

Understanding and supporting a person with dementia



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



Understanding what it is like to live with dementia can help you support someone with the condition to live well. This factsheet will tell you about some of the practical, psychological, emotional and social effects of having dementia.

This factsheet may be particularly helpful for carers, or people who support a person with dementia. It looks at how supporting someone with dementia can affect you, and has advice on managing this.

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1 The impact of dementia on a person

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Every person with dementia experiences the condition individually. Different types of dementia also affect people differently. Their feelings and their experience of living with dementia day by day will be influenced by:

- their relationships
- their environment
- their life history
- their daily routines and activities
- the social and emotional support they have.

When you're supporting a person with dementia it's important to think about how all of these things may influence them.

Everyone has their own likes, dislikes and personality, including people with dementia. This means that there is no single way of supporting a person with dementia. Try to adapt your support to what you know about the person's individual needs and preferences.

Dementia can affect a person's thoughts and feelings, so they may have additional emotional needs. They may experience the same environment and events as you in a very different way. Trying to see things from their perspective, and understanding and acknowledging how they are feeling will help you provide the best support.

As the person's dementia progresses, they will continue to have an emotional connection to people and their surroundings. The way you support them will make a difference to how they feel.

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2 Reactions to a diagnosis

If somebody has recently been diagnosed with dementia they are likely to experience a range of emotions. These might include grief, loss, anger, shock, fear and disbelief.

Some people may struggle to deal with a diagnosis because they may not understand what it means for them, or they may seem unconcerned or be in denial about having dementia – see page 3 for more information. They may feel afraid about the future, what their symptoms mean or the impact dementia will have on those around them. For other people, it is a relief to receive a diagnosis because it is an explanation for problems they have been experiencing.

If somebody close to you is diagnosed with dementia it can be difficult for you, as well as for them. You may need to provide emotional and practical support to help the person come to terms with what they're going through. It's important to ask for help and support for yourself if you need it. For more information see the section 'Looking after yourself if you are supporting someone' on page 17.

Tips for supporting somebody who has received a diagnosis of dementia

- **Always try to see things from the person's perspective.**
- **Give them time to process their emotions.** They may not know how they feel about the diagnosis, and may need time to adjust to the diagnosis and what it may mean for them.
- **Give the person opportunities to talk about their diagnosis** and how they feel. Acknowledge their feelings and show them that you are there for them.
- **While it can be helpful to think ahead and make plans, try to also focus on the time that you have here and now.** If the person doesn't want to talk to you about their feelings, it may help to find someone they would feel comfortable discussing them with. They may benefit from joining a support group or online community, such as Alzheimer's Society's Dementia Support Forum, so they can talk to other people with a diagnosis of dementia.
Go to forum.alzheimers.org.uk

A diagnosis may lead some people to feel depressed or anxious. Support is available for depression and anxiety, including talking therapies, treatment with medicines and lifestyle changes such as gentle exercise. You can talk to the GP about these. For more information see factsheet 444, **Supporting a person with dementia who has depression, anxiety or apathy.**

Booklet 872, **The dementia guide: Living well after your diagnosis** has information and advice for people who have been recently diagnosed with dementia. You can find it at alzheimers.org.uk/dementiaguide

What to do if the person does not acknowledge that they have dementia

When a person is diagnosed with dementia they may not understand or accept their diagnosis. They may feel that nothing is wrong and not recognise that they are experiencing any symptoms. Or they may acknowledge that they are having difficulties doing certain things but believe this is due to a reason other than dementia, such as getting older. A person may be unable to acknowledge their diagnosis or symptoms because of denial or lack of insight.

Denial is when a person doesn't acknowledge certain facts or events, even when they may seem obvious to those around them. It is a psychological reaction that enables a person to cope with a difficult situation that may otherwise make them feel afraid, depressed, ashamed or worried. Over time, a person may come to accept their diagnosis and how it is affecting them.

Lack of insight is when a person with dementia is unable to recognise changes in their behaviour and emotions. It is caused by changes in the brain due to dementia. It is more common in some types of dementia, such as frontotemporal dementia (FTD). Unlike denial, which sometimes lessens over time, lack of insight tends to get worse as dementia progresses.

It can be upsetting when a person does not acknowledge or accept their condition. If you can empathise and try to support the person, it might make it easier to manage the situation.

Give the person time to adapt to their condition and sensitively check every so often to see if they seem ready to talk about it. Even if a person doesn't acknowledge their diagnosis, there are still ways to help them. For example, they may be able to talk about any general concerns or worries they have, such as their memory problems.

For more information see factsheet 533, **Understanding denial and lack of insight**.

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3 Adapting as dementia progresses

As dementia progresses, the person will experience changes in their symptoms and how they are feeling. The support they need, and the things they do to cope, will change over time.

There are many things the person can do to help them manage their condition and adapt to the changes it brings. This might include things they have never done before. People often develop coping strategies without realising it. They may do it gradually, sometimes even before they have a diagnosis, as a way to cope with the changes they are experiencing.

Understanding how the person is adapting to living with dementia will help you to support them. Some common ways of coping include:

- using reminders, prompts and technology to help with everyday tasks
- thinking about and planning for the future, for example:
 - setting up Lasting powers of attorney (for more information see 'Decision-making' on page 15)
 - writing an advance statement
 - preparing an advance decision
 - creating, updating or amending a will. The person may find it useful to read booklet 1510, **Planning ahead**
- finding ways to stay involved and active, such as joining a support or activity group or asking friends and family for help
- seeking spiritual and emotional support
- using humour and focusing on short-term enjoyment and positive parts of their life
- trying to improve their health – for example by exercising, eating more healthily, cutting down on alcohol and quitting smoking.

4 Changes in emotions

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The person is likely to experience a range of emotions as their condition progresses. They will react differently to some situations because of changes to their thinking, such as memory loss or confusion. For example, they may have less control over their feelings and how they express them. They may be more irritable or have sudden mood changes. They may also seem withdrawn or uninterested in things, especially if they lose confidence in their abilities or are unsure of their surroundings.

These changes can be unsettling for the person with dementia, as well as for the people around them. It may help to remember that dementia is caused by damage to the brain.

There are other things that can cause changes in the person's emotions. For example, they might feel anxious, depressed or frustrated about not being able to do the things they used to. It can help to think about ways they can still do things they enjoy, perhaps doing things with them as a shared activity, or breaking them down into smaller, shorter steps. Keeping skills and interests for as long as possible can improve the person's self-esteem and quality of life.

Strong emotions can also be a sign of someone having a need that is not being met. For example, if they become unusually quiet, it could be because they are in pain, embarrassed or feel their opinion doesn't matter. If you are supporting a person with dementia, try to work out what their needs are and find ways to meet them. The next section has examples of needs that might cause changes in behaviour, as well as some tips on how to support the person.

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5 Changes in behaviour

As a person's dementia progresses, they may begin to behave in ways that other people find difficult to understand. For example, they may:

- ask the same question over and over
- become suspicious or paranoid
- follow someone around
- become restless or agitated
- hide, hoard or lose things
- shout and scream
- become very withdrawn and disinterested.

Dealing with behaviour that seems out of character for the person can be one of the most difficult aspects of living with dementia, both for them and for you. Some people may assume that the person's behaviour is a symptom of dementia itself, which isn't always the case. It's important to see beyond the behaviour and think about what might be causing it.

As human beings, we all have the same basic needs. The symptoms of dementia can make it harder for a person to recognise their own needs, know how to meet them, or communicate them. Changes in behaviour may be their attempt to communicate or meet these needs. For example, the person might be behaving differently because they are:

- in pain
- thirsty or hungry
- feeling threatened
- distressed
- frustrated, bored or under-stimulated.

Try to see things from the person's perspective. Changes in behaviour can often be managed by recognising and responding to the person's needs. It's useful to look at the circumstances of their behaviour to see if there is something they could be reacting to, such as an environment, event or person. This can help you make some changes to the person's situation and see if it makes a difference.

There are different ways to support a person with dementia, including:

- asking them what makes them feel safe and listened to
- spending time with them and helping them to stay in touch with other people
- encouraging them to do things they enjoy or find useful
- making changes to their surroundings if necessary (for example, reducing noise, improving the lighting or adjusting the temperature)
- keeping familiar, comforting or personal items close to them, such as photographs or a favourite jumper
- being aware of their beliefs and thoughts and trying not to argue with them. For example, if they believe they need to go and collect their children from school, don't tell them they are wrong. Instead, ask them to tell you more about their children, or move their focus onto an activity.

Psychological therapies, such as cognitive stimulation therapy, can also be helpful. Talk to the person's GP or a professional involved in their care about getting a referral.

For more information see factsheet 525, **Changes in behaviour**.

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We do however, laugh a great deal... and I find procrastination helpful for anything difficult or impossible... 'Is it ok if we perhaps do that tomorrow, love?'

Carer for a person with dementia

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6 Supporting the person in their daily life

As a person's dementia progresses their symptoms will get worse. Over time, they will have more problems with their memory and thinking and find it more difficult to do things. They may need to adjust the way they do everyday tasks such as cooking and paying bills. They may also begin to need support to do the activities and hobbies they enjoy. Eventually they may need help to do most daily activities.

Adjusting to this can be difficult and upsetting, and may cause the person to feel a lack of confidence, self-esteem and independence. This can affect other parts of their life, such as how they communicate, their relationships and their sense of identity.

Communication

Communication with the person will become more difficult as their dementia progresses. Their symptoms may mean that they have problems finding the right word or following a conversation. Communication for a person with dementia can also be affected by pain, side effects of medication and sight or hearing loss.

If the person is not able to express themselves, they can lose confidence, feel anxious or depressed, or become withdrawn. This can be upsetting and frustrating for the person and those around them. Your understanding of the person and their needs may help you to work out what they are trying to communicate. The person's behaviour and body language can also give you signals about how they are feeling.

There are many ways to support someone to communicate with you. For example:

- **Try to make eye contact.** This can help the person to focus on you.
- **Encourage them to use their glasses and hearing aids.**
- **Use gentle touch** to attract their attention, to make them feel safe and to reassure them.
- **Think about the person's environment and turn off distractions** such as the TV or radio. It will also help to make sure you have the person's full attention before you start.
- **Speak slightly more slowly and use short, simple sentences.** Be aware of your tone of voice.

- **You could use more gestures, facial expressions and body language to communicate with the person you care for.** These may become some of the main ways a person with dementia communicates as their condition progresses. Make sure the words you use match the feeling you are expressing and your body language.
- **Try to avoid sudden movements and tense facial expressions,** as these may cause upset or distress.
- **Stand or sit where the person can see and hear you as clearly as possible.** Try to be at eye-level with them, rather than standing over them. Include the person in conversations with others. Try not to complete sentences for them – give them plenty of time to respond.
- **Avoid asking too many questions or questions with more than one part to them.** Too many options can be confusing and frustrating. Questions with a ‘yes’ or ‘no’ answer are easier to answer.

You may like to share these tips with other people.

For more information see factsheet 500, **Communicating**.

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Independence

Feeling independent is important for everyone's wellbeing. This may become more difficult for someone with dementia as their condition progresses and they need more care and support. However, try to support the person to do things as independently as possible. It can be tempting to take over when someone is struggling and do things for them, but this can result in them feeling frustrated and losing abilities they do have.

If the person doesn't want to ask for help, or refuses offers of support, this can be upsetting and frustrating for you. Remember that they may be finding it difficult to adjust to needing support. This could be because they are unaware of their dementia and how it affects them – for more information see page 3. It might also be because they are struggling to accept that things have become difficult for them.

For some people accepting a small change may make them feel powerless and worry that they will be more or completely dependent on help. Try to explain that having help with cleaning or self care earlier rather than later is not a sign that they will need full-time care soon.

There are things you can do to make it easier for a person with dementia to feel independent and adjust to receiving support. For example:

- **Try to support the person to do things for themselves rather than taking over.** It may mean tasks take slightly longer, but it can help them to maintain their skills.
- **When offering support, involve the person with dementia as much as possible.** This may mean doing things in the way they prefer, as long as it's practical and safe to do so.
- **Give them time to think about the change** or help you are suggesting and your reason for it. If necessary, ask again a little later.
- **Think of ways you can adapt activities so that the person can continue doing them independently.** For example, you could pre-set their favourite radio station so they can enjoy it without having to tune the radio themselves. Or if reading books has become difficult, find magazines on a topic the person is interested in that they might enjoy browsing.
- **Don't assume that the person is unable to understand** what is happening or unable to contribute. Allow plenty of time for them to respond.
- **Ask other people (especially professionals) to speak directly with the person first,** and then if they need to, with you.

Confidence and self-esteem

Dementia can cause people to lose confidence in themselves and their abilities. As their condition progresses, some people feel they are no longer in control and may not trust their own judgement. They may need support to manage their health, finances, employment or relationships.

Negative reactions from others may also affect the person's self-esteem. They may find that people treat them differently because of their diagnosis. This is often because others don't understand how dementia affects people, or they are unsure of how to act around someone with the condition. You could show people this factsheet to help them understand more about dementia.

Self-esteem is an important part of living well. If you are supporting a person with dementia you can play a part in maintaining their confidence and self-esteem.

Tips for supporting someone with dementia to maintain their self-esteem:

- Focus positively on the things that the person with dementia can still do, rather than things they can't do, or do as well as they used to.
- Give the person lots of praise and encouragement.
- Avoid criticism or speaking sharply, even if you feel frustrated or angry. If the person makes a mistake, try to be as supportive as possible.
- Make sure they have plenty of time to do the activities they enjoy and find meaningful.
- Aim to do things with, rather than for, the person. If you take over it could make them lose confidence.
- Adapt tasks so that the person finds them more manageable.
- Help the person to maintain their relationships by doing things with friends and family.

People with dementia can often feel cut off from other people. They have a higher risk of being socially isolated and lonely, which can lead to them becoming depressed. The opportunity to be sociable is very important for a person's wellbeing and self-esteem. Group activities can be a great way for people with dementia to socialise, try new things and have fun. They may also help someone retain language skills for longer. Find out what groups or activities are available in your local area – go to alzheimers.org.uk/dementiadirectory

For more information see booklet 77AC, **The activities handbook: Supporting someone with dementia to stay active and involved.**

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Identity

A person's sense of identity (how they see themselves) can change as dementia progresses. If they find familiar activities and hobbies more difficult over time, they may have to give up their job or a role in the community. Their relationships with family and friends are also likely to change.

It can sometimes seem as though the person is not the same as they were before they developed dementia. Having dementia means a person has to do some things differently, but it does not change who they are. You and others around the person have an important role in supporting them to be themselves. Being aware of how dementia is affecting them can help with this.

Focus on the things that make the person a unique individual and make it clear that you value them. This includes respecting their beliefs, preferences and the things that are important to them. This might include elements of their culture or faith, dietary choices or what they like to wear. Support them to keep doing the things they enjoy. Encourage them to talk about their life history and interests to help bring out different parts of their personality.

Think about how the person's background and culture affects them. For example, it might be hard to talk about dementia in their community or they may have experienced stigma. If the person feels isolated or excluded, think of how you can make them feel safe and loved.

If the person has had traumatic experiences earlier in life, they may find some situations very threatening. This could include being washed and dressed by someone else or being encouraged to take medication. You may or may not know about all the events in their life but notice an emotional reaction to certain smells, sounds or other factors. Focus on the person's feelings and offer reassurance. If you feel they need more support, speak to them about services such as counselling. The GP or care professionals involved in supporting the person may be able to help find suitable services offering talking therapies.

If the person you're supporting identifies as LGBTQ+, they may face other challenges living with dementia, and their condition may affect them in particular ways. This can relate to revealing their sexual orientation or gender identity, for example. They may need support that takes this into account.

For more information see factsheet 480, **Supporting an LGBTQ+ person with dementia**.

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. When someone has dementia they may find that some of their relationships change. This might be because they feel less confident, particularly in social situations. Sometimes they may lose contact with people who find it difficult to accept or understand their dementia.

A good relationship between you and the person you are supporting can help you both to live well. You may start to have more responsibilities as you take on more of a caring role. It's important that the person you are supporting still feels included in the relationship and able to contribute to it.

Doing things together can help with this – you could think of ways you can adjust activities or tasks to suit the person's needs, or you could find new things to do together. Life story work (remembering and recording details about the person's life, experiences and beliefs) and reminiscence activities (talking about themes from the past, using prompts such as photos) can be enjoyable and meaningful activities to do together.

You may also need to make other adjustments – for example, taking over tasks the person is no longer able to manage (such as organising finances or driving). It can be difficult for both of you to adjust to these changing roles, especially if they are not tasks you have been involved in before. If possible, it can help to let other people know that you need some support. Even if they can't offer help with day-to-day caring, you could ask a person you trust to help with certain things (such as picking up medication).

As the person's condition progresses, some aspects of your relationship with them will change, such as how you communicate with each other. This can be hard, but remember that the person's symptoms are not in their control. Many positive things in your relationship are likely to remain even as the person's abilities are affected.

For more information on changes to intimate relationships see factsheet 514, **Sex, intimacy and dementia**.

Continuing to take part in social groups, clubs or religious activities can help a person with dementia maintain their relationships with others. You can support a person with this, for example by encouraging them to go, or going along with them. Dementia-specific groups can give people a chance to meet new people with similar experiences, and to talk about living with dementia. Ask your GP about what's available in your area or search online at alzheimers.org.uk/dementiadirectory

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If your relationship was difficult before dementia

Not all relationships are easy. Your relationship with the person you are now supporting may have been difficult before they developed dementia. This can make it hard for you to take on a caring role.

If you've had a difficult relationship with the person in the past, try to get help to develop a healthy and safe relationship with them now. You could ask other family members or friends for support, or look for support from a counsellor (see 'Other useful organisations' on page 18 for details of the counselling organisation Relate).

If you've had a difficult relationship, consider whether you want to care for the person yourself. If you do care for the person, this should be your decision and you should not feel that it's something you have to do, especially if you feel uncomfortable or unsafe. If your relationship has been abusive and you don't feel safe, it's important to tell someone you trust as soon as possible.

Decision-making

As their condition progresses, people with dementia may become unable to make some decisions for themselves. These may include choices about finances or whether to accept medical treatment, for example. When this happens, the person is said to lack the 'mental capacity' to make those decisions.

There are some important things to bear in mind about mental capacity:

- A diagnosis of dementia does not automatically mean a person lacks capacity.
- You must always assume that a person is able to make a decision for themselves, unless it is proved that they can't.
- Capacity can change in both the long term (day to day) and the short term (moment to moment).
- Whether someone has capacity or not is specific to each particular decision at each particular time.
- A person with dementia may have the capacity to make some decisions, but not others.

According to the Mental Capacity Act 2005, to have capacity a person must be able to:

- understand the information that is relevant to the decision
- keep the information in their mind long enough to be able to make the decision
- weigh up the information available to make the decision
- communicate their decision in any way – including talking, using sign language or through simple muscle movements such as blinking or squeezing someone's hand.

A person with dementia should be supported and given the chance to make their own decisions for as long as they can. Even when they lack capacity they should still be included in decisions that affect them.

For more information see factsheet 460, **Mental Capacity Act 2005**.

The person you are supporting can set up a Lasting power of attorney (LPA), if they have not already done this. An LPA is a document that gives somebody close to the person with dementia the authority to make decisions on their behalf if they lose capacity. LPAs must be set up by the person themselves, and they must have the capacity to consent to this. If there is no LPA in place and the person loses capacity, someone can apply to become a deputy which would allow them to make decisions on behalf of the person with dementia.

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If you are appointed to make decisions on behalf of a person with an LPA you will be known as the attorney (or deputy if appointed through deputyship). If an attorney or deputy needs to make a decision for a person with dementia then this must be made in the person's best interests. The decision-maker should always have regard to the least restrictive option and be based on the person's previously expressed wishes, if possible.

For more information see factsheet 472, **Lasting power of attorney** and factsheet 530, **Deputyship**.

7 Looking after yourself if you are supporting someone

Supporting a person with dementia can be positive and rewarding, but it can also be very challenging. As dementia progresses a person's needs and abilities will change. Looking after yourself is important for both you and the person you are supporting. If you stay physically, mentally and emotionally healthy you will be in a better position to support the person with dementia. It can also help you to have a better relationship with them.

You will usually have to adjust to your relationship changing as the person needs more support. It might help to try and have honest conversations about this with the person you are supporting, to find out how you can cope with the new challenges together. There are people who can help you to have these conversations, such as relationship counsellors or support groups. It can also help to talk to family, friends or professionals, or to people in a similar situation to your own. Alzheimer's Society has an online community for anyone affected by dementia – go to forum.alzheimers.org.uk

If you are supporting a person with dementia you might not see yourself as being their 'carer'. You might first and foremost think of yourself as being their partner, spouse, family member or friend. But even if you choose not to identify as a 'carer' it can still be helpful to use the word when you talk to professionals, because it can help you get the right support. You are also entitled to a carer's assessment. For more information on this see factsheets 418 **Assessment for care and support** (for England), W418 (for Wales), and NI418 (for Northern Ireland).

Taking regular breaks from caring is also important for your wellbeing and you will be able to cope better if you make time for yourself. You may want to consider replacement care (respite care) options – for more information see factsheet 426, **Replacement care (respite care) in England**, W462 **Respite care in Wales** or NI462 **Respite care in Northern Ireland**.

For more information on looking after yourself see factsheet 523, **Carers – looking after yourself**.

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It is always helpful to remind myself that “it is the disease not the person”.

Family member of a person with dementia

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Other useful organisations

Carers Trust

0300 772 9600 (9am–5pm Monday–Friday)

info@carers.org

www.carers.org

Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring for a family member or friend.

Carers UK

0808 808 7777 (helpline, 9am–6pm Monday–Friday)

advice@carersuk.org

www.carersuk.org

Carers UK gives advice, information and support to carers including details of local carer support organisations.

Dementia UK

0800 888 6678 (9am–9pm Monday–Friday,

9am–5pm Saturday–Sunday)

helpline@dementiauk.org

www.dementiauk.org

Dementia UK provides specialist dementia support for families through its Admiral Nurse service.

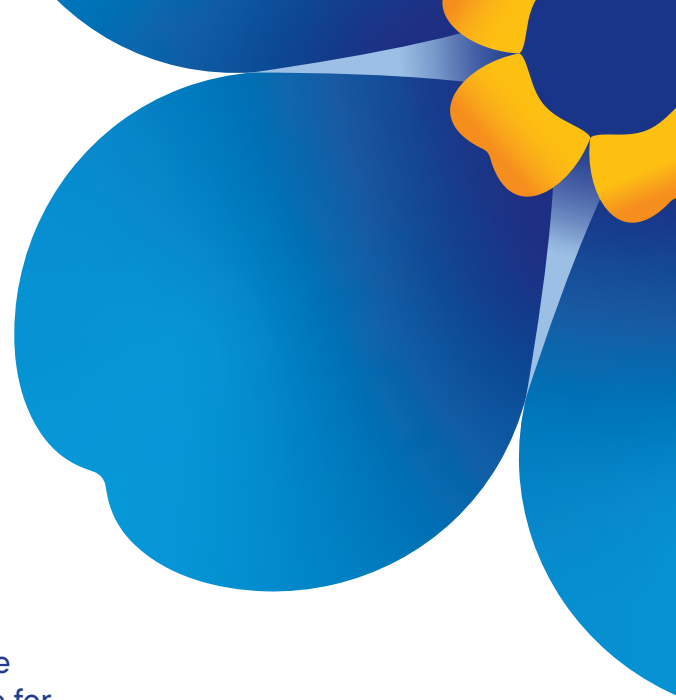
Relate

www.relate.org.uk

Relate provides services including relationship counselling for individuals and couples, family counselling and sex therapy. There is a network of Relate centres across the UK, a group of licensed local counsellors that provide face-to-face counselling and support. Relate also provides phone, email and WebChat counselling.

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Factsheet 524

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

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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 caring for someone with dementia**.

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



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Together we are help & hope
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