

Changes in behaviour

A person with dementia may start to behave differently as their condition progresses. They may develop behaviours that are challenging and distressing for carers, themselves and others around them. This factsheet outlines some behaviours that a person with dementia might develop, and explains some of the common causes for these. It also looks at how carers can support a person with dementia and deal with situations caused by these behaviours.

These out-of-character behaviours can be difficult to understand, are often caused by confusion and distress, and may indicate underlying needs. Looking at the causes of the behaviour and identifying the needs of the person can help to reduce these behaviours, or make them easier to cope with.

This factsheet does not cover behaviour that is verbally or physically aggressive. For more information on this see factsheet 509, **Dementia and aggressive behaviour**.

Causes of changes in behaviour in people with dementia

When a person with dementia behaves differently, this is often mistakenly seen as a direct result of the dementia or simply as another symptom of the condition. However, this is often not the case. The behaviour may have many causes, including difficulties relating to dementia (such as memory loss, language or orientation problems), but also mental and physical health, habits, personality, interactions with others and the environment.

The possible causes of someone behaving out of character may be divided into biological (eg being in pain), psychological (eg perceiving a threat) or social (eg being bored).

The person with dementia may be influenced by an environment that is unable to support or meet their needs. Disorientation is a common feature of dementia, so an environment that is difficult to navigate and confusing can increase distress.

When supporting a person with dementia who is behaving out of character, it's important to see beyond the behaviour itself and think about what may be causing it. Sometimes behaviour can be a result of frustration in the way others around the person are behaving, a sense of being out of control, or a feeling of not being listened to or understood.

People with dementia have the same basic needs as everyone else. However, they may be less able to recognise their needs, know how to meet them, or communicate them. Behaviour may be an attempt to meet a need (eg removing clothing because they are too hot or walking around because they are bored or feel they need to be somewhere), or to communicate a need (eg shouting out because they need the toilet).

Dementia can make the world a confusing and frightening place as the person struggles to understand what is going on around them. Though it may confuse the carer, the behaviour will have meaning to the person with dementia. It is likely to be an attempt to enhance and maintain a sense of wellbeing and ease distress. Any response should involve trying to see things from the person's perspective.

Managing and reducing out-of-character behaviour

When managing a situation where a person with dementia is behaving out of character, it is important not to see the behaviour as just another symptom that needs treating. A problem-solving approach is needed to try to work out why the person's behaviour has changed (see 'Strategies for carers').

Out-of-character behaviours often resolve over time and are often successfully managed by carers. However, there may be times when input from professionals is needed.

Sudden changes in behaviour, particularly those where a person with dementia becomes noticeably more agitated, confused or distressed, are often the result of physical health problems.

In the first instance, it is always a good idea to visit the GP to rule out any physical problems (eg an infection, pain, constipation or poor eyesight or hearing). Side effects of medication or taking several different medicines can also cause behaviour change. A doctor should review all of the person's medication. Mental illnesses such as depression may also contribute to out-of-character behaviour. These can often be managed with medication and non-drug strategies. If health problems have been ruled out and the person is still behaving out of character, the GP may refer them to a specialist.

Reducing the likelihood of out-of-character behaviour

Many things can reduce the chance of a person with dementia developing out-of-character behaviours in the first place. Simple measures include:

- ensuring continued social relationships
- encouraging the person to engage in meaningful activities
- reducing unnecessary noise and clutter
- providing people with familiar personal items
- maintaining a comfortable sleeping environment.

General approaches to managing out-of-character behaviour

If someone does develop changes in behaviour, there are several non-drug treatments that should be tried. These general approaches should be considered first, before any drugs.

These general approaches may include:

- engaging the person in enjoyable and meaningful activities – this could range from making music to exercising
- spending quality time with the person – perhaps chatting or sharing a task together
- developing a structured daily routine
- hand massage – especially for agitation
- aromatherapy and light therapy (although evidence that these are effective is weak).

It used to be that antipsychotic drugs were frequently prescribed to people with ‘challenging’ behaviour. While these may be appropriate and helpful in some situations, they can suppress behaviour without addressing the cause, and may add to the person’s confusion. They should only be prescribed by a doctor when absolutely necessary. Medical guidelines state they should only be used in the first instance if there is evidence of delusions (believing something that isn’t true) or hallucinations (seeing or hearing something that is not there) and the person is severely distressed, or if there is a risk of harm to them or those around them. If antipsychotics are used, they should be regularly reviewed and monitored. For more information see factsheet 408, **Drugs used to relieve behavioural and psychological symptoms in dementia.**

Strategies for carers

Carers may find a step-by-step problem-solving approach can help them to manage out-of-character behaviours. Carers may want to talk to a professional (such as a dementia specialist nurse or dementia support worker) about ways to implement a problem-solving approach.

Firstly, define the problem:

- Is the person's behaviour really a problem?
- Is the problem actually the reaction or attitudes of others towards the person or the behaviour?
- Is it a response to an interaction with the person?

Secondly, consider the situation and look at the circumstances contributing to the problem.

- When and where does the behaviour happen?
- Are there notable instances when the behaviour doesn't happen?
- Does the person always behave the same way in the same place?
- Are there patterns to the behaviour?

Thirdly, assess the person in the situation, and whether they seem to be:

- in pain or discomfort, or unwell
- tired, overstimulated, bored, lacking in social contact or anxious
- embarrassed, ignored or misunderstood
- hallucinating, delusional or depressed
- responding to an unpleasant incident, a change or a provocation.

Once all these have been considered, you may be able to develop a strategy to manage the behaviour. Talk to the person and those around them and come up with a plan. Start to make some changes and review whether they have made a difference. It might take some trial and error to find effective solutions. Make sure the interests of the person with dementia are always at the centre of any solution.

Managing out-of-character behaviour: general tips for carers

The following tips are general approaches that can be tried to support a person who is behaving differently. In the 'Types of behaviour' section there are tips on managing more specific behaviours.

- Try to remember that the person is not being deliberately difficult; don't take it personally. Their sense of reality may be very different from yours and they are responding to their own needs.
- Knowledge of the person and their history will help. For example, if you know someone used to work night shifts, it might explain why they want to stay awake or go out at night.
- Even though a person with dementia may have difficulties with their memory, they still retain emotions. This means they are more likely to respond to the emotional aspects of a situation. It's important to think about how they are feeling, what they are trying to express, and how to support their emotions. It may help to validate the person's feelings (eg 'I can see that this is difficult for you'.)
- People with dementia are likely to respond to your behaviour and communication, so if you are frustrated or angry it may exacerbate the situation. Offer the person gentle reassurance. Alternatively, 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 yourself and the person space to calm down.
- Consider whether the behaviour is really a problem. If it is disrupting a particular activity such as washing or dressing, ask yourself if this task really needs to be done right now or if you could come back to it later. Sometimes ensuring a safe environment and leaving the person to do what they want may be the best option.
- The person should have their eyesight and hearing tested, and if necessary should wear glasses and a hearing aid.
- Support the person to be independent and do as much as they can for themselves. The behaviour may be a response to the person feeling that they are not able to contribute or are not valued by others.

- If you think the person is bored, support them to find engaging and meaningful pastimes. Try to include these as much as possible day to day.
- Try to adapt to the present situation. Insisting that things can go back to how they were before, or expecting too much of the person, can create further problems.
- If you are exhausted by the person's behaviour, ask friends and relatives to spend some time with the person so that you can have a break.
- If the person is frequently or persistently behaving out of character, consult the GP.

Types of behaviour

The following section discusses some of the most common forms of behaviour that a person with dementia may develop, and gives some suggestions to help support the person. Everyone experiences dementia in their own way, and carers will need to find out what works best for the person.

Restlessness

People with dementia may develop various restless behaviours such as fidgeting, pacing and agitation. Causes of restlessness in people with dementia can include:

- pain or discomfort, eg arthritic or dental pain
- a medical reason, eg depression, constipation or the side effects of medication
- a basic need, eg hunger, thirst or needing the toilet
- a feeling, eg anxiety or boredom
- communication problems
- the environment – it may be too hot or too cold, over-stimulating or under-stimulating.

Restless behaviour can be difficult for carers because it can take many forms and can be very tiring. However, there are some things that may help.

Restlessness: tips for carers

- Visit the GP to identify any medical causes and make sure these are effectively managed.
- Try to make sure the person has plenty to eat and drink and that their environment is supportive.
- A daily routine may help.
- Engage the person in meaningful activities and hobbies, particularly those that involve movement, such as housework or gardening.
- Encourage exercise such as daily walks, or seated exercises for those with less mobility.
- Consider issues with continence. Does the person need to use the toilet or have any pads changed?

If the person fidgets a lot, try to give them something to occupy their hands, such as a soft toy or worry beads, or provide a 'rummage box' (a box containing interesting objects). They may also enjoy hands-on tasks such as folding clothes or dusting.

Repetitive behaviour

People with dementia often carry out the same activity, make the same gesture, say the same thing or ask the same question repeatedly. This may be because they feel anxious and frightened, and want comfort, security and reassurance. The person's natural interaction with their surroundings may have been disrupted by memory problems, confusion, disorientation or boredom, so they may be trying to make sense of their situation by asking about and exploring it. Repetition may also be a result of memory loss, and the person not being able to remember what they have done or said, or the answer they received to a question.

Repetition can be exhausting for carers, who may become irritated and frustrated that they can't have a break. Carers may think that the person is being deliberately difficult. It can also be frustrating for people with dementia, especially if their questions are unanswered and they are left feeling anxious and insecure.

Repetitive behaviour: tips for carers

- If the person is repeating questions, try to be tactful and patient. They may not know that they have repeated themselves and may be sensitive to signs of impatience in others.
- It is important to look for the underlying meaning of repetitive questions – is the person in pain, are they lost, do they need the toilet? Is there a common theme to their questions?
- It may be helpful to encourage the person to find the answer for themselves. For example, if the person keeps asking the time, consider buying a clock that is easy to read, and keep it in a position that is visible.
- Some carers find that it helps to write down basic facts (eg what day or date it is) on a notepad or whiteboard. They can then refer the person to the note. However, it's important to consider whether this really meets the person's needs.
- If the person becomes anxious about upcoming events it may help not to give them too much notice of the event, or to give them plenty of notice – whichever works best.

Shouting and screaming

The person may scream, shout or moan or use abusive language, occasionally or repeatedly. This can be very distressing for carers and the person with dementia, and can cause emotional strain between them.

There are many possible reasons for why a person with dementia shouts, including:

- pain or discomfort
- attempting to communicate a need, eg hunger or thirst
- a feeling, eg anxiety, loneliness or boredom
- under-stimulation or over-stimulation
- a response to a hallucination or misperception
- communication problems
- an unsupportive environment – eg it may be too hot, too cold or too dark.

If the person is shouting and screaming it may be aggressive. For specific advice on dealing with these situations see factsheet 509, **Dementia and aggressive behaviour.**

Shouting and screaming: tips for carers

- Don't ignore or talk over the person. Involve them in what is happening and explain what is going on. The behaviour may be a response to them misinterpreting your intentions.
- Try to make sure the person has social interaction and sensory stimulation.
- Consider relaxing approaches such as music, aromatherapy or massage and touch.
- Make sure the person has had their sight and hearing checked.
- Consider how a room looks in the dark and whether anything is potentially frightening. A nightlight in the bedroom may be reassuring.

Walking

Some people with dementia start to walk about more. This may not be a problem for the person with dementia. However, it can be very

stressful for carers, especially if the person stays out for long periods of time or leaves the home unexpectedly or during the night. Carers may feel that the person is walking aimlessly (sometimes referred to as 'wandering'), but there will often be a purpose to the walking. If carers can work out why the person is walking, it will help them put strategies in place.

Some reasons why people may walk include relieving boredom or anxiety, revisiting a past habit (eg collecting the children from school or taking the dog for a walk) or confusion. The person may also feel that they have somewhere to be. Walking may offer the person a chance to be independent, give them something to do and opportunities for exercise.

Walking: tips for carers

- Make sure the person has plenty to do and is getting mental and physical stimulation during the day.
- If you have a garden, use this if the person wants to go for a walk.
- Make the house and garden as safe as possible. For more information see factsheet 503, **Safety in the home**.
- If you're worried about the person's safety when they leave the house, consider going with them or asking someone else to go with them.
- Consider disguising the exit door. You could paint it the same colour as the wall so it is less obvious, or use a curtain. Alternatively, place a large sign saying 'Don't go through this door'. Consider turning off the outside light to prevent the person from walking out towards the light.
- Make sure the person has some form of personal identification with them and are dressed appropriately for the weather.
- Consider using a locator device so you can keep track of the person if they walk off. For more information on these, and advice on the ethical issues, see factsheet 437, **Assistive technology – devices to help with everyday living**.

There will always be some level of risk and it's important to balance any harm the person may come to against maintaining the person's independence and dignity.

For more information see factsheet 501, **Walking about**.

Sleep disturbance and night-time waking

Sleep disturbances are common for people with dementia, and often lead to carers also experiencing problems with their sleep.

A person with dementia may get up repeatedly during the night and may become disorientated when they wake. They may get dressed or try to leave the house. This may make the person tired during the day and they may sleep for long periods. All of this can be very stressful for carers. People with dementia may not be aware that they experience any problems during the night.

Dementia can affect people's sleep patterns. This is separate and different from normal age-related sleep difficulties. It can cause problems with the sleep-wake cycle and also interfere with the person's 'body clock'. Disturbed sleep can have a negative impact on a person's wellbeing (as well as that of their sleeping partner), so strategies to improve sleep will be beneficial.

Sleep disturbance: tips for carers

- Make sure the person has plenty of daylight and activity during the day.
- Think about improving the sleeping environment. Make sure the room is a comfortable temperature and appropriately lit. If it's too light, consider blackout blinds.
- Cut down on caffeine and alcohol in the evening.
- Consider a clock next to the bed which shows whether it is day or night.
- If someone likes to have something to cuddle, consider a soft toy.

- Going for a walk, having a warm milky drink, or having a bath or shower before bed may help the person relax.
- Think about safety – leave a light on in the hall and toilet, consider a nightlight in the bedroom, remove any trip hazards (eg loose rugs or furniture in the way).
- If the person wakes up at night, try gently reminding them that it's night.
- Poor mood can contribute to poor sleep. If you think the person may be depressed see your GP.

Sundowning

Sometimes a person with dementia will exhibit an increase in certain behaviours in the late afternoon or early evening. For example, people may become more agitated, aggressive or confused. This is often referred to as 'sundowning'. This pattern may continue for several months and often occurs in those in the moderate to severe stages of dementia. It can be particularly distressing for carers if they are trying to relax or have some quiet time.

Sundowning may be caused by:

- disturbance to the 24-hour 'body clock' that tells our bodies when to sleep, caused by the physical changes to the brain
- loss of routine at a previously busy time of day
- too little or disturbed sleep
- too little or too much light
- prescribed medication (eg for pain or discomfort) wearing off
- medications that worsen confusion and agitation
- excessive or disturbing noise.

Using the term 'sundowning' may mean that people attribute out-of-character behaviours to dementia and overlook other factors causing the behaviour, such as someone trying to communicate. It is

important to look at and address the potential reasons why someone is behaving out of character.

Sundowning – tips for carers

- Try to give the person something meaningful to do at this time of day, using past activities as a guide.
- Plan quiet and relaxing activities for late afternoon/evening.
- Think about what's happened during the day. Could the person's behaviour be a communication of a need such as requiring the toilet, feeling hungry or being in pain?
- Consider minimising daytime naps and make sure the person gets enough light, especially sunlight.
- Exercise can be beneficial for helping someone to sleep.
- Improving the environment can help someone to sleep better, as can reducing intake of caffeine and alcohol in the evening.
- Keep lighting appropriate – if it's too dark the person may become distressed as seeing things becomes harder, but if it's too bright it may cause overstimulation.

Hiding, hoarding and losing things

A person with dementia may hide, hoard or lose items. This can be very frustrating for carers who may have to spend time finding the items or trying to find out from the person where the objects are. Hiding and hoarding may be an attempt by the person to remain in control of their situation. The person may also be experiencing paranoia or delusions and believe their items will get stolen, meaning they may try to hide or protect them. Losing things may be the result of the person forgetting where they have put them, especially if they have already put them in an unusual place.

Hiding, hoarding and losing things: tips for carers

- Consider a hoarding box or drawer where the person can put objects they want to keep safe.

- Try to work out the person's hiding places so that you can tactfully help find 'missing' items.
- If the person becomes anxious about lost items, try to reassure them and support their emotional needs.
- Don't leave important documents lying around.
- Keep a spare set of things that are often lost such as keys or glasses.
- Consider assistive technology (such as a locator device) to help people find objects. For more information on assistive technology see factsheet 437, **Assistive technology – devices to help with everyday living**.
- If the person hides food or other perishable goods, check hiding places regularly, and discreetly dispose of any perishable items.

Accusing

A person with dementia may make accusations against people around them, including family, friends and carers. The most common accusations are that others are trying to steal from them or harm them. They may also accuse their partner of being unfaithful, or of being an impostor. These false accusations can be distressing for someone caring for a person with dementia. Often the accusations are based on a hallucination or delusion on the part of the person with dementia. For more information on hallucinations see factsheet 527, **Sight, perception and hallucinations**.

Accusing: tips for carers

- Don't take false accusations personally.
- Consider that a person may have confused the past and present, so accusations may be based on past experiences.
- Don't try to argue with or correct the person. What they are experiencing is real to them. Acknowledge their feelings and offer reassurance.

- Try to find the underlying reason for an accusation. If, for example, a person is accusing someone of theft of an item, is it because that person has forgotten where they placed the item?
- If the person is accusing someone else of something, don't automatically assume it is untrue. Investigate any accusations that could possibly be true.

Trailing and checking

A person with dementia may follow their carer around, check that they are nearby, repeatedly call out or ask for people, or ask to go home when they are already there. This can be frustrating and tiring for carers. It can also be upsetting for the person with dementia.

Living with dementia can make people feel insecure and anxious. They may feel a constant need to be reassured, because the world around them no longer makes sense. This is why they may shadow carers and constantly seek reassurance that they are not alone. They may also have forgotten where the carer is and follow them as a means of checking they are still there.

Trailing and checking may also indicate another underlying need. For example, if a person with dementia is asking for parents who have died, or asking to go home when they are actually in their home, it may reflect a need to feel secure and safe.

It is important to address the underlying emotion and need behind what the person is asking for. Confronting them with the truth might not help, and may make the person feel more upset and distressed.

Trailing and checking: tips for carers

- Respond to the emotion behind what the person is doing, saying or asking for.
- If you need to do something it may help to have the person with you, as your physical presence may be reassuring, eg do the ironing in the front room while the person listens to the radio.

- If the person is asking to go 'home', try to understand and acknowledge their feelings and reassure them that they are safe. It may be more related to a feeling of 'home' as a place of safety and security than an actual place.
- If the person is 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.

Losing inhibitions

Sometimes a person with dementia can lose their inhibitions and may behave in ways that others find embarrassing. This can include being rude, saying things that are socially inappropriate (eg commenting that someone is overweight), talking to strangers, undressing in public, and apparent sexual disinhibition (eg touching themselves inappropriately in public).

This can be embarrassing and distressing for both the person with dementia and those around them. They may not understand that what they are doing is inappropriate. It is unlikely that they are being inappropriate on purpose. When addressing the situation, it is important to uphold the person's dignity and prevent unnecessary distress.

Some common causes of losing inhibition include:

- the effects of specific types of dementia (some people with frontotemporal dementia experience a loss of inhibition because of damage to the frontal lobes in the brain)
- needing the toilet (touching themselves) or being too hot (undressing)
- boredom or wanting to talk to someone
- sexual frustration.

Embarrassing situations: tips for carers

- Try to react calmly and remember the person is not behaving in this way on purpose.
- In some situations it may help to think about whether the behaviour really matters. For example, in some situations talking to strangers may not be a problem. The person may be meeting a need to be social and the stranger may be happy to engage with them.
- Try gently distracting the person.
- Be aware of potential triggers – if you know what these are you may be able to prevent the behaviour from happening in the first place. For example, if someone behaves in a sexually inappropriate way when you help them to get changed, it may be that they are misinterpreting your actions. Try to change how you approach the situation and see if this helps.
- If the person is undressing, take them somewhere private, and check whether they are too hot or are uncomfortable, or want to use the toilet.
- If the person behaves rudely, don't attempt to argue or correct the behaviour. Try to distract their attention.
- It may help to explain to other people why the person is behaving in that way. They may be more understanding if they know why something happens and they may have some suggestions to help find solutions.

Changes in behaviour are common in dementia. However, by looking at the meaning behind the behaviour and considering what may be causing it, it is possible to find ways to support a person with dementia to live well. It is also important for carers to look after their own wellbeing and seek support for their needs. For more information see factsheet 523, **Carers looking after yourself**.

Other useful organisations

Carers Trust

32–36 Loman Street
London SE1 0EH

T 0844 800 4361

E info@carers.org

W www.carers.org

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.

Dementia UK

Second Floor
Resource for London
356 Holloway Road
London N7 6PA

T 020 7697 4160

E info@dementiauk.org

W www.dementiauk.org

National charity committed to improving quality of life for all people affected by dementia. They provide Admiral Nurses who are mental health nurses specialising in dementia care.

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This factsheet has also been reviewed by people affected by dementia. A list of sources is available on request.



Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 1122

9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

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