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.

If you are the main person supporting someone with dementia, you may also want to read booklet 600, *Caring for a person with dementia: A practical guide*. This booklet has more detailed information and practical tips on all aspects of caring.
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The impact of dementia on the person

The impact dementia has on a person is not limited to the practical effects of the condition. A person with dementia will still have feelings, thoughts and emotional responses. However, these may be affected by dementia, so someone with the condition may have additional emotional needs. The way somebody feels, and their experience of living with dementia, will also be influenced by other things, such as:

- their relationships
- their environment
- their life history
- their daily routines and activities
- the support they receive.

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

Everyone is unique, with their own likes, dislikes and personality – dementia does not take these away. This means that there is no single way of supporting a person with dementia. Support should always be tailored to the person’s individual needs and preferences, based on what you know about them.

A person with dementia may experience the same environment and events as you in a very different way. Trying to see things from their perspective and knowing how they may be feeling will help you to provide the best support. This factsheet has information and tips to help you with this.
Even as the person’s dementia progresses they will continue to have an emotional connection to people and their environment. The way you support a person will have an impact on them and how they feel. Acknowledging and respecting a person’s feelings is part of giving them support.

Reactions to a diagnosis

If somebody has recently been diagnosed with dementia they are likely to experience a range of emotions, such as grief, loss, anger, shock, fear and disbelief. Some people may struggle to deal with the diagnosis because they may not understand what it means for them, or they may be in denial about having dementia (see page 6 for more information).

Anyone with a diagnosis of dementia is likely to experience a range of emotions as they adjust. You may need to provide emotional and practical support to help them come to terms with what they’re going through. See the tips below for more information.

Tips for supporting somebody who has received a diagnosis of dementia

- Take some time to try and understand their feelings.
- Acknowledge how they are feeling and show them that you are there for them.
- Give them time to process their emotions. They may not know how they feel about the diagnosis, and may need time to adjust to new information.
- Give the person opportunities to talk about their diagnosis and how they feel.
- If they don’t want to talk to you about their feelings, it may help to find someone they would feel comfortable discussing them with.
- Try to focus on the present and not spend too much time thinking about what the future may or may not hold.
- The person may benefit from joining a support group or online community so they can talk to other people with a diagnosis of dementia.
The person you’re supporting may be struggling to adjust to their diagnosis. There might be many reasons for this. They may feel afraid about the future, scared about moments of confusion and forgetfulness, or upset about the impact dementia will have on those around them. For some people, it is a relief to receive a diagnosis because it is an explanation for the changes and symptoms they have been experiencing.

The confirmation of a diagnosis can lead some people to feel depressed or anxious. There are a number of talking therapies and (if needed) drug treatments available for depression and anxiety. You can talk to your GP about these. Lifestyle changes can help too, for example incorporating gentle exercise into daily routines. For more information see factsheet 444, Supporting a person with dementia who has depression, anxiety or apathy.

If somebody close to you is diagnosed with dementia it can be difficult for you, as well as for them. Talking honestly to each other about your feelings can help you both. It can also help you to discuss what you can do to support the person with dementia now and in the future.

You may not want to talk to the person with dementia about how you are feeling – for example if you’re worried about how they feel or how it will impact them. If this is the case, try and talk to someone else you trust – such as a friend or family member.

Dementia Talking Point is our online community for carers and people with dementia. You might find it a helpful place to hear other people’s experiences, or to share your own. Go to alzheimers.org.uk/talkingpoint

Our Understanding your diagnosis booklets have information and advice for people who have been recently diagnosed with dementia. You can find them at alzheimers.org.uk/publications

Give them time to process their emotions. They may not know how they feel about the diagnosis, and may need time to adjust to new information.
What to do if the person does not acknowledge that they have dementia

Some people may not acknowledge that they have dementia, or they may deny that they are having difficulties. They may be aware that things are becoming harder but feel that it is a normal part of ageing. Others may be experiencing denial or lack of insight into their condition, and so may not realise they are having difficulties at all.

Denial is not deliberate, but a psychological response. It often means a person does not ‘see’ their symptoms. This can sometimes be helpful as it may give the person time to come to terms with their diagnosis. Denial tends to fade over time, and the person may slowly become more accepting of their dementia.

Some people have a lack of insight. This can appear similar to denial, but it is caused by changes in the brain due to dementia. This means that it is not a defence mechanism but a direct, physical effect of the person’s condition. Lack of insight is more common in some types of dementia, such as frontotemporal dementia. It may be more pronounced in the later stages of dementia, but usually starts much earlier. For more information on this see factsheet 456, Dementia and the brain.

Coming to terms with dementia is an ongoing process for most people as they experience new changes and challenges. Generally, people will become less aware of their condition and its effects on their abilities as it progresses. This can be frustrating for you, but whether caused by denial or lack of insight, it is not deliberate. It is important to give the person time to process the changes they are experiencing. It can be tempting to regularly remind the person about their condition to help them come to terms with it, but if they are unable to accept or retain this information these reminders may be upsetting rather than helpful.
Adapting as dementia progresses

As dementia progresses, people will experience changes in their symptoms and how they are feeling. There are many things people do to help them manage their condition and adapt to the changes it brings – this might include things they have never done before. The way somebody adapts will depend on:

- their personality
- their previous experiences
- their understanding of dementia
- the social and emotional support they receive
- their environment.

Everyone will find their own way of coping as their dementia progresses. Understanding how someone does this 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, which may include:
  - setting up Lasting powers of attorney
  - writing an advance statement
  - preparing an advance decision
  - creating, updating or amending a will.
- 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.
The support a person needs, and the strategies they use to cope, will change over time and as their condition progresses. 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.

**Changes in emotions**

As dementia progresses the person is likely to experience a range of emotions, and how they react to some situations is likely to change. For example, they may have less control over their feelings and how they express them. They may be more irritable, or experience sudden mood changes. They may also appear unusually distant or uninterested in things.

These changes can be unsettling for the person with dementia, as well as the people around them. It can help to remember that dementia is caused by physical damage to the brain. Changes to a person’s thinking, such as their ability to remember or think clearly about a situation, may mean they react differently to things.

As well as these physical changes in their brain, other things can cause changes in emotions for people with dementia. When someone is adapting to living with dementia, they might feel anxious, depressed or frustrated about not being able to do the things they used to. It may help to think about ways a person can still do things they enjoy, such as making cooking easier by buying pre-prepared or frozen vegetables.

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

*Everyone is unique, with their own likes, dislikes and personality – dementia does not take these away.*
Changes in behaviour

Having dementia can affect a person’s behaviour, and you may notice that somebody behaves differently as their condition progresses. For example, they may:

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

These behaviours may be distressing for the person with dementia, and you may find them challenging. Changes in behaviour are not just a symptom of dementia. Someone could behave in ways that are ‘out of character’ because they have a need that is not being met.

Everyone has different types of needs. People with dementia may be less able to recognise their needs, know how to meet them, or communicate them. They may be trying to communicate or meet one or more of these needs with their behaviour. Someone might behave in a way that is out of character for them because they are:

- in pain
- thirsty or hungry
- feeling threatened
- feeling distressed
- frustrated or under-stimulated.
It is not always easy to work out what somebody needs. Where possible, you should try to look beyond the words or behaviours you can see, to identify the feelings that the person might be trying to express. It is useful to look at the circumstances of the situation, to see if there is something else they may be reacting to such as the environment or a person. This can help you to look for causes of their behaviour, and identify what they may need. Meeting a person’s needs can make these behaviours easier to manage for both of you, or may prevent them from happening in the first place.

There are different ways to support the person with dementia to meet their needs or reduce behaviours that challenge, including:

- helping them to stay in touch with other people
- encouraging them to do things they enjoy or find useful
- making changes to their environment if necessary (for example, reducing noise and improving the lighting)
- keeping familiar, comforting or personal items close to them, such as a favourite jumper
- keeping their sleeping environment comfortable (for example, making sure it isn’t too hot or cold)
- 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, try asking them to tell you more about their children or how they are feeling.

Psychological therapies, such as cognitive stimulation therapy, can also be helpful. Talk to the person’s GP about accessing these.

For more information see factsheet 525, Changes in behaviour.
Supporting the person in their daily life

As a person’s dementia progresses their memory and thinking will become more affected. This means they will find it more difficult to do many practical things, especially as their symptoms get worse and new symptoms develop. 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 needing more support can be difficult and upsetting, and may cause some people 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.

This section will tell you more about these, and suggest ways to help with each of them.

Communication

People with dementia often experience difficulties communicating. Their symptoms may mean that they may have problems finding the right word or following a conversation. Other things that may make communication more difficult include pain, side effects of medication, and sensory impairments (such as sight and hearing loss).

Difficulties with communication may cause a person with dementia to lose confidence or withdraw from social situations – which can then make communication even harder. This can be frustrating, and can increase stress 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. Be aware that they may be trying to communicate how they’re feeling, and not just facts.

The person with dementia may communicate non-verbally (such as using gestures, facial expressions and movement) to express themselves or their needs. Non-verbal communication is also important to consider, as the expressions and gestures you use can affect how the other person thinks and feels.
There are things you can do in the way you communicate which can make it easier for the person with dementia. Some suggestions are listed below.

- Think about the environment and remove any unnecessary 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 simpler words and sentences. Be aware of your tone of voice.
- A person with dementia may use their behaviour and body language to communicate, such as gestures, eye contact and facial expressions.
- Try to maintain eye contact. This can help the person to focus on you.
- Try to avoid sudden movements and tense facial expressions, as these may cause upset or distress.
- Try not to stand too close to or over someone – it may seem intimidating.
- Try not to speak on behalf of a person with dementia, complete sentences for them, or allow others to exclude them. Always try to include them in conversations. If the person is having difficulty, give them plenty of time and remove any distractions like background noise.
- Look at their non-verbal communication – this may help you to work out what they are trying to communicate.
- Avoid asking too many direct questions. Consider giving a small number of options, or asking questions with a ‘yes’ or ‘no’ answer.

You may want to share these tips with other people.

For more information see factsheet 500, Communicating.
Independence

Feeling independent is an important part of wellbeing. This can become more difficult for someone with dementia as their condition progresses and they need more care and support.

Sometimes a person with dementia won’t want to ask for help, or will resist offers of support. This can be difficult for you, and could create conflict between you and the person. Remember that they may be finding it difficult to adjust to needing support. In some cases this will be because the person is unaware of their dementia and how it affects them (for more information see page 6). It might also be because they are struggling to accept that things have become difficult for them.

There are some things you can do to make it easier for someone with dementia to feel independent and adjust to receiving support. Some suggestions are listed below:

- 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 retain their existing skills.

- Involve the person with dementia in the support you offer as much as possible. This may mean doing things in the way they prefer – as long as it does not compromise their safety or wellbeing.

- Avoid assuming that the person isn’t able to understand what is happening, or isn’t able to contribute to a situation. It may just be taking them longer to work out what is happening.

- Think of ways you can adapt tasks to allow the person to continue doing them independently without worrying about failing – for example, pre-setting their favourite radio station so they can enjoy it without having to tune the radio themselves, or encouraging them to read magazines rather than books.
Confidence and self-esteem

Having high self-esteem can help a person with dementia to maintain a good quality of life, and 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.

Focus on the things that the person with dementia can still do, rather than things they can no longer do. This is important, because 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. Encouraging and praising them can boost their confidence and raise their self-esteem.

Negative reactions from others may also affect the self-esteem of a person with dementia. They may find that people do not treat them the same because of their diagnosis. This is often because other people do not understand what dementia is and how it 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 the condition.

Dementia can also have an indirect effect on a person’s self-esteem by affecting other areas of their life. These may include health issues, financial circumstances, employment status and, importantly, their relationships with those around them. These changes can cause some people to lose confidence as they are not able to manage these parts of their life without support.

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

- Offer them plenty of praise and encouragement – focus on positives and what they can do.
- Avoid harsh criticism or comments that belittle the person. Try to keep your tone of voice level, even if you feel frustrated or angry.
- Ensure they have enough time to do the activities they enjoy and that give them purpose. Try to resist always doing things for them.
- Adapt tasks so that the person with dementia finds them more manageable.
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- Try not to remind them of mistakes, and instead point out what they have done well.
- If they make a mistake, try to be as supportive as possible.
- Help the person to maintain existing social relationships and form new ones by doing things such as joint activities with friends and family, joining a group and encouraging conversation.

Some people find that attending groups, activities or classes boosts their confidence. There are activities and groups for people with dementia. These can be good opportunities for meeting new people, or forming new relationships, which can build confidence. You might find it helpful to encourage the person to take part in activities and groups.

Find out what groups or activities are available in your local area by visiting alzheimers.org.uk/dementiadirectory

Identity
A person’s sense of identity – who they think of themselves as – is shaped by many things. These include their relationships, roles in their family and community, hobbies and occupation.

A person with dementia may feel a change in their sense of identity as their condition progresses. They will experience changes in their abilities and may find familiar hobbies and activities more difficult. They may also have to give up activities that played a role in shaping who they are, for example their work or a role in the community.

The people around the person, and how they provide support, play an important role in supporting their sense of identity. Being aware of how dementia affects the person and the changes they are experiencing can help you provide support that maintains their sense of identity.

It can sometimes seem as though the person with dementia is not the same as they were before they developed the condition. Having dementia means a person has to do some things differently, but it does not change who they are. It is important to focus on and support all the things that make them a unique individual, including the things they enjoy doing.
Encourage them to keep doing these things, or to talk about their life history and interests to help bring out different parts of their personality. You and others around the person have an important role in supporting identity and sense of self in a person with dementia. Treat them as an individual and make clear to them that you value them.

If the person you’re supporting identifies as LGB or T (lesbian, gay, bisexual or transgender) they may face unique 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 with this, or that takes this into account.

For more information see factsheet 480, Supporting a lesbian, gay, bisexual or trans person with dementia.

Relationships

Having positive relationships with people is an important part of living well. It can build a person’s confidence and self-esteem and is often a central part of their 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 some people who do not understand what having dementia really means, and are unsure how to react to someone with the condition. You could show people this factsheet to help them to understand more about dementia – it might help them to understand the things they can do to help the person with dementia feel valued and included.

A good relationship between you and the person you’re 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.
Some treatments that help people to manage the symptoms of dementia can be good activities to do together. These include 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).

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 many positive things in your relationship are likely to remain even as the person’s abilities are affected.

You may also need to make other adjustments – for example, taking over certain household tasks the person is no longer able to manage (such as organising finances). 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 paying bills or picking up medication).

There are things it might be helpful to think about when you are finding it difficult to support somebody close to you. Some suggestions are listed below:

- Remember that the person’s symptoms are not within their control.
- Remember that they are still the person they always were, even if the things they are doing are out of character (for more information see ‘Identity’ on page 15).
- The person is likely to find everyday tasks more difficult as their dementia progresses, and they will need more support. There are ways to offer support to make this easier for you and them – see ‘Confidence and self-esteem’ on page 14.
- Think about doing activities together – whether they’re things you’ve enjoyed together in the past, or new activities.
- If you need a break, try to find opportunities to spend time apart, or consider other social support (for example, a carers’ support group or online community).
If your relationship was difficult before dementia

Not all relationships are easy. Your relationship with the person you’re 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, 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 is important to tell someone you trust as soon as possible.

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 look for support from a counsellor, or ask other family members or friends for support.

Continuing to take part in the same social groups, community activities, hobbies or religious activities can help a person with dementia maintain their existing relationships. It can also be a good way to help with their confidence. You can support a person with this, for example by encouraging them to go, or going along with them.

Someone with dementia can also form meaningful new relationships. Taking part in new groups or activities can provide opportunities to do this. 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 or local Alzheimer’s Society about what’s available in your area, or search online at alzheimers.org.uk/dementiadirectory
Decision making
People with dementia often become unable to make some decisions for themselves as their condition progresses. These may include choices about finances or whether to accept medical treatment. When this happens, the person is said to ‘lack mental capacity’ to make those decisions. There are some important things to bear in mind about mental capacity – listed below.

- A diagnosis of dementia does not automatically mean a person lacks capacity.
- It should always be assumed that a person has capacity unless it can be proven otherwise.
- Capacity can fluctuate on a long-term (day to day) or short-term (moment to moment) basis.
- Whether someone has capacity or not is specific to that particular time and decision.
- A person with dementia may have 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
- retain the information long enough to be able to make the decision
- weigh up the information available to make the decision
- communicate their decision by any means possible (for example talking, using sign language or through simple muscle movements such as blinking an eye or squeezing a 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.

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 needs to be made in the person’s best interests. The decision should always choose 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.

Looking after yourself if you are supporting someone

When someone close to you has dementia it can be hard for you as well as for 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.

Over time, you may offer a level of practical support to the person with dementia that means some people will consider you to be their ‘carer’. You may not identify with this term, but using it with some services, such as health and social care or local authorities, can help you to access the right support. For example, you may find information and advice for carers helpful. You are also entitled to a carers’ assessment. For more information on this see factsheets 418, Assessment for care and support in England, W418 Assessment for care and support in Wales or N418, Assessment for care and support in Northern Ireland.
You may find that you have to adapt to constantly changing situations as you cope with both the practical demands of caring and the emotional impact of someone close to you having dementia. You may also find that you take on new roles and responsibilities in the relationship.

It can be difficult to balance supporting the emotional needs of the person you are supporting with your own. You may benefit from support from professionals or from talking to people in a similar situation to your own. For more information on how to manage this, see factsheet 523, Carers – looking after yourself.

If you are supporting someone with dementia, having a healthy relationship with them can help you both to live well. To do this, it is important to look after your own wellbeing. If you find you are becoming overwhelmed you may want to consider replacement care (respite care) options. There are many different ways you can do this, and you may find that it means you are better able to support the person with dementia. For more information on replacement care see factsheet 426, Replacement care (respite care) in England, W462 Respite care in Wales or, NI462 Respite care in Northern Ireland.

It can help to talk to people with similar experiences to your own. Dementia Talking Point is Alzheimer’s Society’s online community for people living with dementia and for people supporting someone with dementia. To find out more, go to alzheimers.org.uk/talkingpoint
Other useful organisations

Carers Trust
0300 772 9600
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 expert advice, information and support to carers.

Dementia UK
0800 888 6678 (9am–9pm Monday–Friday,
9am–5pm Saturday and 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 Live Chat counselling.
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.

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This factsheet has also been reviewed by people affected by dementia.

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

People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need.

To make a single or monthly donation, please call us on 0330 333 0804 or go to alzheimers.org.uk/donate