

A speech and language therapist can provide support and advice to carers on how to maximise communication, both verbal and non-verbal. They can also assess and give advice if there are problems with eating, drinking and swallowing difficulties. GPs, mental health services and Health Boards have details of local adult speech and language therapy services.

# Types of service or support

## **Day centres or day opportunities**

Day centres are generally more suited to people in the later stages of dementia who need more support as they have the staff to offer structured activities. They may also be open in the evenings and at weekends.

## **Dementia cafés and drop-in centres**

These bring together people with dementia and their carers to mix socially, share experiences and get advice and information in a café-like community setting (sometimes an actual café).

## **Home support**

Home support helps the person with dementia continue to do things that are important to them, and not just in their home. It might include supporting them to go shopping or visit friends, or simply providing company.

## **Home care**

Regular, short visits to the person with dementia's home by a care worker can be particularly helpful in the later stages of dementia with things like getting washed and dressed.

## **Respite care**

This can give you and the person you care for a break, or provide the person you care for with some support if you are away. Respite care can mean someone comes to stay in their home or they can stay temporarily in a care home.

## Self-directed support

There are different ways care from your local council is offered and funded. Self-directed support gives you more control over how care and support is provided and new legislation means all councils must offer various options, including payments direct to the person with dementia.

The term 'personal assistant' is often used to describe a person you employ using direct payments to help the person with dementia remain independent and do the things they enjoy. For instance, they may accompany them to social and sporting events as well as helping with everyday tasks like shopping.

## Voluntary services

Local charities and community groups often run schemes that offer the chance to socialise and get involved in activities.



### Further information

Care Information Scotland explains what services are available, including in your area.

**[www.careinfoscotland.scot](http://www.careinfoscotland.scot)**

Care Information Scotland has specific advice on care services for people with dementia.

**[www.careinfoscotland.scot/topics/care-at-home/dementia-services/](http://www.careinfoscotland.scot/topics/care-at-home/dementia-services/)**

The Self-Directed Support in Scotland website explains how people can manage their own care and support.

**[www.selfdirectedsupportscotland.org.uk](http://www.selfdirectedsupportscotland.org.uk)**

Alzheimer Scotland has produced a booklet, *Taking charge – a short guide to self-directed support for people with dementia and their carers*. Copies are available via the Alzheimer Scotland 24-hour Dementia Helpline on **0808 808 3000**, or go to **[www.alzscot.org](http://www.alzscot.org)** and search for 'self-directed support'.

# Long-stay care

## 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 long-stay care 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 take into account 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 help to talk as well to other carers who have had to make a decision about long-stay care.

Alzheimer Scotland has a helpful booklet, *A positive choice: Choosing long-stay care for a person with dementia*. The booklet looks at how to cope with the emotional effects of deciding on long-stay care, and covers the practicalities in detail. Call the Dementia Helpline on **0808 808 3000** for a free copy.



# The decision: **at a glance**

- There may come a time when it is not possible to go on caring at home.
- Involve the person with dementia in the decision as much as you can.
- Involve other people, to share responsibility for the decision.

*'My partner and I went to look at the care home together for his dad. We then took his dad to visit a few. It was really good to look at a few and get a feel for them. We all agreed on our favourite one.'*

## Coping with your feelings

It may be very hard for you to accept that you can no longer provide care for the person with dementia. You may feel guilty or think that other people will disapprove. It may be hard to know what you will do with all the spare time you suddenly have. You may feel lonely without the person you were looking after and feel a sense of loss. It is probably impossible to avoid difficult and painful feelings. It may help to talk to friends or professionals about how you feel, or to call the Dementia Helpline. It can also be helpful to talk to other carers at a carers' support group.

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 run in the car or a day at home may still be possible. You may also be able to help with personal care, or at meal times, if you want to.

# Coping with your feelings: at a glance

- It is normal to have difficult feelings, such as guilt.
- Talk to someone about how you are feeling.

'Admitting to myself that I couldn't go on looking after my partner was very hard. I now realise I struggled for too long. But now she's in a home nearby and she's getting superb care so I feel much better.'

## Arranging long-stay care

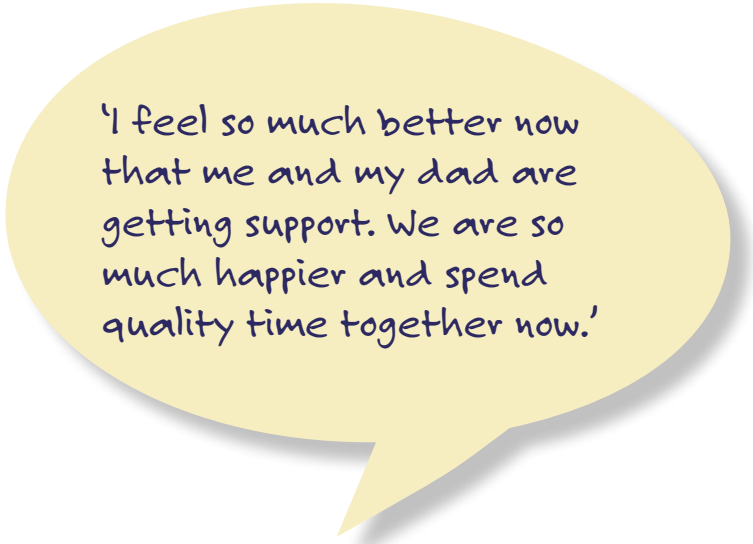
The best way to arrange long-stay care is to ask the social work department for a community care needs assessment. This will make sure the person gets the right kind of care to meet their needs. An assessment is essential for the person to be able to get the free personal or nursing care allowance towards the care home fees. It is also important for the person to have an assessment whether he or she needs help paying the fees now or might need help in the future.

You 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. Adult Carer Support Plans can also be completed by carer services, rather than social workers, in some areas.

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 you want to. If the person is assessed as needing long-stay care, the local authority can arrange it, or you can choose to arrange it yourself. The social work department can help you to find a care home place even if you plan to fund it from the person's own money.

# Arranging long-stay care: at a glance

- Get a community care assessment to see what sort of care the person needs.
- Get a Adult Carer Support Plan or Young Carer Statement for yourself.



'I feel so much better now that me and my dad are getting support. We are so much happier and spend quality time together now.'

## 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 social work department or voluntary organisations. Care homes provide different levels of care – for example, some provide nursing care. All care homes have to meet National Care Standards. All care homes in Scotland are registered and inspected by the Care Inspectorate (see page 168). The Care Inspectorate can give you a list of homes in any area and copies of inspection reports for homes you are considering. The local authority 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 within 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. The booklet *A positive choice* has a useful checklist of what to consider when you visit a home. Go to [www.alzscot.org/information\\_and\\_resources](http://www.alzscot.org/information_and_resources) and search for 'a positive choice'.

You can also choose a different home, anywhere in the UK, as long as it is suitable for the person's needs and doesn't cost more than the local authority 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 social work department informed if you plan on choosing a care home in a different local authority 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. He or she can represent the wishes of the person with dementia without being emotionally involved. Call the Dementia Helpline or the Scottish Independent Advocacy Alliance (see **Further information** on pages 13) to find out about advocacy services near you. A few people with dementia who have very complex needs may need continuing NHS care. This decision is up to the person's hospital consultant.

# Choosing a care home: at a glance

- The Care Inspectorate registers and inspects care homes and can give you information about them.
- Visit several homes before you make a choice.
- You can choose a home in another part of the UK, but keep the social work department informed before the person moves.
- You can choose a more expensive home than the local authority will pay for if someone can top up the fees.
- An independent advocate may be helpful.

'The care home is really nice. The new care manager keeps us up to date with everything that is happening. She has a carers group and we are involved in things in the care home. The Care Inspectorate report is now excellent.'

# Paying the care home fees

## Free personal care

In Scotland, anyone living in a care home who is over 65 and paying some or all of the fees is entitled to free personal care (as long as he or she is assessed as needing personal care). Nursing care in care homes is free for people of any age who are assessed as needing it. The local authority pays the allowance for free personal care or free nursing care, or both, direct to the home. The person then pays the rest of the fees, which are for food, accommodation and so on. From 1 April 2013 the amount for personal care is £166 per week, and for nursing care it is £75 per week.

## Other help towards the fees

Care home fees can be costly. Many people will need some help with paying. The social work department will give the person a financial assessment. They will look at the person's income and capital. The person with dementia's funds will be used to pay the home fees. They should always be left with a weekly personal allowance (at least £25.05 from April 2013, plus up to £5.80 more for some people over the state pension age for women receiving Pension Credit, depending on savings and income).

If the person's income is not enough to pay the full fees, the local authority may help to pay the amount over their income. If the person has savings or property worth more than the 'upper limit' (£26,250 from April 2013), they will have to pay the home fees themselves until the amount reduces to this level. If they have an amount between the upper limit and the 'lower limit' (£16,250 from April 2013), they will have to pay part of the fees and the local authority will pay part. If they have less than the lower limit, the social work department will pay, up to their maximum amount.



## The house

If the person owns a house the social work department 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. But they must ignore the value of the house for the first 12 weeks of the person's stay in the care home. However, the social work department must ignore the value of the house completely if one of these people still lives there:

- person's husband or wife, or opposite sex partner
- a relative who is over 60
- a relative who is disabled or incapacitated.

The social work department 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 the Dementia Helpline or a solicitor if you live with the person with dementia and the social work department 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. If any householder is diagnosed with dementia it would be wise to seek advice on the issue of care costs before the symptoms prevent sensible mitigation steps being taken.

# Paying the home fees: at a glance

- People over 65 paying all or part of their own fees can get free personal care.
- People of any age paying all or part of their own fees can get free nursing care.
- The social work department will do a financial assessment to see how much the person should pay towards the care home.
- The value of the person's house will be counted in some circumstances but not in others.

## 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 fast and are obviously happy in their new home, but others may not adjust so quickly. 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 the home staff how they are 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 for the person with dementia. You can give them important information about their needs and their likes and dislikes. If they have a life story book (see page 56) make sure they take it to the home with them, so that staff can learn about their life. The booklet *Letting go without giving up: continuing to care for the person with dementia*, available from the Dementia Helpline, is for carers who want to continue to be involved in the life of the person they have cared for. It looks at the impact of the move on the carer and on the person, as well as practical ways of staying involved and making visits more enjoyable.

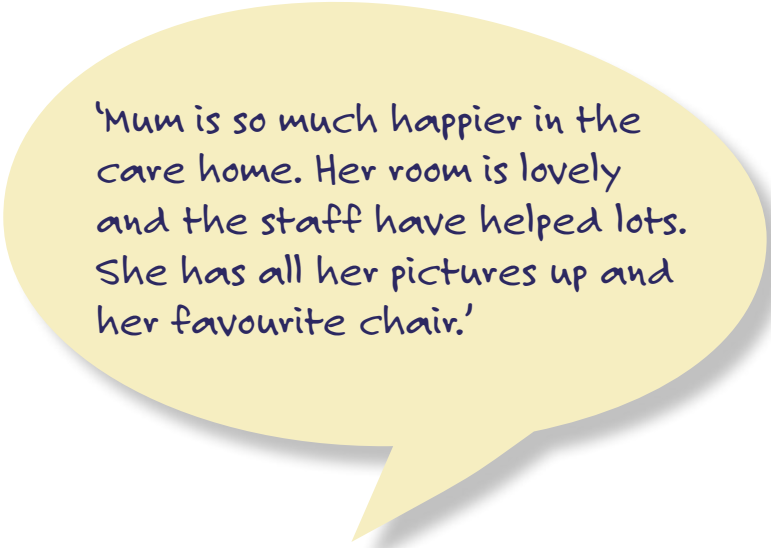
### **If you are not satisfied with the care home**

If you are not satisfied about the person's care at the home, you can make a complaint. All care homes must have a complaints policy. They should give you information about it if you ask. First of all, speak or write to the person in charge of the home. If you are still not satisfied, you can talk to the social work department if they arranged the place in the home. Or you can contact the Care Inspectorate (see page 168).



# The move and after: **at a glance**

- Plan the move.
- Personalise the person's room with familiar things.
- Talk to the home about how they are settling in, and about their care plan.
- Give it time – both you and the person with dementia will need to adjust.



'Mum is so much happier in the care home. Her room is lovely and the staff have helped lots. She has all her pictures up and her favourite chair.'

# Loss and bereavement

Some carers say that dementia itself is like a long slow bereavement. You may feel that you are gradually losing the person you once knew. Many carers 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, some carers feel guilty at 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.

Everyone is different and each person reacts to bereavement differently. Because of the 'slow bereavement' of dementia, many people find that their sorrow when the person dies is mixed with relief that so much suffering is over. Some people feel less sad than they feel they 'should', because they have already done so much grieving. Other feelings are common after bereavement too, such as sadness, confusion, disbelief, anger or guilt. These mixed 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 and old friends. Keep in touch with other carers too. They can help you come to terms with your feelings. Cruse Bereavement Care can help with bereavement counselling – see page 170.

You may find that feelings of stress and emotional upset stay for quite some time. But in time you will begin to remember the person before the illness. And eventually you will begin to pick up the threads of your own life again.

# Loss and bereavement: at a glance

- Carers often feel loss throughout dementia.
- A move into long-stay care can cause a great sense of loss.
- When the person dies you may have a mixture of feelings; this is perfectly normal.
- Make sure you get support for yourself, and give yourself time.

'When my mum died after 10 years of being ill, she was very different from her old self. It's now two years since her death and I will always miss her but I can remember her now as she used to be before she got ill.'

# Useful organisations

## Age Scotland

Causewayside House, 160 Causewayside, Edinburgh EH9 1PR.

Age Scotland exists to improve later life for older people. Age Scotland publishes a series of information guides and fact sheets, online information and advice on topics including health, care, money and housing.

In partnership with Silver Line Scotland, Age Scotland provides a freephone, 24 hour Helpline providing information, friendship and advice to older people.

Phone: **0800 4 70 80 90**

For general enquiries please phone 0333 32 32 400. For publication requests please email **publications@agescotland.org.uk**

Web: **www.ageuk.org.uk/scotland**

## Alzheimer Scotland

22 Drumsheugh Gardens, Edinburgh EH3 7RN.

Phone: **0131 243 1453**

Email: **info@alzscot.org**

Web: **www.alzscot.org**

Alzheimer Scotland 24-hour Dementia Helpline: **0808 808 3000** (freephone) and email address **helpline@alzscot.org**

Alzheimer Scotland is Scotland's leading dementia charity provides direct support services and produces information for people with dementia and their partners, families and carers across Scotland. They also run the Dementia Helpline and provide a network of Dementia Advisors across many local authority areas.



# Alzheimer's Society

Devon House, 58 St Katharine's Way, London E1W 1LB.

The Helpline is open 9 am–8 pm Monday to Wednesday; 9 am–5 pm Thursday and Friday; 10 am–4 pm Saturday and Sunday. It is a confidential service. Calls to the Helpline are charged at local rate from anywhere in the UK.

Phone: **020 7423 3500**

Web: **[www.alzheimers.org.uk](http://www.alzheimers.org.uk)**

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

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and their carers through publications, their National Dementia Helpline, website and more than 2,000 local services. They campaign for better quality of life for people with dementia and greater understanding of dementia.

Alzheimer's Society has an online monitored forum, Talking Point, which many Scottish carers of people with dementia find helpful.

**<http://forum.alzheimers.org.uk>**

# Disability, Carers and Pension Service

Helpline: **0800 88 22 00** – advice on existing claims.

Textphone: **0800 24 33 55**

Email: **[dcpu.customer-services@dwp.gsi.gov.uk](mailto:dcpu.customer-services@dwp.gsi.gov.uk)**

Carer's Allowance: **0845 60 84 321**

Textphone: **0845 60 45 312**

Email: **[cau.customer-services@dwp.gsi.gov.uk](mailto:cau.customer-services@dwp.gsi.gov.uk)**

The Pension Service: **0845 60 60 265**

Textphone: **0845 606 0285**

Monday to Friday 8 am–8 pm. The pension service provides a wide range of information about the State Pension, Pension Credit, Winter Fuel Payment and related benefits.

Job Centre Plus: for benefits for people under the state pension age for women.

Web: **[www.gov.uk](http://www.gov.uk)**

# Care Inspectorate

Headquarters, Compass House, 11 Riverside Drive, Dundee DD1 4NY.

Phone: **0345 600 9527**

Web: **[www.careinspectorate.com](http://www.careinspectorate.com)**

Email: **[enquiries@careinspectorate.com](mailto:enquiries@careinspectorate.com)**

The Care Inspectorate regulates care services for people of all ages in Scotland. Its work includes registering services, inspecting and grading them, dealing with complaints, carrying out enforcement action where necessary, and helping services improve.

It also provides scrutiny of all Scottish local authority social work services, including criminal justice social work and carries out joint inspections, with colleagues from other organisations, such as police, health, education and scrutiny bodies to check how successful services are at working together to deliver the best support for adults and children. Care Inspectorate inspection reports are public documents for all to see and are available at **[www.careinspectorate.com](http://www.careinspectorate.com)**

The Care Inspectorate worked with NDCAN to produce a continence resource that can be found here: [www.careinspectorate.com/index.php/guidance/9-professional/2613-promoting-continence-for-people-living-with-dementia-and-long-term-conditions](http://www.careinspectorate.com/index.php/guidance/9-professional/2613-promoting-continence-for-people-living-with-dementia-and-long-term-conditions)

## Care Information Scotland

Care Information Scotland is a telephone and website service providing information about care services for older people living in Scotland.

Helpline: **0800 011 3200**

Opening Hours: 7 days, 8 am–10 pm

Web: **[www.careinfoscotland.scot](http://www.careinfoscotland.scot)**

## Carers Scotland

The Cottage, 21 Pearce Street Glasgow, G51 3UT.

Phone: **0141 445 3070**

Carers Advice Line: **0808 808 7777** or email:

**adviceline@carersuk.org**

Web: **www.carersuk.org/scotland**

Carers Scotland provides information and advice to carers through their Adviceline and information services. They also publish a range of leaflets for carers in Scotland.

## Carers Trust Scotland

Suite 1–2, Skypark 3, 14/18 Elliot Place, Glasgow G3 8EP.

Phone: **0300 123 2008**

Web: **www.carers.org/scotland**

Carers Trust Scotland works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. With our Network Partners, we aim to ensure that information, advice and practical support are available to all carers across Scotland.

## Citizens Advice Bureau

See your phonebook for your local Citizens Advice Bureau or call Citizens Advice Scotland on **0131 550 1000** or Citizens Advice Direct on **0808 800 9060**

Web: **www.cas.org.uk**

Email: **info@cas.org.uk**

For advice and help with filling in forms for welfare benefits.

# Cruse Bereavement Care Scotland

Riverview House, Friarton Road, Perth PH2 8DF.

Head Office: **01738 444 178**

Web: **[www.crusescotland.org.uk](http://www.crusescotland.org.uk)**

Email: **[support@crusescotland.org.uk](mailto:support@crusescotland.org.uk)**

National Phonenumber: **0845 600 2227**

Cruse provides bereavement support to people throughout Scotland and to its local teams. For further information, please contact our National Phonenumber or visit our website.

## Dementia Helpline

**0808 808 3000** (freephone), 24 hours

Email: **[helpline@alzscot.org](mailto:helpline@alzscot.org)**

Our team are trained to provide confidential information and emotional support to carers, people with dementia and their families and friends. Information is available on any subject to do with dementia, from where to find help to legal and financial matters. Run by Alzheimer Scotland, calls are free from all landlines and most mobile networks.

## Dementia Services Development Centre (DSDC)

Iris Murdoch Building, University of Stirling, Stirling FK9 4LA.

Phone: **01786 467740**

Web: **[www.dementia.stir.ac.uk](http://www.dementia.stir.ac.uk)**

DSDC can be contacted through the online contact form on the website.

DSDC aims to improve care and quality of life for those affected by dementia through education and training for all, expert support and advice, promoting dementia friendly environments and communities and providing useful information about dementia care.

# Alzheimer Scotland Centre for Policy and Practice

University of West of Scotland School of Health, Nursing and Midwifery  
Caird Building, Hamilton Campus, Hamilton ML3 0BA

Phone: **01698 283 100**

Web: **[www.uws.ac.uk/ascpp](http://www.uws.ac.uk/ascpp)**

Alzheimer Scotland Centre for Policy and Practice is a partnership with the University of the West of Scotland. Our mission is to work collaboratively with people with dementia and carers, as well as the scientific and practice communities, to advance evidence-informed dementia policy and practice.

## Department for Work and Pensions

Benefit Enquiry Line for People with Disabilities: **0800 88 22 00** or, for textphone users only, **0800 24 33 55**.

8.30 am–6.30 pm, Monday to Friday

Calls are free except from certain mobile phone networks. Help with applying for attendance allowance, disability allowance and carer's allowance.

## Legal Services Agency

3rd Floor, Fleming House, 134 Renfrew Street, Glasgow G3 6ST.

Phone: **0141 353 3354**

Email: **[lsa@btconnect.com](mailto:lsa@btconnect.com)**

Exists to provide advice and representation in all the relevant courts and tribunals in Scotland.

## The Office of the Public Guardian

Offers advice on power of attorney, including an indication of costs.

**[www.publicguardian-scotland.gov.uk/power-of-attorney](http://www.publicguardian-scotland.gov.uk/power-of-attorney)**

# Appendix 1:

## Types of dementia

There are many types of dementia, some of which you may have heard of, such as Alzheimer's disease. Some kinds, such as fronto-temporal dementia (FTD), are more common in younger rather than older people.

It directs you, where possible, to more information. However, for some forms of dementia, easily accessible information can be more difficult to find.

You should also bear in mind that symptoms vary from person to person and from day to day. You may prefer to cope with any changes as they happen rather than trying to predict the specific impact of the diagnosis.

It is possible for someone to have more than one type of dementia at the same time.

There are many very rare conditions that can cause dementia. There are also conditions that can accompany dementia, such as Parkinson's disease and Huntington's disease.



### Further information

**Alzheimer's Society** factsheet, *Rarer forms of dementia*.

[www.alzheimers.org.uk/rarercauses](http://www.alzheimers.org.uk/rarercauses)

# Alzheimer's disease

This is the best known and most common form of dementia generally. Alzheimer's disease comes on gradually and usually progresses slowly over several years. It can cause particular problems with memory and thinking.

Learning new information can become harder – it may be difficult to remember recent events, appointments or phone messages.

Forgetting the names of people or places and struggling to understand or communicate with others are common symptoms. It can become difficult to find the right words to describe familiar objects and to make decisions.



## Further information

**Alzheimer Scotland** factsheet, *Alzheimer's disease*. Go to **[www.alzscot.org](http://www.alzscot.org)** or phone the dementia helpline on **0808 808 3000**.

# Fronto-temporal dementia (FTD)

FTD is caused by damage to brain cells in the frontal and temporal lobes of the brain. It is sometimes referred to as Pick's disease, although this term is used less often today.

There are two main forms of FTD. One causes changes in a person's behaviour to begin with, and the other affects language and communication. FTD is a complex condition and like other forms of dementia, it is difficult to predict the exact course of the illness in any individual.

People with FTD can lose insight into their condition and can be easily distracted. A person may find it difficult to plan and organise things and may also develop compulsive routines.



## Further information

There is a lack of easy-to-read information about FTD, although this is slowly changing.

**Frontotemporal Dementia Support Group** provides information sheets and runs annual seminars in London on rarer dementias. [www.ftdsg.org](http://www.ftdsg.org)

**The Association for Frontotemporal Degeneration** (US) has some useful resources, including advice on talking to children about FTD. [www.theaftd.org](http://www.theaftd.org)

**Alzheimer's Society** factsheet, *What is frontotemporal dementia?* [www.alzheimers.org.uk/frontotemporal](http://www.alzheimers.org.uk/frontotemporal)



# Vascular dementia

There are various forms of vascular dementia, where the blood supply to the brain becomes blocked and starves brain cells of oxygen, causing small strokes (sometimes referred to as 'mini strokes' or transient ischaemic attacks (TIAs) that affect different parts of the body.

Strokes on the left side of the brain affect the right arm and leg, memory and speech. Strokes on the right side affect the left arm and leg.

Strokes on either side can make it harder to recognise familiar objects and manage complex tasks. They may also cause mood swings and personality changes.

This form of dementia progresses in steps, and it is very difficult to predict how it will affect someone, and when.

Sudden changes, as strokes occur, may be quite mild and last for only a few hours or days, especially in the early stages, and then stabilise.

# Dementia with Lewy bodies

This is caused by clumps of protein – known as Lewy bodies – that build up inside nerve cells in the brain that control thinking and movement. Some people with Parkinson’s disease develop dementia, so symptoms can be very similar.

Dementia with Lewy bodies can be difficult to diagnose because the symptoms fluctuate and don’t necessarily suggest a form of dementia.

Memory can become patchy, although short-term memory may be unaffected to begin with. Drowsiness and lethargy are common symptoms. It might become difficult to solve problems, form organised sentences and make plans.

Other common symptoms are feeling confused and experiencing visual hallucinations – seeing colours, shapes, animals, people, or objects that aren’t there. Occasionally hallucinations are auditory – hearing music or voices – or involve taste, smell and touch.

To someone with dementia, these hallucinations can seem puzzling, rather than upsetting or frightening. They may also experience delusions – false ideas about another person or situation.

Physical effects can include muscles feeling weak, stiff or rigid, which can make it hard to start moving and to move quickly. As a result, someone with this form of dementia may become clumsier and have problems walking and keeping their balance.

There may be changes in voice and facial expression. Some people experience double vision and difficulty judging distances. Others find their sleep patterns change, falling asleep easily during the day but staying awake at night, talking in their sleep or acting out dreams.



## Further information

Alzheimer Scotland factsheet, *Dementia with Lewy bodies*.  
Go to [www.alzscot.org](http://www.alzscot.org) or phone the dementia helpline on **0808 808 3000**.

Parkinson’s UK factsheet, *Dementia with Lewy bodies*  
[www.parkinsons.org.uk/parkinsonsdementiaandlewybodies](http://www.parkinsons.org.uk/parkinsonsdementiaandlewybodies)

# Alcohol-related dementia or Alcohol Related Brain Damage (ARBD)

Alcohol-related dementia is a form of dementia caused by prolonged use of alcohol. There is also a particular brain disorder associated with heavy drinking called Korsakoff's syndrome, caused by lack of vitamin B1 (thiamine). This is not strictly a form of dementia but has similar symptoms, especially memory loss, personality changes and difficulty learning new skills. It does not progress once the person stops drinking – indeed it may initially improve.



## Further information

**Alzheimer Scotland** factsheet, *Alcohol-related brain damage*.  
Go to [www.alzscot.org](http://www.alzscot.org) or phone the dementia helpline on **0808 808 3000**.

# Treatment for dementia

There is no cure for dementia, but various treatments, including drugs, can help manage symptoms. They may not be suitable for everyone, but knowing what is available may help you discuss appropriate treatments with your doctor. Always consult a doctor before starting any treatment, including herbal and other alternative remedies, as they can have serious side-effects.

## General treatments

A healthy lifestyle, with plenty of fresh vegetables and fruit and daily exercise, is important. As well as aiming to do 30 minutes of activity a day, we should try to reduce the amount of time we spend sitting or being inactive.

Widely available treatments, not just for dementia, may help with certain symptoms and general mental and physical health.

- Physiotherapy can help with problems with flexibility and walking.
- A dietitian can give you advice on healthy eating, and help if you find your eating habits change because of dementia.
- Speech and language therapy can be helpful with problems with speaking clearly, communicating or swallowing.
- Occupational therapy helps maintain skills and abilities.
- Music and aromatherapy may reduce anxiety and improve low moods.
- There are drugs for depression, and to relieve restlessness and problems sleeping.

There are a range of 'talking' and other psychological therapies that can help with different aspects of dementia, including stress and anxiety.

## Specific treatments

A doctor and psychiatric consultant can advise on what drugs might be suitable, taking into account what form of dementia and other factors, including possible side-effects.

## **Alzheimer's disease**

The drugs most commonly used to treat Alzheimer's disease are donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl). Another drug called memantine (Ebixa) is also available for people in the middle to later stages of Alzheimer's disease.

## **Vascular dementia**

Aspirin is widely used to reduce the risk of further brain damage, including reducing the risk of strokes. There are also drugs available to control high blood pressure, to help prevent strokes and to treat diabetes and high cholesterol levels.

## **Drugs used for dementia symptoms**

These can be used to treat restlessness, aggression and some of the other psychiatric symptoms which can appear in people with dementia. They include drugs for anxiety and depression, drugs to help sleeping difficulties and antipsychotic drugs. But because of their potential side-effects, they should only be used if other options fail. The dose should be as low as possible for as short a time as necessary and carefully monitored. This is particularly relevant with antipsychotic drugs.

Antipsychotic drugs should not normally be given to people with dementia with Lewy bodies or Parkinson's disease. You should check with your doctor as they can cause a very severe reaction if taken incorrectly.

# Dealing with specific symptoms

Other sections of this publication look at how to cope with the impact of various symptoms in certain situations and settings, like making your home safer.

You can get specific advice about changes in behaviour. There is rarely a right or wrong way – just what works for you and the people who care for you.



## Further information

Alzheimer Scotland factsheet, *Behaviour that challenges – Understanding and coping*.

Go to [www.alzscot.org](http://www.alzscot.org) or call the dementia helpline on **0808 808 3000**.

This book is for you if you care for someone in the middle to late stages of dementia. Every person with dementia is different. Caring for someone who has dementia can be stressful, but it can also be rewarding. This book describes many common experiences and makes practical suggestions. It aims to help you to provide the best possible care and to look after yourself too.

Sections include:

- about dementia
- coping with caring
- money and legal matters
- practical caring
- getting help
- long-stay care.

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

