

# Understanding denial and lack of insight



### What is denial?

Denial is very common in people who are showing early signs and symptoms of dementia, and in their family and friends. They will be worried about what is happening and how it will change their life, and may try to find another explanation for the changes they are experiencing, such as normal ageing, tiredness, health problems, relationship issues and work stress.

It is also common for people who have recently been diagnosed with dementia and their families to be in denial – for example, they may believe that they have been misdiagnosed, or in the case of younger people, that they are too young to have dementia.

Denial can be defined as a refusal to acknowledge and accept something unpleasant or the reality of a situation, even when it is obvious to other people. It is a defence mechanism that helps people manage their fear and anxiety around these difficult situations, such as the possibility of dementia.

Over time, the person with signs of dementia and their family will likely begin to recognise that the changes they are observing are progressing. They will realise – or be persuaded – that their symptoms need investigating by a healthcare professional.

If a person has recently been diagnosed with dementia and they and/or their family are reluctant to accept this, it is likely that in time, they will move through their denial and recognise the need for support.

### Why does denial occur?

Dementia is the most feared health condition for people over the age of 40. Reasons for this include:

- worries over losing control and independence



- fear of what will happen in the future
- knowing that there is currently no cure
- lack of understanding of dementia
- experience of seeing other people with dementia
- stigma and discrimination
- the media's portrayal of dementia

Fears about being diagnosed with dementia may lead to the person denying that they have a problem and refusing to seek medical advice.

The person's family and friends may avoid mentioning the changes they have noticed to avoid upsetting them. They may be worried that their relationship may be affected if they raise their concerns.

In addition, it is easy to attribute the early signs and symptoms of dementia to other causes, for example concentration issues to stress

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or lack of sleep; difficulty remembering where things are to other people moving things; or memory lapses to advancing age.

Denial can be a particular issue if the person is younger, as many people wrongly assume that dementia is a condition of old age. The person and their family may put the changes down to reasons such as menopause, work stress or the pressures of family life.

Denial can also be a bigger problem if someone is experiencing a rarer form of dementia – which tends to be more common in younger people – where memory loss may not be one of the early symptoms.

### What is lack of insight?

Lack of insight is when someone lacks awareness of their own dementia signs and symptoms, such as changes in behaviour and difficulty regulating their emotions. It generally gets worse over time.

Unlike denial, lack of insight will only occur in the person with dementia symptoms, rather than in their family and friends. This can cause frustration and distress for those around them – for example, if the person is reluctant to seek a diagnosis or accept support.

### Why does lack of insight occur?

In some forms of dementia, the frontal lobe of the brain (the area immediately behind the forehead) can be affected. This area controls insight as well as other abilities such as judgement; decision-making; sequencing and planning; and memory and concentration.

People who have frontal lobe damage – for example frontotemporal dementia – often lack insight into the changes in their mood, behaviour and social functioning. This can cause difficulties in their family life, relationships and employment.

Please see **Sources of support on p10** for our information on frontotemporal dementia.

### The impact of denial and lack of insight

If a person with signs and symptoms of dementia and their family are in denial about what is happening, it can lead to:

- a delay in getting an assessment to rule out other potentially treatable conditions
- a delay in getting advice and support, including medication to slow the progression of certain types of dementia, help with daily living and accessing benefits
- mental ill health (eg depression and anxiety) due to worrying about what is happening
- relationship changes: the person and their family may find it difficult to talk about their concerns or have differing viewpoints on what is happening and what to do
- distress for children who may think they are to blame for the changes in their parent or other relative's behaviour
- avoidance of social situations, resulting in loneliness and isolation
- the person continuing to drive when it is unsafe for them to do so
- problems at work – such as making mistakes or failing to complete tasks – which may be put down to carelessness or laziness
- the person being taken in by scams and fraudulent activity, which may be avoided if they have the right support

If the person is reluctant to request or accept assessment or support, it may affect their health – for example, if they refuse help from professionals, family and friends, it may increase the risk of falls, accidents in the home, nutritional problems and mistakes with taking medication.

When someone has dementia, it is important to plan ahead – for example, by making decisions about their future health and social care. This can be difficult if the person or their family are in denial about what is happening.

This can lead to a delay in making financial and legal arrangements such as applying for lasting power of attorney and writing a Will, and may mean that the person loses capacity to share their views and give their informed consent around future plans.

In some cases, denial and lack of insight can cause a high level of distress and heightened emotions in the family, which could lead to verbally or physically aggressive or abusive behaviour – for example if the person with confirmed or suspected dementia will not accept support from family members and reacts negatively when it is offered.

### **Tips for coping with denial**

Often, with time and space, people who are in denial will come to accept their dementia symptoms or diagnosis. Give the person time to speak about their fears and worries, listen to what they are saying and respond accordingly.

If the person is reluctant to see their GP, explain the benefits of doing so: for example, you could say that their symptoms may be due to another condition that could be treated; or that if it is dementia, getting support in place as soon as possible could help them maintain their independence and quality of life.

If the person is still unwilling to seek advice, you could contact their GP explaining your concerns, eg what is happening, for how long, and how it affects the person and those around them. They will not be able to breach the person's confidentiality by discussing their medical care with you, but they may call them in for a health check.

You could also ask another family member or friend to speak to the person – sometimes, people are more willing to accept advice from someone who is slightly detached from the situation.

Spend some time thinking about the issues that the person is concerned about, and the possible solutions to these – if they can see ways around the problems that they may encounter, they may be able to work through their denial.

For example, if they are worried that a dementia diagnosis will mean they have to stop driving, you can explain that many people with dementia can continue to drive for some time. Or if they are worried that they will have to give up work, you could come up with a list of adaptations that their employer could put in place so they can keep working and are legally protected from discrimination at work.

Please see **Sources of support on p10** for our information on driving and employment for people with dementia.

You can also develop a long-term plan together – but while it is important to think about issues like applying for lasting power of attorney, make sure you also focus on what the person can still do, and may be able to do for some time, rather than on what they cannot do now or may not be able to do in the future.

### Denial in family members

If family members are in denial about the person's dementia symptoms or diagnosis, take the time to explain what you are concerned about. You could keep a diary of symptoms to show them, or give them our information on signs and types of dementia (please see **Sources of support on p11**).

If a child or teenager is struggling to accept a dementia diagnosis in a family member, ensure you explain the changes in age-appropriate

language and give them time to talk – there are lots of books for children of different ages to help them understand dementia. Please see **Sources of support on p10-11**.

If you are finding it hard to accept a dementia diagnosis in a loved one, support is available. You can speak to your GP, look for online or local carers' groups, or contact our dementia specialist Admiral Nurses – please see **Sources of support on p10** for details.

### Tips for coping with lack of insight

People who have damage to the frontal lobe of the brain may not accept that they are experiencing the changes other people are describing. They are less likely to attend the GP voluntarily or agree to an assessment, as they do not believe anything is wrong.

It can be very difficult for families to cope with a lack of insight in the person with possible or confirmed dementia, but there are some ways this can be managed:

- Avoid arguments and confrontation – remember that the person's lack of insight is due to physical changes in the brain and not intentional
- If the person is reluctant to attend the GP for a dementia assessment, encourage them to get a general health check and send a brief note to the GP indicating your concerns to aid in their assessment
- Try to find out how the person is feeling and what they are concerned about and give time for them to respond as they may then find it easier to identify some of the issues they are facing
- Provide non-critical feedback, information and support when an issue occurs





- Try to focus on the person's strengths and what they can still do – they can still have a good quality of life and take part in activities they enjoy
- Be aware that the person's decision-making and judgement may also be affected, and this may lead to impulsive behaviour
- Seek professional support and advice about how to manage lack of insight – your GP may be able to recommend support groups or dementia training, or you can contact our Admiral Nurses (**see Sources of support on p10**)

## Sources of support

To speak to a dementia specialist Admiral Nurse about denial, lack of insight or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am–9pm, Saturday and Sunday 9am–5pm) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

To book a phone or video call appointment with an Admiral Nurse, please visit [▶ dementiauk.org/book](https://dementiauk.org/book)

### Dementia UK resources

#### Books about dementia for children

[▶ dementiauk.org/books-about-dementia-for-children](https://dementiauk.org/books-about-dementia-for-children)

#### Different symptoms of young onset dementia

[▶ dementiauk.org/young-onset-dementia-different-symptoms](https://dementiauk.org/young-onset-dementia-different-symptoms)

#### Driving and dementia

[▶ dementiauk.org/driving](https://dementiauk.org/driving)

#### Employment and young onset dementia

[▶ dementiauk.org/employment](https://dementiauk.org/employment)

#### Frontotemporal dementia

[▶ dementiauk.org/frontotemporal-dementia](https://dementiauk.org/frontotemporal-dementia)

#### Getting a diagnosis of dementia

[▶ dementiauk.org/how-to-get-a-diagnosis-of-dementia](https://dementiauk.org/how-to-get-a-diagnosis-of-dementia)

#### Lasting power of attorney

[▶ dementiauk.org/lasting-power-of-attorney](https://dementiauk.org/lasting-power-of-attorney)

### **Stigma and discrimination**

➤ [dementiauk.org/dealing-with-stigma](https://dementiauk.org/dealing-with-stigma)

### **Supporting children and adolescents when a parent has young onset dementia**

➤ [dementiauk.org/supporting-children-and-adolescents-when-a-parent-has-young-onset-dementia](https://dementiauk.org/supporting-children-and-adolescents-when-a-parent-has-young-onset-dementia)

### **Symptoms of dementia**

➤ [dementiauk.org/what-are-the-symptoms-of-dementia](https://dementiauk.org/what-are-the-symptoms-of-dementia)

### **Types of dementia**

➤ [dementiauk.org/types-of-dementia](https://dementiauk.org/types-of-dementia)

### **What is young onset dementia?**

➤ [dementiauk.org/what-is-young-onset-dementia](https://dementiauk.org/what-is-young-onset-dementia)

### **Other resources**

#### **Carers UK**

➤ [carersuk.org](https://carersuk.org)

#### **Dementia Carers Count: free support courses for family carers**

➤ [dementiacarers.org.uk](https://dementiacarers.org.uk)

#### **Dementia Engagement and Empowerment Project (DEEP): a network of groups of people living with dementia**

➤ [dementiavoices.org.uk](https://dementiavoices.org.uk)

#### **Rare Dementia Support**

➤ [raredementiasupport.org](https://raredementiasupport.org)

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

Contact our Helpline:  
**0800 888 6678** or [👉 helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:  
[👉 dementiauk.org/book](https://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](https://dementiauk.org/donate)
- Scan the QR code

**Thank you.**



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Helping families face dementia



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