

Your relationships



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



We are reviewing this publication. If you would like to give us any feedback, you can email us at **publications@alzheimers.org.uk** or call us on **020 7423 7455**

Contents

1	Your relationships	3
2	Telling people about your diagnosis	4
3	How dementia can affect you and your relationships	6
4	Coping with other changes	11
5	People close to you	19
6	Staying connected	29
	Other useful organisations	32



1 Your relationships

Relationships are important for all of us. Our connections with other people help to improve our wellbeing, give us comfort and support, and maintain our sense of identity.

Dementia will affect many areas of your life, including your relationships. However, there are ways to prepare for and adapt to these changes.

The people around you may have supported you in the past – for example, they may have helped you in practical ways or given you advice. These same people may still be able to help you.

Over time, relationships with different people change for a variety of reasons. Dementia can also cause changes in relationships. It can be difficult for you and the people around you to adjust and it may take some time.

However dementia affects what you say and do, you are still you. You have your own feelings and ways of doing things. Your experience of dementia will be different from everyone else's. It may be helpful to let people in your life know this too.

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.



2 Telling people about your diagnosis

When you've been told you have dementia, you may have close relatives or friends who you want to turn to first. There may be others who you feel 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.

2

How different people respond to your diagnosis will depend on their personality and also whether they have experienced dementia with other people. Keep this in mind when you're talking about your diagnosis. You'll find your own way of having each conversation that feels comfortable to you.

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.

Some people you are close to may even feel reassured to know why you've been having difficulties and that you have options for support.





2

You might know people who find that humour makes things – including your dementia – easier to talk about. For tips on talking to children and young people about your diagnosis, see page 23.

You might find it helpful to talk to a professional about your thoughts and feelings. Ask someone involved in your support, such as a GP or community nurse, to help you find someone who can help you to adjust.

You may also want to involve someone important to you, such as a partner or friend, in these conversations. Or you can call our Dementia Support Line on **0333 150 3456**.

“

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

Person with dementia

”



Call our Dementia Support Line on **0333 150 3456**

3 How dementia can affect you and your relationships

Dementia affects everyone differently. This can include difficulties with memory, thinking, problem-solving or language, and changes in mood, perception and behaviour.

All of these symptoms can affect your relationships in different ways. However, with the right support, it is possible to adjust to these changes.

Having dementia also means you will come to depend more on the people in your life over time. This might be difficult for you or them to accept. However, in time you may also find it brings you closer together.



When someone takes on a caring role

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

- If your partner takes on this role, it might be difficult to feel that you are still 'equals' in the relationship.
- If you are a parent, 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 around.
- If you are a younger person with dementia, your parent might care for you. This can be difficult for you both to accept, as you might have thought you would be caring for your parent as they grew older. You both might not have imagined that they would care for you again once you became an adult.



For more information see booklet 688,
Young-onset dementia: Understanding your diagnosis.



Call our Dementia Support Line on **0333 150 3456**

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. However, caring can also be a positive experience – some people find it rewarding and satisfying.

When you are in contact with health and care professionals such as doctors or social workers, they might refer to the person who helps you as your ‘carer’. You might not think of the person in this way. Instead, you might think of them as you always have – for example, they are your wife, husband, partner, child or friend rather than your carer. They might feel the same way too.

3

However, it can be helpful to refer to this person as your carer when you are talking to health and social care professionals, or if you are looking for support. This is because it makes it clear to people that this person has 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. You may find depending on others difficult at first, especially if they mostly relied on you in the past.

However, spending time with friends and family can be good for both of you. Try to accept any changes around care and support 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.





“

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

”



Call our Dementia Support Line on **0333 150 3456**



Relationships that were difficult before dementia

Not all connections with people are easy. You may have relationships that were difficult before you had dementia. For example, you could have difficult family issues to deal with, and your relationship may even have been abusive at times. You or the other person might have had problems with alcohol or other drugs, or physical or mental illness.

Any problems are not likely to go away because you have dementia. You might still have difficult or painful feelings, or you may not want to accept help from certain people.

Difficult relationships can affect how someone feels about caring. There might be negative feelings between you and the other person. This can mean they are less understanding when you have difficulties because of your dementia.

There are ways of developing healthy and safe relationships, even when these feel difficult. You could get support from a counsellor, or ask other family members or friends to be part of any conversations you have with the person.

If you don't feel safe, it is important to tell someone you trust as soon as possible. This could be your GP, another health or social care professional, or an organisation such as Relate (see 'Other useful organisations' on page 32).

4 Coping with other changes

Having dementia means that you may change in ways that affect your relationships. This may feel difficult and upsetting at times. However, there are things you and the people around you can do to adapt to these changes and live as well as possible.

Communication

Over time, dementia can make it more difficult for you to communicate. This can be very frustrating, as communication is so important in a relationship. When you're trying to communicate with someone, the following tips can make it easier:

- Make eye contact.
- Listen carefully and give each other your full attention.
- Get rid of things that make communicating more difficult – for example, turn off the TV and radio if noise from these is causing problems. Try to make sure the room is bright so that you can see each other clearly.
- Give yourself enough time for a conversation so you don't feel you have to rush.
- Prompts can be helpful – for example, pointing at a photo or object if you have trouble finding the right word.





Any of the changes listed in this section can mean you have to talk about things that you might find difficult to discuss with other people, such as money, sex or how you are feeling. However, these conversations will mean that trusted friends, family members or professionals such as counsellors can support you with practical activities and your emotional wellbeing.



The people in your life may also find it helpful to read factsheet 500, **Communicating**.



I have found noisy social gatherings and having to keep up with conversations quite stressful. So one thing I won't be doing is large gatherings, whilst letting friends and family know how I struggle with this.

Person with dementia



4



Call our Dementia Support Line on **0333 150 3456**

Memory

Memory loss is a common symptom of dementia. If you are affected by this, 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.

Let people know how they can support you with this. For example, it might help if they don't remind you that you repeat things or have forgotten them. They can also introduce themselves or other people (for example, 'here's our neighbour, Bill').



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

Feelings and behaviour

You might notice changes in the way you feel, and those around you might notice changes in your behaviour. For example, some people with dementia become more withdrawn or less patient than they used to be.

This may be difficult for other people to understand and accept as they may think you feel differently about them. Let them know that these changes are because of the dementia and not because your feelings towards them have changed.



For more information visit [alzheimers.org.uk](https://www.alzheimers.org.uk)

You and the people who care for you may also feel low, stressed or anxious at times. These feelings can affect your relationship. If you or those caring for you find that these feelings are causing problems, talk to your GP. There are also organisations who can help. For contact details see 'Other useful organisations' on page 32.

Daily living

Everyday activities such as cooking, making appointments or doing family finances become more difficult as dementia progresses. You may be used to doing these things by yourself, but now you take longer or need someone to help you.

You may be able to make adaptations to make tasks easier, or let someone else take on parts you find difficult. Both you and the person helping you might find this difficult at first, so take the time you both need to adjust.



For more tips see booklet 1506,
Keeping active and involved.

4



Call our Dementia Support Line on **0333 150 3456**

Sex and intimacy

As your brain changes over time, you may find your interest in sex changes. You may have much more interest in sex or feel less like being intimate. If you are in a physical relationship with a partner, you may notice changes in their interest in sex too. If your partner is the main person 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 other ways you can try to stay close and connected – for example, cuddling or other physical contact, watching a favourite film together, or doing other activities that you both like and enjoy doing with each other.

This will be different for every couple and you might need to try a few different things to find what works for you both. For more information about relationships with partners, see 'Couples' on pages 19. Your partner may also find it useful to read factsheet 514, **Sex, intimacy and dementia**.

“

I've got a very supportive wife. Sometimes I give her a hard time, but the truth is I love her to bits.

Person with dementia

”



Changing plans

You don't need to cancel any plans you have, such as going on holiday or moving home, just because you have dementia. However, there may be a good reason why you need to change plans or put them on hold. For example, you might have to make changes to a holiday or theatre trip because you have difficulties with your memory or concentration.

This might make you feel disappointed or frustrated. 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.

“

A big thing is to accept that normal is new and different, almost every day. That there are things that you can't do anymore, or at least in the same way you used to. Another big thing is accepting that you might need help and letting people help you.

Person with dementia

”

4





5 People close to you

Your close relationships will change in different ways after your diagnosis, depending on who the person is and the kind of relationship you have with them.

Let people close to you know that you're still the same person and tell them how you are feeling. There are also opportunities to get to know new people too.

As your dementia progresses, those close to you will give you more support. You can make it easier for them to do this in practical ways, for example, by setting up a Lasting power of attorney (LPA).

For more information on useful conversations to have and the ways other people can help, see booklet 1510, **Planning ahead**.

Couples

All couples have good times and difficult times. You might find you switch between the two more often as things become challenging in different ways now that 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. 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. See 'Sex and intimacy' on page 16.



These changes can be difficult, so it's important to tell your partner how you're feeling. It may help to get further support. See 'If relationship problems develop' on page 28.

When one partner develops dementia, some couples find that people in their wider families or friend groups spend less time with them. This may be because they are uncomfortable talking about dementia or don't want to say the 'wrong' thing.

You could try helping them understand more about dementia, or you may feel more comfortable focusing on your friends and family members who are more supportive.

It may be that you are in a relationship that your family members or friends have already struggled to accept – for example, due to sexual orientation, religious or cultural reasons. In this situation, it can be even more difficult for you if they then don't want to talk about dementia.

It may help to connect with other people with dementia who have had similar experiences, for example, on our Dementia Support Forum at **forum.alzheimers.org.uk**

If you are lesbian, gay, bisexual or transgender, you may find that dementia affects your relationships in other ways. To find out more about this and the support available, see booklet 1511, **LGBTQ+: Living with dementia.**



Children and young people

It's important to tell any children and young people in your life that you have dementia. These might be your children or grandchildren, your siblings' children 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 tell them about your diagnosis and answer their questions for a number of reasons:

- It's likely that children will notice if you are showing signs of your dementia. It may help them to know that changes in your behaviour are because of your condition, and are not directed at them.
- It can help children to learn important skills in understanding how others are feeling and managing difficult situations.
- If you don't tell children and they later find out about your dementia, they may be upset that they weren't told earlier. They may feel they could have helped earlier.

Children may experience different feelings about your dementia, including sadness, fear, anger and relief. They may not know many other people in the same situation.



It may be especially difficult for an older child having a parent with dementia, as they may feel very few people can relate to them. It is important that children are supported to manage their feelings. They may wish to talk to a professional, including someone at their school, college or university.

Talking to the children in your life about your dementia can also bring you closer in some ways and provide new opportunities to spend time together.



If any of your close friends and family members have children or care for young people, they may find it useful to read factsheet 515, **Supporting children and young people when a person has dementia.**





Tips for telling children and young people about your diagnosis

Children and young people will respond to the news of your dementia in different ways. This will be affected by their age and how they deal with things. You might find it easier to talk to them with another family member or friend.

You may find these tips useful:

- ✓ Explain what dementia is clearly and calmly at a level that the child or young person can understand. You may need to repeat your explanations on different occasions.
- ✓ Listen carefully to what they have to say and try to imagine the situation from their point of view.
- ✓ Acknowledge things that are happening that might seem strange – for example, you might forget things you've talked about with them – and explain that this is because of your dementia.
- ✓ Encourage them to ask any questions they have and to be honest about how they are feeling. Let them know that they can always talk to you.
- ✓ Look for signs that they may be anxious or worried, and try to reassure them. Sometimes children try to hide their feelings.
- ✓ Give them plenty of reassurance and hugs, where appropriate.
- ✓ Let them know you are still the same person and the way you feel about them hasn't changed.
- ✓ Use humour, if it feels appropriate. It often helps if you can laugh together.

Other family members

You may have family members who struggle to accept that you have dementia. They may not know what to say, or how to act or feel. This can be difficult, especially when you might be adjusting to your dementia yourself and need support from them. Let people come to terms with your dementia in their own way and time.

For some family members, learning more about dementia could help them to understand how they might be able to support you. This is also the case for friends (see page 25).

There is information on all aspects of dementia on our website and we can provide print copies for free. You can find out more at **alzheimers.org.uk/publications**

Other family members and friends may be able to give you the support that you need. If your relationship with one or more family members has become difficult and is not getting better, help is also available from other support services.

You can call our Dementia Support Line on **0333 150 3456** where our dementia advisers can give you practical and emotional advice. They can also connect you to local services and groups that can support you.



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 may have done so in the past. These friends can help you to keep connections with things that are important to you.

Friends may be willing to help in practical ways, like caring for you for short periods or even full-time. You may choose a close friend instead of, or as well as, a partner or family member, to become your attorney through a Lasting power of attorney (LPA).



For more information on LPAs in England and Wales, see factsheet 472 **Lasting power of attorney** and for Northern Ireland, see factsheet NI472 **Enduring power of attorney and controllership**.





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 that you are around and able to enjoy the things 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 can see what's available in your area by searching on **alzheimers.org.uk/dementiadirectory**.

You can also join our Dementia Support Forum at **forum.alzheimers.org.uk** where people affected by dementia support each other.

5

“

I was diagnosed last year with FTD [frontotemporal dementia] and I go to a group every other Wednesday... for anyone under the age of 70... I also go to a tea dance and Singing for the Brain.

Person with dementia

”



Call our Dementia Support Line on **0333 150 3456**



If 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 deal with these problems.

You can get help from different services, such as support lines, support groups or counsellors.

To find services in your local area, you can call our Dementia Support Line on **0333 150 3456**, ask your GP or search online at **alzheimers.org.uk/dementiadirectory**

6 Staying connected

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

The people around you can play a big part in helping you cope with your diagnosis. The following tips can help you to get the most out of your important relationships, and make new ones, so that you can live as well as possible with dementia.

- **Let people know that you want to keep your relationship with them.**

Communicate with the people who are important to you when you're ready. Tell them you have dementia, how it is affecting you, and how they can help you. This may also reassure people if they don't know what to say or how to treat you following your diagnosis of dementia.

- **Keep in touch in different ways.**

Many people enjoy meeting their friends and family face to face. If this isn't possible, there are lots of different ways to communicate. This could be over the phone, through video calls, or using messaging services on your mobile phone or tablet.



- **Be open to new friendships or relationships.**

Getting to know new people in your life can be a great way to stay active and involved. You can find activity and support groups in your area by searching **alzheimers.org.uk/dementiadirectory** or calling our Dementia Support Line on **0333 150 3456**. You can also connect with people on our Dementia Support Forum at **forum.alzheimers.org.uk**

- **Try to get used to doing things in new ways.**

You are likely to need to make changes to adjust to your dementia. Being open to these changes can help you to keep doing things you enjoy with the important people in your life. Together you can support each other to get used to new ways of doing things.

Only make the changes you need to, and don't feel you must change every aspect of your life just because you have dementia. Some areas of your life and relationships may not change very much – or at all.





Other useful organisations

Age UK

0800 678 1602 (advice line, 8am–7pm)

www.ageuk.org.uk

Age Cymru

0300 303 4498 (advice line, 9am–4pm)

Monday–Friday)

advice@agecymru.org.uk

www.agecymru.org.uk

Age NI

0808 808 7575 (advice line, 9am–5pm)

Monday–Friday)

advice@ageni.org

www.ageuk.org.uk/northern-ireland

Age UK, Age Cymru and Age NI aim to improve later life for everyone through information and advice, services, campaigns, products, training and research.

British Psychological Society (BPS)

0116 254 9568

info@bps.org.uk

www.bps.org.uk

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

Counselling Directory

0333 325 2500 (10am–4pm Monday–Friday)

www.counselling-directory.org.uk

Counselling Directory is a comprehensive database of UK counsellors and psychotherapists.

Dementia UK

0800 888 6678 (helpline, 9am–9pm

Monday–Friday, 9am–5pm Saturday and Sunday)

helpline@dementiauk.org

www.dementiauk.org

Dementia UK provides specialist dementia support through their Admiral Nurse service, offering both face-to-face and telephone support.

The Dragon Story

www.gloriousopportunity.org/thedragonstory

The Dragon Story is a four-minute cartoon for children aged five to nine, explaining dementia and how it can affect their family members.

Hourglass

0808 808 8141 (helpline)

helpline@wearehourglass.org

www.wearehourglass.org

Hourglass works across the UK to protect and prevent the abuse of vulnerable older adults.

LGBT Foundation

03453 303030 (9am–9pm Monday–Friday,

10am–6pm Saturday and Sunday)

helpline@lgbt.foundation

<https://lgbt.foundation/>

LGBT Foundation is a national charity delivering advice, support and information services to lesbian, gay, bisexual and trans communities.

Mind

0300 123 3393 (Infoline, 9am–6pm Monday–Friday)

info@mind.org.uk

www.mind.org.uk

Mind is a national charity that provides information on all aspects of mental health and a range of support through local associations.

Relate

0300 003 2972 (to book telephone counselling,

9am–7pm Monday–Thursday, 9am–5pm Friday–Sunday)

natenquiries@relate.org.uk

www.relate.org.uk

Relate has centres and licensed counsellors based across the UK, supporting local communities by offering face-to-face relationship and family counselling and workshops. It also provides phone, email and online ‘live chat’ counselling.

The Silver Line

0800 4 708090 (helpline, 24-hour)

www.thesilverline.org.uk

The Silver Line provides a 24-hour helpline for older people across the UK.

YoungMinds

020 7089 5050 (general enquiries)

0808 802 5544 (parents' helpline,

9.30am–4pm Monday–Friday)

www.youngminds.org.uk

YoungMinds is a charity that provides information, advice and support for young people affected by mental health issues.

Reviewed by: Dr Sarah Butchard, Consultant Clinical Psychologist and Psychology Lead for Older People's Services, Mersey Care NHS Foundation Trust

This booklet has also been reviewed by people living with dementia.

To give feedback on this publication, or for a list of sources, please email **publications@alzheimers.org.uk**



Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**



Registered with
**FUNDRAISING
REGULATOR**

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. Alzheimer's Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

© Alzheimer's Society, 2024. All rights reserved. Except for personal use, no part of this work may be distributed, reproduced, downloaded, transmitted or stored in any form without the written permission of Alzheimer's Society. Alzheimer's Society maintains editorial independence over the content of this publication.

Last reviewed: July 2021
Next review due: July 2024

Registered charity no. 296645. A company limited by guarantee and registered in England no. 2115499. Alzheimer's Society operates in England, Wales and Northern Ireland.

At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Adjusting to life with dementia**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimerers.org.uk**



Patient Information Forum



Together we are help & hope
for everyone living with dementia

Alzheimer's Society
43-44 Crutched Friars
London EC3N 2AE

0330 333 0804
enquiries@alzheimerers.org.uk
alzheimerers.org.uk

Code 1507