

Unusual behaviour

As dementia develops, it can cause behaviour changes that can be confusing, irritating or difficult for others to deal with, leaving carers, partners and family members feeling stressed, irritable or helpless. By learning to understand the meaning behind the actions, it can be easier to stay calm and deal effectively with the challenges that arise. This factsheet outlines some typical sorts of unusual behaviour in people with dementia and explains some common causes.

Each person is an individual, with their own preferences and character traits. However, certain forms of behaviour are particularly common in people with dementia. If the person you are caring for has difficulty expressing him or herself in words, the unusual behaviour may become more extreme. By working out what each behaviour means, and finding ways to overcome the problem, the situation can become more manageable.

Common types of unusual behaviour

Repetitive behaviour

People with dementia often carry out the same activity, make the same gesture, or ask the same question repeatedly. Medical professionals sometimes call this 'perseveration'. This repetition may be because the person doesn't remember having done it previously, but it can also be for other reasons, such as boredom.

It is not unusual for a person with dementia to go through the motions of the activity they may previously have carried out at work.

This can indicate a need to be occupied and to feel there is a purpose and structure to their life. Specific types of repetitive behaviour may include:

- **Asking the same question over and over again** – As well as memory loss, this can be due to the person's feelings of insecurity or anxiety about their ability to cope. Try to be tactful and patient, and encourage them to find the answer for themselves. For example, if they keep asking the time, and you know they are able to understand the clock, suggest that they look at the clock themselves. It may help if you to move the clock to a position that is more visible. People with dementia may become anxious about future events such as a visitor arriving, which can lead to repeated questioning. It may help if you don't mention the event until just before it takes place.
- **Repetitive phrases or movements** – This can be due to noisy or stressful surroundings, or boredom. Encourage the person to do something active, such as going for a walk. It can also be a sign of discomfort, so check that the person isn't too hot or cold, hungry, thirsty or constipated. Contact the GP if there is any possibility that the person may be ill or in pain, or experiencing a side-effect of medication.
- **Repetitive actions** – Actions such as repeatedly packing and unpacking a bag, or rearranging the chairs in a room, may relate to a former activity such as travelling or entertaining friends. If so, this may serve as a basis for conversation. Alternatively, it could signify boredom or a need for more contact with people.
- **Repeatedly asking to go home** – This may take place in residential care, or when the person is already at home. It can be a sign of anxiety, insecurity, fear or depression. The concept of 'home' might evoke memories of a time or place where the person felt comfortable or safe, or of a home, family and friends that no longer exist. If the person doesn't recognise their present environment as 'home', then it isn't home for them. Try to understand and acknowledge the person's feelings and reassure them that they are safe and loved.

- **Multiple phone calls** – Some people with dementia phone their loved ones over and over again – particularly in the middle of the night. This can be very frustrating and distressing. The person with dementia may forget that they have already called, or may be insecure or anxious. If you are receiving repeated calls, it may help to get a phone with a number recognition display or an answerphone so you can decide whether you want to answer, and switch mobiles and ringers off at night. You may feel guilty about not answering every call, but it's important to look after yourself and get some rest.

Restlessness

Some people with dementia experience general restlessness. This can be a sign of hunger, thirst, constipation or pain, or the person may be ill or suffering from the side-effects of medication. Other possibilities are boredom, anger, distress or anxiety, stress due to noisy or busy surroundings, or lack of exercise. It may also be due to changes that have taken place in the brain. If the person seems upset, try to find the reason, give them some reassurance, then try to distract them with an interesting activity, or by involving them in some form of exercise.

- **Pacing up and down** – Pacing may indicate that the person wants to use the toilet but is unable to tell you. Try asking the person whether they need to use the toilet, or lead them towards it. If they are adamant that they want to pace, try to find somewhere they can walk safely. If a person has always been active and walked regularly, they may be feeling frustrated and want some fresh air. Help to choose comfortable clothes and shoes, offer drinks and snacks, check their feet regularly for redness, swellings or blisters, and try to persuade them to rest from time to time.
- **Fidgeting** – Someone with dementia may fidget constantly. As with pacing, try to distract their attention and offer reassurance. Try giving the person something to occupy their hands, such as a soft toy or worry beads, or provide a 'rummage' box containing interesting objects.

Shouting and screaming

The person may continually call out for someone, shout the same word, or scream or wail over and over again.

- They could be in pain or ill, experiencing difficulties with visual perception or hallucinations, or the behaviour could be a result of brain damage. In these cases, talk to the GP.
- A person with dementia may feel lonely or distressed, if their short term memory is damaged they may not remember that you are in the next room and believe they are alone. They may feel anxious about their failing memory, bored, or stressed by too much noise and bustle.
- If the person shouts out at night, a nightlight in the bedroom may be reassuring.
- Consider how the room looks in the dark. Are there shadows or shapes that cannot be seen when the light is on but that could be misinterpreted and look frightening in the dark?
- If they are calling for someone from their past, try talking to them about this period in their life and respond to the feelings the person is showing. Avoid harsh facts that may cause distress – if the person they are asking for has died, they may not remember this fact and will feel they are hearing it for the first time.

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, this may be due to specific damage to the brain. Try to react calmly.

- Some people with dementia may undress in public, having forgotten when and where it is appropriate to remove their clothes. If this happens, take the person somewhere private, and check whether they are too hot or are uncomfortable or want to use the toilet.

- Stroking or exposing genitals in public, or apparently inappropriate sexual behaviour, may be a result of the physical damage to the part of the brain that allows us to recognise acceptable social behaviours. If this happens, discourage the person tactfully and try to distract their attention. It is important to remember that having a dementia does not mean a person no longer has physical or sexual needs – simply that inhibitions and social skills may not be functioning. If such behaviour is frequent or persistent, consult the GP.
- Some actions, such as lifting a skirt or fiddling with flies, may not be related to sex at all – it may simply be a sign that the person wants to use the toilet.
- If the person behaves rudely – for example, by insulting people or swearing or spitting – don't attempt to argue or correct the behaviour. Try to distract their attention, and explain to other people later that the behaviour is due to dementia and is not directed at them personally.

Night-time waking

Many people with dementia are restless at night and find it difficult to sleep. Older people often need less sleep than younger people in any case. Dementia can affect people's body clocks so that they may get up in the night, get dressed or even go outside. This can be very worrying – and exhausting – for carers.

- Make sure the person has enough exercise during the day and that they use the toilet before bed.
- Try a walk before bedtime, a warm milky drink and soothing company before they fall asleep.
- If the person wakes up, gently remind them that it is night-time.
- During the light summer months it can feel like daytime even late at night or very early in the morning, so put a clock that shows whether it is am or pm next to the bed and consider darker curtains or blackout blinds.

Trailing and checking

Living with dementia makes many people feel extremely insecure and anxious. This can result in the person constantly following their carers or loved ones around, or calling out to check where they are. A few moments may seem like hours to a person with dementia, and they may only feel safe if other people are nearby.

- This behaviour can be very difficult to cope with, but try not to speak sharply.
- If you are busy, give the person something absorbing to do – perhaps distraction through a pet, task or activity, or you can hum or sing, or put the radio on.
- Make sure you also find some time for yourself.

Hiding and losing things

People with dementia sometimes hide things and then forget where they are – or forget that they have hidden them at all. The wish to hide things may be due to feelings of insecurity and a desire to hold on to what little the person still has.

- However impatient you feel, try to be reassuring.
- Don't leave important documents lying around, and make sure you have a spare set of keys.
- Try and find out the person's hiding places so that you can tactfully help find 'missing' items.
- If the person hides food, check hiding places regularly, and discreetly dispose of any perishable items.

Suspicion

Some people with dementia can become suspicious. If they have mislaid an object they may accuse someone of stealing it, or they may imagine that a friendly neighbour is plotting against them. These

ideas may be due to failing memory, an inability to recognise people, and the need to make sense of what is happening around them.

- If this happens, state calmly what you know to be true, if appropriate, and then reassure and distract the person.
- Try to remember that although the person's interpretation may be wrong, the way the person feels is real.
- Explain to others that they should not take unfounded accusations seriously.
- Don't automatically dismiss the person's suspicions if there is any possibility that they may be true.

Sleeplessness and 'sundowning'

Many people with dementia, especially in the middle stages, experience periods of increased confusion at dusk, with their disorientation continuing throughout the night. These periods of what is known as 'sundowning' usually diminish as the dementia progresses.

Sundowning may be caused by:

- mental and physical tiredness at the end of the day
- reduced lighting and an increase in shadows
- less need for sleep, common among older adults
- an upset 'body clock' with the body mixing up day and night.

See sections on 'Restlessness' and 'Night-time waking' for suggestions on how to deal with the effects of sundowning.

Tips: Coping with unusual behaviour

- Try to remember that the person you are caring for is not being deliberately difficult, their sense of reality may be very different to

yours but very real to them. Dementia can affect a person's ability to use logic and reason so things that may seem obvious to you might appear to be very different for the person with dementia.

- Ask yourself whether the behaviour is really a problem. If the behaviour is linked to a particular activity such as washing or dressing, ask yourself if this task really needs to be done right now or if you could leave it for a while until the person has calmed down.
- Try to put yourself in the person's situation. Imagine how they might be feeling and what they might be trying to express.
- Offer as much reassurance as you can.
- Remember that all behaviour is a means of communication. If you can establish what the person is trying to communicate, you will resolve the problem much more quickly.
- Distract the person with calming activities such as a hand massage, stroking a pet, a drive in the country or by playing their favourite music.
- Try to make sure that you have support for yourself and breaks when you need them.
- Some people find unusual behaviours, particularly a repetitive behaviour, very irritating. If you feel you can't contain your irritation, make an excuse to leave the room for a while.
- If you find the person's behaviour really difficult to deal with, ask for advice from professionals or other carers before you become too stressed. Medication may sometimes be used for these behaviours, but this should be monitored and reviewed very carefully. Ask about the possible side-effects of any drugs so that if they appear you do not automatically assume that the dementia has become worse.
- Remember that it is possible to be the cause of the behaviour through a lack of understanding of what the person is trying to communicate. Try stepping away from the situation, look at the person's body language and try to understand what they might be feeling at that time. Give the person space to calm down and offer reassurance.

For details of Alzheimer's Society services in your area, visit alzheimers.org.uk/localinfo

For information about a wide range of dementia-related topics, visit alzheimers.org.uk/factsheets

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Reviewed by: Cathy Baldwin,
Programme Delivery Manager,
Knowledge and Learning, Alzheimer's
Society

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Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–5pm Monday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

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