

Understanding and supporting a person with dementia

Living with dementia can have a big emotional, social, psychological and practical impact on a person. Many people with dementia describe these impacts as a series of losses and adjusting to them is challenging. This factsheet aims to give people – and carers in particular – a better understanding of what it is like to have dementia. It looks at ways to support someone to live well with the condition, based on that understanding. It also looks at how supporting someone with dementia can affect carers.

The way a person with dementia feels and experiences life is down to more than just having the condition. There are many other factors aside from the symptoms of dementia that play a huge role in shaping someone's experience. These include the relationships the person has, their environment and the support they receive.

Personal relationships and someone's social environment are central to life, regardless of age or mental ability. People can recognise this by being as supportive as possible. Carers, friends and family, can help a person with dementia to feel valued and included. Support should be sensitive to the person as an individual, and focus on promoting their wellbeing and meeting their needs.

When supporting a person with dementia, it can be helpful for carers to have an understanding of the impact the condition has on that person. This includes understanding how the person might think and feel, as these things will affect how they behave. The person may be

experiencing a world that is very different to that of the people around them. It will help if the carer offers support while trying to see things from the perspective of the person with dementia, as far as possible.

Each person is unique, with their own life history, personality, likes and dislikes. It is very important to focus on what the person still does have, not on what they may have lost. It is also important to focus on what the person feels rather than what they remember.

However, dementia has many effects. Most people experience memory difficulties and problems with thinking. These in turn may lead to the loss of:

- self-esteem
- confidence
- independence and autonomy
- social roles and relationships
- the ability to carry out favourite activities or hobbies
- everyday skills of daily life (eg cooking, driving).

Despite all these things being lost, the person will still retain some of their abilities, and will still feel an emotional connection to people and their environment, even later on in the condition.

Practical impact of dementia

Having dementia makes it difficult for people to do many practical things. This will affect their day-to-day life and they may need to adapt how they do things. When supporting the person, there are approaches carers can take that can reduce the impact of these practical difficulties and help the person maintain a sense of normality for as long as possible. This will help the person to feel independent and maintain their self-esteem.

Communicating

People with dementia often experience difficulties communicating – for example, problems with finding the right word or following a conversation. Other factors that may affect communication include pain, other conditions, side effects of medication, and sensory impairments. Difficulties with communication may cause a person with dementia to lose confidence or withdraw from social situations. Families, friends and carers may find that these difficulties are frustrating and can increase stress.

Communicating with a person with dementia: tips for carers

- If the person finds verbal communication difficult, speak slightly more slowly and use simple words and sentences. Be more aware of the tone you adopt.
- A person with dementia may use their behaviour and body language to communicate, such as gestures, eye contact and facial expressions. Carers' non-verbal communication is also important, and the person with dementia can notice or pick up on expressions and gestures.
- Try to maintain eye contact. This will help the person 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 or stand over someone when communicating – it may make them feel intimidated.
- Make sure the person is included in conversations. Try not to speak on their behalf, complete sentences for them or allow others to exclude them.
- Listen to the person. Give them plenty of time, remove distractions like background noise and try to work out the meaning they are trying to convey. The message may be about feelings, not just facts.
- Avoid asking too many direct questions. Consider giving the person options or asking questions with a yes or no answer.

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

Independence

A person with dementia may gradually lose their independence and become more reliant on the care and support of others around them. This can be a hard change to make and can be distressing for everyone involved.

It is important that, where possible, families, friends and carers support the person to do things for themselves rather than 'taking over'. This increases the person's wellbeing and helps maintain their dignity, confidence and self-esteem, rather than making them feel helpless or worthless.

The person's attempts to keep their independence may cause conflict between them and others providing care and support. The person may resist help because they don't want to accept that things have become more difficult for them or don't want to ask for help. Carers and others should avoid assuming that the person isn't able to understand what is happening or contribute to a situation. It is important for the person to be involved as much as possible. This can mean enabling the person with dementia, within reason, to do things their way. However, carers will need to balance the independence of the person with dementia against any safety concerns and the desire to support the person to stay safe and well.

Supporting the person with dementia to remain independent: tips for carers

- Do things together – try to do things with the person rather than for them when offering assistance.
- Focus on things the person can do, rather than those they can't.
- Offer help in a supportive way.
- Try to be patient, allowing plenty of time for tasks and offering reassurance, praise and encouragement.

- Break down tasks into smaller, more manageable steps.
- Try to adapt tasks to take account of particular difficulties. If the person is happy, keep doing the things they enjoy – just differently. Focus more on the process rather than the completion of a task.

Decision-making

A person's ability to make decisions for themselves is called 'mental capacity' (often just 'capacity'). It means being able to weigh up different options, decide on one and communicate the decision. A person with dementia may eventually lose capacity to make certain decisions (eg choices about finances), but it should always be assumed that a person has capacity unless it can be shown otherwise.

People with dementia should be supported to make decisions for themselves for as long as they can. If someone else needs to make decisions for the person with dementia, these decisions need to be made in the person's best interests, taking the least restrictive option and based on the person's previously expressed wishes. For more information see factsheet 460, **Mental Capacity Act 2005**.

Psychological and emotional impact of dementia

The impact that dementia has on a person is not limited to the practical effects of the condition. The person still experiences feelings, thoughts and responses just as a person without dementia does. However, living with dementia will affect these. It is important to recognise and respond to the person's emotional needs and responses.

Reactions to diagnosis

A diagnosis of dementia can have a huge impact on a person's life. Someone recently diagnosed with dementia is likely to experience a range of emotions. These may include grief, loss, anger, shock, fear, disbelief and even relief.

Some people may struggle to deal with these emotions and they may move between emotions as they adjust. They may feel afraid about the future, scared about moments of confusion and forgetfulness, and upset about the impact dementia has on those around them.

The confirmation of a diagnosis may trigger depression and anxiety in some people. There are a number of talking therapies and – if needed – drug treatments available for depression and anxiety. Lifestyle changes can help too. For more information see factsheet 444, **Depression and anxiety.**

Those around the person will also have their own emotional reactions to cope with. It is important that both the person with dementia and the people around them feel able to, and are encouraged to, express their feelings.

Some people experience positive reactions when they receive a diagnosis of dementia. They may be relieved to know what is wrong or be glad to be able to plan ahead. Some may use the experience to re-evaluate their situation and focus on the activities and relationships that make them happy.

Supporting the person's emotional responses: tips for carers

- Try to understand how the person with dementia feels.
- Do not dismiss a person's worries – listen and show them that you are there for them.
- Try to enjoy the moment and try not to spend too much time thinking about what the future may or may not hold.
- A sense of humour may help, if the time feels right.

Emotions and feelings

People with dementia often experience changes in their emotional responses. They may have less control over their feelings and how they express them. For example, someone may be irritable, or prone to rapid mood changes or overreacting to things. They may also appear unusually uninterested in things or distant.

These changes are often difficult for carers to deal with. It can help if carers remember that they are partly caused by damage to the person's brain. Someone may react more emotionally to a situation than might be expected (eg by becoming tearful or agitated) because some of their factual memories or ability to think clearly about the situation have declined. It is important to look beyond the words or behaviours you can see to the feelings that the person might be trying to express. Strong emotions may also be caused by unmet needs. Carers should try to work out what these needs are and meet them where possible.

Confidence and self-esteem

Dementia may cause people to feel insecure and lose confidence in themselves and their abilities. They may feel they are no longer in control and may not trust their own judgment. They may also experience the effects of stigma and social 'demotion' – not being treated the same way by people – as a result of their diagnosis. All of this can have a negative impact on the person's self-esteem.

Dementia may also have an indirect effect on someone's self-esteem by affecting other areas of a person's life. Health issues, financial circumstances, employment status and, importantly, relationships with those around them may suffer.

Some people, however, form new relationships as a result of their diagnosis, through activities such as attending a class or a support group. High self-esteem allows some people to cope better with chronic health conditions.

Supporting the person with dementia to maintain self-esteem: tips for carers

- Offer the person plenty of praise and encouragement – celebrate successes and focus on positives.
- Avoid harsh criticism or belittling comments.

- Ensure people have time to do the activities they enjoy and that give them purpose.
- If a person makes a mistake, try to be as supportive as possible.
- Help people to maintain existing social relationships and form new ones. This can be done by facilitating joint activities with friends and family, joining hobby groups and encouraging conversation.

Coping with dementia

As the condition progresses, each person will find their own way of coping with, and reacting and adapting to, the changes that dementia brings. Developing these coping strategies can be a gradual and subconscious process.

Coping strategies may include:

- practical strategies – eg setting up reminders or prompts, preparing advance decisions or a Lasting Power of Attorney for the future
- social strategies – eg relying on family help, seeking spiritual support, joining new activity groups
- emotional strategies – eg using humour, focusing on short-term pleasure or living for the moment, focusing on positive aspects
- health improvement strategies – eg exercising more, adopting a healthier diet, cutting down on alcohol or smoking.

If a carer understands the person's coping strategies, they will be able to support them better.

Responses to dementia

The way a person reacts to dementia, and the ways they adapt and cope with the condition, will be influenced by a range of factors. These include their personality, their previous experiences, their understanding of dementia, the social and emotional support they receive, and their environment. People will react differently and may adopt different strategies at different times.

Some people may not acknowledge that they have dementia or deny that they are experiencing difficulties. Others may be aware that things are becoming harder but feel that it is a normal part of aging rather than part of dementia. It is important to understand that these responses may be a person's way of making time and space to accept a diagnosis of dementia.

As dementia progresses, people may become less aware of the condition and its effects on their abilities. This is more likely in the later stages of the disease, but it can develop earlier on in people with certain types of dementia (eg frontotemporal dementia). It is important for carers and others to understand that people who lack this awareness will not realise their abilities or behaviour has changed.

Identity

A person's sense of identity – who they think of themselves as – is shaped by many things, including their relationships, roles in the family and community, hobbies and occupation. For example, a person may identify themselves as a keen gardener.

Changes in people's abilities caused by dementia, however, may lead to changes in their sense of identity. It is important that the people around the person with dementia are aware of this as they are able to influence how the person sees themselves. They should try to treat the person with dementia as an individual, and value them as such, rather than defining them by the condition or focusing on negative aspects such as lost abilities.

Changes in behaviour

People with dementia often behave differently as their condition progresses. They may start to behave in ways that are challenging and distressing, both for themselves and those around them. For example, a person with dementia may:

- become restless or agitated
- shout out or scream

- become suspicious of others
- follow someone around
- ask the same question repeatedly.

Rather than just being a symptom of the dementia, these out-of-character behaviours can occur because the person has a need that isn't being met or they can't communicate. The behaviour will have meaning to the person. They might be in pain, be thirsty or hungry; maybe they misunderstood something or someone and feel threatened; or perhaps they are frustrated or under-stimulated.

It is important to look at why the person is behaving this way and try to identify which needs are not being met. This will mean trying to see things from their perspective as much as possible. Meeting a person's needs appropriately can make these behaviours easier to cope with, or prevent them from happening in the first place. For more information see factsheet 525, **Changes in behaviour**.

Relationships, roles and responsibilities

Our relationships with the people around us form a central part of our identity. Relationships often change when someone has dementia. People with dementia can easily become isolated or avoided by those around them. They may lose contact with friends and family, who may fear not knowing how to react to them.

Carers can help by supporting existing relationships and encouraging continued participation in social groups, community activities, religious activities and hobbies. Dementia cafés provide an opportunity to meet other people, talk about living with dementia and participate in group activities in an informal social environment. The GP surgery, local library or council office will also have information about other social groups.

Carers and others can also help in creating a dementia-friendly community. This is a community in which local people have an understanding of dementia. It is geared towards empowering people

with dementia to feel confident, knowing that they can contribute to their community and participate in activities that are meaningful to them. Carers can do this by involving people with dementia in their own social groups, informing others (eg shopkeepers, local business and neighbours) about the nature of dementia, and challenging mistaken ideas or fear of dementia if, or when, it occurs.

Dementia may also change the relationships between the person and those closest to them, who may find they have taken on the identity of a 'carer'. A carer may find they have an increasing number of roles in the relationship. While taking on more responsibility may be necessary, it is important that the person with dementia continues to feel involved with, and able to contribute to, the relationship.

As the dementia progresses, some aspects of the relationship may become harder, such as the ability of a person with dementia to support those around them. However, many positive elements from the relationship (eg mutual affection) will remain. Carers and those around the person with dementia may find it helpful to focus on these positive aspects.

A healthy relationship between the person with dementia and the carer can be an important factor in making sure the person has a good quality of life. Finding ways to maintain the relationship – for example, things such as accessing replacement/respite care that reduce the stress that carers experience – may help. It is important for a carer to balance their own wellbeing with that of the person with dementia. A person with dementia may feel confused, anxious or isolated if their usual carer is temporarily replaced by respite care, but it is equally important for carers to have time to rest and recuperate.

Maintaining a positive relationship with the person with dementia: tips for carers

- Try to focus on the relationship as it is now rather than thinking of how it used to be.

- Consider ways to support the relationship, such as life story work, reminiscence, creative activities (including art and music) and shared hobbies.
- If there are long-standing difficulties in the relationship, try to find opportunities to spend time apart, or consider other social support (eg a carers' support group or online forum). You could also consider counselling and relationship support.
- Don't be afraid to talk to people about the changes in the relationship – this could be a friend, family member or professional (eg counsellor).

Carers: looking after yourself

As well as the impact on the person, dementia also has a considerable effect on those supporting the person. Family members and friends have to come to terms with the effects dementia has on them and their sense of who they are. They may change from being a partner, friend or child to becoming defined as a carer. This is often a role that is taken on without a conscious decision being made and many people may not identify themselves as a carer.

Carers of people with dementia often find themselves adapting to constantly changing situations, and they need to cope with both the practical demands of caring and the emotional impact of the person's dementia. The carer may have to take on more roles and responsibilities. As dementia progresses, there may be fewer opportunities to share meaningful activities with the person with dementia, or a need to do these differently.

Carers often have to balance supporting the person's emotional needs with their own. This can be very difficult as they are likely to see the situation from different perspectives. They may also benefit from support from professionals and other carers. For more information on carers looking after themselves see factsheet 523, **Carers: looking after yourself**.

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This factsheet has also been reviewed by people affected by dementia. A list of sources is available on request.



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