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In this resource you will see references to Health and Social Care Partnerships. These partnerships were created in April 2016 and are the organisations formed as part of the integration of services provided by Health Boards and councils in Scotland. They are responsible for the planning, funding and delivery of a range of community health services and social work/social care services.



Introduction

This publication is for you if you care for someone in the middle to late stages of (moderate to severe) dementia. More information about the different types of dementia can be found in Appendix 1 on p. 172.

This publication has been developed in consultation with other carers of people with dementia. It suggests things that other carers found useful and that can make life easier and happier for you and the person with dementia. They have suggested that you may want to dip in and out of this information, rather than reading it all at once.

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. 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 on 0808 808 3000 for more details.

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.

The DVD, *Coping with dementia* – a practical DVD for carers, is also included at the back of this publication. You may find it helpful to watch this before reading the booklet.

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*, *Younger people with dementia: living well with your diagnosis* or *Understanding dementia: a guide for young carers* are the suggested resources for you. They are all available free from the Alzheimer Scotland Freephone 24-hour Dementia Helpline on 0808 808 3000 or email helpline@alzscot.org for information and support.

Since 2013, the Scottish Government has committed to ensuring that those diagnosed with dementia are offered a minimum of one year of post-diagnostic support from a named dementia link worker. The Scottish National Dementia Strategy 2017–20 recognises that many people are diagnosed later in life, and already have significant care needs. The strategy sets out a commitment to work towards offering post-diagnostic support to those people as part of their existing care support but with an emphasis on a more coordinated approach. Those who are diagnosed earlier in the illness and who have little or no need for formal health or social care support will continue to be offered post-diagnostic support from a named dementia link worker. This represents a change in approach but this will be developed throughout the period of this strategy.

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, Younger people with dementia and Understanding dementia 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 can't work as well as it should. Around 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 or not 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.

Is dementia inherited?

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



Further information

Alzheimer Scotland information sheet, Genetics and dementia. Go to www.alzscot.org or call the Dementia Helpline on 0808 808 3000.

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 it can be variable. People can live well with a diagnosis for many years, enjoying full and varied lives.

Appendix 1 on p. 172 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.

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'.

Most people keep fairly strong physically for a long time. In the later stages of the illness, people with dementia become physically very frail.

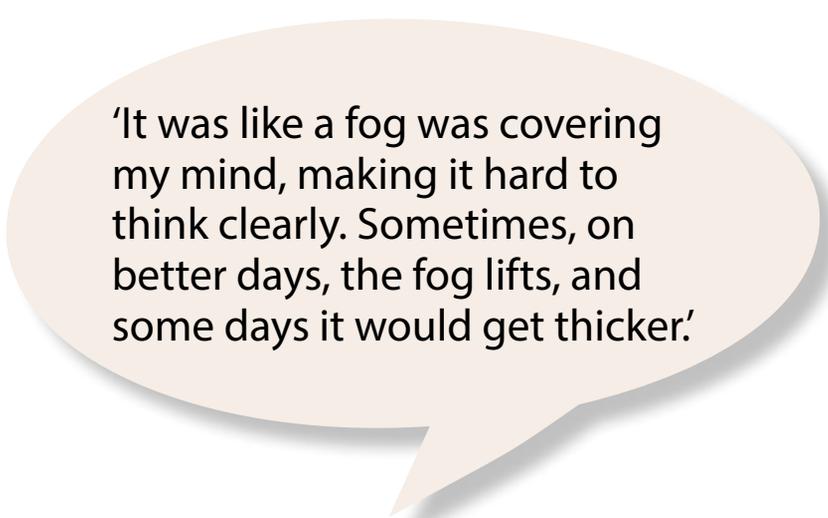
In the very last stages even the person's ability to resist simple infections is lost and, sadly, the illness is eventually fatal. However, as it is such a long-lasting illness, and because many people are older when they get it, many people with dementia die of completely unrelated causes.

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 booklet 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 experience all of the symptoms described in this booklet.
- 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.

The PANEL principles are some underlying principles which are of fundamental importance in applying a human rights-based approach in practice. These are:

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

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

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

Empowerment: Individuals and communities should understand their rights and should be fully supported to participate in the development of policy and practices that affect their lives.

Legality: A human rights-based approach requires the recognition of rights as legally enforceable entitlements and is linked in to national and international human rights law.

There are a wide range of legal provisions that are designed to provide rights and protection in Scotland. 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/charter_of_rights

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 timely diagnosis
- be regarded as a unique individual and to be treated with dignity and respect
- 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 (carers.org) and has been endorsed by the Royal College of Nursing in Scotland.

People caring for a person with dementia are entitled to an Adult Carer Support Plan (ACSP) or, for a young person, a Young Carers Statement (YCS). There is no need for the carer to be providing a regular and substantial amount of care in order to get an ACSP or a YCS drawn up. This entitlement was introduced in April 2018 and replaces the old carer's assessments. To find your local carer centre visit carers.org/our-work-locally or call 0300 772 7701.



Further information

Alzheimer Scotland's booklet, *Standards of care for dementia in Scotland*. A guide for people with dementia and their carers, provides a guide to what you should expect when the standards are met and the quality of care, support and treatment you should receive to stay well, safe and listened to.

www.alzscot.org/standards

or call the Dementia Helpline on 0808 808 3000.

Alzheimer Scotland explains what the Charter of Rights for people with dementia and their carers in Scotland covers.

www.alzscot.org/charter_of_rights

or call the Dementia Helpline on 0808 808 3000.

Care Information Scotland outlines where you can help with caring.

www.careinfoscotland.scot

Mental Welfare Commission for 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

Carers Scotland's Advice Line can advise on your rights as a carer on 0800 389 6809. You can also visit www.carersuk.org/scotland for more information.

Being involved

The person with dementia and their family or carer should be involved in decisions about their care and given as much choice as possible. Any services they access 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 views of the person with dementia 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 524 1975 or visit www.siaa.org.uk

Rights for people with dementia and those who care for them: at a glance

- People with dementia have the same human and legal rights as everyone else following a diagnosis of dementia.
- People with dementia have the right to get involved in decisions about care and choices available.
- People with dementia should 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.

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 education or work 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. 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 on 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 because of 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.'

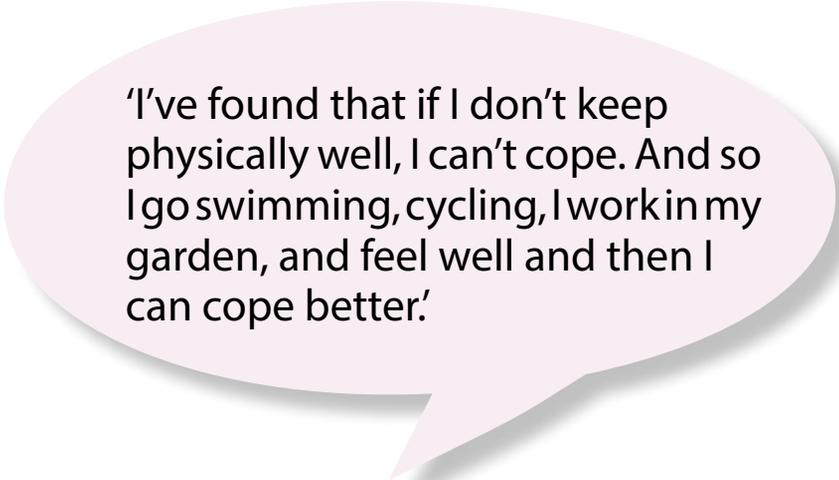
'When something goes wrong, I say to myself, "Relax, don't panic. I have coped so far and there is no reason why I won't continue to." It seems to help somehow.'

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 that will be able to provide you with the support and advice you need. Information on The Scottish Young Carers Services Alliance can be found by contacting Carers Trust Scotland on 0300 123 2008. Carers Trust (carers.org/country/carers-trust-scotland) can also help adult carers to find their nearest carer centre.
- 2 The Alzheimer Scotland Freephone 24-hour Dementia Helpline is available on 0808 808 3000. Trained volunteers offer emotional support and information, whenever you want to call.
- 3 Ask your Health and Social Care Partnership, 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're 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 cafes where carers and people with dementia can meet others in a similar situation.

Emotional reactions: at a glance

- Caring can be both rewarding and stressful.
- Many things can affect your reactions.
- Talk about your feelings.
- Call the 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.



'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.'

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.
- 6 If you are unable to cope with the person's care it may be time to consider if their needs would be met better in another setting such as a care home (see p. 150 for more information).



Further information

NHS Health Scotland booklet, Steps to deal with stress.
www.healthscotland.com/documents/5828.aspx

Breathing Space is a free, confidential service. It provides 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 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 (Mon to Fri: 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 about bringing 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 or spiritual leader or the doctor could help.



Further information

NHS Health Scotland. Understanding dementia: A guide for young carers.

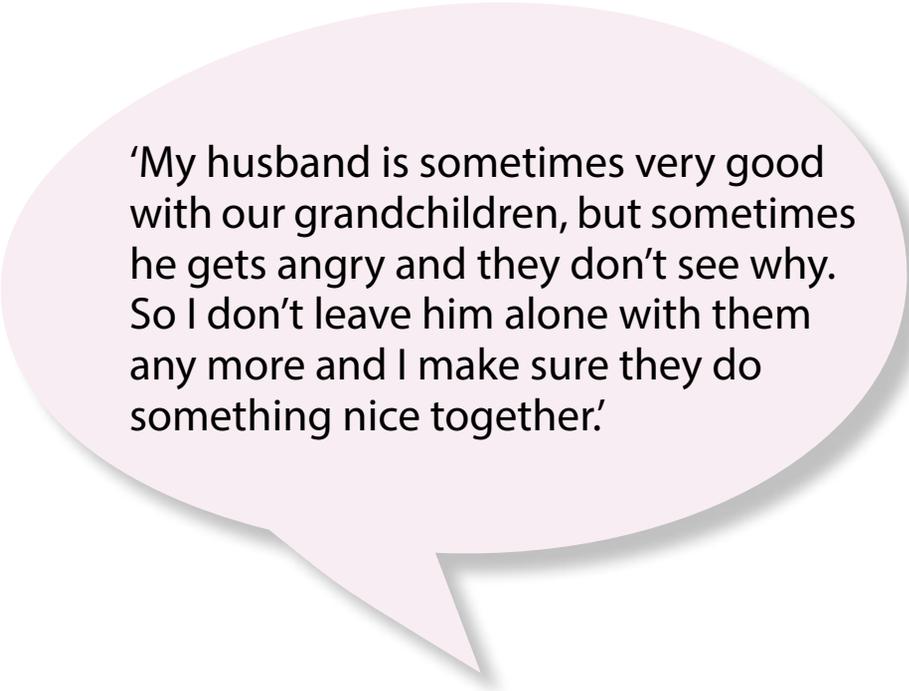
www.healthscotland.com/documents/3884.aspx

You can ask for a copy of this guide from the Dementia Helpline on 0808 808 3000 or by emailing helpline@alzscot.org

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

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 any more 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.

Dementia Helpline

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

Courses for carers

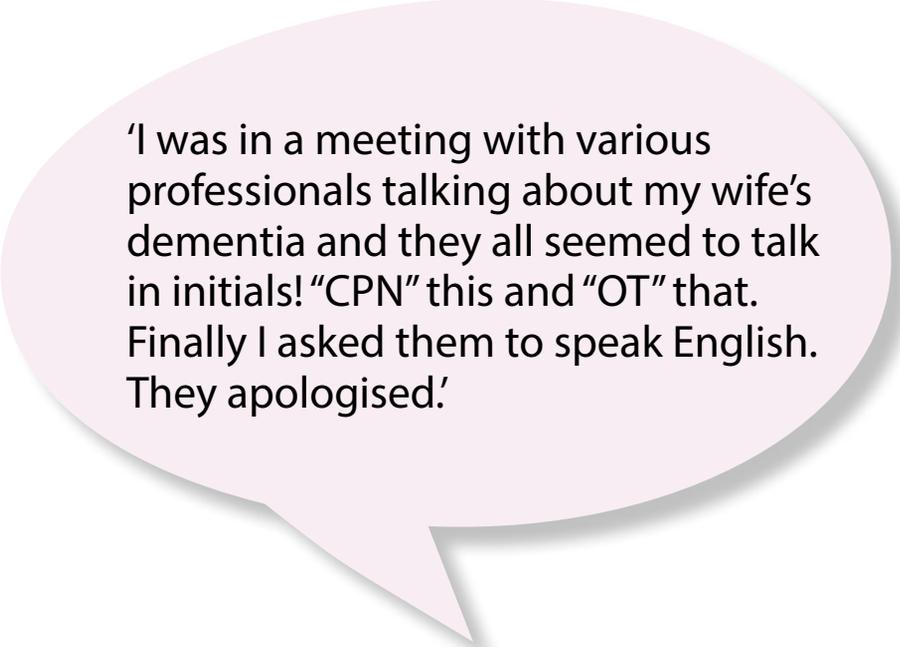
Although caring can be a full-time job, few carers get any training on how to do it. So you may feel you have to learn by trial and error. Alzheimer Scotland and carers' organisations arrange courses for carers through their local services. A carers course can give you the chance to get accurate information 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.

Alzheimer Scotland's 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. See www.alzscot.org/ndcan for further information.

Getting information: at a glance

- Better information makes caring easier.
- Go to www.alzscot.org or 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's 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 your social worker, 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 p. 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 cafe 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 with dementia 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.

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. People in the middle to later stages of dementia are likely not to be able to make legal arrangements any more.

They should check with their doctor if they or their solicitor are 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 (spouse, partner or carer) and grant them power of attorney (PoA). There are three types of PoA:
 - continuing PoA, which gives powers to deal with money and/or property
 - welfare PoA which gives powers to make decisions around health or personal welfare matters
 - combined PoA which gives both continuing and welfare powers.
- Make a will.

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

- 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.

- An Advance Statement: this can be a document in which someone states, in advance, what is important to them. They state their preferences about the kind of care, support and treatment they want in the future when they may not be able to communicate well enough. An Advance Statement can also be a formal document which has legal effect in our mental health law.
- 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.



Further information

Go to www.alzscot.org or call the Dementia Helpline on 0808 808 3000.

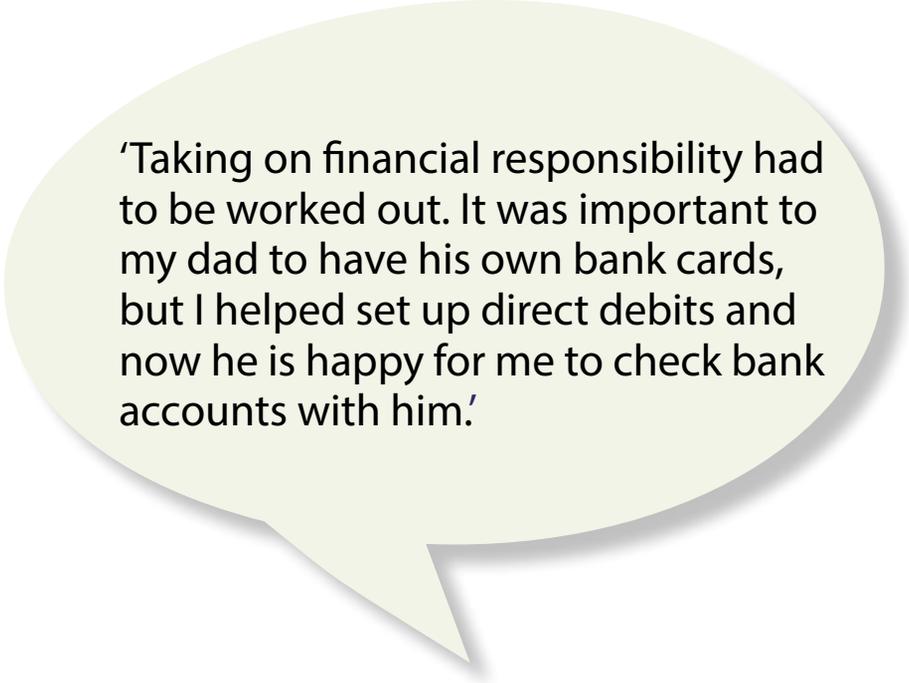
What you can do:

- 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 are not under pressure from anyone else. They can:
 - choose one, two or more people as joint powers of attorney
 - choose the same or different people to handle their financial and welfare matters
 - choose other people in case their first choice can't carry on looking after 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.slab.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, 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.

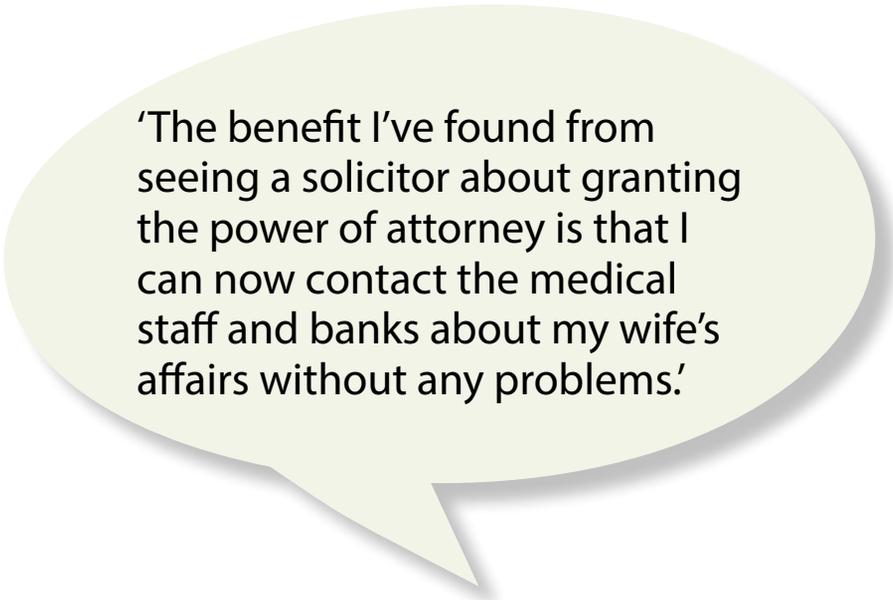
What you can do:

- 1 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.
- 2 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 or go outside with large sums of money.
- 3 If the person with dementia loses money, gives it away or forgets that they have spent it, they may mistakenly accuse others of taking it. Reassure the person that they have enough money.
- 4 In some cases, 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.
- 5 People with dementia 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.

- 6 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 p. 46). Once it is registered, you (or the person named as their attorney) can use it to manage the person's finances.
- 7 If you are concerned that someone is misusing the person's money, for example using a power of attorney, the Public Guardian can investigate.
- 8 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.
- 9 If the person has money in an account in their sole name, and they are no longer able to manage it, you can apply to access the money yourself to spend it on their behalf. (But you can't do this if someone has a financial power of attorney, or financial guardian, for the person.) You don't need a solicitor to apply. You can get an application form for Authority to Access Funds from the Dementia Helpline or the Public Guardian. On the form you write down 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.
- 10 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, normally used for a one-off decision or short series of actions.

What you can do:

- 1 Go to www.alzscot.org or phone the Dementia Helpline on 0808 808 3000.
- 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 changes to welfare legislation.

It's always a good idea to get help from a benefits advisor 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 Health and Social Care Partnerships also provide benefits and welfare rights advice. You should check how to access this with your social work department. The Citizens Advice Bureau can also help you claim benefits. Visit the Citizens Advice Scotland website www.cas.org.uk or call the Citizens Advice Direct helpline on 0808 800 9060.

The Department for Work and Pensions (DWP) offers support to people claiming benefits related to disability (including dementia) and their carers.

The person with dementia can appoint someone as a joint account holder or ask the bank or Post Office to issue a second card to the carer to allow them to withdraw money on their behalf.

It's always worth seeking advice – even if you don't think you are entitled. Try the government's online benefit calculator to get an idea of what you're entitled to. www.gov.uk/benefits-calculators

For people 65 or over with dementia

Attendance Allowance

This is a social security benefit for people aged 65 or over who are physically or mentally disabled and need help with personal care or require supervision to remain safe.

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 Jobseeker's Allowance. You can also claim when Statutory Sick Pay ends.

Personal Independence Payments (PIP) for people aged under 65

People with dementia may be able to get help with some of the extra costs caused by long-term ill health. This is a benefit that may be available to people with dementia to help with some of the costs associated with long-term ill health.

Universal Credit

Universal Credit was introduced to replace Income Support, Income-related Jobseeker's Allowance, Income-based Employment and Support Allowance, Tax Credits and Housing Benefit. Since 2014, people who get the old benefits are being moved across to the new system.

Help with council tax

If you're aged 65 or over, 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.



Further information

www.gov.uk/browse/benefits/disability; www.gov.uk/disability-benefits-helpline or call the Dementia Helpline on 0808 808 3000.

For carers

Carers may also be eligible for financial support. In addition to the benefits listed below you may be entitled to claim other benefits, such as disability benefits for yourself if you have an illness or disability.

Carer's Allowance

A carer 16 or over who looks after a person with dementia for at least 35 hours a week and doesn't study for more than 21 hours per 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. Income Support is a means-tested benefit and entitlement will depend on how much income and savings or investments you (and your partner) have.

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.

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

For information on carer entitlements, contact the Carer's Allowance Unit on 0800 731 0297 (textphone 0800 731 0317). 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 the 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 Payment Exception Service. You will be able to collect your benefit from a PayPoint outlet. 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 and proof of ID in order to collect your cash. If you don't have a card, or you've lost a card, you can be sent a voucher or text message with a unique reference number to collect your benefit at the PayPoint outlet. The DWP does not need your agreement in order to pay you in this way. If you have any queries you should contact the DWP office which pays your benefit.



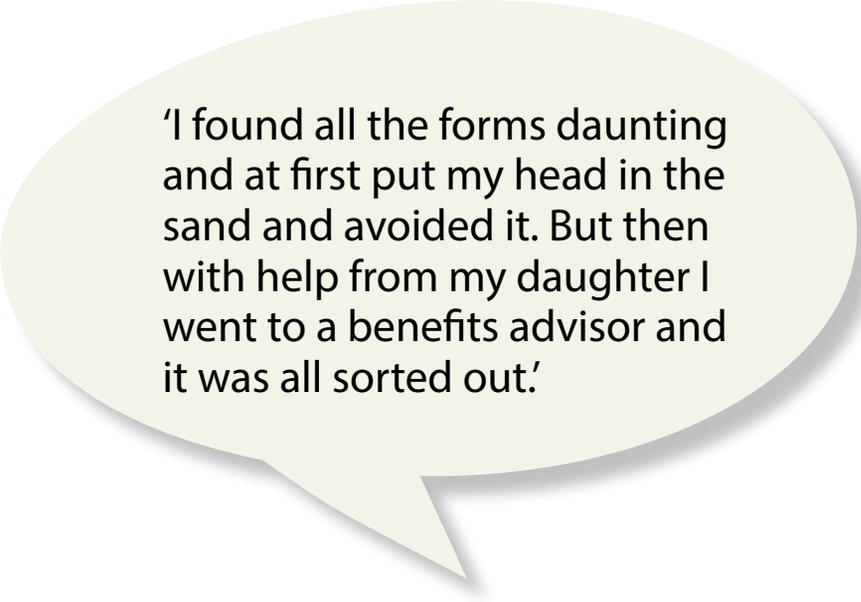
Further information

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

Welfare benefits: at a glance

- If you have dementia or are caring for someone with dementia you may be entitled to financial help from the benefits system.
- You have a right to apply for carer's benefits if you're 16 or over.
- Not all benefits are only available to people on low incomes.
- The benefits system is complex. It is always a good idea to seek expert benefits advice and to get help.



'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 advisor 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 Freephone 24-hour Dementia Helpline on 0808 808 3000 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.

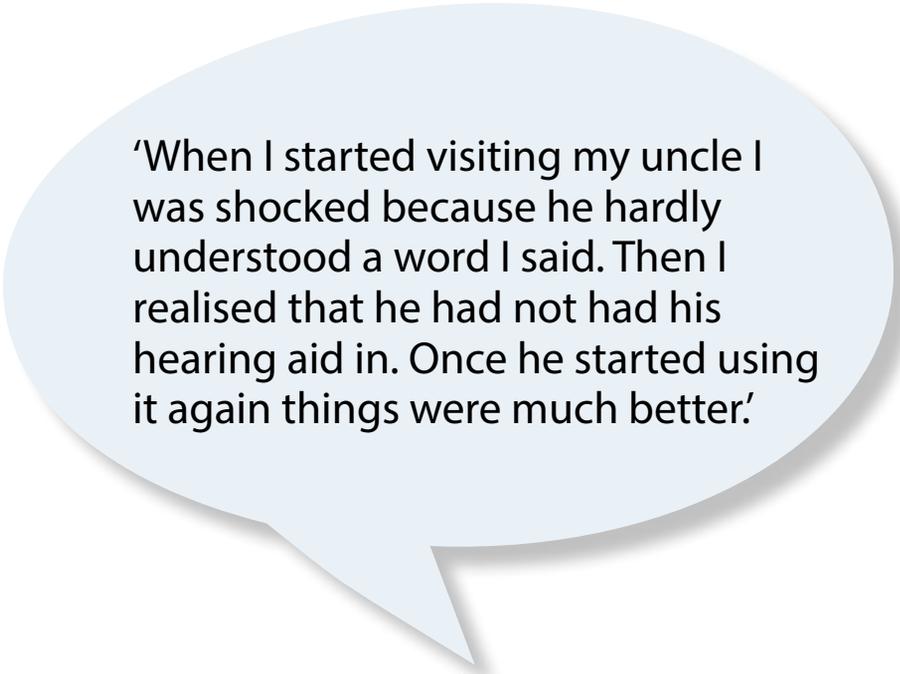
Physical wellbeing

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 sight, hearing, infections or discomfort (for example, constipation) can make life harder for a person with dementia, and add to their confusion.

It can be more difficult for the person with dementia to tell you if something is wrong. If the person seems irritable, or more confused than usual, they should see their doctor.

It is likely that the person's confusion will improve when the cause of their discomfort has been identified and treated.



'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.'

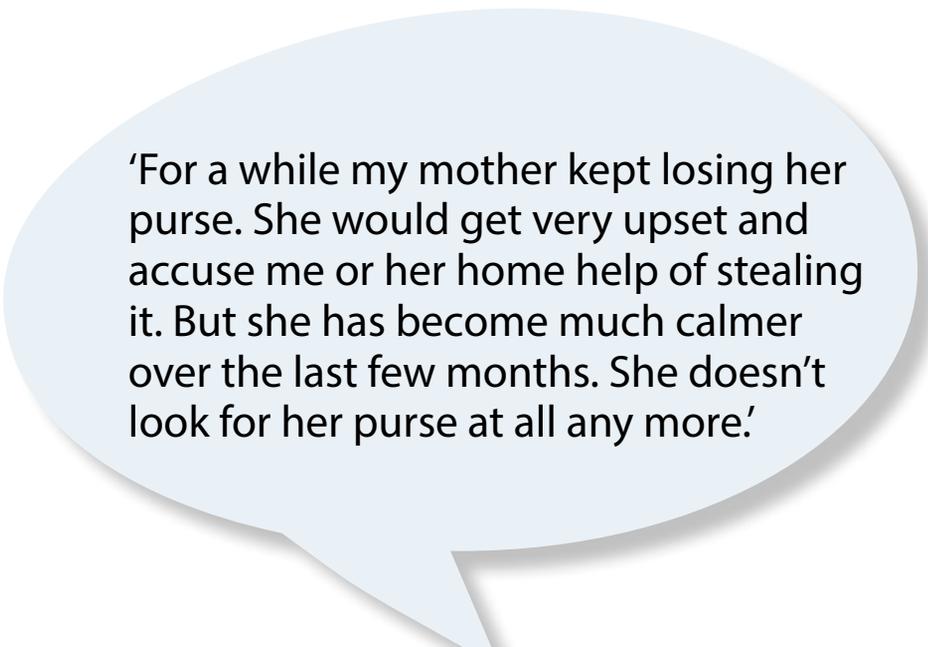
What you can do:

- 1 Try to make sure the person has enough to eat. Ask for advice from a dietitian or speech and language therapist 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, optometrist or hearing specialist. It is important that they can see and 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 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 that 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.
- Symptoms of confusion generally improve following treatment for physical illnesses.



'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 any more.'



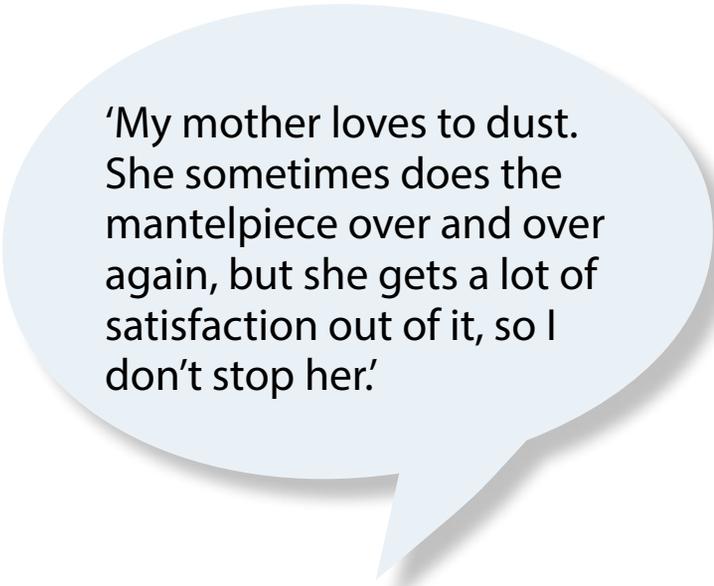
Mental stimulation

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.

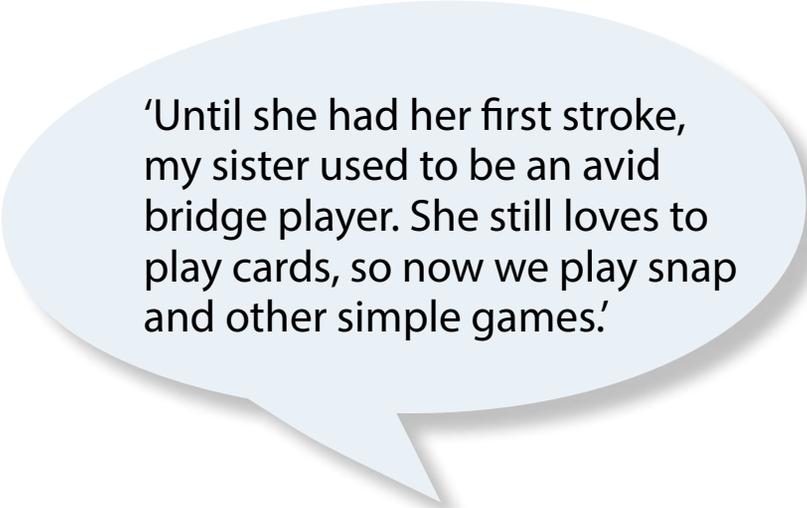
Don't feel you must provide something to do every minute of the day. Quiet time is important too. Try to find help with caring so that you are under less pressure. A day centre can offer enjoyable and stimulating activities for the person and give you time for yourself. See Getting help on p. 122.



'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
- 7 Remember that even if the person doesn't remember an activity, it's 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 or postcards. It 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 audiobook 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 audiobook 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 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.

However, be aware that there may be some memories that the person with dementia would rather not relive. Discuss each addition to the life story book with them and take out anything that might upset them.

What you can do:

- 1 Use a scrapbook, photograph album or audio-recording device to make the life story book.
- 2 Help the person look through 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, for both 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. For example, this may include religious worship, meditation, books, songs or chants, symbols, places or other things.
- 2 If the person attended religious worship, 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.
- 3 Help the person to stay in contact with other people from their place of worship. Encourage visitors.
- 4 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.
- 5 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.'

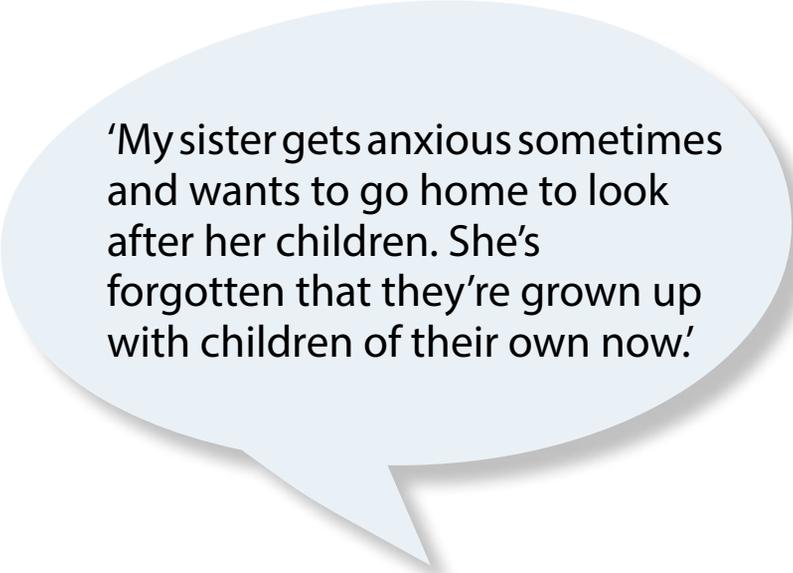
Decline in memory

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.

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.

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.



'My sister gets anxious sometimes and wants to go home to look after her children. She's forgotten that they're 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 (using words or pictures) on doors to help the person find their way around.
- 5 Use a memory board or notice board as a reminder of what is going on. Put it somewhere 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 and may be unable to understand certain words. 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 clean, in good working order and are the correct prescription. Poor sight and hearing can make people more confused and conversation difficult. See www.actiononhearingloss.org.uk for more information on getting the most from your hearing aid.
- 2 Speak clearly, simply and slowly but don't shout. Make sure the person can see your face when you speak.
- 3 Try using different words if you feel what you've said hasn't been understood.
- 4 Try to get one idea across at a time.
- 5 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.'
- 6 Use questions that ask for a simple answer. Instead of asking, 'What would you like to do this afternoon?', you could say, 'Do you want to go for a walk, or shall we look at some photographs?'

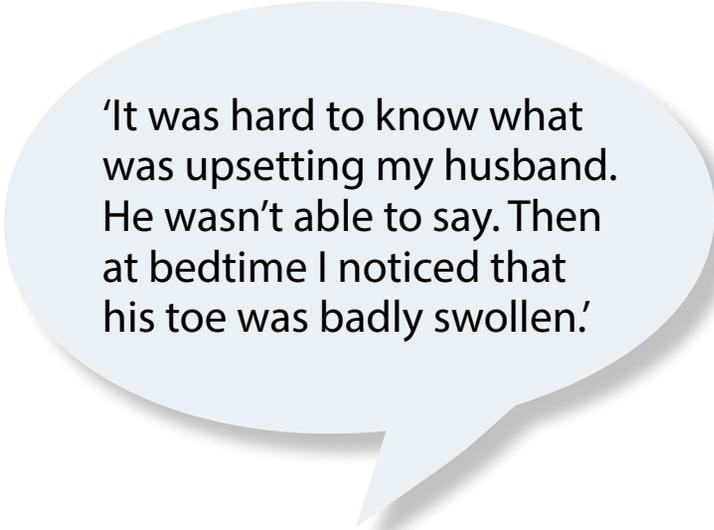
- 7 Allow plenty of time for the person to take in what you say and to reply.
- 8 Try not to confuse or embarrass the person by correcting them bluntly.
- 9 If the person with dementia can't find the right words, ask them to describe what they mean and suggest a word. But don't get into the habit of 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.
- 10 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.
- 11 Many people with dementia enjoy talking about the past. You may both enjoy reliving some of these memories together. Talking about things that 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 p. 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.'

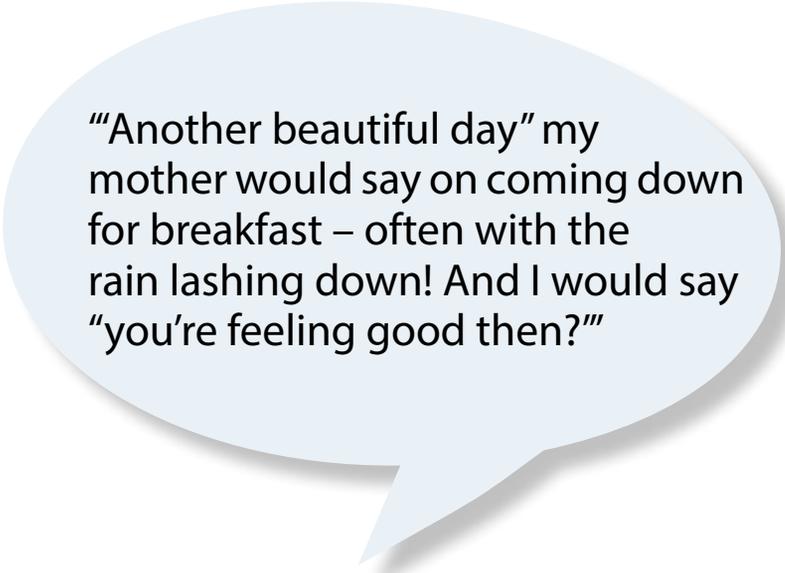
Confused thinking

As dementia progresses the person's thinking may become 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:

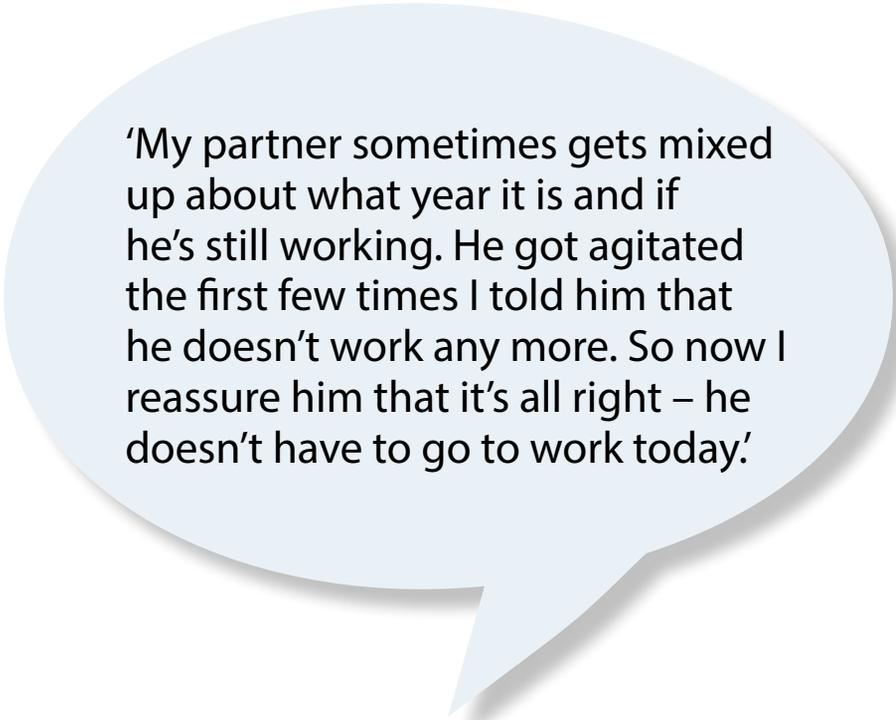
- 1 Try diverting them onto another subject until they forget.
- 2 Respond kindly to the person's feelings without agreeing with what they are saying.



“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 any more. So now I reassure him that it's all right – 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.'

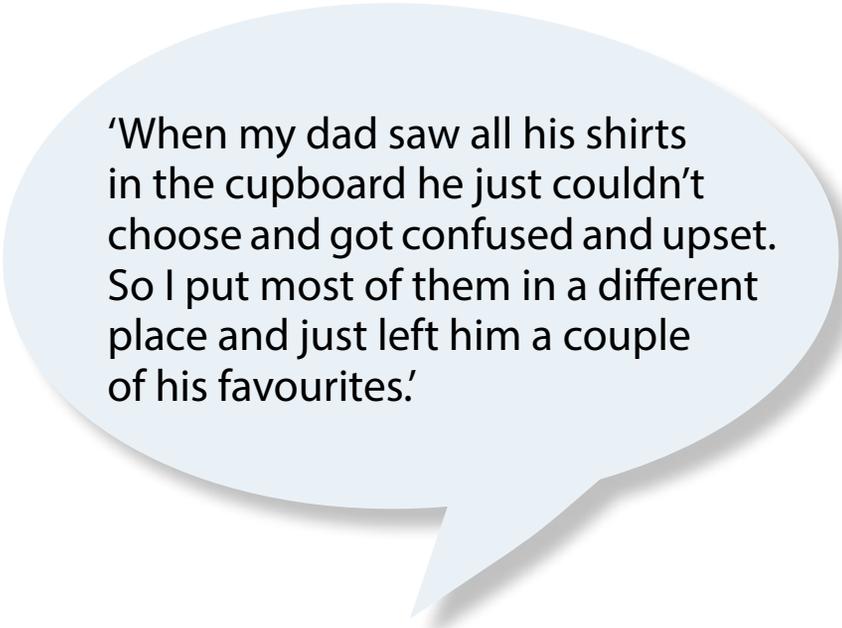
What you can do:

- 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 wear slippers for only 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 and 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 fingernails and toenails 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.knowledge.scot.nhs.uk/home/portals-and-topics/personal-footcare.aspx
- 5 A trip to the hairdresser 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

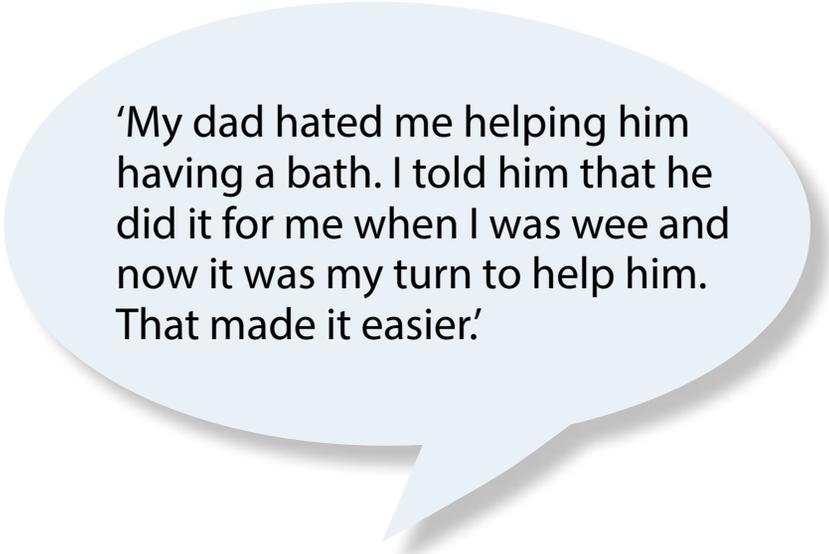
It may be difficult to persuade the person with dementia to have a bath. They may believe that they have recently taken one, when you know they haven't. Bathing can have its own problems. Some people forget how to wash themselves, wash one area several times and forget others, forget to use soap or forget 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 and 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, or hand rails on the side of the bath can 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 that some carers find useful. Ask the occupational therapist.
- 6 In some cases, a shower may upset the person with dementia if they are not used to them.
- 7 There are products (e.g. No Rinse) which can be used for personal hygiene in place of conventional shampoos.

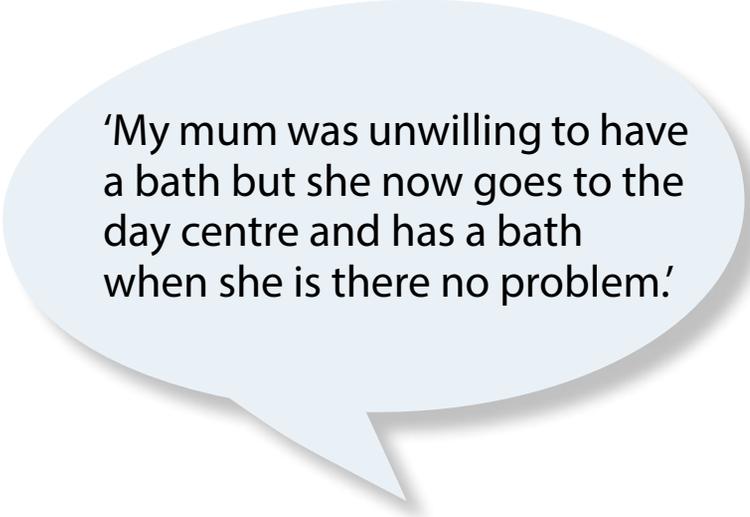
- 8 Washing intimate areas of the body is important, but can feel embarrassing. Often this can feel especially awkward if you are helping a parent of the opposite sex. Try giving the person the cloth or sponge and guiding their hand. Some people find it easier to be bathed by someone they don't know, 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 can't 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 experience urinary or faecal incontinence.

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.

Urinary incontinence may be the result of an infection or some physical problem. For instance, in men it may be caused by an enlarged prostate gland. Infections can be treated. 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 throughout the day and bed-linen at night. Ask the doctor if there is a continence advisor in your area and ask about incontinence aids. Call the Dementia Helpline for an information sheet on urinary and faecal incontinence.



'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 advisor. The nurse or advisor 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's 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, such as fruit, vegetables, wholewheat 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 social work department for more information.

Managing continence: at a glance

- See the nurse first of all.
- Don't make a big issue of incontinence.
- Try occasional reminders or regular visits to the toilet.
- 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 a poor appetite. They may not be very interested in eating. Some people with dementia seem to lose weight even when they are eating properly and 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. Some may experience dehydration if they aren't drinking enough fluids. 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 to encourage the person to help with the preparation of food, especially if they have always enjoyed cooking. This can help them maintain an interest in food, and take enjoyment in an activity.

What you can do:

- 1 Allow plenty of time for meals. Make sure mealtimes 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 tablecloths 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 6–8 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 their favourite music, a game of cards or gardening – anything that 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 that are not there (hallucinations). This is especially common for people with Lewy body dementia. Some may believe things that are not true (delusions).

More often, people with dementia may mistake what they hear or see for something else, or confuse events. For example, someone may mistake a reflection in the window for someone in the room. Or someone may think things have been stolen because they have forgotten putting them away.

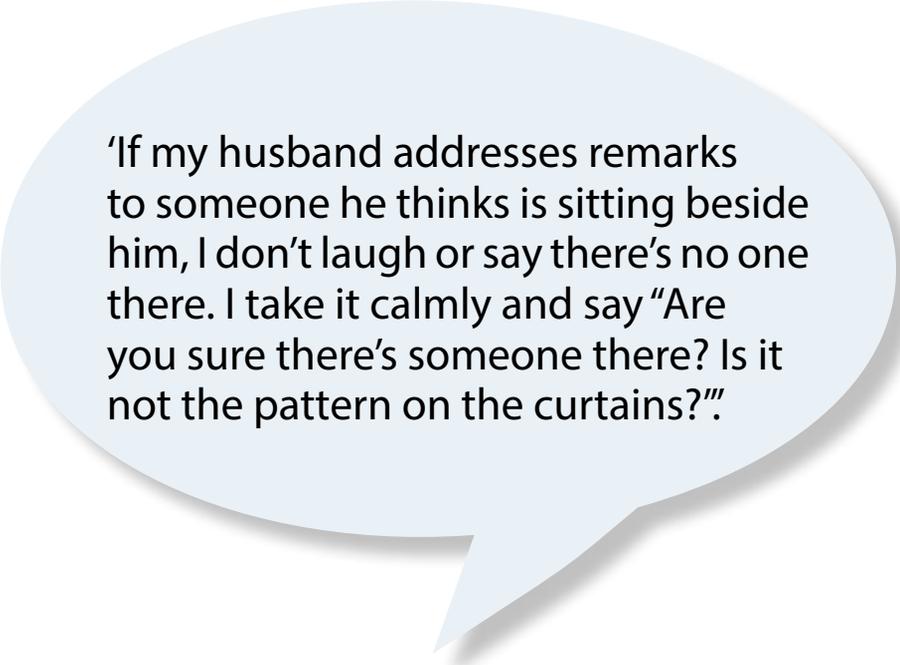
In some cases they may be upsetting or frightening, but in other cases the person with dementia may find them comforting.

What you can do:

- 1 If the person starts to have hallucinations, make sure they see the doctor. The problem may be caused by an infection which can be treated, 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 that 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 can't 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 or not 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 to reassure them they're not under suspicion.

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. 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 that may help.

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 if there is really a problem. If the person goes out, do they find their way home again? Are they able to cross the road safely? Perhaps 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 exercising 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 that will hold the person's interest. Walking about is less likely if they have something to do. See www.pathsforall.org.uk/pfa-home for walking tips.
- 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.
- 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 to the person experiencing dementia. Visit www.playlistforlife.org.uk



'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.
- 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 Health and Social Care Partnership, 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.

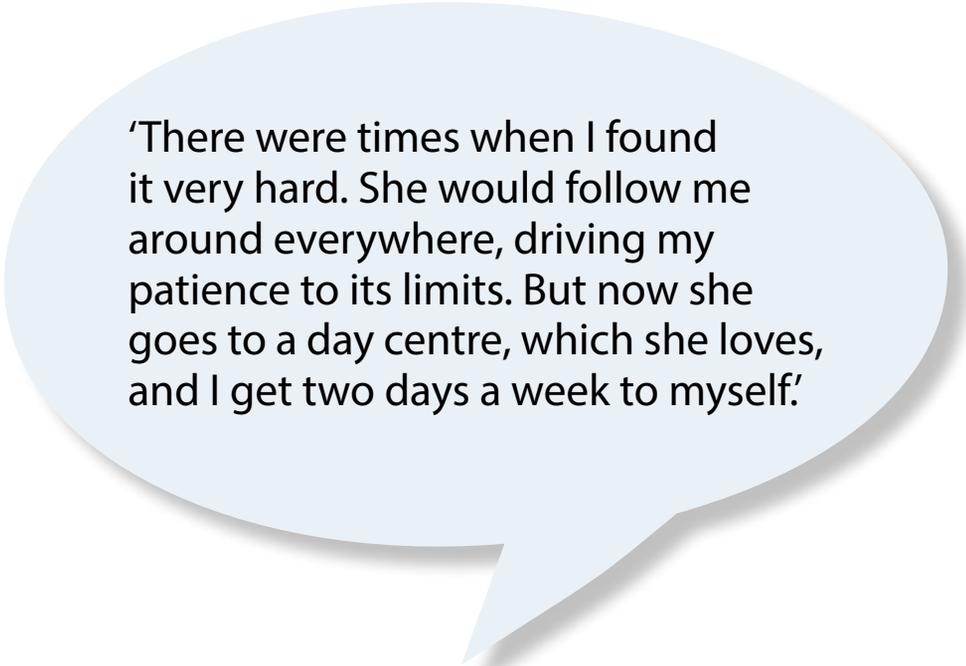
'When he has gone to a nearby shop, and not come back, I have to go out searching. I keep my cool when I find him. Sometimes he smiles and says "I'm glad to see you, I've had a long walk"'

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:

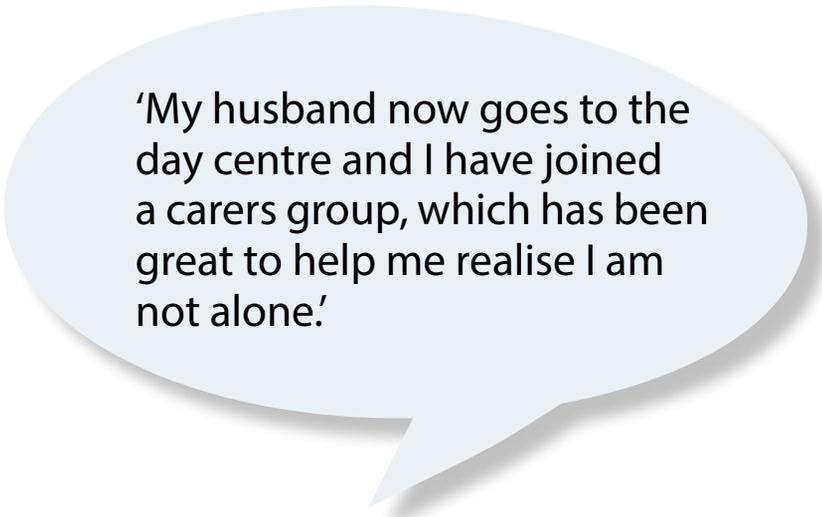
- 1 Remember that the person may be feeling insecure and offer plenty of reassurance.
- 2 Remember that your wellbeing is important too. You will find it easier to cope with the person's need for attention if you get some time off.
- 3 Ask for help from family and friends to spend time with the person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

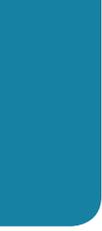
Shouting

The person with dementia may begin to raise their voice, or use abusive and hurtful language, which can come as a shock to the people around them. There are a variety of reasons that the person is raising their voice or shouting.

Perhaps the person is in pain, is trying to communicate a feeling or need (for example being frightened or needing the toilet), or is struggling to find the words to tell you something.

What you can do:

- 1 Remain calm if you can, though this is easier said than done, and try not to take it personally.
- 2 Speak calmly and gently, and try to keep a calm and pleasant expression.
- 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 Have the person's eyesight and hearing checked.
- 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 someone at the Dementia Helpline.
 - 10 Do not feel guilty if you occasionally do get angry back. None of us can remain calm all of the time.

Shouting: at a glance

- Keep calm.
- Don't get involved in an argument.
- Speak to the doctor about what might be causing a problem.

Losing inhibitions

Sometimes a person with dementia can behave in ways that others find embarrassing, without realising what they are doing is inappropriate. This can include socially and sexually inappropriate behaviour in public, for example shouting at visitors or undressing in public. This can cause both the person with dementia and their carer to feel embarrassed and distressed.

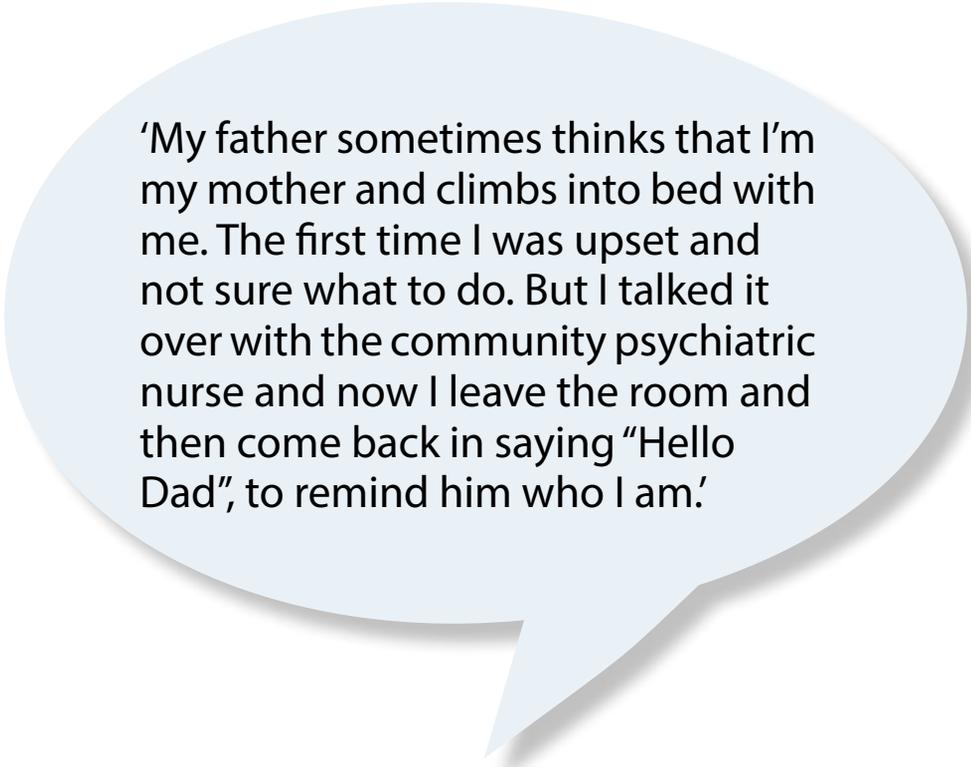
People with dementia lose their inhibitions for different reasons. For some people it may be the effect of dementia (this is specific to frontotemporal dementia, owing to the damage to the frontal lobe); they may need the toilet or be too hot; or they could be feeling anxious or frustrated.

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.

Losing inhibitions: at a glance

- Remember that the person with dementia will not realise what they are doing is inappropriate.
- Deal with the situation as calmly as possible.
- 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. Your partner's personality may have changed.

You may want to carry on your sexual relationship but worry about if 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 if 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. Call the 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 walking about. 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. This 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 leave only 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 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 can't 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 that 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 their way about at night.
- 4 Fit smoke alarms and make sure neighbours know this has been done.
- 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 non-slip 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 Home Energy Care Free Gas Safety Check 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 can't use appliances safely make sure that they only use them when someone is there. For example, asking the gas company to fit an isolation tap on the cooker so it can only be used when someone else is there.
- 11 If the person with dementia is a smoker, ensure that they can still use matches, lighters or a gas flame safely (see p. 116 for more information).
- 12 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.
- 13 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.
- 14 Ask the Health and Social Care Partnership about alarm systems. In some areas systems are available that 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 Service, see www.firescotland.gov.uk/your-safety/for-householders/home-fire-safety-visit

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

In general, people with moderate to severe dementia will not be able to continue to drive. If you are not sure if the person is safe to drive, their doctor can refer them to the Scottish Driving Assessment Service to check if they are still safe to drive. You must tell the insurance company and the DVLA about a diagnosis of dementia. Not doing so may invalidate the insurance cover. Driving without valid insurance is a criminal offence and can result in a fine. If a doctor advises against driving for a period of three months or more then the person must surrender their driving licence.

If the person is not safe to drive, discuss it with them – they may be ready to give up. It is a difficult issue but don't wait until there is an accident. If you can't persuade them to stop, contact the DVLA. They will check with their doctor and if necessary they can take away the person's licence.

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 and point out the benefits of not having a car, for example, walking more and no longer paying for insurance and MOTs.
- 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. Some groups, such as the Royal Voluntary Service, may be able to help with transport. Check with the Health and Social Care Partnership, as some have taxi schemes for people with disabilities, or visit www.royalvoluntaryservice.org.uk/get-help/getting-out-and-about/community-transport
- 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 they should stop driving.
- 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, p. 177). 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.

Scottish Government guidelines recommend that to keep health risks from alcohol to a low level it is safest not to drink more than 14 units a week on a regular basis. If you regularly drink as much as 14 units per week, it is best to spread your drinking evenly over 3 or more days.

For further information, see Making a change, www.healthscotland.scot/publications/alcohol-brief-intervention-resources

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.

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's 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 or not the person can have any alcoholic drink and, if so, how much. This is essential if the person is taking medicines.



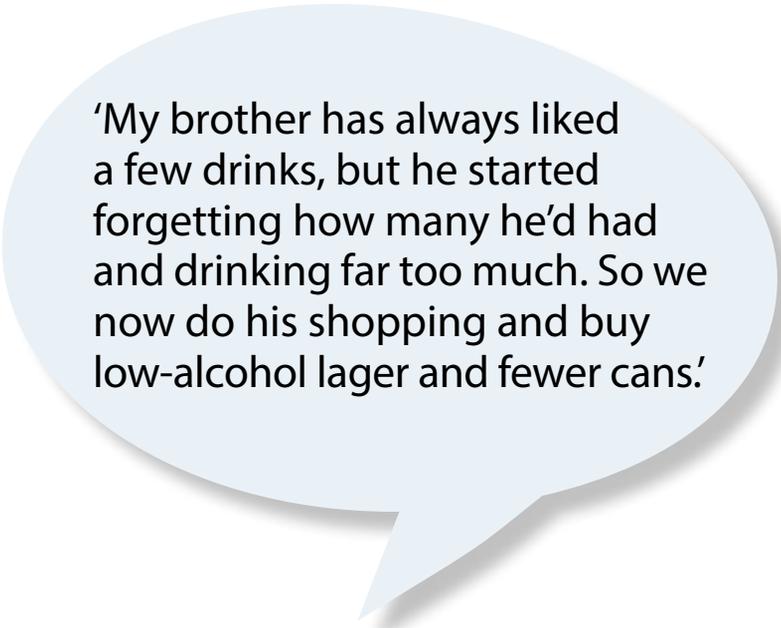
Further information

Alzheimer Scotland information sheet, *Healthy living with dementia*. Go to www.alzscot.org or call the Dementia Helpline on 0808 808 3000.

For more information about how many units are in a drink see *Making a change*, www.healthscotland.scot/publications/alcohol-brief-intervention-resources

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 or not.



'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

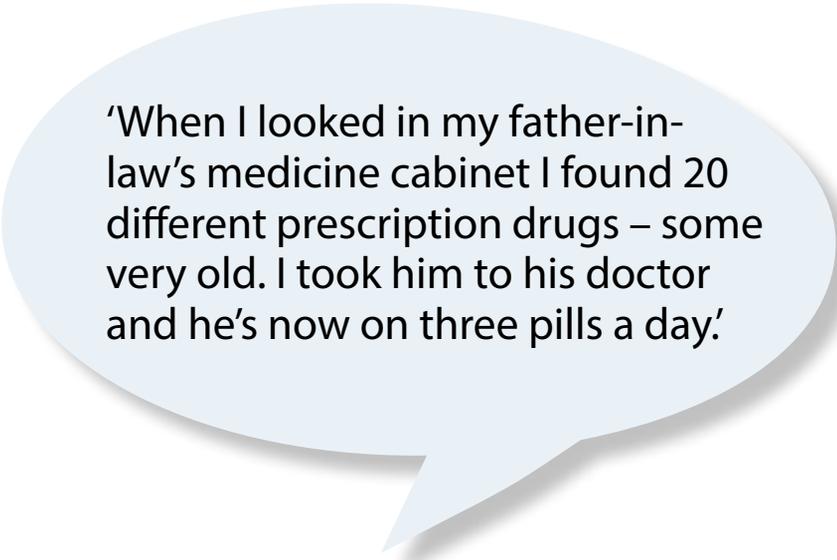
You will have to take special care if the person with dementia is on any sort of medication. The person with dementia may accidentally take too much or not take it at all. Check with the doctor to make sure the person is only taking what is necessary.

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 The pharmacy can have medications sorted into timed and dated blister packs. This is arranged with a GP.
- 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 you're not sure, 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 that 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.

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 Health and Social Care Partnership or contact Alzheimer Scotland's Freephone 24-hour Dementia Helpline on 0808 808 3000 for information about other services in your area.

Support services

The local social work department is the main route to getting support services in your own home or through services near where you live. See p. 133 for information on free personal care and charges for services.

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



Further information

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 emotional or professional support when you go to appointments, as they can be very overwhelming.

If English is not your first language, or if you are deaf or hearing impaired, you may find it useful to arrange to have an interpreter 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. They may be able to refer you to suitable support.



Further information

Alzheimer Scotland carer training.
www.alzscot.org or call the Dementia Helpline on 0808 808 3000.

Alzheimer Scotland guide for carers, Looking after yourself.
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

Carers Scotland offers a voice for carers as well as practical help and advice on coping. www.carersuk.org/scotland

Carers Trust offers information, online training and a discussion forum. carers.org/article/dementia

Deaf Action leaflet, Dementia and deafness: What you need to know. www.deafaction.org.uk

Royal National Institute of Blind People (RNIB) offers advice on dementia and sight loss.
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 health or care services for access to local interpreting services.

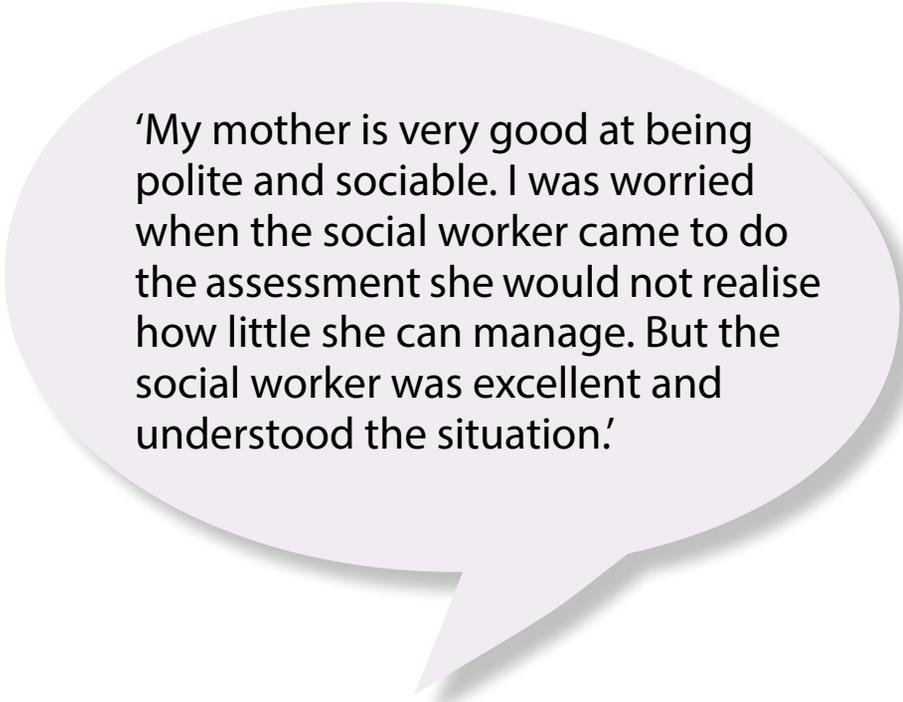
Scottish Council on Deafness. Call 0141 248 2474, textphone 0141 248 2477, text 07925 417338 or visit www.scod.org.uk

Action on Hearing Loss. Call 0141 341 5330, textphone 0141 341 5350, email scotland@hearingloss.org.uk or visit www.actiononhearingloss.org.uk

Deafblind Scotland. Call 0141 777 6111, text 07715 421377, email info@dbscotland.org.uk or visit dbscotland.org.uk

Carer 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.
- 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

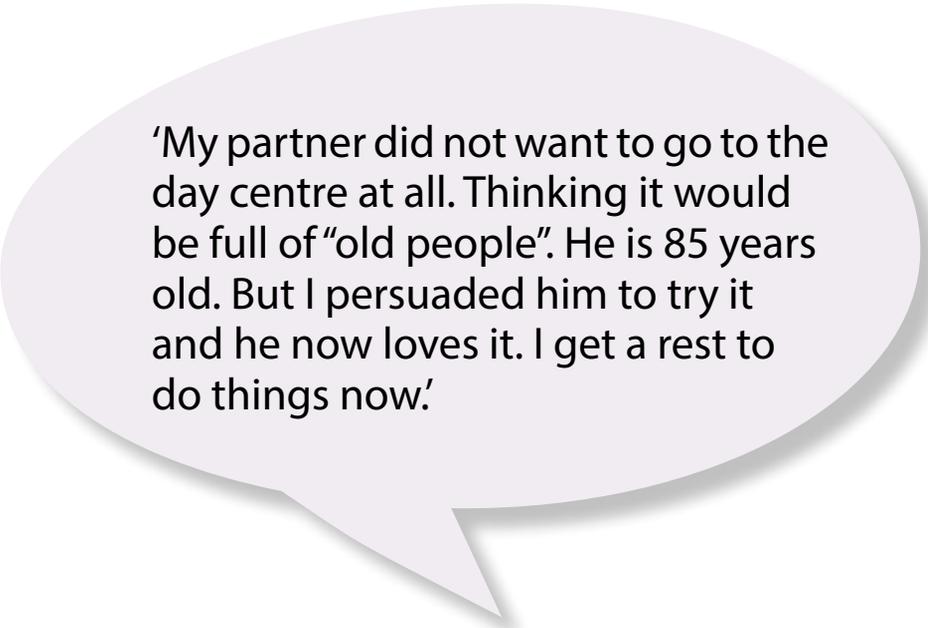
Home care services (sometimes called domiciliary services) can offer care for the person with dementia in their own home, depending on what they need. For example, a home help might help the person to prepare a meal, or a care assistant might help them to get dressed or go out for a walk. For many carers, 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 Health and Social Care Partnership or call the Dementia Helpline for details of services in your area.

Home support services

Some voluntary organisations provide home support or 'sitter' services, with trained care assistants to help look after the person with dementia. They can provide stimulating activities for the person with dementia or take them on outings, for example. Private nursing or care agencies can also provide care assistants or nurses during the day or at night.

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. Some day centres are run by the Health and Social Care Partnership, others by voluntary organisations, such as Alzheimer Scotland. Specialist day centres provide activities suited to the person's abilities. They can often even cater for people whose dementia is quite severe. In some areas there are now day centres particularly for younger people with dementia (under the age of 65), 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 Health and Social Care Partnership 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

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, will give you the chance to recharge your batteries. Perhaps you might take a holiday, or maybe just have some time for yourself at home. Don't feel you have to visit the person – this is a time to give yourself a break – ask family if they can visit during this time. In some areas, social workers or health professionals can arrange a programme of regular respite breaks for you.

When the person is on their short break, it might be useful to put familiar items in their room and share with the staff their life story book. It may also be useful to complete and bring along a document called Getting to know me, which is available from Alzheimer Scotland. This document 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

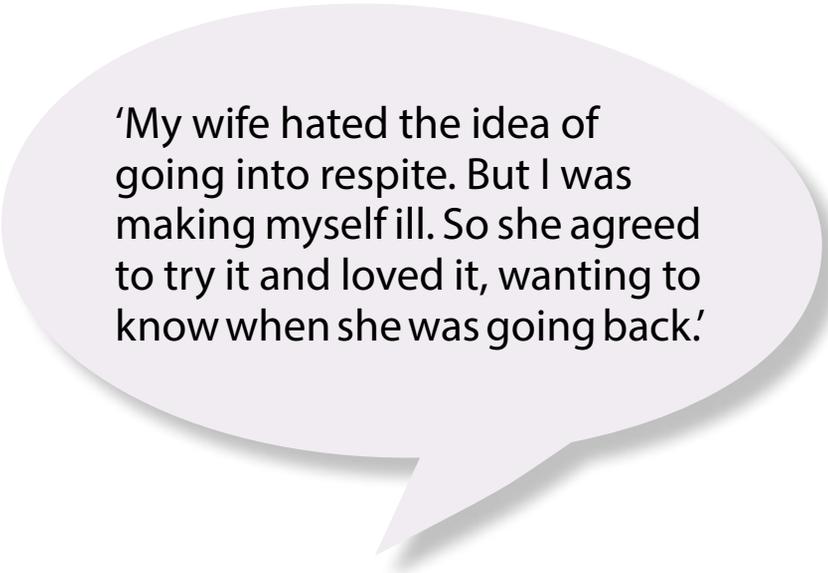
If the person with dementia is 65 and over and they are assessed as needing help at home with personal care, they will not have to pay for this help. Currently, people under 65 still have to pay; however, Scottish Government has plans to extend this so that personal care will be free for everyone who requires it, including people aged under 65. 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 Health and Social Care Partnership 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 65 and over can get free personal care at home. Scottish Government has plans to extend this to include people aged under 65.
- 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 Health and Social Care Partnership

Depending on the level of needs of the person with dementia they may be eligible for support services from your Health and Social Care Partnership. 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 Health and Social Care Partnership 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 is about people making informed choices about their support and having as much control over it as they want.

It's also about offering people flexibility so they can use their support in the ways, and at the times, that suit them best.

The Health and Social Care Partnership must offer four options to everyone they are going to provide support to. The four options are:

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

Individual service funds

This is another way of giving more control over the person with dementia's own support, but without the responsibility of the direct payment in which they or their carer (if power of attorney is 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 their own or with assistance from other people. If a power of attorney is in place (see Planning for the future on p. 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).



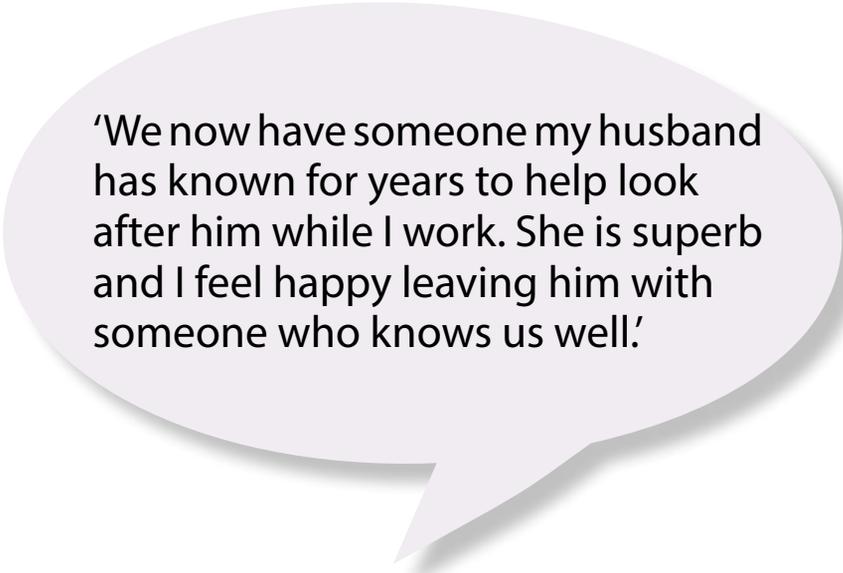
Further information

See the Self-directed Support in Scotland website www.selfdirectedsupportscotland.org.uk.

Alzheimer Scotland leaflet, Self-directed Support and dementia. Go to www.alzscot.org or call the Dementia Helpline on 0808 808 3000.

Self-directed support: at a glance

- People with dementia can be given more control and choice over how they receive services.
- The Health and Social Care Partnership must offer the four options to everyone they are going to provide support to.



'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 GP. 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 try to schedule a general health review 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.

Discuss with the person beforehand if they'd like you to 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.

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 (chiroprody). 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 NHS has a complaints procedure.

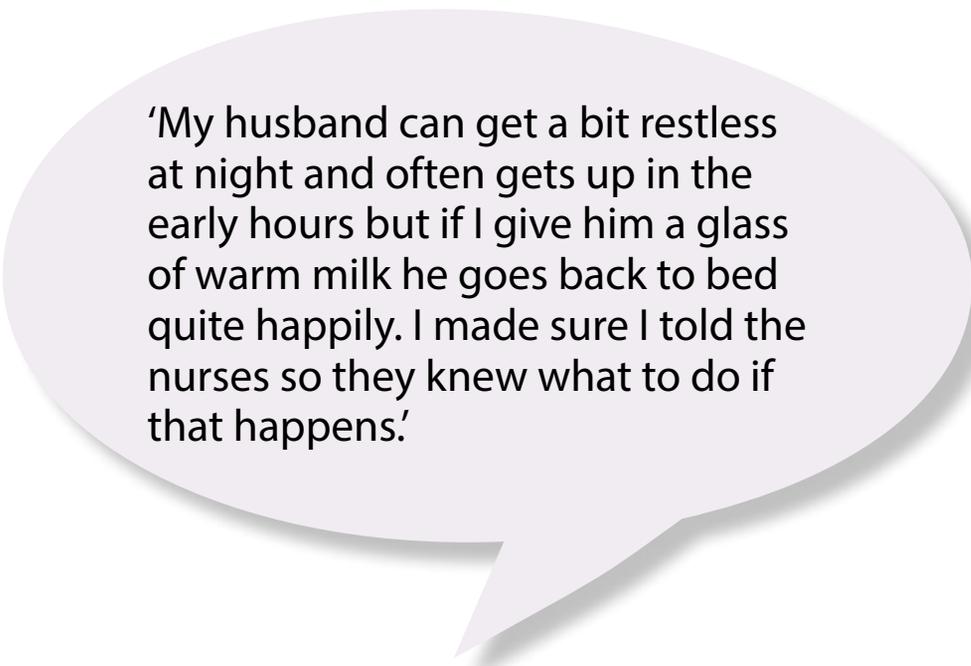
Admission to hospital

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 a 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 Alzheimer 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

Call the Alzheimer Scotland Freephone 24-hour Dementia Helpline on 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 Health and Social Care Partnership 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 Health and Social Care Partnership, the Dementia Helpline or the Scottish Independent Advocacy Alliance (see Further information on p. 13).

Carer's 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. Alzheimer Scotland provides 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 p. 166 for more details on individual voluntary organisations.

Information and support: at a glance

- The Dementia Helpline on 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 working with the consultant psychiatrist, who will help the person and his or her carer and family cope with the diagnosis and everyday living.

Alzheimer Scotland dementia advisor

Alzheimer Scotland dementia advisors 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 or post-diagnostic support 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

Dentists are qualified to treat the diseases and conditions that affect the teeth and gums. 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 for someone who has dementia to eat well and stay hydrated. A dietitian can give advice on good nutrition, and help if the person's eating habits change because of dementia. A dietitian can work with the person's speech and language therapist to provide advice on how the person with dementia can maintain a healthy, balanced diet if they're 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 OT can also advise carers on how to support someone living with dementia to maintain skills, routines and roles. You can find an OT through the Health and Social Care Partnership, your 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 (chiroprpodists) 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. It is usually, but not always, a psychiatrist who makes and gives a diagnosis of dementia. They can prescribe drugs as well as advise 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 on p. 122). They are employed by the local authority and work as part of the Health and Social Care Partnership.

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. 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 cafes 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 cafe-like community setting (sometimes an actual cafe).

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

Self-directed Support is about people making informed choices about their support and having as much control over it as they want.

The Health and Social Care Partnership must offer the four options to everyone they are going to provide support to.

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

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

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

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 and search for 'Self-directed Support'.

Care homes

The decision

Eventually, you may not be able to go on looking after the person with dementia at home. Perhaps they have become so ill they need a team of people to care for them, or perhaps your own health has changed.

Not everyone can be a carer and not everyone can go on caring as long as they wish they could. It is important to understand and accept what you can and can't do. Many people with dementia will need to move into a care home in the later stages of their illness.

Try not to take this difficult decision on your own. Involve the person as much as you can, and 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 a care home.

For further information on care homes call the Dementia Helpline on 0808 808 3000.

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 mealtimes, 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.'

Moving to a care home

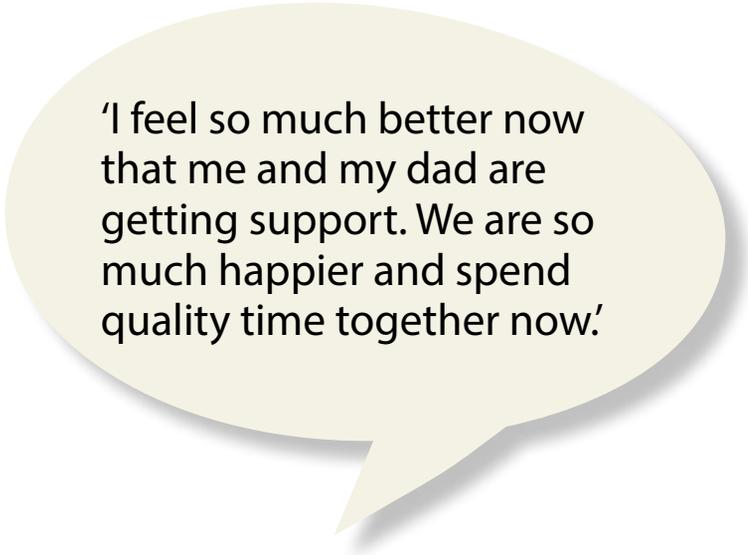
The best way to arrange the move to a care home is to ask the social work department for a community care assessment. This will make sure the person gets the right kind of care to meet their needs. An assessment is essential for the person to be able to get the free personal or nursing care allowance towards the care home fees (see p.158 for more information). It is also important for the person to have an assessment to find out whether he or she needs help paying the fees now or might need help in the future.

You 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 the person is assessed as needing long-stay care, the social work department can arrange it, or you can choose to arrange it yourself. The social work department can also 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 an 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 Health and Social Care Partnership 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 p. 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 social work department has a maximum amount they will normally pay for home fees. They should offer the person a place in a home that is suitable and equal to or below this maximum. Or they may provide a list of homes for you to choose from. If you can, visit several homes before you decide on which would best suit the person with dementia. Perhaps you and the person can visit together.

You can also choose a different home, anywhere in the UK, as long as it is suitable for the person's needs and doesn't cost more than the social work department normally pays. Or, if it costs more, you or someone else can agree to pay the extra, bearing in mind that, if you stop paying for any reason, the person may have to move. It is important to keep the Health and Social Care Partnership informed if you plan on choosing a care home in a different area from where the person usually lives, particularly if you are expecting the person to receive the free personal and nursing care allowance.

It may be helpful to involve an independent advocate when you are making these decisions. 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 p. 13) to find out about advocacy services near you. A few people with dementia who have very complex needs may need hospital-based complex care. This decision is up to the person's hospital consultant.

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 Health and Social Care Partnership informed before the person moves.
- You can choose a more expensive home than the Health and Social Care Partnership 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 assessed as needing care in a care home who is 65 or over and paying some or all of the fees is entitled to free personal care, and, if assessed as needing nursing care, a payment towards nursing care costs. Scottish Government has plans to extend this to include people aged under 65. Free personal care and nursing care are a financial contribution paid by the Health and Social Care Partnership towards the care home costs. The social work department in the Health and Social Care Partnership 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 may include the remaining costs of personal and nursing care, food, accommodation and so on.

Other help towards the fees

Care home fees can be costly. Many people will need some help with paying. The social work department will carry out a financial assessment to work out how much financial assistance is needed to pay the care home fees. They will look at the person's income and capital. Income and capital are either taken into account in full, partially disregarded or fully disregarded. Financial assessment is used to work out how much contribution the person will pay towards the care home fees. No one should be left with less than a weekly personal expenses allowance which is set each year by the Scottish Government.

If the person's income is not enough to pay the full fees, the social work department may help to pay the amount over their income. If the person has savings or property worth more than the 'upper limit', they will have to pay the home fees themselves from their savings until the savings reach the 'lower limit'. This is called tariff income and is added to a person's assessed income to decide the level of contribution. If they have an amount between the upper limit and the lower limit, they may still be entitled to financial help, over and above any free personal and nursing care payments. If they have less than the lower limit, the social work department will pay, up to their maximum amount. Only the income and capital of the person moving to the care home should be considered when calculating any financial contribution towards care home fees (a carer's capital or income is excluded from the financial consideration).

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. 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 the following people still lives there:

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

The 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. The financial assessment process is complex and it is a good idea to get expert advice. Seek advice if you disagree with the outcome of a financial assessment, you may be able to challenge the decision.



Further information

Care Information Scotland information on care homes
www.careinfoscotland.scot/topics/care-homes

Paying the home fees: at a glance

- People 65 or over paying all or part of their own fees can get a free personal care payment towards their care home fees.
- People of any age assessed as needing nursing care and paying all or part of their own fees can get a nursing care payment towards their care fees.
- The social work department will do a financial assessment to see how much the person should pay towards the care home.
- Only the income and capital owned solely by the person (or their share of joint income or capital) can be taken into account in the financial assessment.
- The value of the person's house will be counted in some circumstances but not in others.
- It is a good idea to seek expert advice about the financial assessment process.

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 p. 56) make sure they take it to the home with them, so that staff can learn about their life.

If you are not satisfied with the care home

If you are not satisfied 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 Health and Social Care Partnership if they arranged the place in the home. Or you can contact the Care Inspectorate (see p. 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 about handing over much of the task of caring. Getting used to not being responsible for day-to-day caring can be hard. It may leave a big gap in your life.

Talking about this with other carers can help, for example at a carers' support group. Even if you haven't been to a support group before, now might be a good time to join one.

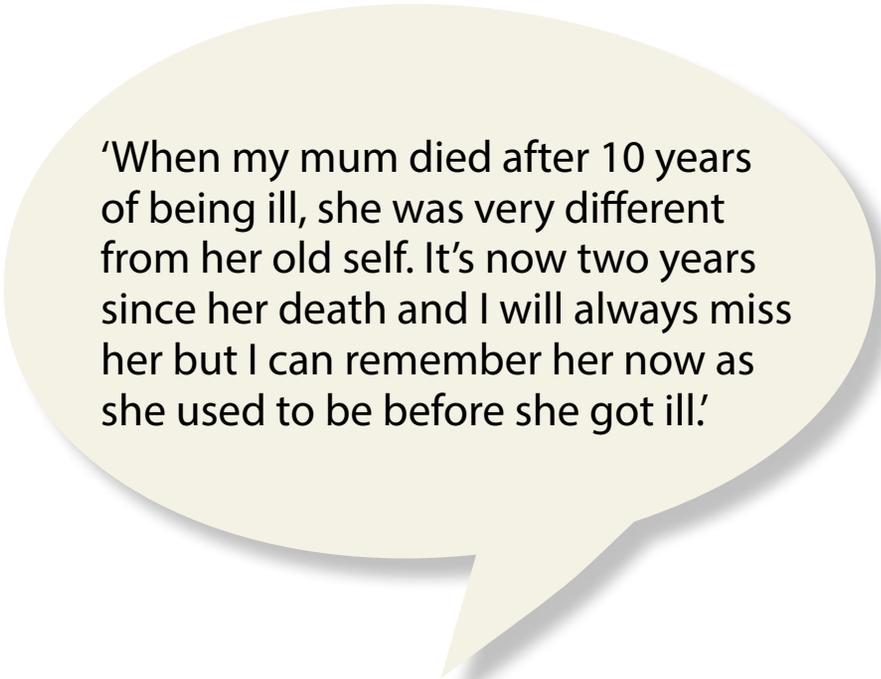
Everyone is different and each person reacts to bereavement differently. Because of the 'slow bereavement' of dementia, many people find that their sorrow when the person dies is mixed with relief that so much suffering is over. Some people feel less sad than they feel they 'should', because they have 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, friends and other carers. They can help you come to terms with your feelings. Cruse Bereavement Care can help with bereavement counselling – see p. 169.

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.

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.

Phone: 0800 12 44 222

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

160 Dundee Street, Edinburgh EH11 1DQ.

Phone: 0131 243 1453

Email: helpline@alzscot.org

Web: www.alzscot.org

Alzheimer Scotland Freephone 24-hour Dementia Helpline:
0808 808 3000 and email address helpline@alzscot.org

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

Alzheimer Scotland Centre for Policy and Practice

University of the 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/news/alzheimer-scotland-centre-for-policy-and-practice

Alzheimer Scotland Centre for Policy and Practice is a partnership with the University of the West of Scotland. Their 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.

Alzheimer's Society

43–44 Crutched Friars, London EC3N 2AE

The helpline is open 9 am–8 pm Mon to Wed; 9 am–5 pm Thurs and Fri; 10 am–4 pm Sat and Sun. It is a confidential service. Calls to the helpline are charged at local rate from anywhere in the UK.

Phone: 0300 222 11 22

Web: www.alzheimers.org.uk

Email: enquiries@alzheimers.org.uk

Alzheimer's Society is the UK's (covering England, Wales and Northern Ireland) 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.

forum.alzheimers.org.uk

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: Mon–Fri 8 am–10 pm; Sat–Sun 9 am–5 pm

Web: www.careinfoscotland.scot

Care Inspectorate

Compass House, 11 Riverside Drive, Dundee DD1 4NY

Phone: 0345 600 9527

Web: www.careinspectorate.com

Email: 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 Health and Social Care Partnership 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

Carers Scotland

The Cottage, 21 Pearce Street, Glasgow G51 3UT

Phone: 0141 445 3070

Email: info@carersuk.org

Carers Adviceline: 0808 808 7777

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

Spaces, Tay House, 300 Bath Street, Glasgow G2 4JR

Phone: 0300 772 7701

Web: carers.org/country/carers-trust-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 its network partners, it aims to ensure that information, advice and practical support are available to all carers across Scotland.

Citizens Advice Scotland

Phone: 0808 800 9060

Web: www.cas.org.uk

Email: advice@citizensadvisedirect.org.uk

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

Cruse Bereavement Care Scotland

CBCS Headquarters, 29 Barossa Place, Perth PH1 5HH

Head Office: 01738 444 178 (for management and administrative enquiries only)

Web: www.crusescotland.org.uk

Email: support@crusescotland.org.uk

National Helpline: 0845 600 2227

10 am–8 pm Mon, Tues, Wed;

10 am–9 pm Thurs;

10 am–4 pm Fri.

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

Dementia Helpline

0808 808 3000 (freephone), 24 hours

Email: 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

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.

Department for Work and Pensions

Website: www.gov.uk/government/organisations/department-for-work-pensions

Carer's and disability benefits: 0800 055 6688 (advice on new claims)

Textphone: 0800 023 4888

The Pension Service: 0800 731 7898 – help making a new claim.

Mon to Fri 8 am–6 pm. The Pension Service helps with State Pension eligibility, claims and payments.

Legal Services Agency

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

Phone: 0141 353 3354/0800 316 8450

Email: lsa@btconnect.com

Web: www.lsa.org.uk

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

MECOPP (Minority Ethnic Carers of People Project)

Maritime House, 8 The Shore, Edinburgh EH6 6QN

Phone: 0131 467 2994

Email: info@mecopp.org.uk

Web: www.mecopp.org.uk

Works to support black and minority ethnic carers to access supports and services appropriate to their caring situation.

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

Appendix 1:

Types of dementia

Dementia describes a group of symptoms that may include memory loss, difficulties with planning, problem-solving or language and sometimes changes in mood or behaviour.

Dementia occurs when the brain is damaged by disease. There are many known causes of dementia; the most common is Alzheimer's disease. Other common types of dementia include vascular dementia, dementia with Lewy bodies and frontotemporal dementias.

Each disease affects the brain in different ways and everyone will experience the condition in their own way. How it affects a person over time is also unique to the individual – their own attitude, relationships with others, other health conditions and their environment will all have an impact.

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



Further information

Alzheimer Scotland's information sheets on types of dementia www.alzscot.org or call the Dementia Helpline on 0808 808 3000.

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 information sheet, Alzheimer's disease. Go to www.alzscot.org or phone the Dementia Helpline on 0808 808 3000.

Frontotemporal 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

Alzheimer Scotland information sheet, Behaviour variant frontotemporal dementia (FTD). Go to www.alzscot.org or phone the Dementia Helpline on 0808 808 3000.

Alzheimer's Research UK booklet on FTD.
Go to www.alzheimersresearchuk.org

Vascular dementia

There are various forms of vascular dementia in which 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.



Further information

Alzheimer Scotland information sheet, Vascular dementia.
Go to www.alzscot.org or phone the Dementia Helpline on 0808 808 3000.

Alzheimer Scotland information sheet CADASIL.
Go to www.alzscot.org or call the Dementia Helpline on 0808 808 3000.

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 information sheet, *Dementia with Lewy bodies*. Go to www.alzscot.org or phone the Dementia Helpline on 0808 808 3000.

Parkinson’s UK factsheet, *Dementia with Lewy bodies*
www.parkinsons.org.uk/information-and-support/dementia

Korsakoff's syndrome and alcohol-related dementia

Korsakoff's syndrome is caused by lack of thiamine (vitamin B1), which affects the brain and nervous system. People who drink excessive amounts of alcohol are often thiamine deficient. 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 information sheet, Korsakoff's syndrome. Go to www.alzscot.org or phone the Dementia Helpline on 0808 808 3000.

Posterior cortical atrophy

Posterior cortical atrophy (PCA) is a rare degenerative condition similar to Alzheimer's disease. The first symptoms tend to occur when people are in their mid-50s, but are often subtle and can take time to diagnose.

In the early stages the main problems are with vision, such as difficulty recognising faces and objects in pictures, literacy and numeracy. As the disease progresses, people also develop the typical symptoms of Alzheimer's disease, such as memory loss and confusion.



Further information

The PCA support group, run through the National Hospital for Neurology and Neurosurgery, offers the opportunity for contact with other people who have had a diagnosis of posterior cortical atrophy. It holds several meetings a year and circulates a newsletter to members between meetings. www.raredementiasupport.org/pca

The RNIB website offers advice on dementia-related sight loss. Go to: www.rnib.org.uk

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 when discussing appropriate treatments with the person with dementia's doctor. A doctor should always be consulted before starting any treatment, including herbal and other alternative remedies, as they can have serious side effects.

General treatments

It's important that the person you care for has a healthy, balanced diet and gets some exercise. The longer they stay fit and healthy, the better their quality of life will be.

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 advice on healthy eating, and help if 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 the form of dementia and other factors, including possible side effects.

Alzheimer's disease

The drugs most commonly used to treat mild to moderate 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 the home safer.

You can get specific advice about changes in behaviour. There is rarely a right or wrong way – just what works for both you and the person with dementia.



Further information

Alzheimer Scotland information sheet, *Stress and distress*.
Go to www.alzscot.org or call the Dementia Helpline on 0808 808 3000.

NHS Health Scotland booklet, *Steps to deal with stress*.
www.healthscotland.com/documents/5828.aspx