

The emotional impact of a dementia diagnosis



When someone is diagnosed with dementia, it is natural to go through a range of emotions, including feelings of shock, distress and hopelessness.

Understanding why you and the person with dementia are having these feelings and how to manage them can help you 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 comes as a surprise
- disbelief – especially in the case of young onset dementia (where symptoms develop before the age of 65)
- relief – for example, if you have been worried about symptoms and now have an explanation for them
- 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

Your emotions may change from day to day – or even hour by hour. Sometimes you may feel you are managing well; others, you may feel that you cannot cope.

What matters is that you understand that these feelings are normal and can find support at this difficult time.

Emotions in the person with dementia

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

- their age
- 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

- 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 (ie

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 may experience significant anxiety and/or depression. 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, and needing constant reassurance.

Please see Sources of support on p10 for our information on anxiety and depression in dementia.

The emotional impact on family and friends

The family and friends of a person with dementia will also be affected by their diagnosis. Some may feel a degree of relief, as they now understand what is happening to the person. But it is natural to experience a range of upsetting emotions, too.

Friends and family may try to hide these emotions for fear of 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.

Some families are shocked by the diagnosis and have difficulty accepting it. This can be particularly true if the person is younger, or if their symptoms do not match up with their perceptions 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, and hallucinations or delusions.

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.

Children and teenagers

Explaining a diagnosis of dementia to children or teenagers 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 a person with dementia
- confusion about 'role reversal'
- a sense of loss or grief
- anger
- rejection

You may wish to speak to your GP about support for your child or teenager, such as specialist support services for young carers, or look into local or online support groups. There are many good books about dementia for children of all ages, and we also have resources for parents and children on our website: please see Sources of support on p11 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 be reassuring for everyone involved and give the person with dementia the chance to communicate their choices and wishes.

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 also be helpful to involve a more neutral family member or friend, or ask for 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 clinics appointment – see p10 for details.

Maintaining independence

Once 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.

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 build their self-esteem, help them maintain their independence, 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 to feelings of anxiety and depression resulting from their diagnosis.

Dementia can also cause difficulties processing information. The person may struggle to make sense of 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. You can find lots of information at dementiauk.org/get-support 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 going on allows them to offer understanding and support
- Don't be afraid to talk to trusted family or friends about your thoughts and feelings. Isolating yourself and bottling things up always make things worse
- If you are struggling to cope with your emotions, consider asking your GP about counselling – you can also refer yourself for talking therapy at nhs.uk/service-search/mental-health/find-a-psychological-therapies-service although there may be a long wait
- 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 the diagnosis. Consider issues as they arise and look for solutions. Our specialist dementia nurses can provide practical advice and support with any aspect of dementia – please see Sources of support on p10 for contact details
- Plan ahead: having a family discussion about future plans, including applying for lasting power of attorney and making an Advance Care Plan, can give you all the peace of mind that you are prioritising the person’s wishes (see Sources of support on p10 for information)

Finding hope and purpose

Coping with dementia can be difficult, but if you and the person with the diagnosis can find purpose and enjoyment in life, you will both be better equipped to cope with challenging times. 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’ve always wanted to do, take some time out to travel, or meet new people through support groups or other activities

Sources of support

To speak to a dementia specialist Admiral Nurse about the emotional impact of a dementia diagnosis or anything else related to dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit dementiauk.org/closer-to-home

Dementia UK resources

Managing anxiety and depression in dementia
dementiauk.org/managing-anxiety

Lasting power of attorney
dementiauk.org/lasting-power

Advance Care Plans

dementiauk.org/advance-care-planning

Changing roles and relationships

dementiauk.org/changing-roles-and-relationships





Dealing with stigma
dementiauk.org/dealing-with-stigma

Tips for better communication
dementiauk.org/tips-for-better-communication

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

Grief, bereavement and loss
dementiauk.org/bereavement

Looking after yourself as a carer
dementiauk.org/looking-after-yourself-when-you-care

Resources for parents
dementiauk.org/parents

Information for young people
dementiauk.org/young-people

Other resources

Young Dementia Network
youngdementianetwork.org

Relate relationship counselling
relate.org.uk

Mind – the mental health charity
mind.org.uk

Samaritans
Tel: 116 123 (24-hour helpline)
samaritans.org

DEEP – the UK Network of Dementia Voices
dementiavoices.org.uk

Carers Trust
carers.org

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

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For more information on how to support Dementia UK, please visit dementiauk.org/donate or call **0300 365 5500**.
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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email helpline@dementiauk.org

Open Monday-Friday, 9am-9pm
Saturday and Sunday, 9am-5pm



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