



PBO 930022142 NPO 049-191

Unusual behaviour

People with dementia sometimes behave in ways that other people find puzzling or difficult to handle. This advice sheet looks at a number of different behaviours and suggests ways of coping.

Each person with dementia is an individual with individual needs. Much of their behaviour is an attempt to communicate their needs or how they are feeling. Once we understand the reasons why someone is behaving in a particular way, it is easier to find ways of coping.

If the person is unable to tell you how they are feeling, try a number of approaches. Ask for advice from professionals or other carers before you become too stressed.

Doctors may sometimes prescribe medication for these behaviours, but these treatments will need very careful monitoring by the doctor and should be reviewed regularly. Ask about any side-effects the medication may have so that if they appear you do not automatically assume that the dementia has become worse.

Always remember that the person you are caring for is not deliberately being difficult. Ask yourself too whether the behaviour is really a problem. Make sure that you have support for yourself and breaks when you need them. Carer stress is one of the risk factors for elder abuse.

Unusual behaviour may be related to:

- Physical illness or discomfort
- Side effects of medication
- Overstimulation; sensory overload
- Unfamiliar surroundings
- Complicated tasks
- Frustration; communication challenges.

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Repetitive questioning

A person with dementia may ask the same question over and over again. They probably do not remember asking the question or the answer you gave because of their short-term memory loss.

Feelings of insecurity or anxiety about their ability to cope may also play a part in a person's repetitive questioning. Always try to put yourself in their situation and try to imagine how they might be feeling and what they might be trying to express.

- Be tactful when answering. Don't say: 'I've already told you that' as this will increase feelings of anxiety. Try to get the person to find the answer for themselves if possible. For example:

Q - 'Is it lunch time?'

A - 'Have a look at the clock.'

Q - 'Do we need more milk?'

A - 'Why don't you look in the fridge?'

- Try to distract the person with an activity if appropriate.
- If you cannot contain your irritation, make an excuse to leave the room for a while.

People with dementia often become anxious about future events and this can lead to repetitive questioning. If this seems to be the case consider telling them that someone is coming to visit or that you are going shopping just before it happens. This will give them less time to worry.

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Repetitive phrases or movements

Sometimes people with dementia repeat the same phrase or movement many times. You may hear this referred to by medical professionals as 'perseveration'

- This may be due to some kind of discomfort. Check that the person is not too hot or too cold, hungry, thirsty or constipated. Contact the GP if there is any possibility that they are ill, in pain or if you suspect that their medication is affecting them.
- The surroundings might be too noisy or stressful.
- Encourage an activity as the person might be bored. Some people find stroking a pet, going for a walk or listening to favourite music, for example, calming and very enjoyable.
- It may be the person's way of soothing themselves. We all have different ways of comforting ourselves.
- It may be due to damage to the brain.

Simply offer as much reassurance as you can.

Repetitive behavior

You may find that the person seems to be constantly doing the same thing such as packing and unpacking a bag or rearranging the chairs in a room.

- Look for a reason behind the repetition.
- Focus on the emotion not the behaviour.
- Turn the action into a similar activity e.g. dust the table.
- Accept their behaviour and learn to live and work with it.

The behaviour may relate to a former activity or occupation such as traveling, organizing an office or entertaining friends. You may be able to work out what this activity might be, which will help to understand what the person is feeling and trying to do. It may also serve as a basis for conversation.

The person may be bored and need more stimulating activities or more contact with other people.

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Trailing and checking

We know that for many people, the experience of living with dementia makes them feel extremely insecure and anxious. A person with dementia may therefore constantly follow you or call out to check where you are. Memory loss and confusion about time means that a few moments may seem like hours to a person with dementia and they may only feel safe if you are nearby. This behaviour can be very difficult to cope with.

- Try not to speak sharply. If you do it will only increase the person's anxiety.
- Provide something absorbing for the person to do if you are busy with something else – perhaps a pet or a familiar cuddly toy or doll.
- It may be reassuring for the person to hear you hum or sing. If you are in another room, putting the radio on may be calming.

Shouting and screaming

The person may continually call out for someone, shout the same word or scream or wail over and over again. There are several possible reasons for this behaviour.

They may be ill or in pain, they may be experiencing hallucinations. If any of these possibilities seem likely, consult the GP.

They may be lonely or distressed. At night, a night light in the bedroom may be reassuring.

They may be anxious about their failing memory. Try to reassure or distract them. If they are calling out for someone from their past, then talking to them about the past may be helpful.

They may be bored. Everyone needs to be occupied, including people with dementia. Listening to music together or giving the person a gentle hand massage are just some of the things that people have found helpful.

There may be too much noise and bustle. They may need a quieter environment.

It may be the result of brain damage due to dementia. Ask your GP to refer the person to a specialist if you think that this is the case.

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Laughing and crying

The person may laugh or cry uncontrollably for no apparent reason.

This may be associated with hallucinations or delusions (seeing or hearing people or things that are not there, or believing things that are not true). If you think that this may be the case consult the GP.

This may be due to the effects of brain damage. It is more common among people who have vascular dementia. It does not necessarily mean that the person is very sad or very happy. They may prefer you to ignore these episodes. On the other hand they may respond to reassurance.

Lack of inhibition

The person may behave in a way that other people find embarrassing because of their failing memory and general confusion. In a few cases it may be due to specific damage to the brain. Try to react calmly.

Undressing or appearing naked in public may simply indicate that the person has forgotten when and where it is appropriate to remove their clothes. Take them somewhere private and check whether they are too hot, uncomfortable or whether they want to use the toilet.

Lifting a skirt or fiddling with flies may be a sign that the person wants to use the toilet.

If a person starts to stroke their genitals in public, discourage them tactfully and try to distract their attention. If such behaviour is frequent or persistent, consult the GP.

If the person behaves rudely – for example, by insulting people or swearing or spitting – do not attempt to argue or correct them. Try to distract them. You can explain to other people later that their behaviour is due to the dementia and is not directed at them personally.

Pacing

There are a number of reasons why a person with dementia may pace up and down a room.

- They may be hungry or thirsty or constipated, in pain, or may simply want to use the toilet and be unable to tell you. Check on these possibilities.
- They may feel ill or be suffering the side effects of certain medicines. If you suspect that this may be the case, contact the GP.

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- They may be bored, or they may not be using up all their energy. Try to find appropriate activities or enjoyable forms of exercise.
- They may be upset by noisy or busy surroundings and may stop walking up and down if they can find a quiet place to sit.
- They may be angry, distressed or anxious. Try to find out how they are feeling and show that you understand.

However, in some cases, pacing may be due to changes that have taken place in the person's brain. Try to distract them. However, if you are unable to prevent the person from pacing:

- Try to find somewhere they can walk in safety without disturbing anyone else.
- Encourage them to choose comfortable clothes and supportive shoes.
- Check their feet regularly for any redness, swellings or blisters, which may need attention. Contact the GP or (community nurse) if you are concerned.
- Try to persuade them to rest from time to time and offer drinks and snacks.

Fidgeting

- A person with dementia may fidget constantly. They may be uncomfortable, upset, bored or need more exercise. The fidgeting may be associated with the damage in the person's brain.
- Check whether the person is too hot, too cold, hungry, thirsty or whether they want to use the toilet.
- If they seem upset, try to find the reason and reassure them.
- Try to distract their attention with an interesting activity or involve them in some form of exercise.
- Give them something to occupy their hands such as a soft toy or worry beads, or provide a 'rummage' box containing interesting objects. Make sure there are no small items that may be confused with food/sweets and eaten.

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Hiding and losing

The person may deliberately hide objects to keep them safe and then forget where they are or, indeed, that they have hidden them at all.

- The wish to hide articles may be partly due to feelings of insecurity and a desire to hold on to the little that they still have. Try to reassure the person, however impatient you may feel.
- Do not leave important documents lying around and make sure you have a spare set of keys if they are likely to lock things away.
- Try to find the person's hiding places so that you can tactfully help them to find 'missing' articles.

Some people may also hide food, perhaps intending to eat it later. If this is the case you may need to check hiding places regularly and discreetly dispose of any perishable items.

General Rule for problem behaviours:

Identify and examine the behaviour:

- Is it harmful to the patient or others?
- What was person doing just before incident?
- How did you react?
- What happened after behaviour occurred?

Explore potential solutions:

- Are needs being met?
- Can the environment be adapted?
- Can you change your approach or reaction?
- Are you responding calmly and supportively?

Did your new response help?

- Do you need to try another approach?
- What can you do differently?

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Suspicion

People with dementia sometimes become very suspicious. They may worry that other people are taking advantage of them or intend to harm them in some way.

For example, when they mislay an object, they may accuse someone of stealing from them, or they may imagine that a friendly neighbour is plotting against them.

Such ideas may be partly due to failing memory or an inability to recognize people they know. We all have a need to make sense of what is happening around us.

- Although such attitudes can be very difficult to live with, try to avoid arguing. State calmly what you know to be true, if appropriate, and then reassure or distract.
- You should not automatically dismiss the person's suspicions if there is any possibility that they may be true.
- Explain to others who are in contact with the person that any unfounded accusations are caused by the dementia and that they should not be taken seriously.

The Alzheimer's Society UK would like to thank Janet Keane of the Department of Psychiatry at Oxford University for helping with the preparation of this advice sheet.

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