

The emotional impact of a diagnosis of dementia



When someone is diagnosed with dementia, it is natural for both you and the person to go through a range of emotions, including feelings of shock, distress and hopelessness. Understanding why you are having these feelings, and how to manage them, can help you both to come to terms with the diagnosis and face the future with more confidence.

What emotions might you feel?

Every person affected by dementia will have a different emotional response to the diagnosis. However, some of the emotions you might feel include:

- shock, particularly if the diagnosis was unexpected
- disbelief – especially in the case of young onset dementia (where symptoms develop before the age of 65)
- relief – for example if you now have an explanation for worrying symptoms
- stress/anxiety
- feelings of being overwhelmed
- helplessness/hopelessness
- fear about what the future holds
- a sense of isolation or loneliness
- grief/loss
- low mood/depression
- resentment, for example if the diagnosis is having an impact on your work, family life and other activities



Your emotions may change from day to day – or even hour to hour. At times, you may feel you are managing well; at others, you may feel that you cannot cope. What matters is that you understand that these feelings are normal and know where to find support.

Emotions in the person with dementia

How a person responds to a diagnosis of dementia can depend on many factors, including:

- their age – it can come as a bigger shock for younger people, who may be less prepared for a dementia diagnosis
- the strength of their family network and other relationships
- how effectively their family communicates
- their beliefs and fears about what will happen as dementia progresses

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- their ability to accept the changes dementia can bring, and to adapt their life to cope with them
- their usual coping strategies for managing problems and distress
- the impact on their lifestyle, eg employment, hobbies, socialising, looking after children
- any spiritual or cultural beliefs
- stigma around a dementia diagnosis
- cognitive changes (changes taking place in the brain) that affect how the person understands and processes information
- personality and behaviour changes caused by dementia

Some people with dementia experience significant anxiety and/or depression. This is more common in people with certain types of dementia that affect the emotions, such as frontotemporal dementia. You may notice signs such as:

- low mood
- withdrawing from other people
- loss of interest in their normal activities
- difficulties at work
- tearfulness
- irritability
- difficulties with attention and concentration
- agitation
- sleep problems
- needing constant reassurance



Please see Sources of support on p16 for more information on anxiety and depression in people with dementia.

If the person with dementia is struggling to cope with the emotional impact of their diagnosis, it is important that they have support. The type of support will depend on factors like their stage of dementia, their ability to communicate, and their willingness to accept support.

Family and friends can often provide a great deal of comfort and reassurance, but you may wish to speak to their GP or dementia specialist about other support they can access, for example from a Community Mental Health Team. Support groups can also be helpful, giving them a space to share experiences and form important social connections.

Some people with dementia experience thoughts of suicide or self-harm. This may be related to changes in personality and behaviour, or to difficulties in accepting their diagnosis. If the person is expressing or showing signs of these feelings, contact their GP straight away. If you believe they are in immediate danger, go to A&E.

The emotional impact on family and friends

The family and friends of a person with dementia will also be affected by their diagnosis. They may feel a degree of relief, as they now understand what is happening to the person. But they may also experience sadness, grief, anger, depression and fear. It is natural to go through a range of emotions, both positive and negative.

Some people are shocked when someone close to them is diagnosed with dementia and have difficulty accepting it. This can be particularly true if the person is younger. A diagnosis of young onset dementia can be especially challenging for family and friends and cause additional worries, such as whether the person will be able to continue to work, how it will affect the family's finances, or the impact on their children or teenagers.

The diagnosis may also come as a shock if the person's symptoms do not seem 'typical' of dementia. Many people assume that memory problems are the main symptom of dementia. But while that is the case for some people (particularly those with Alzheimer's disease), there may be other less recognised symptoms such as:

- difficulties with language and communication
- changes in personality
- difficulties with problem-solving and decision-making
- hallucinations or delusions



These different symptoms are particularly common in people with young onset dementia, and in those who have a rarer type of dementia (which are more common in younger people, although they can occur in older people too).

Guilt is a very common emotion when someone close to you is diagnosed with dementia, and this often becomes more intense as their condition progresses. For example, you might resent the impact your caring responsibilities are having on your work or family life, and then feel guilty about feeling this way. Or you might feel guilty if you are struggling to cope with caring and are considering getting extra support. Please see Sources of support on p16 for our leaflet on guilt.

Feelings of grief and loss are also common. Changes in personality and behaviour in the person with dementia may trigger a sense of grief for the person they were before their diagnosis, or you may feel

a sense of loss of the future you imagined together. This is known as ‘anticipatory grief’.

The person’s loss of memory may also trigger grief as they may forget people who they are close to and the experiences they have had together. If they are aware that this is happening, it could be very upsetting for them, and for their family and friends. It could also be confusing for young children who may not understand why the person does not remember them. Please see Sources of support on p17 for more information on grief and loss.

Family and friends may try to hide their emotions to avoid upsetting the person with dementia. This can lead to difficulties in communicating with each other and may cause disagreements about coping with the person’s symptoms or making decisions in their best interests.

It is important to have support when someone close to you is diagnosed with dementia, and as their condition progresses. This could be informal support from other family members or friends, talking therapies like counselling, and/or joining a support group where you can share experiences. If you work, you may be able to access support through your employer, such as through an employee assistance programme (EAP) or carers’ network.

It is especially important to seek support from your GP if you are having persistent symptoms of depression or anxiety as these can often be managed through medication and/or therapy.

Children and young people

Explaining a diagnosis of dementia to children or young people can be very difficult, especially if their own parent, rather than a grandparent or other older relative, has been diagnosed. They may experience a range of reactions, thoughts and feelings, including:

- sadness
- fear and anxiety about what will happen in the future
- irritation or boredom if the person repeats stories and questions, and perhaps guilt for feeling this way
- embarrassment about being seen with the person, especially if they behave in unusual ways
- confusion about ‘role reversal’ where they feel they are caring for their parent, grandparent or other relative, rather than being cared for
- a sense of loss or grief
- anger and resentment, especially if the person’s dementia affects their ability to invite friends over, go on holiday, etc
- a sense of rejection if the person with dementia seems less interested in their life, or if the caring responsibilities of other adults mean they have less time together

It is a good idea to inform your child’s school or college that someone close to them has been diagnosed with dementia. This will enable them to look out for changes in behaviour that may suggest they need extra support, put that support in place, and be flexible if the child needs time off school.

You may also wish to speak to your GP about support for your child or teenager, such as specialist support services for young carers, or do some research into local or online support groups.

We have resources for parents and children on our website: please see Sources of support on p17 for details.

Talking about the future

At some stage, many people with dementia and their family and friends come to accept the diagnosis and start to make decisions and plans for the future. This can give the person with dementia the chance to communicate their choices and wishes; and avoid misunderstandings and tension between family members later on. It can also provide reassurance that there is a plan in place for when things become more difficult.

Not all family members feel able to take part in these discussions and decisions. Even within close families, there can be disagreements about what is best for the person living with dementia, and this can lead to communication and relationship issues.

It is always best to try to keep conversations open and honest, and to make the person with dementia central to everything you discuss. If tempers start to fray, you may wish to pause the conversation and return to it another day. It may be helpful to involve a more neutral family member or friend. You may also wish to seek advice from a health or social care professional.

For support, you can speak to a dementia specialist Admiral Nurse on our free Helpline or book a virtual clinic appointment – see p16 for details.

Maintaining independence

When someone is diagnosed with dementia, family and friends may become overprotective or focus on what the person can no longer do, rather than on what they can do. This can affect the person's self-esteem and confidence, and cause frustration and resentment.

It is important to concentrate on the person's strengths and what they can still do. Supporting them to continue with things that give them enjoyment and purpose – such as work, hobbies, travel and



socialising – can maintain their self-esteem, independence and quality of life; and keep relationships positive.

Social connections

Some people feel embarrassed or ashamed about their dementia diagnosis and may withdraw from social contact. Similarly, some family members may feel shame or embarrassment, particularly if the person's social behaviour changes in conspicuous ways, or if they begin to physically neglect themselves. However, withdrawing socially can lead to feelings of isolation and hopelessness, which can have a negative impact on the self-esteem and mental wellbeing of both the person with dementia and their family.

Sharing the news of the diagnosis with family, friends and colleagues can allow them to support you, help you maintain meaningful relationships, and have a positive effect on your emotions and your ability to cope.

Understanding one another

People with dementia may have difficulty controlling their emotions due to the physical changes happening in their brain, or experience feelings of anxiety and depression resulting from their diagnosis. They may also have difficulty processing information: they may struggle to understand other people's emotions or misinterpret their words or actions, leading to tension and distress.

Understanding that these changes are caused by the person's dementia may help you all relate to one another with compassion and tolerance. For example, when the person shows signs of distress, think to yourself:

- Why are they responding this way?
- What might they be feeling?
- What can I do to help them with their feelings?

Practical advice for coping with your emotions

There are some practical things you can do to provide emotional support to the person with dementia and cope with your own emotions.

- Join a social or peer support group, either in person or online, to meet other people in a similar situation and share advice and support
- Find out about any companionship, befriending or respite schemes in your area for yourself and the person with dementia
- Educate yourself about dementia so you understand the changes in the person with the diagnosis. Please see Sources of support on p16 for our information resources, or ask your GP or other health or social care professional if there are courses or training that you could attend



- Share the diagnosis with family, friends and colleagues. Telling people what is happening will enable them to provide understanding and support
- Do not be afraid to talk to trusted family or friends about your thoughts and feelings
- If you are struggling to cope with your emotions, consider asking your GP about counselling – you can also refer yourself for talking therapy although there may be a long wait (please see Sources of support on p18 for details)

- Investigate local services that can support you and the person with dementia with emotional, practical and social needs. Social Services, your local council website or your GP are good places to start
- Aim to develop coping strategies to live as well as possible with dementia. Consider issues as they arise and look for solutions
- Have a family discussion about future plans, including applying for lasting power of attorney and making an advance care plan – this can make you feel more prepared and give you peace of mind that you are prioritising the person's wishes (see Sources of support on p16-17 for information)

Our specialist dementia nurses can provide practical advice and support with any aspect of dementia – please see Sources of support on p16 for contact details.

Finding hope and purpose

Coping with dementia can be difficult, but despite the many emotions that a diagnosis can trigger, it often progresses slowly, and the person may be able to live an independent and active life for a number of years. Even in the later stages, there are ways for you and the person with dementia to find purpose and enjoyment in life.

Here are some ideas to try:

- Make time for activities that bring you and the person with dementia peace and joy, such as listening to favourite music, taking care of a pet, reading, craft or going for walks
- Encourage everyone involved in the person's life to support them with activities that improve their wellbeing and self-esteem



- Try to avoid negative comments or correcting the person if they get something wrong or muddled up
- Take it day by day. Rather than looking too far into the future, focus on setting achievable daily goals, such as, “Today I’ll phone my friend”; “Today we’ll walk to the shop”; or “Today we’ll have pancakes for breakfast”
- Stay active and involved in your hobbies and social networks
- Think about new opportunities and interests – this could be a chance to try a skill you have always wanted to do, take some time out to travel, or meet new people through support groups or other activities

Sources of support

If you are caring for someone with dementia or living with the condition yourself, you can register for our free online sessions, ‘Dementia: what next?’ at dementiauk.org/dementia-what-next

To speak to an Admiral Nurse on our free Helpline, call **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email helpline@dementiauk.org

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit dementiauk.org/book

Dementia UK resources

Anxiety and depression in dementia

dementiauk.org/-managing-anxiety

Advance care plans

dementiauk.org/advance-care-planning

Books about dementia for children

dementiauk.org/books-about-dementia-for-children

Changing relationships and roles

dementiauk.org/changing-relationships-and-roles

Coping with feelings of guilt

dementiauk.org/coping-with-feelings-of-guilt

Dealing with stigma

dementiauk.org/dealing-with-stigma

Grief, bereavement and loss

dementiauk.org/bereavement



Lasting power of attorney

➤ dementiauk.org/lasting-power

‘Let’s talk about dementia’ animation for children and young people

➤ youtu.be/IjdLf7gQWJs

Looking after yourself as a carer

➤ dementiauk.org/looking-after-yourself-when-you-care

Supporting children and adolescents when a parent has young onset dementia

➤ dementiauk.org/supporting-children

Talking about dementia with children and adolescents

➤ dementiauk.org/how-to-talk-about-dementia-with-children-and-adolescents

Tips for better communication

➤ dementiauk.org/tips-for-communication

Young onset dementia support groups and services

➤ dementiauk.org/find-support

Other resources

Carers Trust

➤ carers.org

DEEP – the UK Network of Dementia Voices

➤ dementiavoices.org.uk

Mind – the mental health charity

➤ mind.org.uk

NHS talking therapies self-referral

➤ nhs.uk/service-search/mental-health/find-an-NHS-talking-therapies-service

Relate relationship counselling

➤ relate.org.uk

Samaritans

Tel: 116 123 (24-hour helpline)

➤ samaritans.org

tide: together in dementia every day

Support and training for dementia carers

➤ tide.uk.net

Young Dementia Network

An online community of people living with young onset dementia, their family and friends, and health and social care professionals – hosted by Dementia UK

➤ youngdementianetwork.org



**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:
0800 888 6678 or helpline@dementiauk.org

Book a virtual appointment:
dementiauk.org/book

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit **dementiauk.org/donate**
- Scan the QR code

Thank you.



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