

Understanding change

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Alzheimer National Helpline
1800 341 341

This factsheet offers suggestions for people who are caring for a person with dementia. We consider why behavioural changes occur, how we can respond, and what we might try if things get difficult.

Dementia affects every person differently. We know from research and from experience that the way people behave can change, as dementia progresses. These changes in behaviour can be upsetting for both the person with dementia and people who are caring for them.

In the past, these changes were often called 'challenging behaviour', because the behaviour of the person with dementia was seen as a problem for people who were caring for them. Unfortunately, this type of labelling can lead us to respond in wrong ways to people who are clearly having difficulties.

It is more helpful for the person with dementia if we think about how we might reduce their distress, help them feel more contented and encourage them to interact with other people.

Understanding the cause of particular changes in behaviour should help to identify the most appropriate responses. The causes could include pain, anxiety, frustration, fear or a change in their surroundings.

**Dementia affects every
person differently.**

What changes might you observe in a person with dementia?

The first thing to remember is that we all express emotion, experience changes in mood and react to our surroundings. People with dementia are no different, except that they may have more difficulty in understanding or communicating the way they are feeling.

Common changes in behaviour that a person with dementia might experience include:

- **Repetitive questioning** – where they forget that they've asked a question or that they've received an answer, and keep asking the same question.
- **Walking** – where they seem unable to sit still and want to walk around.
- **Shadowing** – where they follow another person around (often the carer).
- **Apathy** – where they show a lack of interest in the world around them. They might also appear to lack emotion or motivation.
- **Depression** – where people feel sad or have lost interest in things they used to enjoy.
- **Sleep disturbance** – where they wake during the night and feel disorientated.



Understanding change

➤ **Misplacing items** – where they might hide things or put them away in ‘safe’ places and then forget the hiding place. It can also mean putting items in the wrong place, such as placing the house keys in the fridge.

➤ **Fidgeting** – where they can’t keep still.

Less common changes we might see include:

➤ **Disinhibition (or lack of inhibition)** – where they might say or do something inappropriate or at the wrong time. For example, they might shout in a library, be rude to a friend or show inappropriate sexual behaviour.

➤ **Shouting and screaming** – when they are very distressed.

➤ **Excessive anger** – where they could be verbally angry or even physically violent.

➤ **Sensory changes** – this can involve changes to a person’s vision, hearing, touch, taste or smell.

People with dementia may have more difficulty in understanding or communicating the way they’re feeling.

Should we respond to all changes in a person’s behaviour?

Most changes in behaviour will resolve themselves within a few weeks and require no special treatments or interventions.

If a person’s actions are not a risk to themselves or to others and they do not appear to be distressed, then it may be best to do nothing.

How to respond to changes in behaviour

Try and stay calm and don’t get involved in an argument if possible. This is easier said than done but try and remember that the person with dementia is not acting this way on purpose.

➤ Think about **what might be causing** the change in behaviour:

- Is the person unwell? Do they have an infection or are they in pain (including dental pain)?
- Has something in their life changed recently (such as their medication, routine, or home environment)?
- Is there a pattern to the change in behaviour, which might indicate the cause? For example, does it occur at certain times of the day or when you are carrying out particular tasks (such as helping with personal care)?

- If possible, take time to **watch and wait**. The situation might resolve itself.
- Make sure their **surroundings are calm** and free of noise or disturbance.
- Think about the **emotion** behind the change in behaviour. For example, if a person keeps asking about a deceased parent, perhaps they are looking for the reassurance, support or love that a parent would have offered.
- Try to **distract** them. To deal with most of the behaviour that you see, distracting the person is one of the most useful things to try. For example, you could try going for a walk, listening to music or taking part in a favourite pastime.

Keeping to routines

We all use routines in our daily life because they provide a structure to our day. Routines can be very useful ways to manage changes in behaviour because we repeat our daily rituals (such as getting out of bed, washing, getting dressed and eating). These become habits that can continue even when a person's memory is impaired. It is best to set a routine early in the disease process.

A routine of regular tasks or events can be very reassuring for a person with dementia because it:

- Helps maintain independence
- Helps maintain feelings of control over our lives
- Helps maintain self-esteem and self confidence
- Minimises any negative changes in their behaviour

Routines from the past can sometimes help in our understanding of current behaviour. For example, a person who was used to doing a particular task at a certain time of the day (such as picking up the kids from school or going to work) may appear restless or anxious during those hours. If you know this, then you can plan relaxing activities for these times of day.

Self-care

It is important for you as the carer to take regular breaks away from the person you are caring for. This will give you a chance to 'recharge your batteries' and to keep stress levels down. You should try and find a little time each day where you can have a break from the other person. Longer breaks might be helpful, such as taking a full afternoon once a week, or one weekend a month, or an annual holiday away from home.

It is also important to remember that no individual is perfect and mistakes will be made. We should try not to blame ourselves if things go wrong. Remember to reach out for help if you are feeling overwhelmed or don't know what to do.

The Alzheimer Society of Ireland can provide information and emotional support. It also provides resources on activities and maintaining skills for people with dementia for all stages, including later stages of dementia. For more information or for a copy of the resources, call the Freephone Helpline on 1800 341 341 or go to www.alzheimer.ie.

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Understanding change

How to handle common changes in behaviour

Some changes cause particular difficulties to people with dementia and their carer.

- When answering a question, try presenting the answer in different ways. You could write it down, use a calendar, use an easy-to-see clock, show a picture etc.
- Explore the emotions behind the action, story or question (such as anxiety, worry or fear) and try to reassure the person.

Repetition

Repeating questions, stories or tasks is a very common feature of dementia, particularly Alzheimer's disease. It often arises when a person finds it difficult to learn new information, remember that information and then recall it when needed.

Sometimes, repetition relates to a worry or an emotional need and this should not be ignored.

Tips

- Don't get frustrated and angry – this will only make things worse.
- Answer a repeated question as if it's the first time you've been asked, and remain patient.
- If there's no harm in repeating a story, question or task, then let it happen.
- Communicate clearly with the person. Turn down the TV or radio. Ensure that hearing aids are working and switched on.

Misplacing items

Sometimes people with dementia put things away in the wrong place. For example, they might put milk into a cupboard rather than the fridge. Some items might become lost because the person can't remember where they put them. On other occasions, they may hide an item on purpose, perhaps because they are worried it might be stolen.

Losing or misplacing things can be stressful for both the person with dementia and their carer. It can also take up a lot of time trying to find these items again, especially if they have been 'put away in a safe place'.



Assistive technology

Tips

- De-clutter. With less clutter around, it might be easier to find things.
- Try locking away the really important things, such as documents and jewellery.
- Have a box, a bowl or a drawer where you put items that are used every day (such as wallets or purses, house keys and reading glasses).
- Have two or three spare sets of items, like keys or glasses, which can be used until the original is found.
- Label cupboards and drawers so that people know what's inside. A label with a picture and words might work best.
- Sometimes, you might need to distract the person with another task or activity.
- Use 'assistive technology', such as item locators.
- Sometimes a person may continue to believe that the item has been stolen and this may start to cause significant distress for everyone involved. It may be necessary to get medical advice at this point.

Walking around

Walking around is a very common experience for people with dementia and their carers. It is sometimes called 'wandering'. But this suggests that there is no purpose to the action, which is unhelpful because people walk around for a reason.

There can be many reasons a person with dementia wants to take a walk:

- Pain or discomfort
- Needing to use the toilet
- Boredom
- Needing to exercise
- Searching for something or someone
- Fear
- Feeling uncomfortable in their surroundings (is it too hot, too cold, too noisy, too bright, too dark?)
- An old routine, such as going to work or going shopping

If there's no risk involved and the person seems content, then don't try to stop them from walking. As walking is exercise, it should be encouraged when and where possible.

Tips

If there are potential risks in the person walking around, then you could consider the following:

- Make sure there are no trip hazards. Remove rugs, trailing cables and so on. Establish clear paths of movement by rearranging furniture.
- Encourage the person to go to the toilet regularly. Put a sign (picture and words) on the toilet door, if they cannot locate the right room.
- Make sure that they aren't in any obvious pain, as discomfort can cause restlessness.
- Make sure that they aren't hungry or thirsty.
- Set up a regular routine for accompanied walking, where someone goes out with the person.
- If they carry a mobile phone, make sure the appropriate contact numbers are stored on it.
- Keep a diary of when the person is walking. If they want to walk at a regular time each day, this may be due to a lifelong habit. An accompanied walk at this time might help.
- Distract them with a household chore or another activity.
- Make sure that they have some type of identification on them. (Consider using the ASI help card.)



If you're worried that the person might become lost when out walking, you could consider the following:

- Make sure that they have a mobile phone with them.
- Ask trustworthy neighbours and people working in the local community to keep an eye out for them.
- Inform the community Garda of your situation.
- If you're concerned that the person may leave the house during the night, install an alarm that will alert you if any doors are opened between certain hours.
- The use of assistive technology such as a GPS tracking device. There are important ethical questions about using trackers, and you should always try and get the person's agreement to use one.

Shadowing

Shadowing, or constantly following a carer around, can put an immense strain on people and their relationships. The most likely explanation for shadowing is that the person with dementia feels insecure.

As their memory becomes worse and the world around them becomes less recognisable, a person with dementia will hang on to people, places and things that are most familiar and reassuring to them. In many cases, this means their home environment and their main carer, so they often become anxious if this person is not with them.

Tips

- Show the person with dementia that everything is okay. Offer reassurance, understanding, kind words or a hug.
- Give them simple meaningful tasks to do while they are with you.
- If you're going out, write down the time you will return and ensure they can see a clock.
- Stick to daily routines. Performing everyday tasks can often give reassurance to a person with dementia.
- Take regular breaks. It's important to get some time for yourself.

Apathy

Apathy is a lack of interest, motivation or concern. It should not be confused with depression. It is not intentional and it isn't laziness. A person with dementia does not behave with apathy on purpose. It is a result of the changes in their brain, caused by dementia. Apathy tends to be quite persistent so it may be something that a carer learns to live with.

It can affect people in different ways:

- A person might appear emotionally unresponsive or not give the appropriate response to good or bad news. They may appear indifferent and lacking in warmth.
- A person may be unable to start a task, or may leave a task unfinished, even though they are physically capable of doing it.
- A person may find it difficult to start a conversation or plan an activity.

Tips on how to deal with apathy

- Gently prompt them to do a task. Don't demand or order.
- Encourage them to do tasks that they previously enjoyed.
- Encourage them to do small and simple tasks at first. Break down bigger tasks into manageable chunks.
- Use their daily routines to prompt activity.
- Take regular breaks to 'recharge your batteries'.
- Get medical advice to ensure that they are not depressed.
- Join a support group. Other caregivers often have good suggestions that may help.



Understanding change

People with dementia and their carer need support to live well

Support is available from the following organisations:

Alzheimer Society of Ireland

Alzheimer Society of Ireland provides information, advice and a range of dementia-specific specialist services throughout Ireland. These include dementia advisers, social clubs, Alzheimer cafes, home care and day care.

Helpline: 1800 341 341
(free calls from landlines and mobiles)

Monday to Friday, 10am-5pm

Saturday, 10am-4pm

Email: helpline@alzheimer.ie

Website: www.alzheimer.ie

HSE

You can also talk to your public health nurse or doctor about home support, day care and respite care. You can contact the public health nurse at your local health centre. Or you can contact the HSE:

Phone: 1850 24 1850
(calls are not free)

Email: hselive@hse.ie

Website: www.hse.ie

Understand Together

Understand Together is a public support, awareness and information campaign. The website includes information about dementia supports and services in Ireland.

Website: www.understandtogether.ie

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Other publications you may find useful include:

Practical tips for living well with dementia

HelpCard: for people with dementia when out and about

Practical steps to support your independence

Loss and grief when a family member has dementia

For a free copy, call
1800 341 341



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The Alzheimer Society of Ireland, ASI, has taken great care to ensure the accuracy of the information contained in this factsheet. ASI is not liable for any inaccuracies, errors, omissions or misleading information.

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