

Understanding denial and lack of insight

Factsheet 533LP
June 2020



When a person is diagnosed with dementia they may not understand or accept their diagnosis. They may also have limited or no awareness of their symptoms and the difficulties they are having, even when these are obvious to those around them. This may be because the person is in denial, or because they have what is known as 'lack of insight'. In either case it will be harder to talk to the person about their dementia and how to support them.

This factsheet is for people who have a friend or family member with a diagnosis of dementia, including those who may be caring for them. It tells you about denial and lack of insight in a person with dementia, and offers advice on how to manage this situation. It also includes advice on coping when other people struggle to accept or come to terms with a person's diagnosis.

Contents

- When a person doesn't accept their diagnosis of dementia
- What is denial?
- What is lack of insight?
- Coping with denial or lack of insight
 - Tips for supporting a person with denial or lack of insight
 - Support for family and carers
- Accepting support and care
 - Support and care at home
 - Living positively with dementia
- When a carer, friend or family member is in denial
- Other useful organisations

Understanding denial and lack of insight

When a person doesn't accept their diagnosis of dementia

Every person who is diagnosed with dementia will react to the news in their own way. Many people find it difficult to come to terms with, or adjust to, a diagnosis of dementia. Some people may feel that nothing is wrong and not recognise that they are experiencing any problems. Others may acknowledge that they are having difficulties doing certain things but believe this is due to a reason other than dementia. For example, they might say their memory loss is because they are getting older. They may avoid talking about their condition by changing the subject if someone mentions it.

When a person accepts their diagnosis, it can enable them to access support and care, as well as plan for the future. If the person you support doesn't accept that they have dementia or doesn't seem to be aware of their symptoms, you might find it frustrating or distressing. You may feel like they are deliberately avoiding dealing with changes that have become obvious to you and others. However, it is important to remember that this lack of awareness is often outside of the person's control.

Sometimes a doctor will decide not to tell a person with dementia about their diagnosis because they believe it's not in the person's best interests. For example, if the doctor believes this will cause the person too much distress. Usually, if a person is not told about their diagnosis, it's a decision taken by the doctor and the people closest to the person. Some professionals will avoid using the word 'dementia' at all, which can cause further confusion.

A person may be unable to acknowledge their diagnosis or symptoms because of denial or lack of insight. These are different, and there is more information about them in the next section of the factsheet. It may also be much harder for people with confusion and memory loss to acknowledge their symptoms, as they may not recognise or remember the difficulties they have.

What is denial?

Denial is when a person doesn't acknowledge certain facts or events, even when they may seem obvious to those around them. It is a psychological reaction that enables a person to cope with a difficult situation that may otherwise make them feel afraid, depressed, ashamed or worried. They may feel – or think other people may feel – there is a stigma about having a diagnosis of dementia.

Denial is not someone's deliberate attempt to deny reality – it is likely that they're not even aware they are in denial. They may have developed their own way of explaining or coping with things they find difficult or uncomfortable. For example, a person may dismiss a question they don't know the answer to as not being important, or they may insist that they can still drive because they've 'driven for many years', even though they are no longer driving safely.

Over time, a person may come to accept their diagnosis and how it is affecting them. As their condition progresses and they start to have more problems, they may begin to talk about these with you or other people they trust.

What is lack of insight?

Lack of insight is when a person with dementia is unable to recognise changes in their behaviour and emotions (that are caused by physical changes in their brain). Lack of insight is related to loss of activity in areas in the front of a person's brain (known as the frontal lobes). It is more common in some types of dementia that are linked to damage in this part of the brain, such as frontotemporal dementia (FTD). But a person with any type of dementia can have lack of insight.

Like denial, lack of insight can be difficult to understand if a person is having problems that are very obvious to others. However, they may be aware of some symptoms or changes and be completely unaware of others. For example, the person may mention that they often forget where they have left their keys, while at the same time not recognising that they no longer cook certain meals. This can sometimes look like the person is deliberately avoiding issues that you think are obvious. It is important to remember that this isn't the case.

Unlike denial, which sometimes lessens over time, lack of insight tends to get worse as dementia progresses.

Coping with denial or lack of insight

It can be upsetting when a person does not acknowledge or accept their condition. This can be especially difficult if they seem not to be open and honest with other people about the problems they've been having. It's very common for people with dementia to do this with their GP or social care professionals. However, if you can empathise and try to support the person, it might make it easier to manage the situation.

Even though a person may not acknowledge their diagnosis, there may still be ways to help them. For example, they may be able to talk about any general concerns or worries they have, such as memory problems. This can be a useful way to find out about any difficulties that they accept they're having, which may give you ideas about how you might be able to approach these.

Even if someone is in denial, they might still react emotionally to not being able to do some things they've always been able to. For example, they might feel upset, angry or anxious because they can no longer follow conversations as they used to. Ask them how they feel and talk to them sensitively about the changes they're going through. This may help you both to work out what they would find helpful.

Tips for supporting a person with denial or lack of insight

- Try to understand that the person may be in denial because they are afraid or anxious. Remember that denial and lack of insight are not deliberate.
 - Give the person time to adapt to their condition and sensitively check every so often to see if they seem ready to talk about it. Think about whether it matters that the person isn't acknowledging their diagnosis. Are you reminding them about it for a reason, such as to encourage them to accept help? If not, it may be better not to keep reminding them.
 - Listen carefully to what the person says without interrupting or correcting them, and try not to directly contradict their account of what is happening. This can help you to find out more about how they're feeling and what they need, and how to approach these conversations in future.
 - Always try to be supportive, gentle and calm when you're talking to the person. If you're angry or stressed it will make things worse.
- **If the person does not want to use the words 'dementia' or 'Alzheimer's' it is important to respect this. Instead, talk to them about changes they've noticed in themselves or specific problems they're having. This might lead them to talk about their feelings and you can then give them reassurance or suggest support to help with these.**
- Try not to confront the person or attempt to convince them of their diagnosis. It isn't possible to persuade someone to suddenly accept their condition if they are in denial or experiencing lack of insight, and it will likely be upsetting for you both.
 - Look for services that can help people with dementia come to terms with their condition, such as support groups, talking therapies and creative therapies.

- If a person does not realise they are having problems with some activities, it may help to point out the benefits of doing things differently. For example, if a person is no longer able to drive safely, it may help to talk about the benefits of not driving. You could focus on the money they will save on petrol, road tax and insurance. If someone else drives, the person may also enjoy being a passenger without the pressures of driving. For information about supporting someone who is no longer driving, see factsheet 439, **Driving and dementia**.
- Think about the person as an individual and what might persuade them to accept support if they need it. Some people who think they don't need help might accept visits from a professional carer if they feel it would benefit someone else in their home, such as a family member.
- If a person has stopped taking their medication because they don't think they need it, it's especially important to talk to them about any problems that they do feel they're having, even if they don't believe they are dementia-related. This can help you to know how much insight they have into their condition, as well as to encourage them to take their medication. You can also talk to their GP about this, either by telephone, letter or email, or by going to an appointment with the person.
- Some people find it helps to give the person information about the difficulties they're having. For example, if they need help with remembering things, you could show them booklet 1540, **The memory handbook**. Introducing information that refers to dementia in a gentle way might help them to understand that the problems they are having could be due to the condition.

Support for family and carers

If you're feeling exhausted and worried about someone not acknowledging their diagnosis, this can lead you to feel irritated too. You may want the person to accept their diagnosis and the problems they're facing so that you can address these. Perhaps you've got ideas about how to help them with specific activities or tasks. You might also want them to be able to go to specific care services such as support groups.

It can help to look at the situation from the person's perspective. If they are in denial or experiencing lack of insight then, as far as they are aware, they don't have any problems. Think about how it might feel if their family and health professionals keep insisting that they do and that they need help. Looking at the situation from this perspective can help you understand the emotions they may be feeling, which might help you find ways to help them.

It is also very important to look after yourself and talk to other people about how you are feeling, as well as the impact on you. You could talk to a friend or family member you trust, or to a professional such as a counsellor or dementia adviser. You can also call Alzheimer's Society on **0333 150 3456** or talk to other carers in our online community Talking Point – go to [alzheimers.org.uk/talkingpoint](https://www.alzheimers.org.uk/talkingpoint)

As well as talking to others about the impact that a person's denial or lack of insight has on you, there are other ways you can look after your own health and wellbeing. These include making sure you take regular breaks, maintaining a healthy lifestyle and relaxing to help reduce stress. For more information see factsheet 523, **Carers – looking after yourself**, or for general information on all aspects of caring, including looking after yourself, see booklet 600, **Caring for a person with dementia: A practical guide**.

Accepting support and care

When someone doesn't understand or acknowledge that they are having difficulties, it can be hard to suggest they might need help and support. Support might help with practical aspects of everyday life. The person might be struggling with tasks such as shopping or taking medication, or household chores such as cooking or cleaning. An assessment for care tells you what needs the person has, and what needs you may have as their carer. It also shows what care and support will meet these needs.

For more information see factsheets 418, **Assessment for care and support in England**, W418, **Assessment for care and support in Wales** or NI418, **Assessment for care and support in Northern Ireland**.

There are a wide range of products and equipment designed to help with daily living. Items may be very simple or more hi-tech, but they can make a big difference to addressing specific problems that people with dementia might have. Many products are available from our online shop (see shop.alzheimers.org.uk).

There are also many groups and local organisations that provide services for people with dementia. These can help them get out, take part in enjoyable activities and meet new people. Find out what is available near you with our dementia directory at alzheimers.org.uk/dementiadirectory

Try to think about what is important to the person and what could motivate them to accept help. You know them best. Start by thinking about other times where you needed to persuade them of something, and try to adapt what worked then to this situation.

Support and care at home

If the person doesn't think they are having problems, they will not see the need for extra help at home. Consider different ways to talk to them about this suggestion. You could focus on the benefits to both of you of someone else helping with practical things at home such as preparing meals or doing the laundry, rather than focusing on what the person can't do.

If you're arranging care at home, it can be helpful to introduce this idea gradually. It might be easier for the person to understand if you talk about getting some help more generally. If the person is reluctant to have help at home, talk to a homecare agency or your local adult social services team about this. It might be possible for them to arrange a trial period or to gradually build up visits. This can help to develop the relationship between the person with dementia and the homecare assistant. It may help the person accept the amount of help they need, whether this is help with taking medication, household tasks or personal care.

Living positively with dementia

Some people may avoid accepting help because they feel there is a stigma around having a diagnosis of dementia. Encouraging the person to gain a better understanding about the condition can help, and they may become more familiar with the types of help and support that are available. Looking at how other people live positively with dementia can also help them feel more comfortable with the idea of accepting help and support. You could do this together by looking at our Dementia together magazine at alzheimers.org.uk/magazine, our online community Talking Point at alzheimers.org.uk/talkingpoint, or our YouTube channel at www.youtube.com/alzheimerssociety. You can use our dementia directory to find activities or support groups near you at alzheimers.org.uk/dementiadirectory

Over time, the person may begin to accept that they are having difficulties and they may become more accepting of help and support. However, this depends on the individual person and how much they are affected by denial or lack of insight.

There may be a point where you think it would be in the person's best interests to arrange for them to have support. This might be even if they do not acknowledge that they need help, because you feel they no longer have the ability (known as the 'mental capacity') to make some decisions for themselves. For more information on making these decisions see factsheet 460, **Mental Capacity Act 2005**. For more support you can also call our support line on **0333 150 3456**.

If the person won't accept support, and this means that they or someone else are in danger, contact their GP or the safeguarding team at your local authority.

When a carer, friend or family member is in denial

It is not only people with dementia who may not accept their diagnosis. Friends or family members, including those who are caring for the person, can also be in denial and find dementia difficult to accept. This can mean that they avoid the subject, do not see the need to arrange support or care for the person, or find it hard to accept that the person might benefit from daily living aids.

If the partner of the person with dementia is in denial, they may be worried that their relationship will change. It can be very difficult to accept that plans they have made together will also have to change. They may have always relied on the person to do certain tasks and might be worried or scared about having to do these things for themselves. An adult whose parent has dementia can also experience denial because of these reasons. They may also be worried that they might develop dementia themselves, and so do not want to recognise the diagnosis. For more information see factsheets 450, **Risk factors for dementia** and 405, **Genetics of dementia**.

If the person with dementia is in denial, their carer may simply agree with them, to avoid having to talk to the person about their need for support. This might mean that neither the person with dementia nor their carer will access the information and support that they both need. When someone else and the person with dementia are in denial, it can have a negative effect on the health of them both.

Denial in carers has been associated with mental health problems such as depression. Denial may also cause problems between other members of the person's family or their friends. There may be disagreements between those who do accept the diagnosis and those who don't about whether (or how much) care the person needs. Some carers and family members may not see the need to get involved, while others may be avoiding the situation because they are worried about the consequences of facing it.

Some carers, friends or family members may not know much about dementia and not recognise the symptoms as being part of the condition. It may be useful to talk to them about dementia and help them understand more about how the condition can affect people. You could explain the range of difficulties that a person with the condition can experience. It might also be useful for them to attend GP, or other, appointments with the person. This may help them to understand better the difficulties that the person is having, as well as helping them to understand dementia more. You could also show them information such as factsheet 400, **What is dementia?**, or our booklet **5 things you should know about dementia**, which you can download at alzheimers.org.uk/about-dementia/five-things-you-should-know-about-dementia

As dementia progresses, it is likely that those around the person will eventually accept their condition. Being in denial may be helping someone cope with a very distressing situation and give them time to accept the reality. Therefore, rather than trying to persuade them to accept the dementia diagnosis straightaway, for some people it may be best to try to understand how they're feeling and offer them support in the meantime.

Let them know that it's natural to worry when you see someone close to you go through changes you can't control. Try to explain that accepting these changes is important so that the right care and support can be put in place. This can benefit the person with dementia and those around them. Other friends or family members may be able to explain the reality of dementia in a sensitive way.

Other useful organisations

British Association for Counselling and Psychotherapy (BACP)

01455 883300
bacp@bacp.co.uk
www.bacp.co.uk

BACP is a national organisation that represents counsellors and psychotherapists. It can provide a list of counsellors and psychotherapists in your area.

British Psychological Society (BPS)

0116 254 9568
info@bps.org.uk
www.bps.org.uk

BPS provides access to a list of clinical and counselling psychologists that offer private therapy services.

Carers Direct

0300 123 1053 (helpline, 9am–8pm Monday–Friday, 11am–4pm Saturday–Sunday)
carersdirectenquiry.serco.com/newcareremail (online enquiry form)
carersdirectenquiry.serco.com/visitor/EntryPage.htm (webchat)

Carers Direct is an advice service for people who need help with their caring role and want to know what options are available to them.

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, unpaid, for a family member or friend who is ill, frail, disabled, or has mental health or addiction problems.

Carers UK

0808 808 7777 (helpline, 9am–6pm Monday–Friday)

advice@carersuk.org

www.carersuk.org

Carers UK was set up to help people who care for family members or friends. It provides information and advice about caring as well as practical and emotional support for carers.

Health and Care Professions Council

0300 500 6184

www.hcpc-uk.org

The Health and Care Professions Council is a regulator that keeps a register of health and care professionals who meet set standards for their training, professional skills, behaviour and health. You can search the register to check whether a named psychologist is included. You can also make complaints about registered professionals.

Relate

0300 003 0396

www.relate.org.uk

Relate offers relationship counselling for individuals, couples and families in England and Wales. It provides advice and support face-to-face, by phone and through its website. (For Relate in Northern Ireland visit www.relateni.org or call 028 9032 3454.)

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. Alzheimer's Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

© Alzheimer's Society, 2020. All rights reserved. Except for personal use, no part of this work may be distributed, reproduced, downloaded, transmitted or stored in any form without the written permission of Alzheimer's Society.

Factsheet 533LP

Last reviewed: June 2020

Next review due: June 2023

Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

Reviewed by: Danuta Lipinska, Specialist in Ageing and Dementia Care, and Cath Burley, Consultant Clinical Psychologist

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

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.

For support and advice, call us on **0333 150 3456** or visit alzheimers.org.uk



Alzheimer's Society operates in England, Wales and Northern Ireland. Registered charity number 296645.

