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Introduction

This booklet is for you if you're a young person, and someone you're close to has dementia. Maybe it's your mum or dad, one of your grandparents, another relative or a family friend. This booklet will help you to:

- understand what dementia is, and what's happening to the person with dementia
- cope with the effect the person's illness has on you
- find help and support if you need it.

There are two things to remember when you're close to someone with dementia:

Remember

Look after yourself!

Try not to blame yourself or the person with dementia – blame the illness!

Most people with dementia will gradually have more trouble remembering things and doing what they used to do, as time goes by.



What is dementia?

1

Dementia is an illness that affects the brain. As time goes by, most people with dementia will have more and more difficulty remembering, and doing the things they used to do. This means that they will need more and more help and support from their family and the people close to them.

Most people with dementia are over the age of 65. Some people can develop it when they are in their 40s or 50s, and sometimes when they are even younger, but this is rare.

Different kinds of dementia

There are different kinds of dementia, depending on what is causing the damage to the person's brain. You might be told that the person you are close to has one of these kinds of dementia and sometimes they might have more than one kind at the same time:

- Alzheimer's disease
- Vascular dementia
- Alcohol-related dementia (including Korsakoff's syndrome)
- Lewy body dementia
- Frontotemporal dementia
- Posterior cortical atrophy.

What all these illnesses have in common is that they damage brain cells.

'We knew something was wrong with Dad when he got lost on the way home from the shops. My mum forgets things too, and everyone has times when they forget what they are looking for, but this was different. At first the doctor said it was depression, but after more tests they told us it was dementia.'

Alzheimer's disease – This is the most common kind of dementia. It is more common in older people, but it can also affect people in their 40s or 50s or even younger. With this kind of dementia, the brain cells are gradually damaged.

Vascular dementia – The damage to the brain in vascular dementia is caused by problems with the blood supply to the brain cells. The person may, for example, have a series of little strokes which damage small areas of the brain.

Alcohol-related dementia (including Korsakoff's syndrome) – Some people who drink a lot of alcohol for many years can damage their brains. For people with Korsakoff's syndrome, the damage is to the part of the brain which controls recent or 'short-term' memory. If the person stops drinking, the damage will not get any worse.

Lewy body dementia – Under a microscope, some of the brain cells of people with Lewy body dementia have little clumps of protein called 'Lewy bodies' in them, which affect how well the cells work. A person with this kind of dementia might also be a bit clumsy and find their movements are more difficult. People with Parkinson's disease may develop a similar form of dementia.

Frontotemporal dementia – If the person has frontotemporal dementia, the frontal lobes (the areas behind your forehead) and the temporal lobes (the regions behind your ears) are progressively damaged. This means the person's memory may be unaffected in the early stages of the illness, but they can have problems with things like language and making plans, and they sometimes behave in a way that is not usual for them.

Posterior cortical atrophy – This is similar to Alzheimer's disease but it affects the back (posterior) of the brain.

There are also many other diseases which can cause dementia.

How do brains work?

Your brain controls everything you do. It analyses and makes sense of everything you see and hear. It tells your body how to move and how to do things. Your brain contains all your memories, wishes and everything that makes you who you are.

No one understands all the details of how the brain works, but we know it is made up of a network of millions of brain cells which connect to each other. Every time you have a thought, move part of your body, or see something, these cells send messages around your brain.

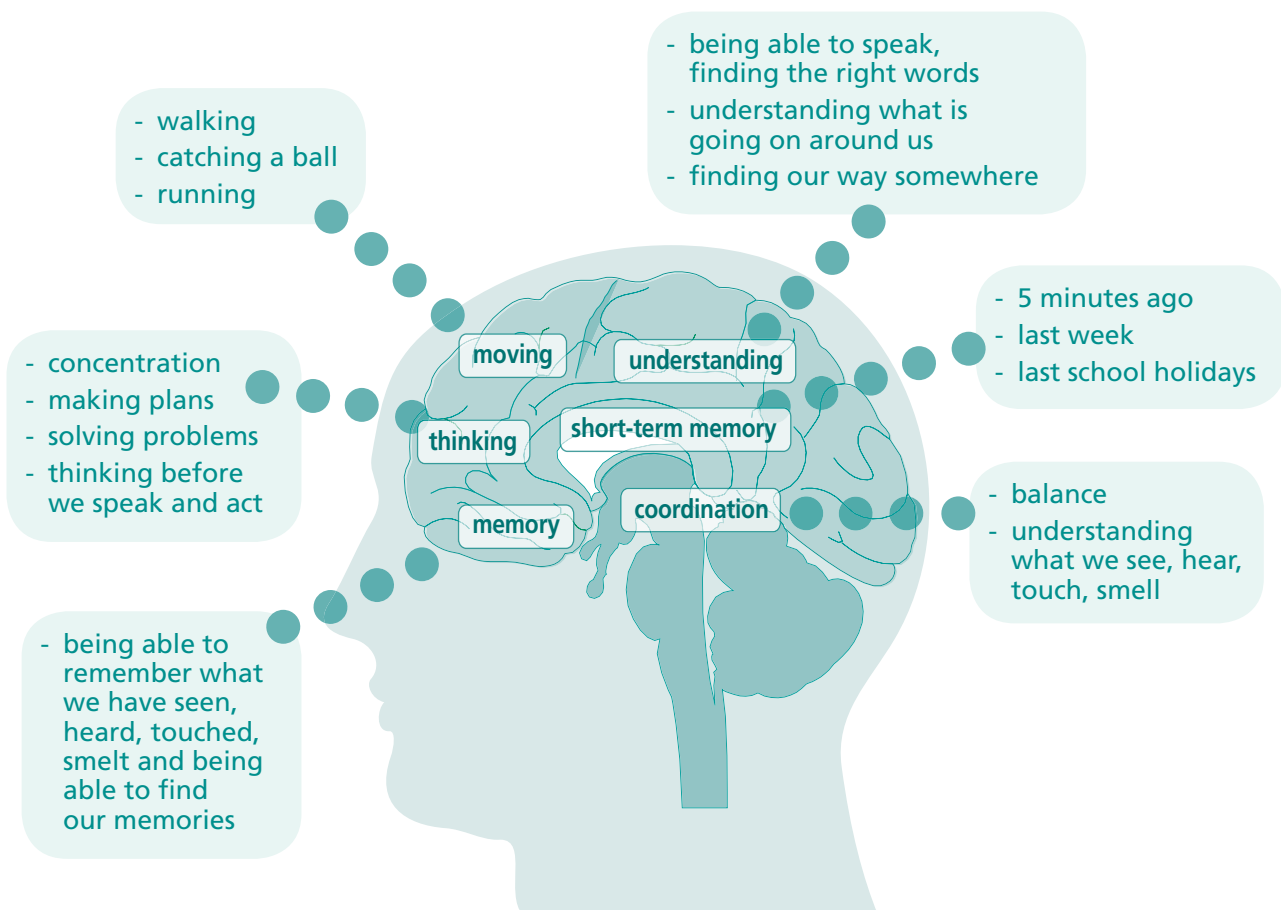


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www.mentalhealth.org.uk

What goes wrong in dementia?

The problem for someone with dementia is that some of the connections between brain cells aren't there any more. The brain cells may be dead or they may not work any more. This means some of the messages just can't get through. The person may not remember something or recognise a person or an object. Sometimes finding the right word might be more difficult.

Exactly what problems a person with dementia has depends on which parts of the brain are damaged. Most people with dementia gradually lose their memory, especially for short-term events. Someone might forget what they just had for lunch, but remember all about a wedding 40 years ago. People with dementia gradually forget how to do everyday things like cooking or dressing, so may need help to remember when and how to do these things. They may get mixed up about what day it is or get lost even in a familiar place, but often the person will stay physically well and active for a long time.

You may notice that the person with dementia has a change in personality. This might be because of the damage to the brain, or because of the person's reaction to the problems they are dealing with – or both. They may get frustrated and angry over small things that don't seem important to other people, seem sad and depressed, or lose interest in things.

Many people with dementia are able to stay at home through most, or even all, of their illness. Others may go into a care home or a hospital, usually if they need more help than the family and support services can give. Eventually, and usually after a long time, a person may die because of the illness.

Will I get dementia too?

You can't catch dementia. Just because a close relative has dementia, it doesn't mean that you will also get it when you're older. So the answer to that question is – probably not.

Genetics is the science that looks at what you inherit from your parents, for example your hair or eye colour. We pass on these, and other characteristics, through packages of information called 'genes'. You get half of your genes from your mother and half from your father.

A lot of work has been done on the genetics of dementia, and Alzheimer's disease in particular. So far they have found several genes which can make someone more likely to get the illness, but most forms of dementia are not inherited.

The best thing about genetic discoveries is that they help researchers understand what causes the illness. That way they can start to work out how to prevent and treat it in the future.

'I was really stressed out because I didn't know if I was going to end up like Dad. I was getting headaches all the time. I couldn't ask anyone because I was scared they'd tell me I'd get dementia too. Then the social worker asked me straight up. She told me it wasn't likely, and gave me all the information I needed. It was such a relief.'

What can be done?

At the moment, dementia can't be cured, but doctors can treat some of the things that can make the person worse, like depression. So it's important that the person sees a doctor.

A lot can be done to help not only the person with dementia to cope, but also to help you, other family members and friends.

If you want to know more about dementia, see the **Finding help** section, p. 37, for details of who you can talk to, and what other information is available.

**Other people may not
see the changes in
the person in the way
that you do.**



Am I a carer?

2

Looking after someone with dementia can be very stressful. One of the hardest things for you might be living with your feelings about caring.

Because of your relationship with the person, you might see and experience things that others do not. This can sometimes make it hard for others to understand what caring for the person with dementia is really like for you.

What is a carer?

A carer is someone who helps a person who is ill. You are a carer if you:

- help in the house because the person with dementia can't do some things any more
- look out for the person with dementia to keep them safe
- help the person with dementia by reminding them how and when to do things
- help the person with dementia with personal tasks like dressing, eating or going to the toilet
- comfort and reassure the person with dementia.

Some young carers might be doing all of these things. For example, you might live alone with a parent or grandparent who has dementia. Other young carers might help the person do some of these things, or give them emotional support.

Just remember that first and foremost you're still their child or grandchild, and so on, even in your new caring role.

A lot of young people don't think of themselves as carers, even when they are, but it can help you to see just how important your help is. Perhaps you could do with some help too.

Being a carer can be a big responsibility. No one should have to do it alone. Remember, it's all right to ask for help and it's all right to choose not to be a carer if you don't want to.

'Before my mother got ill I didn't do much in the house – just some washing up. Now I have to cook tea for me and my wee sister, because Dad's busy looking after Mum. Or if he cooks I look after her because we can't leave her alone for long. At first I didn't think of it as caring, but now I do. I'm a carer.'

You might just want to talk, or need someone to help you make decisions. Sometimes you might need a shoulder to cry on.

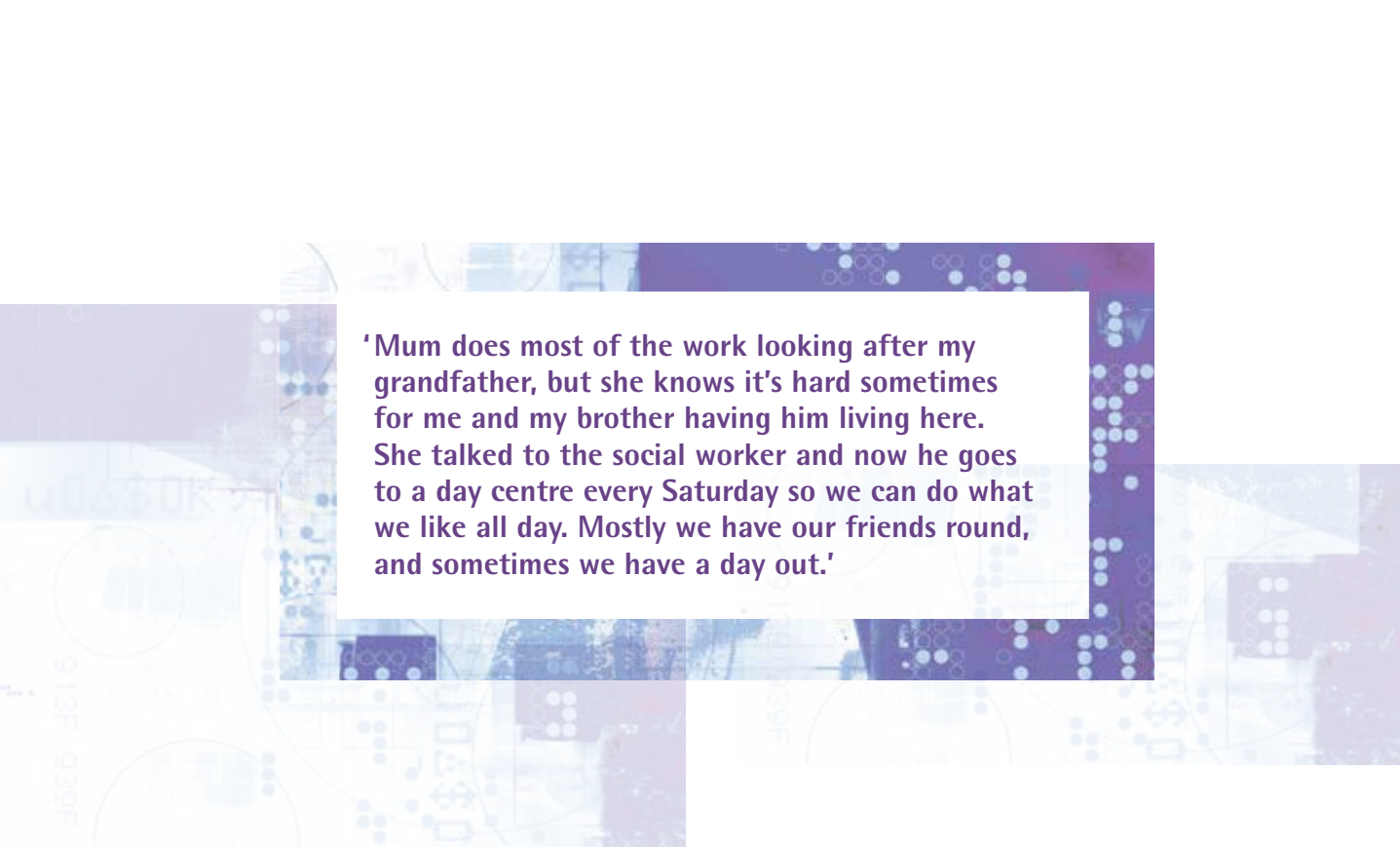


Looking after yourself

3

Watching someone you know gradually getting more ill is very upsetting. Dementia is an especially sad illness because it can slowly change the person you care about. The person with dementia may be your parent or grandparent.

Maybe you aren't very close to the person with dementia, but other people are more involved, like your parents. This might mean they aren't always around when you need them, so you might have to look somewhere else when you need to talk.



'Mum does most of the work looking after my grandfather, but she knows it's hard sometimes for me and my brother having him living here. She talked to the social worker and now he goes to a day centre every Saturday so we can do what we like all day. Mostly we have our friends round, and sometimes we have a day out.'

You can't care for the person with dementia, or support other people who are close to you, unless you look after yourself too. Here are some things you can do:

- **Make sure you get time to yourself.**
- **Find a good listener who you can really talk to.**
- **Keep hanging out with your friends and doing the things you enjoy.**
- **Write down your thoughts and feelings if it helps.**
- **Tell your friends and teachers what's going on so they understand.**

Time out

Take a break! Sometimes it feels hard to get away on your own, especially if you live with the person with dementia. But spending time away and doing things for yourself is important. You might need to talk to the rest of your family or the social worker involved with the person with dementia. Tell them what you need. See if you can work out a plan together so that you can have a rest.

Sometimes it might seem that you always have to go out to get a break – some people can't stay at home because the person with dementia is there and doesn't understand. If this is bugging you, talk to your family, the social worker or another professional. Maybe someone could take the person with dementia out for a bit, so that you get to stay indoors if you want to. They could go shopping, for a walk or to visit a friend.

'Whenever I'm at home, my dad keeps following me around. It gets really annoying. But now he has a support worker two days a week who takes him out to the golf course or for a walk. It is great to get a rest.'

Feelings

Some people say that losing someone you love, a little bit at a time, is especially hard. When someone dies, it's a shock, and it takes time to get over it. But it's often even harder to get over losing someone when they are still there. Whether or not you're a carer, you're probably going to have some difficult feelings to cope with sometimes.

You might feel sad, angry, guilty, depressed, tired, fed-up, lonely, frustrated, annoyed, responsible, frightened, or many other things – and sometimes you might feel all these things at once.

'I feel like I should be sad about my gran, because I do love her. But sometimes I just get really fed up because she's living with us. I have to share a room with my brother now and I have to put up with Gran's questions all the time. I feel annoyed about it all, and then I feel guilty because it's not her fault. It helps when I can talk with Mum about it.'

Of course, there can be good feelings too. It can feel good to help someone, whether it's the person with dementia or someone else who is caring for them. You may feel proud that you are able to take on the responsibility. You might feel happy when the person with dementia is enjoying something.

It's perfectly normal to have any or all of these feelings, at different times. Sometimes you might find this mixture of feelings confusing – that's normal too. It's easier to cope with strong feelings if you don't keep them to yourself. Find someone you can talk to – **see the list on the next page** for different people who can help. Remember: you don't have to be feeling unhappy to need a bit of support.

Having a sense of humour can help you cope. Don't laugh at the person, but have a laugh and share in the joke if something funny happens.

Who can I talk to?

There will always be someone to talk to you about any questions you may have. Talking to a member of your family may help, or there are a number of professionals and helplines you can share any worries with.

Dementia Helpline

You can call the Alzheimer Scotland Freephone 24-hour Dementia Helpline on **0808 808 3000**. They can give you lots of information about dementia, or they can listen if you just want to talk. Calls are confidential and you don't even have to say who you are.

The people who work on the helpline know about dementia and about being a carer. They can also help you find extra support if you need it. It's free to call from a landline, but some mobile networks may charge. You can also email the helpline at: **helpline@alzscot.org**

Professionals

Don't be afraid to talk to the professionals, and to ask them for help or advice. You may find that a lot of professionals come to see the person with dementia. However, you may need to speak to someone too. Perhaps you need a break from caring to focus on school work, or maybe you need some emotional support.

Professionals might be able to give you practical help, be someone to talk to, or both. Here are some of the people who might be able to help. Any of them might be the right person for you to talk to – see who you get on with best:

- **Social worker** – can find services like day care or home support for the person with dementia, which also give the carer some time off.
- **Teacher** – could give you extra time for homework or help with problems in school.
- **Guidance teacher** – could be a good person to talk to about how you are feeling, and they can help with school problems and talk to other teachers for you.

- **Counsellor** – you can ask your doctor or other professionals about how to find a counsellor to talk to regularly about your feelings.
- **Doctor** – can give you information about the illness and how to find help.
- **Community psychiatric nurses or practice nurses** – often know a lot about dementia and are good to talk to. Ask at your doctor's surgery about how you can contact them.
- **Young carers' project worker** – could be a good person to talk to, if there is one in your area. They are there to help support all young carers.

Family

Your family know what's going on. Talk to them about how you feel, and also about how they feel. Often other family members like aunts and uncles can help too.

'My aunt's brilliant to talk to. She really listens when I need to talk about what's going on with my dad. We're a lot closer now than before he got ill.'

Friends

Don't keep your feelings to yourself. Find people you trust to talk to about what's going on. They might help you see things from a different angle – and remember, you don't have to take their advice if you don't want to. If you're worried about talking, think about what you'd do if things were the other way round. Would you want to know what a good friend was going through? Maybe you could show your friends this booklet to help them understand.

Family relationships

Family relationships can change, and families can feel under a lot of pressure when someone gets dementia.

Remember

Try not to blame yourself or the person with dementia – blame the illness!

The person with dementia will change as time goes by and their illness progresses. The people who are closest to them can change too. Perhaps they have taken on extra responsibility, especially if they are caring for the person with dementia, or perhaps whoever they used to rely on can't handle it any more.

Don't be surprised if you start to feel differently about the person with dementia or about other people in the family. You may find you drift away from some people, and grow closer to others. This is no one's fault. Try not to blame the person with dementia or other family members.

'I feel like I've changed a lot. My mother was still treating me like I was a child – all her time and energy revolved around Dad. Eventually I told her it felt like I was losing her as well as Dad. We finally sat down and talked until 2 am. Now we always talk about things and she treats me more like an adult.'

'I help Dad look after Mum every night after my homework. My sister never helps. I thought she just didn't care. But one night we talked about it and she's really upset – worse than me I think. She cried, and said that she misses how Mum used to be and that it hurts too much to be near her. I still wish she'd help out more, but I understand better now.'

Sometimes brothers, sisters and other family members cope in very different ways. Some people become very involved with caring for the person with dementia. Others find it easier to be less involved, perhaps because of the emotional effects. Each way of coping has its good and bad points. Being a carer helps the person with dementia and the other people involved, and it might make you feel good. But sometimes it might feel like hard work and you might resent it. Trying not to be involved can make it easier for you to keep your own life going, but this may make you feel guilty or left out from the rest of the family. The important thing is to think about what you're feeling, and find someone to talk to. (See the **Who can I talk to?** section, p. 20.)

Remember

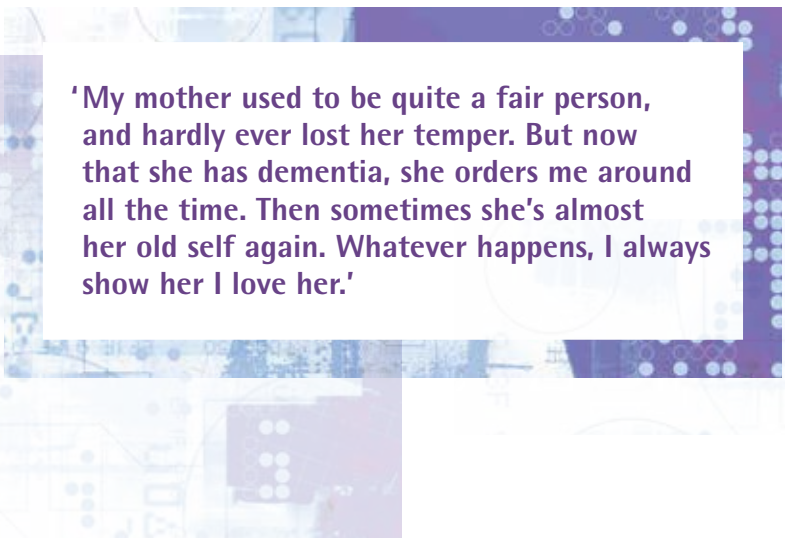
The person you are caring for is still the same person and it is not their fault they have this illness.

If it's your parent

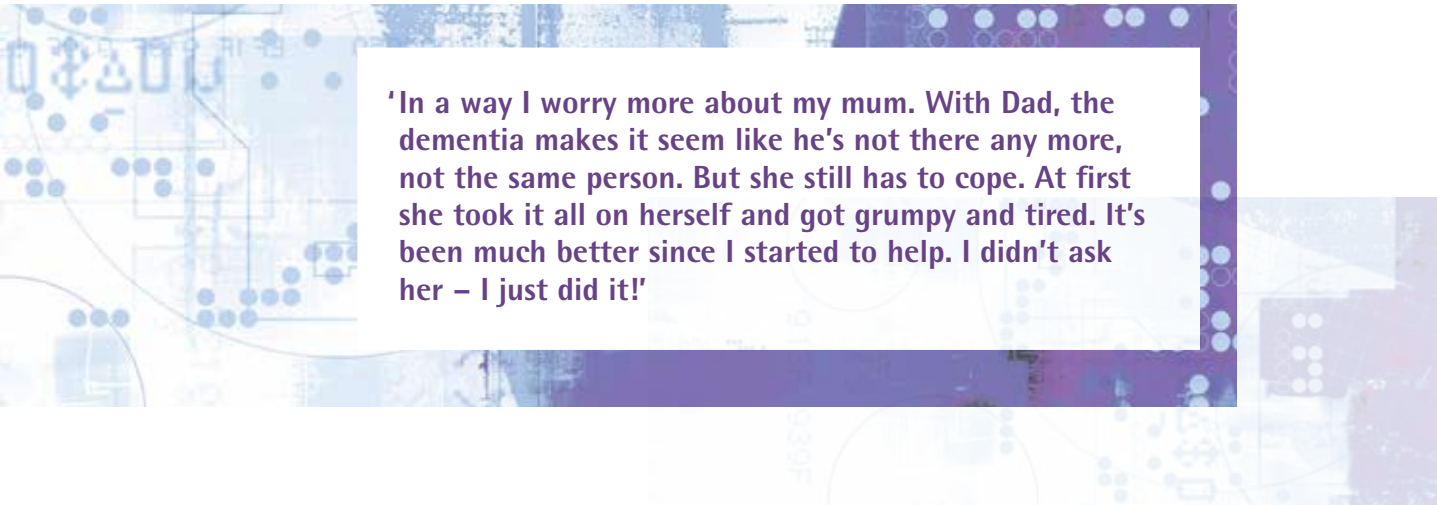
If the person with dementia is your mum or dad, or someone else you are very close to, their dementia is probably going to have more of an impact on you.

Your relationship with the parent with dementia is likely to change. They will start to depend more on you and other people. They may do odd things which embarrass, frustrate, irritate or even alarm you. They probably won't be able to give you as much attention as before.

You may feel your parent has lost interest in you. Always remember that it's because of their illness – your parent isn't doing it to get at you. People with dementia often seem self-centred, because the damage to the brain makes it hard for them to remember even the little things, like asking how school went today. Your parent may also be feeling depressed because they can't do the things they used to do. However, with support, many people with dementia can live well and enjoy new interests.



'My mother used to be quite a fair person, and hardly ever lost her temper. But now that she has dementia, she orders me around all the time. Then sometimes she's almost her old self again. Whatever happens, I always show her I love her.'



'In a way I worry more about my mum. With Dad, the dementia makes it seem like he's not there any more, not the same person. But she still has to cope. At first she took it all on herself and got grumpy and tired. It's been much better since I started to help. I didn't ask her – I just did it!'

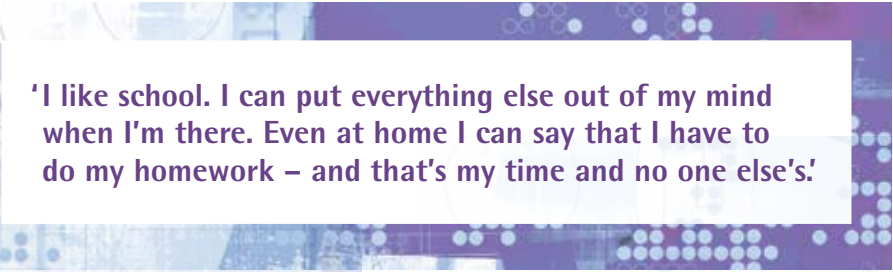
Your relationship with your other parent, if you have one, may also change. Some people find they become closer, working together to look after the person with dementia and each other. Others may find that they don't get as much attention, because caring is taking up so much time and energy.

The key to ensuring you are both offering the person with dementia the best care is to work as a team. Keep your thoughts and feelings as open as possible.

Try to talk honestly with your parent if this happens. Try not to blame anyone, but work together to see what might make things better, for everyone.

School

Sometimes caring for someone, or watching someone you love getting ill, can cause problems at school. Maybe you find it harder to concentrate. The person with dementia may be restless in the evening so you can't get homework or studying done, or enough sleep. Or perhaps you're doing a lot of caring or housework, and you don't get enough time for schoolwork. On the other hand, perhaps school helps you get away from having to think about what's going on at home.



'I like school. I can put everything else out of my mind when I'm there. Even at home I can say that I have to do my homework – and that's my time and no one else's.'

Your school needs to know what's going on. They may be able to help you. You or your parents should speak to your teacher or the guidance teacher.

They might:

- give you a quiet place to do your homework at lunchtime
- allow you extra time for work
- give you time with the guidance teacher to talk about things
- understand if you're tired or upset
- put you in touch with a local youth project, which can give you some time to yourself and extra support if you need it.

Bullying and teasing

If other people at school are giving you a hard time, or bullying or teasing you, tell a member of staff. Your school should have a policy on how they deal with bullying. Don't just put up with it.

Some people bully because of ignorance. If they knew more about dementia they might not find it funny. Perhaps you or a teacher could explain it to them.

Remember, dementia is nothing to be ashamed of – it's an illness which could happen to anyone.

Sometimes people can be cruel by accident, especially if they don't understand what's going on.

'One time I had a bunch of mates round, and my grandad came in and started taking his clothes off! I was too embarrassed to explain and for weeks everyone was slagging me off at school. In the end I told them he has Alzheimer's disease and what that means, and they were okay after that.'

Everyone with dementia is different, and not everyone will face every problem.



Practical coping

4

It can be hard to know the best way to cope with some of the difficulties people with dementia can have. Don't feel you have to work it all out by yourself.

The best thing you can do is get help. You can always benefit from other people's experience and knowledge. Many people enjoy attending a dementia cafe where you can meet others who have a diagnosis of dementia and families to chat over what helps. And don't forget that you can call the **Dementia Helpline** on **0808 808 3000** anytime you need more information or support.

Communication

A person with dementia may struggle to find the word they're looking for, repeat themselves or become stuck on certain sounds. If the person with dementia can no longer communicate as effectively as before they may lose confidence in speaking, and feel anxious or withdrawn. Try to be patient with them. It can be difficult sometimes, but giving the person time to find the word, or gently prompting them, can really help.

In some cases, if English is not a person's first language, they may find it easier to communicate in a language they're more comfortable with. If you do not speak this language it can make communication very difficult.

There are organisations that can help with this. Speak to another family member, or your doctor, who can help you find support.

As the illness gets worse, the person may find it harder to have a conversation. He or she might not be able to understand if you say something complicated. Try making what you say a bit simpler. It can help to break it up into shorter sentences. If you have to repeat something, try putting it a bit differently the second time. For example:

You: That's your washing done now, Nan, and I've put it out on the line. Don't worry about remembering it, I'll ring you tonight like I always do for a chat, and I'll tell you then to make sure you don't leave it out all night – or if it rains I'll ring you too, okay?

Nan: Is it raining? Oh dear, I was going to put the washing out.

You: Don't worry, Nan, I've hung the washing out. I'll give you a ring to remind you to take it in.

Nan: Thanks, Son.

If the person says something you know isn't right, or accuses you of something, try to keep calm and be tactful. Sometimes you might be able to correct them, but sometimes you might just have to let it go. It's often better not to get into an argument. Sometimes changing the subject or distracting the person can help.

You might need a lot of patience if the person repeats things or tells you what to do. If you think you're losing your temper, try leaving the room for a while to calm down. When you go back in, the person may have forgotten what they were saying, and it might be easier to move on to a different subject.

Always ensure you are checking that there is nothing wrong, as often very minor issues can seriously distress someone.

It can also help to drop simple 'reminders' into what you say. Often you can cleverly remind the person what time and day it is, what's going on and what they need to do without pointing out that they have forgotten something.

'Oh dear – it's already eight o'clock on a Monday morning, Mum. I'll have to go to school in a minute. Fiona's coming to see you this morning, isn't she? She said she was going to go along to the shops with you.'

Communication isn't just about words. It can be about eye contact, body language and touch too. Look at the person when you talk, to help keep their attention. Try holding their hand if it seems to help. A hug might tell them how much you care better than words.

Some hints

- Check out what the person can still do, and then help them with the bits they can't handle.
- Try to let them do as much as possible, instead of taking over. The person needs to keep a sense of independence to feel good about him or herself. So doing a task successfully – even with a little help – can be important.
- Some people with dementia are better on some days, or at certain times of the day, than others. Don't assume that the person can't do something, if they want to try.

Using reminders

A lot of the problems people with dementia have are to do with memory, so using reminders can help. These might be simple written notes to help the person when they are alone, or gentle reminders when you're around about what to do next. A diary, or a mobile phone with a calendar function and alarm, can be very helpful. Keeping to routines can make life easier for the person too.

Take things one step at a time if you need to help with something. For example, helping someone to wash up might go a bit like this:

'If you wash, Gran, I'll dry.

That's great, lots of hot water... maybe you'll need some cold water, too?

Now, where's the washing-up liquid? That's it.

I think that's probably enough, don't you?

You usually put the dirty dishes on this side and clean ones there, don't you?

Okay, if you wash that plate I'll start drying over here...'

Everyone with dementia is different. What helps one person might not help someone else and what helped yesterday might not work today. If what you're doing doesn't work, try something else. Don't feel bad if something goes wrong.

Behaviour

Because dementia affects the brain, the person may do things that seem strange. This can be a way of communicating. If the person can't find the words to tell others that they feel frustrated, uncomfortable, in pain or restless, they might try to show it instead. For example, someone might shout or yell. You might be able to work out what the person is trying to communicate and do something about it.

Some things might be because of memory problems – like putting the teapot in the fridge. This might be because the illness has damaged the part of the brain that makes sure you don't actually do everything that pops into your head. Sometimes people with dementia may think they are doing something that is perfectly reasonable. For example, someone might take their clothes off ready for bed, but they might do it at the wrong time, or in the wrong place – like in the kitchen.

If the person does something strange, often it doesn't matter. You and the person may even have a laugh about it. But sometimes it does matter. The person's behaviour may be embarrassing for them, and for you, or maybe it isn't safe. If this happens, try to talk to someone.

A support worker or community psychiatric nurse can help you find ways of dealing with the problem. The book, *Coping with Dementia* (see the **Further information** section, p. 41), has more information about coping with odd behaviour.

Remember

Try not to blame yourself or the person with dementia – blame the illness!

Caring on your own

If you're caring on your own, you might have to track down the help you need yourself. The Alzheimer Scotland Freephone, 24-hour **Dementia Helpline** on **0808 808 3000** can help you work out what might help and where to go to find it.

If you're worried about money, ask the social worker about benefits that are available for the person with dementia and their family, such as the Attendance Allowance, Personal Independence Payment, and Employment and Support Allowance.

Losing the person with dementia

People with dementia gradually get more and more ill. It's impossible to say how long the illness will go on for, because everyone is different. Eventually, the person will die. When this happens, you may have all sorts of feelings. You may feel sad, lonely, angry, relieved, confused, and many other things too.

Give yourself time. It can take a long time to get over losing someone, but it's easier if you don't do it on your own. Don't shut your feelings in. Try to talk about the person who has died and your feelings.

'When my grandmother died she was very ill. She wasn't really herself any more. In a way I felt glad she died, but I missed her too. My mother and I talk about her a lot. I don't want to forget her or pretend it never happened. Now I remember her more as she was before she became ill – the things we used to do together when I was younger.'

No one should try to cope on their own. There are lots of ways to get help, and to make life easier.



Finding help

5

If you want to talk to someone, or need to find more information, a good place to start is the Dementia Helpline.

The Dementia Helpline is a free, 24-hour service. Call **0808 808 3000** to talk things over confidentially with someone who understands, and for more information on anything to do with dementia – from how to cope with a particular problem, to where to find extra help.

You can also visit www.alzscot.org for more information.

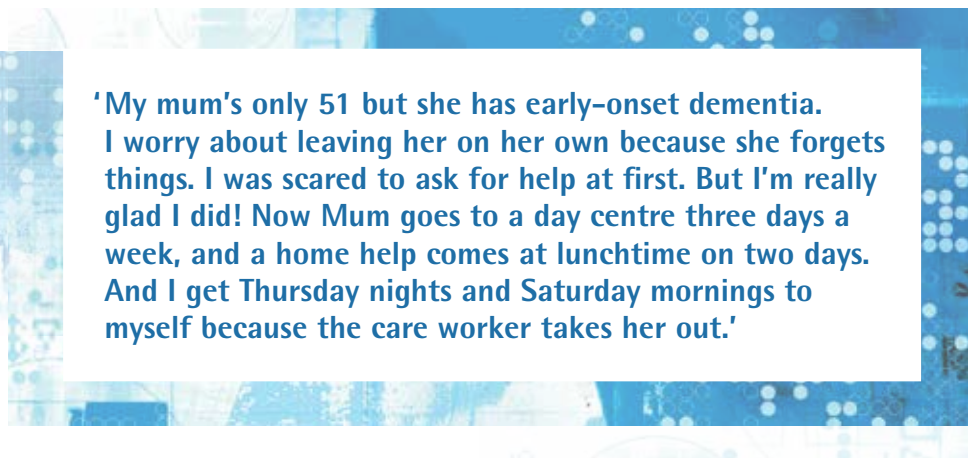


People who can help

Social work department

Social work departments arrange community care assessments to work out what you and the person with dementia need, and find services to help. You'll find their number on your local council's website, or ask the **Dementia Helpline** on **0808 808 3000** for more information.

Anyone who is ill or disabled has a legal right to an assessment. Carers are also entitled to an assessment no matter who they care for and no matter what age they are. You can ask for this assessment even if the person you care for doesn't want to receive help from the social work department. All assessments are free.



'My mum's only 51 but she has early-onset dementia. I worry about leaving her on her own because she forgets things. I was scared to ask for help at first. But I'm really glad I did! Now Mum goes to a day centre three days a week, and a home help comes at lunchtime on two days. And I get Thursday nights and Saturday mornings to myself because the care worker takes her out.'

An assessment means that a social worker or another professional worker will talk to you, the person you are caring for, the doctor and anyone else involved, about what you may need. They will then try to find the right kinds of help or equipment. For example, if the person with dementia needs more stimulation and a chance to socialise, visiting a day centre might help. If you need time off, support from a care worker at the right time could help.

The Care Inspectorate offers information on choosing and using care services. **www.careinspectorate.com**

Many services are available to help make life easier for both you and the person with dementia:

- **Day centres** – the person with dementia can get involved with stimulating activities for the day, and the carer gets some time off.
- **Home support** – a support worker might help the person with everyday activities and errands, or offer practical care like dressing or meals.
- **Respite care** – the person with dementia gets extra support at home, or goes away for a few days to give the carer time off.
- **Day hospitals** – the person receives medical and occupational therapy, or assessments.
- **Equipment** – this includes things like bathroom equipment, memory and eating aids, and other equipment to help day-to-day activities.

Young carers' projects

In some areas there are young carers' projects. These provide information, support and the chance to meet other young people who care for someone. Most young carers' groups are for people who care for someone with any kind of illness or disability, not just dementia. They also organise outings and activities.

Ask the social work department or the Dementia Helpline on **0808 808 3000** about young carers' projects in your area. You can also find a project near you at **www.youngcarer.com** or for more information about caring visit **carers.org**

Doctor

The GP or hospital specialist will make sure that the person with dementia stays as well as possible. They can also arrange services such as visits to the day hospital, extra nursing support, or help with managing the person's behaviour.

Link worker

After diagnosis a person with dementia is entitled to at least one year's support from a named link worker.

Childline

Call Childline on **0800 1111**, or visit **www.childline.org.uk** to talk confidentially about anything that's bothering you and to find out how you can get help.

Breathing Space

Anyone can feel down or depressed from time to time. Visit **breathingspace.scot** or call **0800 83 85 87** to talk to someone in confidence, and for advice and information.

Steps to deal with stress

Stress doesn't just make you feel bad, it's not good for your health. Thankfully, there are steps you can take to start dealing with it. Research shows that small steps can make a big difference.

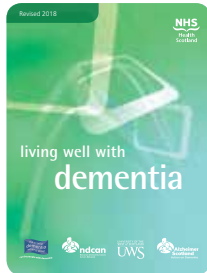
You can find the booklet Steps to deal with stress at:
www.healthscotland.com/documents/5828.aspx

And you can find more information, and exercises to relieve stress, at: **www.nhsinform.scot/healthy-living/mental-wellbeing#stress**

Further information

Living well with dementia

NHS Health Scotland, Edinburgh



This booklet contains lots of information for people with dementia, including practical arrangements and coping with feelings. Copies are available free from health promotion departments at your local Health Board, and from the Dementia Helpline on **0808 808 3000**.

Living well with dementia DVD

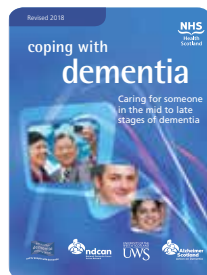


This DVD is aimed at people recently diagnosed with dementia. It is based on the experiences of people with dementia and their carers. It comes free with the Living well with dementia book (above). It is also available from the NHS Health Scotland website:

www.healthscotland.com/topics/stages/healthy-ageing/dementia-resources.aspx

Coping with dementia: caring for someone in the mid to late stages of dementia

NHS Health Scotland, Edinburgh



This is a useful booklet that covers most aspects of caring for someone in the middle to late stages of dementia, with lots of practical information. Copies are available free from health promotion departments at your local Health Board, and from the Dementia Helpline on 0808 808 3000.

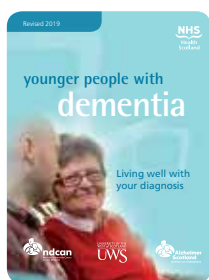
Coping with dementia DVD



This DVD helps carers to understand about dementia and provides practical suggestions about caring for someone in the middle to late stages of dementia. It comes free with the Coping with dementia book (above). An extract of the DVD is also available from the NHS Health Scotland website:

www.healthscotland.com/topics/stages/healthy-ageing/dementia-resources.aspx

Younger people with dementia: living well with your diagnosis NHS Health Scotland, Edinburgh



This booklet provides insights from younger people with dementia and their families on what it feels like to take on board the diagnosis, how to manage the symptoms and where to go for further support.

Younger people with dementia DVD



This DVD hears from younger people with dementia and their families on living well with a diagnosis and gives tips on telling your employer and keeping connected with friends and family. An extract of the DVD is also available from the NHS Health Scotland website:

www.healthscotland.com/topics/stages/healthy-ageing/dementia-resources.aspx

**The milk's in the oven: a booklet about dementia
for children and young people**
Mental Health Foundation, London



This is a short booklet aimed at children aged between 10 and 12 years, which discusses the feelings and behaviour of people with dementia, and the effect this can have on others. The booklet may also be suitable for younger brothers and sisters. Copies are available free to carers from the Dementia Helpline on **0808 808 3000**.

Forster M (2004).
Have the men had enough?
Vintage, London

A novel about a family looking after a grandparent with dementia. Part of the story is seen through the eyes of the grandchild. It is available from most booksellers, or for loan from your local library.

Pulsford D and Thompson R (2013)
Dementia: support for family and friends
Jessica Kingsley Publishers, London

A step-by-step guide taking carers through the journey of dementia. It discusses the difficult challenges that people face and suggests solutions to problems, as found useful by experienced carers. Written by experts, this book seeks to improve understanding and provide practical support to people with dementia and those who care for them.

Graham N and Warner J (2009)
Understanding Alzheimer's disease & other dementias
Family Doctor Publications, Poole

This book is intended for anyone who has, or may be worried that they or their family and friends have, dementia. It is also for people who live or work with someone with dementia.

