



Your relationships

Living with
dementia series





Your relationships

Living with dementia is likely to affect many areas of your life. It will also have an impact on the people around you.

These people may already have helped with practical things, given you advice or just listened. The same people can help now that you have dementia. You may also find yourself getting to know new people and doing new things, perhaps at a group or club.

Over time, your relationships with the different people you know and meet will probably have already changed for a variety of reasons. Dementia is another reason these relationships may change. It can be difficult for you and the people around you to adjust, and may take some time. Dementia may affect what you say and do but you are still you, with your own feelings and ways of doing things. Your experience of dementia will be different from everyone else's.

This booklet will help you understand how your relationships might change when you have dementia. It also gives information on what you can do to prepare for and live with these changes, and how other people can support you.



After you've been diagnosed: talking about dementia

When you've been told you have dementia, there are probably people you want to turn to first or who it's important to tell.

Talk to these people about your diagnosis when you're ready. Be honest and let them know how you're feeling. For most people, talking is a good way of coping with emotions.

The relationships you have with people work in different ways, so bear this in mind when you talk to them about dementia. You'll find your own way of having this conversation that feels comfortable to you. You might even find that some humour helps make it easier to talk about.

When you were first told you have dementia, you may have felt a range of different emotions. When you tell other people about your diagnosis for the first time, they may feel a range of emotions too, including shock, sadness or fear. Any feelings will be individual to the person – there is no 'right' or 'wrong' way for people to feel about your dementia.

You might find it helpful to talk to a professional about your thoughts and feelings. Ask someone involved in your care, such as a GP or community nurse, to help you find someone who can support you to adjust. You may also want to involve someone who is important to you – such as a partner or friend – in these conversations.





How might dementia affect me and my relationships?

There are many ways that your relationships with different people will change. Over time, you will come to depend more on the people in your life. This might be difficult for you or them to accept. However, in time you may also find it brings you closer together.

When someone becomes your carer

A partner, close family member or friend may over time take on the role of caring for or supporting you. This could raise the following issues:

- If your partner takes on this role, it might be difficult to feel that you still are 'equals' in the relationship.
- One of your children may take on this role. This might be difficult for you both to accept at first because in the past you cared for them, and now it's the other way round.
- If you are a younger person with dementia, your parent might care for you. This can also be difficult for you both to accept, as you might have thought you would be caring for your parent as they grew older. You might not have imagined that they would care for you again once you became an adult.



Caring can often be challenging, and this is likely to affect how the person caring for you is feeling. They may sometimes be sad, stressed, frustrated, fed up, or just tired. But caring can also be a good experience – some people find it rewarding and satisfying.

Other people might refer to the person who helps you as your ‘carer’. This includes health and care professionals such as doctors or social workers. You might not think of the person in this way – instead you see them in terms of their relationship to you. For example, they are your wife, husband, partner, son, daughter or friend rather than your carer and they might feel the same way too.

In spite of this, it can be helpful to refer to this person as your carer when you are talking to health and social care professionals, or when looking for support. This helps to make it clear to people that they have an important role in supporting you.

Although one person may become your regular carer, other people you know may sometimes help you for short periods. Though you may find depending on others difficult at first, spending time with friends and family should be good for both of you. Try to accept any changes in your relationships with other people, and enjoy your time with them.

It can also help to explain to people how they can support you. Let them know the things that you can still do independently, and the things that you need more help with.



Coping with other changes

Communication

Your dementia means that you will also change in ways that affect your relationships. You may gradually find it more difficult to communicate. This can be very frustrating, as communication is so important in a relationship. When you're trying to communicate with someone, there are things you can both do to make it easier:

- Make eye contact.
- Listen carefully and give each other your full attention.
- Get rid of things that make communicating more difficult – turn off the TV and radio if noise from these is causing problems.
- Give yourself enough time for a conversation so you don't feel you have to rush.

Memory

If you are experiencing memory loss, you may start to forget the names of people you know. This can be uncomfortable and frustrating for them and for you. However, people close to you are still going to enjoy spending time with you even if you sometimes forget their names. Ask those around you to help by not reminding you that you repeat things or have forgotten them. They can also introduce themselves or other people you know (for example, 'here's our neighbour, Bill').



**For more tips on coping with memory loss see
Alzheimer's Society booklet 1540, The memory handbook.**





The way you feel

You or those around you might notice changes in the way you feel or behave. For example, some people with dementia become less patient and more easily irritated than they used to be. This may be difficult for other people to understand and accept. It doesn't mean you feel differently about them – these changes are because of the dementia.

Keeping well

People with dementia and the people who care for them may feel low, stressed or anxious at times. These feelings can affect a relationship. If you or the person caring for you often have these problems, talk to someone. Help is available.

Sex and intimacy

As the brain of a person with dementia changes over time, some people find their interest in sex changes. Occasionally, they show much more interest in sex. Others feel less like being intimate. If you are in a physical relationship, you may notice changes in your partner's interest in sex. For example, if your partner is caring for you, they may be more tired and less interested in sex. If you and your partner don't feel the same way, there are ways you can try to stay close and connected. (See 'Couples' on pages 14 and 15).

Daily living

You will find that some activities including cooking, making appointments or doing family finances will become more difficult as dementia progresses. In the past, you may have done these things independently, but you may now take longer or need someone to help you. Both you, and the person helping you, might find this difficult at first.



Changing plans

If you have plans such as going on holiday or moving home, you don't need to change these just because you have dementia. However if there is a good reason why you should change plans or put them on hold, try to be honest about how that makes you feel. Talk to the people you'd made the plans with, or to another person you trust. Try to adapt to what is now possible and don't focus on what you can no longer do.

Any of these changes can mean you now have to talk about things you find difficult to discuss with other people, such as money, sex, or how you are feeling. However, you can ask trusted friends, family members or professionals – such as counsellors – for support to help you manage both practical activities and your emotional wellbeing.

'The most important advice I can give you is to keep contact with whatever family and friends you have already and try to make new ones through whatever associations there are locally.'

Person with dementia



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

Relationships that were difficult before dementia

Not all relationships are easy. You may have had relationships that were difficult before you had dementia. For example, you or the other person might have had problems with alcohol or other drugs, or with mental illness. Your relationship may even have been abusive at times.

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

If you have had a difficult relationship with a person who is still in your life, try to get help to develop a healthy and safe relationship with them now you have dementia. You could look for support from a counsellor, or ask other family members or friends to be part of any conversations you have with the person. If your relationship has been abusive and you are worried about this happening again, it is important to talk to someone. Consider whether you want the person to care for you.



People close to me

Although your relationships with different people will change, there are lots of ways to stay in touch with people who are important to you.

Sometimes people with dementia worry about talking to others, or think people won't want to spend time with them. Let people know you're still you! Most of the people you already have relationships with will hopefully still want to spend time with you. You may get to know new people too.

You may also be able to get help and support from people you know – including children. This may happen in different ways, depending on who the person is and the kind of relationship you have with them.

Couples

Some couples find that people in their wider families or friend groups spend less time with them when one of the couple develops dementia. This is often because they are uncomfortable talking about dementia or don't know what to say. If you are in a same-sex relationship and have already had family members or friends who struggle to accept this, it can be even more difficult for you if they then don't want to talk about dementia.





Some couples feel closer to one another when one person has dementia, because they are helping each other through the experience. Other couples find they feel less close than they used to. Although many relationships have ups and downs, you might find things become less settled now you have dementia. This can be difficult for both of you to adjust to. You might also find that your feelings or your partner's feelings change. (see 'Sex and intimacy' on page 10).

These changes can be difficult, so it's important to tell your partner how you're feeling about them. It may help to get further support. (See 'When relationship problems develop', page 21).



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

'My friends and I played out yesterday... we had a full day of Edwardian experiences. We dressed up, learned how to make chocolate and got a free chocolate lolly!'

Person with dementia



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Children and young people

It's important to tell any children and young people in your life that you have dementia as soon as you're able to. These might be your own children or grandchildren, nieces or nephews or children of close friends. When you talk to your own children, you might find it helpful to ask other adults who know you both to be part of any conversations. If your child is at school, it's often a good idea to let their school know too.

It's natural to want to protect children from difficult or upsetting situations, but it's important to be honest with them about your diagnosis for a number of reasons:

- It's likely children have noticed things are different if you have shown signs of your dementia. They may feel relieved to know that changes in your behaviour were because of your dementia, and were not directed at them.
- It can help children to learn important skills in dealing with difficult and distressing situations.
- If you don't tell children and they later find out about your dementia, they will realise you didn't tell them the truth. This may be more upsetting to them.

Your child may experience different feelings, including sadness, fear or anger. It may be especially difficult for a young person having a parent with dementia. If they don't know many other people in the same situation, they may feel like very few people can relate to them.

It is important that children are supported with these feelings. They may wish to talk to a professional, including someone at their school, college or university.





Talking to children of different age groups

Children and young people will respond to the news of your dementia in different ways. This will partly be affected by their age and how they tend to deal with things.

Pre-school

At this age, children are mostly interested in what's going on at the moment. Explain your dementia to them as simply as you can – for example, tell them you might not remember things you've talked about, or may lose things sometimes.

Primary school age

Children at this age can be very honest and ask difficult questions. Encourage them to do this and say how they feel. From the age of eight or nine, children can often understand more difficult concepts like illness and death.

Sometimes children of this age try to hide their feelings. They may be anxious – this could show in disturbed sleep or bad dreams, or aches and pains that don't seem to have a cause. It's important to listen to their worries.

Teenagers

Teenage years can be difficult because of the changes people go through at this age. Try to allow teenagers the time and space to come to terms with your dementia in their own way. They may not show their emotions and may be easily embarrassed. Show them you are there to listen to them but try not to make them talk about their feelings if they don't want to or are not ready.



Other family members

You may have other family members who you want to tell about your dementia. How they react will depend partly on the relationship you have with them, as well as their personalities. This is true for anyone you tell about your dementia.

You may have relatives who struggle to accept that you have dementia, or don't know what to say. This can be difficult. It's important to allow people to come to terms with your dementia in their own way and time.

Friends

Friendships are important throughout life, and continue to be important when you have dementia. For some people, friends are the main or most important people who support them. Whether or not this is true for you, it can be helpful to have people to talk to outside your family. You may find it easier to talk to friends – especially if you have difficult relationships with any family members.

You may have special memories or interests in common with friends. You may socialise, play a sport with them or work together – or have done so in the past. These friends can help you keep this connection with things that are important to you.

Friends may be willing to help in practical ways, like caring for you for short periods so your main carer can take a break, or even being your full-time carer. You may choose a close friend to become your attorney through a Lasting power of attorney (LPA).



For more information on LPAs see Alzheimer's Society booklet 1510, Planning ahead.



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



At the same time, some friends may find it difficult to accept that you have dementia. Some may struggle with how to continue being part of your life. There may be some friends who no longer stay in touch, and this might be hard to come to terms with.

Let your friends know you're around and able to enjoy the activities you did before you were diagnosed with dementia. You might have to adapt some of these activities, but friends can support you with this.

You may also have opportunities to make new friends. For instance, you might attend activities or local support groups where you can get to know other people who have dementia. You could also join our online discussion forum Talking Point, where people affected by dementia support each other. This can be accessed at **alzheimers.org.uk/talkingpoint**

When relationship problems develop

Some people with dementia find that problems develop in one or more of their relationships. Talking to the other person can often help, but sometimes you might feel you need support from other people to help with these problems.

You can find help from different services. There are peer support groups (for example dementia cafés), dementia support workers at your local Alzheimer's Society, or counsellors.

To find services in your local area you can search Dementia Connect at **alzheimers.org.uk/dementiaconnect** or ask your GP.



Staying connected

It's important to stay in touch with the people who matter to you. They can help you cope with your dementia, make you feel valued, and support you to keep doing the things you enjoy

Make the changes you need to, but don't feel the need to change every aspect of your life just because you have dementia.

The following tips will help you to stay in touch:

- Communicate with the people who are important to you when you're ready – tell them you have dementia, how it will affect you, and how they can help you. Let people know you want to keep your relationship with them.
- Try to adjust to getting help from other people and doing things with them. Your partner or carer may need to help with things you normally take care of on your own (for example, cooking or managing your household budget) so it might help to start doing things together with them now.

'If you can't get help from your family, try to get help from the professionals.'

Carer for a person with dementia



- Get to know new people in your life – be open to new friendships or relationships.
- Try to get used to the changes that happen now you have dementia. You and the people in your life can support each other to adjust to these changes.

The people around you can play a big part in helping you cope with your diagnosis. Staying in touch in these ways can help you to make the most of your important relationships and so live well with dementia.



Other useful organisations

British Psychological Society

St Andrews House
48 Princess Road East
Leicester LE1 7DR
0116 254 9568
enquiries@bps.org.uk
www.bps.org.uk

Provides access to a list of clinical and counselling psychologists who offer private therapy services.

Counselling Directory

Building 3
Riverside Way
Camberley
Surrey GU15 3YL
0333 3447 990 (9am–5pm Mon–Thu, 9am–4pm Fri)
www.counselling-directory.org.uk

Comprehensive database of UK counsellors and psychotherapists.

Mind

15–19 Broadway
Stratford
London E15 4BQ
0300 123 3393 (helpline, 9am–6pm weekdays)
info@mind.org.uk
www.mind.org.uk

Charity that provides information on all aspects of mental health and provides a range of support through local associations.



Relate

Premier House
Carolina Court, Lakeside
Doncaster DN4 5RA
0300 100 1234
www.relate.org.uk

Centres and licensed counsellors based across the UK working to support local communities by offering face-to-face relationship and family counselling and workshops. Also provides phone, email and online 'live chat' counselling.

The Silver Line

40 Queen Anne Street
London W1G 9EL
0800 4 70 80 90 (helpline, 24 hour)
info@thesilverline.org.uk
www.thesilverline.org.uk

Provides a 24-hour helpline for older people across the UK. Also provides telephone and letter friendship schemes.

YoungMinds

Suite 11, Baden Place
Crosby Row
London SE1 1YW
020 7089 5050 (general enquiries)
0808 802 5544 (parents' helpline, 9.30am–4pm Mon–Fri)
www.youngminds.org.uk
ymentquiries@youngminds.org.uk

Charity that provides information, advice and support for young people affected by mental health issues.



This publication has been reviewed by people affected by dementia and health and social care professionals. A full list of sources is available on request.

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

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



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