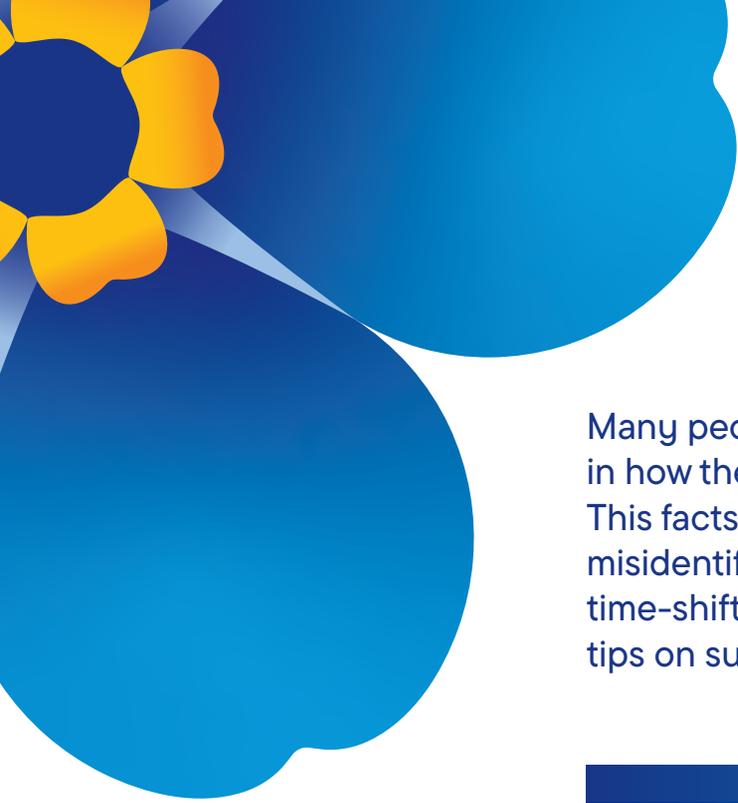


# Changes in perception



**Alzheimer's  
Society**

It will take a society to beat dementia



Many people with dementia experience changes in how they understand the world around them. This factsheet looks at misperceptions and misidentifications, hallucinations, delusions and time-shifting. It is written for carers and includes tips on supporting the person with dementia.

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# 1 Dementia and changes in perception

How a person with dementia experiences (or perceives) things often changes as their dementia progresses. They may seem to experience reality differently to you, or to misunderstand what is happening around them. This is because in dementia there is damage to the brain, which can cause the person to experience things differently.

Understanding the problems they may face and giving the right help, support and reassurance can help people living with dementia to feel safe. This is especially important at a time when how they perceive the world around them is changing. If you are able to help the person you care for to make sense of the world, you may find it can maintain their wellbeing and sense of self. Changes in perception can be frustrating, confusing and distressing for the person, and for carers.

## Delirium

If you notice a sudden change in the person with dementia (over hours or days), it could be delirium, which is a medical emergency. You should make an urgent appointment with the GP or call the NHS 111 telephone service. Delirium can be triggered by an untreated health condition. Most of the causes of delirium are treatable, such as constipation, dehydration or infections. Delirium can cause people to have hallucinations or delusions, and to become confused, drowsy or distressed. For more information, go to [alzheimers.org.uk/delirium](https://www.alzheimers.org.uk/delirium)

## What is perception?

Information from the sense organs (for example, the eyes or ears) travels to the brain. The brain processes this information, to understand it. The brain then analyses it alongside other information already in the brain, such as thoughts and memories and their associated emotions. Then the person becomes aware of what has been sensed (perceived).

## Space for your notes

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**My 93-year-old mother has been having false memories. No matter what evidence is shown to her to prove that what she is claiming never happened, she will not back down and begins to get angry.**

Family member of a person with dementia

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### How can dementia affect perception?

Dementia can interrupt or slow this process down, which changes how a person understands the world around them. Damage to the eyes or parts of the brain may cause misperceptions, misidentifications, hallucinations, delusions and time-shifting.

### How can changes in perception affect a person with dementia?

These problems can cause the person with dementia to say or do things that do not make sense to others. This can be upsetting and difficult for carers, especially if the person is experiencing a different reality to yours. By responding in a supportive way, you can keep up their confidence and help them to cope with the misunderstanding.

Some carers have to deal with these changes on a regular basis. If your caring role is becoming increasingly difficult, it may be useful to contact your local authority and request a carer's assessment. You could also ask about care packages or respite care if you need a break. See factsheet 523 **Carers – looking after yourself**. For general information on all aspects of caring, including looking after yourself, see booklet 600 **Caring for a person with dementia: A practical guide**.

Talking about the impact of caring can help. Talk to a friend or family member, or a professional such as a counsellor or dementia adviser. Call our Dementia Support Line on **0333 150 3456** or talk to other carers in our online community Dementia Support Forum – go to **forum.alzheimers.org.uk**

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# 2 Misperceptions and misidentifications

The most common type of misperceptions and misidentifications are visual. They are caused by damage to the eyes, or by problems with another part of the visual system and the brain. For some people they are caused by both.

**Misperceptions** happen when the person sees one thing as something else (for example, mistaking blue floor tiles for water).

**Misidentifications** happen when the person has problems identifying specific objects and people (for example, mistaking their son for their husband).

Some mistakes could be caused by either. For example, someone may mistake their television remote for their mobile phone because:

- their visual system is damaged, and it's not clearly seen (misperceived) as a television remote
- or, it might be clearly seen as a television remote but damage in the brain causes it to be incorrectly understood (misidentified) as a mobile phone.

A person with dementia may also have 'visuospatial difficulties', when the brain has problems processing information about 3D objects. This can affect a person's spatial awareness or the ability to judge distances. They may have difficulties using stairs, parking a car or recognising objects.

## What causes misperceptions and misidentifications?

Even if the eyes of a person with dementia are healthy, their vision may be affected if the brain is damaged. Different parts of the brain process different types of information. The occipital lobes at the back of the brain process visual information. If the occipital lobes become damaged, a person may find it hard to work out what they see in front of them. This causes misperceptions.

The brain's temporal and parietal lobes are involved in recognising faces and objects, and in judging distances. So if these lobes become damaged, a person with dementia may have problems recognising faces or objects. This causes misidentification.

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Misperceptions and misidentifications increase with age because eyesight can get worse with age. Older people are more likely to have poor eyesight, as well as long-term eye conditions such as glaucoma and macular degeneration. These can make their vision very blurry, or only allow them to see some of what they are looking at.

### How does a person with dementia experience misperceptions and misidentifications?

Sometimes, the person may need to look twice at something to realise they were mistaken the first time. For example, they may think they have seen a spider in the corner of the room, but when they look again realise it is a shadow, or a mark on the wall.

If a person is experiencing misperceptions or misidentifications, they may mistake furniture or decorations for something more troubling. For example, they may understand a dark coloured doormat as a deep, black hole. This can make them feel nervous.

Some misperceptions and misidentifications can lead a person with dementia to make errors in how they use an object. For example, they may try to use a bus pass as a payment card, or not use the right coins to pay for something.

### Supporting a person experiencing misperceptions and misidentifications

A person with dementia who is misperceiving or misidentifying things may feel unsure about their surroundings, and feel less confident and independent. You can support the person by reassuring them when they make mistakes, and build their confidence and willingness to go to new places. If they do not notice that they are making mistakes, it could be that they lack insight into their dementia. They may become irritated or more easily frustrated if you point out mistakes. For more information, see factsheets 500 **Communicating with a person with dementia** and 533 **Understanding denial and lack of insight**.

Familiar surroundings can be helpful to a person who is misperceiving or misidentifying. This is because they may rely more on memory and habit than on perception to move safely around their home. Try not to move furniture or change where things are kept, as this can make it more difficult for them to relate to their space.

## Space for your notes

If a person doesn't understand what an object is, or appears not to recognise someone, try not to assume they have forgotten. They may be perceiving it as something different, or mistaking the person for someone else. A person with dementia may disagree if you insist they have forgotten. To them, what they are seeing is correct.

Most of the following tips will be helpful whether the person is experiencing misperception, misidentification, or memory problems:

- Speak to their GP if they often have misperceptions and misidentifications, especially if these are upsetting.
- Try not to draw attention to their mistakes. Instead, gently remind the person of what is really in front of them. If they realise they have made a mistake, try to laugh about it together, if it feels appropriate. Being corrected can undermine their confidence, and they may become reluctant to join in conversations or activities.
- If a person with dementia misidentifies someone, it can be distressing for everyone. If this happens, ask friends and relatives to introduce themselves when they arrive, and wear name stickers or tags. Try to reassure the person that everyone makes mistakes and find tactful ways to help them, including frequent name reminders or explanations about why people are there.
- Try to keep doing the things they enjoy. For example, if they enjoyed reading but can't due to problems with their vision, try audiobooks instead. For more information on activities and staying involved, see booklets 1506 **Keeping active and involved** and 77AC **The activities handbook**.
- Try to be reassuring and help the person with dementia to feel safe. For example, they may be reluctant to cross a shiny floor, as it may appear to them as wet or icy. Offer them an arm, or lead them by walking ahead, so that they can see the floor is safe to walk on.
- Improve lighting levels and reduce visual clutter to see if this helps. For example, an ornament's shadow could resemble the 'dog' or 'person' they say they can see. This may be helped by simply changing the lighting.
- If the person wears glasses or a hearing aid, make sure they are wearing them and that they are working correctly.
- At mealtimes, it may help to tactfully describe the food and drink, where it is on the table and which cutlery to use. This may prevent them mistaking the jug of water for their glass, or something similar.
- When passing something to a person with dementia, remind them how it is used.
- Tell the person when someone enters or leaves the room, to avoid confusion and misidentification.

## Space for your notes

You can try to prevent or reduce misperceptions and misidentifications for a person with dementia at home. Booklet 819 **Making your home dementia friendly** can help with practical tips.

For more information on how assistive technology can help, see factsheet 437 **Using technology to help with everyday life**. You can find a range of assistive technology to support independence and safety in our online shop – visit [shop.alzheimers.org.uk/helpful-products](https://shop.alzheimers.org.uk/helpful-products)

## 3 Hallucinations

A hallucination is an experience of something that is not really there. It can involve any or all of the senses. Visual hallucinations (seeing things that are not really there) are the most common type experienced by people with dementia. They can be simple (for example, seeing flashing lights) or complex (for example, seeing animals, people or strange situations).

People with dementia are often thought to be hallucinating when in fact they are simply mistaken about what they have seen (see 'Misperceptions and misidentifications' on pages 3–6).

### What causes hallucinations?

Visual hallucinations are usually caused by damage to the brain. They are more common in people with dementia with Lewy bodies and Parkinson's disease dementia. People with Alzheimer's disease can also have hallucinations.

Hallucinations can also be caused by physical illness including fever, seizure, stroke, migraine and infection. Diseases that cause inflammation and infection, such as pneumonia, can interfere with brain function and cause delirium. Some people with delirium will have hallucinations. Delirium is a medical emergency – for more information, see page 1.

Hallucinations are a rare side effect of many medications. The medicines for Parkinson's disease can often trigger hallucinations. Speak to the GP before making any changes to medication.

Some people with worsening vision start to see things that aren't there (visual hallucinations) because of their deteriorating sight and not from any other condition, such as dementia or a mental health problem. This is called Charles Bonnet syndrome.

### How does a person with dementia experience hallucinations?

Some people with dementia will have hallucinations in different senses – for example:

- **auditory hallucinations** – hearing things that aren't there, like voices or footsteps
- **olfactory hallucinations** – smelling things that aren't there, such as smoke or perfume
- **tactile hallucinations** – physically feeling things that aren't there, such as being kissed or insects crawling over their skin
- **gustatory hallucinations** – tasting things that aren't there, such as a metallic taste in their mouth.

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**My father has hallucinations of people in the house. I am finding it hard which way to react.**

Family member of a person with dementia

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## Space for your notes

Visual hallucinations are more common in people with dementia with Lewy bodies, and often take the form of complex, vivid and very realistic hallucinations of people or animals. They often last for several minutes and happen frequently.

Hallucinations can be extremely distressing, and can lead to the person with dementia becoming frightened and in need of support. However, some people find the hallucinations pleasant or comforting. It often depends on what they are hallucinating and how others respond. For tips on how to respond, see 'Supporting a person experiencing hallucinations' on page 9.

### Treatments for hallucinations

Treatments and medicines are often not that helpful for people with dementia. However, hallucinations, particularly in people with dementia with Lewy bodies, may respond to anti-dementia medicines.

Antipsychotic medication can sometimes help to reduce severe or distressing hallucinations. They should only be used when other treatments have not worked, as they can cause unpleasant or dangerous side effects. This medication should be regularly reviewed. People with dementia with Lewy bodies are at particular risk of severe harmful reactions to antipsychotic medication.

For more information, see factsheet 408 **Antipsychotic drugs and other approaches in dementia care**.

## Supporting a person experiencing hallucinations

If the person you care for regularly hallucinates, make an appointment for them to see their GP. Make sure the person has regular medication reviews with a pharmacist or GP as new medications, or the combination of their medications, can be a cause of hallucinations.

When a person is hallucinating, how you respond has a big impact on their experience and wellbeing. If a person is hallucinating, try the following tips:

- If the person's hallucinations involve multiple senses, seek medical help immediately, as this can be a sign of serious illness. You should seek medical attention if:
  - the hallucinations frighten the person
  - the hallucinations last a long time
  - the hallucinations happen often
  - the person seems more confused than usual (which may be a sign of delirium – see page 1).
- Calmly explain what is happening. If they cannot retain this information, repeat it when they are more relaxed. If this is still not possible, don't argue with them – it will not help. Trying to convince someone that they are mistaken can lead to more distress.
- Stay with the person and try to reassure them. Ask them to describe their hallucination.
- Hallucinations may be limited to a particular setting. Gently leading someone away from where they are having the hallucinations can help make them disappear.
- Check that the person is not hungry, thirsty or uncomfortable. Dehydration, constipation or infection can lead to delirium, a cause of hallucinations.
- It may help to distract the person and see if this stops the hallucinations.

People are less likely to hear voices that are not there when they are talking to someone real. Having company may help. They could try a befriending service – see 'Other useful organisations' on pages 22–23.

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### How can you tell if someone is hallucinating?

Sometimes the person may appear to be hallucinating, but there is another cause (for example, it is a misperception instead).

The following tips can help to identify hallucinations:

- Hallucinations differ from misperceptions or misidentifications. Listen to what the person is describing, and check if anything could be causing what they are experiencing. For example, if they describe a 'swarm of insects' and there is a busy pattern on a carpet, it may be a misperception. By changing or covering the carpet, the misperception may stop.
- If the person seems to be having auditory hallucinations (hearing things that aren't there), arrange to have their hearing checked. If the person wears a hearing aid, check that it is working properly at the right setting, and encourage them to wear it. The person may be having problems with their hearing, rather than hallucinating.
- If the person seems to be having gustatory hallucinations (tasting things that aren't there), make sure they are getting regular dental check-ups to rule out other causes such as tooth decay or denture cream. For more information, see factsheet 448 **Dental and mouth care**.

### Visiting the GP

When visiting the GP for support with hallucinations, it will help to bring details of:

- what the person saw or sensed
- what time of day it happened, and after what event (for example, a nap, meal or exercise)
- where it happened, and how long it lasted
- how the person responded (for example, if they were distressed) and the words they used to describe what they experienced
- any medication the person is taking and the dosage (including any over-the-counter medications)
- key details of the person's medical history, including any long-term health conditions, previous conditions and mental health issues
- the person's use of alcohol or other recreational drugs.

## 4 Delusions

Delusions (or strongly held false beliefs) are a common symptom for a person with dementia. They can take the form of paranoia, which makes the person feel threatened, even if there is no or little reason to feel this way. Dementia can make a person suspicious of the people around them. A person experiencing a delusion may feel that they are being watched, or that someone is acting against them. They may jump to conclusions without much evidence. For example, if their neighbour has made a nasty comment about them once, they may believe that the neighbour is directing a hate campaign against them. Because of dementia, the person may no longer be able to moderate intense or wild thoughts.

If the person you care for has delusions, this can be very difficult to cope with, especially if they are convinced that you have done something wrong or are trying to harm them. Try to remember that their delusions feel as real to them as your reality feels to you. You will not generally be able to convince a person experiencing delusions that they are wrong or mistaken. Talking about this with a dementia adviser or another carer who understands what you are going through can help. Call our Dementia Support Line on **0333 150 3456** or talk to other carers in our online community Dementia Support Forum – go to **forum.alzheimers.org.uk**

**If this is a sudden change, make an urgent appointment with the GP to rule out delirium (which is a medical emergency). If delusions are ongoing and causing distress, the GP may consider a medicine treatment.**

### What causes delusions?

A person with dementia may be unable to put bits of information and memories together correctly, which can lead them to draw false conclusions and believe something that isn't true. It is more likely that a person will have delusions over time as their dementia gets worse.

Delusions are more common in dementia with Lewy bodies, and can affect people with Alzheimer's disease and vascular dementia, particularly in the later stages. They are less common in people with frontotemporal dementia.

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**My mother is constantly frightened and believes that people are against her and doing things to hurt her including myself.**

Family member of a person with dementia

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### How does a person with dementia experience delusions?

Delusions tend to be divided into two types. Sometimes, a person will believe that someone is trying to do them harm – for example, that someone is trying to steal their money, have an affair or leave them. Other times, the person will identify something wrongly – for example, that their partner is actually an impostor (Capgras syndrome), or that their home is not really their home.

Delusions often create negative feelings in a person with dementia. Some of the most common delusions include the following:

- **Theft** – for example, if a person with dementia can't find a particular item of clothing, this can cause them to believe it has been stolen. This worry can also lead to them hiding things in unusual places, which in turn leads to more items going 'missing'.
- **A belief that those closest to them are trying to harm them** – this could range from believing that a friend is bringing them food because they want to poison them, to believing a partner is being unfaithful.
- **Not believing their home to be their real home** – this is a delusion if they believe their home to be somewhere they have never lived. However, if they think of home as one they used to live in, often this is caused by 'time-shifting'. See 'Time-shifting' on pages 15–21.

Remember that for a person experiencing a delusion, their reality is very true for them. If they accuse you, it is natural to feel upset, and to want to tell the person that it is not true. However, it is often impossible to convince a person who has delusions of the truth. Trying to do so is much more likely to cause them distress than change their mind. There are better ways to support a person who is having delusions.

## Supporting a person experiencing delusions

The following tips can be helpful when discussing a specific delusion with the person:

- Encourage them to talk through their thoughts. It may reveal what is behind their delusion. For example, if they don't believe their home is their home, it may be due to a recent change in furnishing or because unfamiliar people are in their house (such as professional carers).
- Acknowledge their distress and how they must be feeling. Dismissing their concerns, or trying to distract them without acknowledging their concerns first, can cause the situation to escalate and cause them to lose trust in their carer. For example, if the person thinks a carer has been stealing, listen to them. Instead of immediately dismissing their worry or distracting them, acknowledge how they must be feeling and suggest supporting them to find the missing items. Gently suggest another activity first, which may distract the person and cause them to forget their delusion.
- Try to gently offer an alternative explanation for what may have happened, and present this as another possibility alongside their delusion, rather than an opposing view.
- Reassure them that their concerns are being taken seriously.
- If the delusion is ongoing and causing significant problems, try ways to avoid further distress. For example, if they believe their friend is bringing over poisoned food and this is causing them to stop eating, look into local meal delivery options or microwave meals they can make themselves. Ask them what they would prefer to do instead.

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### Preventing or reducing delusions

You can try to prevent delusions in the following ways:

- Choose set places for things that become lost easily, such as keys or glasses, and keep spares just in case. Make sure items are returned to the same place. For example, always hang keys on the key hook. This can help the person to find things more easily, and may reduce the delusion that missing or misplaced items have been stolen.
- Make sure the person has regular eye tests and hearing checks, to avoid any additional problems caused by sensory impairment. If they hear or see something incorrectly, it can lead to a delusion.
- Avoid unnecessary changes to the person's home. Routine and familiarity can help them to make sense of the world around them, and reduce paranoia. Try to balance the benefits of making a home more dementia friendly with the likelihood of delusions if familiar furniture or items are removed. For tips, see booklet 819 **Making your home dementia friendly**.
- Make sure the person has regular medication reviews with a pharmacist or GP. Introducing new medications, or the combination of a person's medications, can be a cause of delusions.
- Introduce stimulating activity and socialising into the person's routine. These may help reduce loneliness and isolation, which increase the risk of delusions. For more information, see booklet 1506 **Keeping active and involved**.

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## 5 Time-shifting

Time-shifting is when a person's experience is that they are living at an earlier time in their life. The person may not understand what more recent technology is or does. They may not recognise friends and family as they look now, expecting them to be much younger. They may think that people who have died are still alive. They may also not recognise themselves in a mirror, as they are expecting to see a much younger version of themselves. They may seem to be experiencing a different reality to you. Try to remember that what they perceive is as real to them as your reality is to you.

### What causes time-shifting?

Memory is important in understanding the world. To understand what is happening now, the brain uses information from the senses, and memories. A person with dementia often has damage to their short-term memory. This means they may rely more on older memories to make sense of things now.

A person with dementia may not recognise an object or how to use it, even though they can see it clearly. For example, the person you care for may put their electric kettle onto the stove to boil water. If the parts of the brain that store and find more recent memories are damaged, they cannot remember using an electric kettle. They may, however, be able to recall earlier memories from their life, perhaps one where they put a kettle on a gas hob or the stove. They have shifted to a time in their life before they used electric kettles. The person may feel like they are living in the past, because they're using older memories to fill in the gaps to make sense of the present.

Time-shifting may be more common in Alzheimer's disease than other types of dementia. However, people with all types of dementia are more likely to experience it as their condition progresses. A person may not always be time-shifted, but they may move in and out of being time-shifted and living in the present, perhaps over the course of a day.

## Space for your notes

### How does a person with dementia experience time-shifting?

A person with dementia may experience time-shifting in the following ways:

- Asking if they can collect the children from school, or when they can speak to their mother. They are recalling memories from much earlier in life, and possibly showing an unmet need.
- Not recognising themselves in the mirror, as they believe they are much younger, and the reflection is of someone much older. They can't access recent memories of themselves.
- Not recognising their adult children or family, believing their children to be much younger. Their memory of them is from a much earlier time.
- Struggling to identify newer technology and what it is for.
- Interpreting people around them in a role they were familiar with in the past. For example, if the person used to run a bed and breakfast, they may think other care home residents are guests. They could help to set out tables for lunch, which is a meaningful occupation for them.

## Supporting a person experiencing time-shifting

As with delusions, pointing out mistakes to a person with dementia who is time-shifted can be very upsetting. Often you won't be able to convince them to recognise their current situation or surroundings, or that time-shifting is not logical. This is because time-shifting is due to damage to the brain and is not a choice for the person with dementia. It is real to them. If the person with dementia is happy and content, think about whether correcting them is in their best interests.

The following tips can help if you are caring for someone who is experiencing time-shifting:

- Announce your name when entering the room by saying "Hi, it's (name)" or similar. Other family members, friends and professionals should do the same. This may help prevent the person from becoming confused and mistaking others for people in their past.
- Attend carefully to what the person is saying and doing, to understand their reality. Acknowledge their worry, and explain you will try to help. They are more likely to be gently distracted once they feel heard.
- Avoid contradicting the person's experience. They shouldn't be told what is or is not true in a confrontational manner. They may become frightened or upset.
- Remember that emotional memories are often easier to retrieve. Staying open, calm and friendly can help the person with dementia to associate a carer with positive emotions, even if they struggle to understand who you are in the present.
- Try to remain calm. If you become frustrated that the person you care for is struggling with the present, take yourself out of the situation until you feel calmer. For example, you can take some time out of the room by making a drink for both of you.
- Remember the positive difference you make to the person with dementia. They don't need to fully understand your reality to feel happy, so continue to try and do what makes them feel content.

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### Preventing or reducing time-shifting

These tips may prevent or reduce time-shifting:

- Remove or replace mirrors and shiny surfaces at eye height. Some people may not recognise themselves in the reflection if they have time-shifted to when they were much younger. They may believe their reflection to be a stranger in their home, and this can cause distress and alarm.
- Unless there is a problem with any appliances they have, such as their TV, avoid changing them for newer technology. They may not be able to use newer and unfamiliar items. It is better that they continue to use their appliances without help, than to introduce newer technology that they need assistance with.
- Talk to them about simple solutions. For example, if using the radio causes confusion, try replacing it with a model that they used when they were younger.
- Try and find out about their life history. This can include former job roles, daily routines, interests and important relationships. Understanding their past may help to understand how they are interpreting their present. It may also help understand questions and actions that seem odd to others (for example, someone getting up very early 'to clock on for work'). Giving someone meaningful occupation often helps.

If a person with dementia is living in a care setting or staying in hospital, any problems they have communicating can affect the care and support they receive. We produce a simple form called **This is me**<sup>®</sup> to help record personal information about a person. This includes how they communicate, any difficulties they have, and how care and support staff can tailor their care for the person as an individual.

To order a free copy, email [orders@alzheimers.org.uk](mailto:orders@alzheimers.org.uk) or call **0300 303 5933**. **Dyma Fi** is also available in Welsh.

## Space for your notes

### Time-shifting and difficult questions

A person may ask you questions as a result of time-shifting, such as ‘When am I going to go home?’ when they are at home, or ‘When is my mum coming to see me?’ when their mum hasn’t been alive for a long time. It can be difficult to know what to say to the person you care for.

Telling the truth can cause the person with dementia to have an emotional response and, in some cases, may make things worse. Not telling the truth can also make the person with dementia more suspicious, if they realise that those around them aren’t being truthful. It may also make you feel uncomfortable to lie to them. There is no right or wrong way to respond to these difficult questions. Try to decide what is in the person’s best interests and be consistent in whatever you decide.

Certain times of the day might be worse than others. There may be triggers. For example, if the question happens near meal times, a snack might help. You may notice that the person asks when the environment is noisier than usual, or perhaps later in the day. If you see a pattern, you can take steps to lessen or avoid some of the triggers.

An ideal solution is one that you feel comfortable with, and which considers the best interests of the person you care for. This includes not causing them distress. However, it is often not easy to manage these questions on a regular basis and it is important you have as much support around you as you need. It can be helpful to hear from other carers about approaches they have tried, and what worked for them. For support at any time of day or night, join our online community Dementia Support Forum – go to [forum.alzheimers.org.uk](https://forum.alzheimers.org.uk)

To talk to a dementia adviser, call our Dementia Support Line on **0333 150 3456**. For more advice and information, see factsheet 523 **Carers – looking after yourself** and booklet 600 **Caring for a person with dementia: A practical guide**.

## Space for your notes

### Asking for a partner, friend or relative who has died

If the person with dementia is asking for a partner, relative or friend who has died, telling them the truth may shock and upset them, as it will feel like the first time they have heard the news. If they have short-term memory problems, they could experience the shock of grief repeatedly if they continue to be told every time they ask.

Some carers choose to tell the person initially, but do not repeat if it becomes a recurring question. You may feel that reducing the person's distress is more important than telling them the truth. If you choose to tell the truth in this scenario, try to give them the news in a sensitive and compassionate way, offering warmth and support. Think about whether it is in their best interests to continue to be told this news every time they ask. Try not to give details of how and when it happened if it was long ago, as this can add to the confusion caused by their time-shifting.

Try not to ignore the question. The person may continue to feel distressed if their concern for their loved one is being dismissed. You may need to acknowledge their question first, perhaps by saying 'I don't know the answer to that at the moment. Is there a reason that you need them?'. Or, instead of answering the question directly, you could say 'Do you miss your mum?' and encourage them to talk about their mother, possibly using photos to reminisce.

They may have an unmet need that the person they are asking for provided earlier in their life. This could be a sense of security a partner gave them, or the love their mother gave them. Try and explore this, and allow them to talk about the person they miss. You might use phrases to show you understand how they are feeling, such as 'It sounds like you're missing your mum at the moment?' or 'You must be lonely without your husband?'. Try to meet the need (for example, for security or affection) as best you can.

## Asking to go home

The following tips may help if the person you care for is asking to go home, describing a place they have lived in the past:

- Try not to argue about whether where they are is 'home'. If they don't recognise it as 'home' at that moment, then for that moment it isn't home.
- Ask if there is anything you can do to make them happier where they are now. Often, when a person with dementia asks to go home, it refers to the sense of home rather than home itself. Find out where 'home' is for them – and what they like about it.
- Reassure the person that they are safe and cared for. Check that they are comfortable – not too hot or cold, hungry or thirsty, or needing to use the toilet.
- Keep a photograph album to hand, to gently distract them. Sometimes, looking at pictures from their past and being given the chance to reminisce will ease feelings of anxiety. It might be best to avoid asking questions about the picture or the past. Instead, try to make comments like 'That looks like Uncle Fred. Granny told me about the time he....'
- Distract the person with food or other activities, such as a walk.

Ask them as many details as possible about their home and consider completing a 'Herbert Protocol' with previous addresses in case they try and return there. A Herbert Protocol is designed to help the police if a vulnerable person goes missing. Visit the website for your local police for more information.

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your notes**

## Space for your notes

# Other useful organisations

### **Carers UK**

0808 808 7777 (helpline, 9am–6pm Monday–Friday)  
advice@carersuk.org  
www.carersuk.org

Carers UK provides advice, information and support to carers.

### **The Lewy Body Society**

01942 914000  
info@lewybody.org  
www.lewybody.org

The Lewy Body Society produces a guide to dementia with Lewy bodies. You can also access support and information from them by phone or email.

### **Macular Society**

0300 3030 111 (9am–5pm Monday–Friday)  
help@macularsociety.org  
www.macularsociety.org

Macular Society is a national charity offering support and advice for anyone affected by central vision loss.

### **Mind**

0300 123 3393 (infoline, 9am–6pm Monday–Friday)  
info@mind.org.uk  
www.mind.org.uk

Mind provides advice and support to empower anyone experiencing a mental health problem.

### **Parkinson's UK**

0808 800 0303 (helpline, 9am–6pm Monday–Friday;  
10am–1pm Saturday)  
hello@parkinsons.org.uk  
www.parkinsons.org.uk

The Parkinson's UK helpline is a free and confidential service providing support to anyone affected by Parkinson's.

### **Royal National Institute of Blind People (RNIB)**

0303 123 9999 (helpline, 9am–6pm Monday–Friday)  
www.rnib.org.uk

RNIB is a charity that offers support and advice to blind and partially sighted people in the UK.

**Royal National Institute for Deaf People (RNID)**

0808 808 0123 (8.30am–5pm Monday–Friday)

[contact@rnid.org.uk](mailto:contact@rnid.org.uk)

[www.rnid.org.uk](http://www.rnid.org.uk)

RNID is a national hearing loss charity. It offers free, confidential and impartial information on a range of subjects relating to deaf issues, hearing loss and tinnitus.

**The Silver Line**

0800 470 80 90 (helpline)

[www.thesilverline.org.uk](http://www.thesilverline.org.uk)

The Silver Line (run by Age UK) is a free, confidential helpline providing information, friendship and advice to older people. It is open 24 hours a day, every day of the year.

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Factsheet 527

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Next review due: January 2024

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This factsheet has been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please email [publications@alzheimers.org.uk](mailto:publications@alzheimers.org.uk)

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We are reviewing this publication. If you would like to give us any feedback, you can email us at [publications@alzheimers.org.uk](mailto:publications@alzheimers.org.uk) or call us at **020 7423 7455**.

At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Symptoms and treatments**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit [alzheimers.org.uk](http://alzheimers.org.uk)

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit [alzheimers.org.uk/donate](http://alzheimers.org.uk/donate)



*Patient Information Forum*



**Alzheimer's  
Society**

It will take a society to beat dementia

Alzheimer's Society  
43-44 Crutched Friars  
London EC3N 2AE

**0330 333 0804**  
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[alzheimers.org.uk](http://alzheimers.org.uk)

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