



Behaviour that challenges -understanding and coping

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Introduction

The changes that take place in the brain of a person with dementia can affect not just their memory – it can also affect their mood, personality and behaviour.

There can be many reasons why a person with dementia’s behaviour changes. It may be a direct result of the changes in the brain caused by the dementia, or it could be due to other factors, such as frustration at no longer being able to carry out tasks, depression, feeling unwell, or being unable to express pain.

These behavioural changes, which are often completely out of character, can be extremely distressing and difficult for people to cope with.

These behaviours can include:

- Aggression
- Agitation
- Walking (sometimes called wandering)

- Apathy or disinterest in anything or anyone
- Disinhibition – this might involve sexual behaviour, swearing, making personal remarks about strangers
- Shouting or screaming

This information sheet is aimed at partners, relatives and friends of people with dementia who may be struggling to understand what is happening to the person they care about. It may also be useful for staff in care settings.

It can help to try to understand why the person with dementia is behaving in a particular way. This may help to avoid what is causing the behaviour or assist in managing behaviour that challenges.

Understanding and knowing the person

Caring for someone with dementia can be stressful; carers often feel low or tense as a result. It can be particularly upsetting when someone you love behaves in a strange or hostile way towards you. This can feel worse if the person behaves differently with other people. You may feel that they are “getting at you”. The first thing to remember is not to take it personally and that people with dementia may behave differently in different situations and with different people.

Dementia is a result of changes that take place in the brain. These changes can affect a person’s behaviour. For example, we know that damage to the frontal lobe of the brain can result in a person doing or saying things they would not normally do or say.

Dementia affects different people in different ways. If you can understand why someone is behaving in a particular way, it may feel less stressful and may give you some ideas on how to cope. How the person is behaving may be to do with their surroundings. For example, is the person bored and therefore restless, or is a crowd of people too stressful?

Behaviour may also depend on who is around and how they react. For example someone who approaches quickly from behind may frighten a person with dementia and this may explain why he hits out at her.

As well as considering what is going on at the time, knowledge of what the person was like in the past may be helpful. A man who has been physically active in his youth may become restless as he develops dementia and may start to wander.

Perhaps if he has been sociable in the past, 'wandering' may be his attempt to go back to his old haunts such as the pub or the bowling green. So what is seen as a purposeless activity (wandering) can be viewed as having a purpose (walking).

Problems in behaviour are sometimes a result of a person realising that things are not quite right. Our attempts to help and do things for that person may inadvertently reinforce the fact that their competence is failing. Trying to help the person to maintain independence as long as possible may be beneficial.

Coping

We cannot 'prescribe' tried and tested ways of dealing with behavioural problems but certain strategies have been shown to be helpful. Carers have found that sometimes they discover these by trial and error. Often by understanding the possible reason behind the behaviour, the person can be helped to settle before things get worse.

Anger and aggression

Some people with dementia can be angry and aggressive at times as a result of the dementia. Aggressive behaviour can be verbal or physical; verbal abuse is more common than physical aggression. It can be difficult to understand when a gentle person becomes angry and aggressive. The person may only act in this way with their carer and be well-mannered to other people.

Possible causes

There are many possible explanations for angry and aggressive behaviour. It may be as a direct result of the dementia, as the part of the brain that controls reactions may be damaged. The person may be frustrated at no longer being able to do things they used to be able to do and may feel humiliated because they are forced to accept help and their privacy and independence are being threatened.

The person may misunderstand what is going on and over-react to something that has happened. They may feel frightened because they no longer recognise certain places or people. They may misplace something and think that it has been stolen. Other possible explanations are tiredness, adverse effects of medication, feeling unwell or being in pain.

What to try

Have you or someone else approached the person quickly, so that he or she perhaps hasn't recognised you? If so, approaching slowly in full view may help. Have you explained what you are going to do? If not, try using short simple statements, such as 'I'm going to help to take your coat off' and so on. Without such explanation, your help may feel like an attack and the aggression is self-defence.

Does aggression 'pay'? That is, does the person get something out of being aggressive? If so, trying to anticipate needs may help. You may be able to let the person have what he or

she wants, if this is appropriate, before he or she becomes aggressive.

Is the aggression due to frustration? Locking the door to prevent the person going out may reduce that behaviour but may result in frustration.

Remain calm and speak in a reassuring manner. Try not to get into an argument or become angry, as this will make the situation worse. However, if you lose your temper do not feel guilty. It may be a sign that you need a break and additional support. Remember that it is the illness and not the person that is making them act in an angry and aggressive manner.

Touching the person's hand may help to relax them but not everyone will like it. Remind the person what is going on and what will be happening next. Distract the person's attention away from the situation. If the person is gripping you try not to struggle.

Afterwards try and work out what caused the upset and see if there is anything you can do to change it. However, trying to prevent aggression may not always work. Do not blame yourself if the person still becomes aggressive. Talk to someone you can trust such as a friend, community psychiatric nurse, social worker or the Dementia Helpline on 0808 808 3000. Ask your doctor for a specialist assessment if you are worried. They will be able to check whether there is an illness causing the aggression and provide advice.

Anxiety and depression

For some people, anxiety may be a distressing symptom of dementia. The person may be unable to tell you what is upsetting them. They may seem agitated or keep asking the same question. They may become restless or follow you about. Anxiety is more common earlier in the illness when the person is more aware that something is wrong.

The symptoms for anxiety and depression are similar. It can be hard to know if someone with dementia is depressed. Possible indications that a person is suffering from depression are acting withdrawn, not sleeping well, lack of energy, more emotional than normal or easily confused.

What to try

Both anxiety and depression can be treated, so it is important that the person visits their doctor. If the person seems anxious, try to reassure them and be positive.

A familiar routine can help someone feel more secure. Try to do important tasks at times of the day when the person will be at their best and focus on the things that the person can still do.

Walking

Sometimes people with dementia walk – this is often called 'wandering'. This can be worrying for the carer. They may walk around the house or they may leave their home, sometimes at odd hours of the day or night. The person may not be able to tell you what they are doing but that doesn't mean they are wandering aimlessly. There will almost certainly be a purpose behind it.

Possible explanations

The person may be bored or in need of stimulation. Perhaps they are going for a walk, as they have always done. For many people, walking is a lifelong habit, and they go for walks for pure enjoyment. They may set off doing something but then forget where they were going. The person may be feeling lost or uncertain in a new environment. Sometimes people may not recognise their own home, or believe they still live in a house they moved away from years ago.

It is common for a person with dementia to become confused about the time. They may wake in the middle of the night and think it is time to get ready for the next day.

Walking can relieve tension or physical discomfort. If a person has toothache or constipation, sitting still with nothing to do can make mild discomfort feel worse.

What to try

Try to make the house as safe as possible so you don't have to worry about the person walking about. Make sure the person is comfortable and warm at night and reassure them. Think about what the risks are and don't try and prevent it if there is no real risk. For example, can they find their way home, are they able to cross the road safely? However, if the person is likely to get lost or be at risk outside you may have to stop them going out alone. Go along for a walk too and try a distraction.

Keep a current photo. Give the person ID such as a card, bracelet or pendant. And if the person is lost tell the police at once. Ask the Dementia Helpline (0808 808 3000) for a Helpcard, which the person can carry and show to someone if they get confused. The Helpcard also has a space for contact details for emergencies.

For more information on walking see our information sheet 'When people with dementia walk – guidance for carers'. Call the Dementia Helpline on 0808 808 3000 or download a copy from our website www.alzscot.org/pages/info/walking.htm

Embarrassing and odd behaviour

People with dementia may appear to lose social manners and behave in a way that can be thoughtless, rude or even offensive. This can place strain on carers and family. The person may take clothing off in inappropriate places or make unkind comments.

The person may be confused about where they are or forget what they should be doing. They may mistake the identity of people and so act in an inappropriate manner. The illness may have damaged the part of the brain that controls the person's inhibitions. It is

important to remember that it is the illness and not the person, who may not realise that their behaviour is upsetting.

What to try

It is important to ask yourself whether the behaviour matters and why. Try to stay calm and do not over react to the situation. It may be possible to distract the person from what they are doing. It may be appropriate to explain the behaviour to other people to take the pressure off the carer.

The behaviour may be as a result of discomfort such as uncomfortable clothing or a medical condition. Make sure the person sees their doctor who can check for a physical illness and provide advice.

Hallucinations and false ideas

Some people with dementia may hear or see things that are not there (hallucinations). This is especially common with Lewy Body dementia. Hallucinations are sensory experiences that cannot be verified by anyone other than the person experiencing them. Although these experiences are imaginary they seem real to the person and can cause panic.

People with dementia can also believe in things that are not true (false ideas). The person may become suspicious as a result of their failing memory. They may forget they have put something away and believe that it has been stolen. Or they may see a reflection in a window and mistake it for someone else in the room. Whilst these are not true hallucinations they can still be very upsetting to the person.

What to try

If the person is experiencing hallucinations, do not tell them that they are imagining it, as it will feel real to them. Explain that you cannot see or hear what they can but you understand how they feel. Reassure and comfort the person in a calm manner, this may help to bring them back to reality. Make sure they

see a doctor. The hallucinations could be caused by an infection or be the side effects of medication. If this is not the case the doctor may still be able to prescribe something to stop the hallucinations. If medication is prescribed it should be reviewed regularly by the doctor.

Look for practical solutions that may avoid the hallucinations. For example close the curtains or switch on a light. Visual hallucinations may be a result of poor eyesight. It cannot always be improved but you should arrange regular eye examinations, encourage the person to wear their glasses and check that their glasses are clean. If the person thinks someone is stealing from them check whether this is true. If you are sure that it is a false idea, speak to anyone who may be accused of stealing e.g. home support workers, children.

Needing attention

Some people with dementia need to be with their carer all the time. They may feel insecure and try to follow their carer everywhere. The person may not have any perspective on time and not realise how long their carer has been away. This may make the person want to try and stay with their carer all the time and it will be very difficult to cope with this lack of privacy.

What to try

It is important that the carer gets time to themselves, to relax and recharge. This will make it easier to cope with caring and the persons need for attention. Offer the person reassurance; explain what will happen and when you will return. Family and friends may be able to help out by spending time with the person either at home or taking them out on a trip. Day care and home support also offer the opportunity for carers to have time for themselves. For information on how to get services call the Dementia Helpline on 0808 808 3000.

Repetitive questioning

Sometimes giving information may help but it is often quickly forgotten. It can be very stressful when you are asked for the tenth time what day it is or when mother is coming home. It may help if you can understand that for the person with dementia, each time feels like the first time they have asked the question.

What to try

If explanation doesn't help, distraction sometimes works. It may help to acknowledge the *feeling* expressed, for example, "I know it's upsetting when you think you've got to get a meal ready".

Doing is often better than telling. For example, telling your husband that his mother died 30 years ago may not help and may be upsetting (but taking him to visit her grave could be more effective).

Getting help

Dealing with challenging behaviour day in, day out is not easy, but understanding why problems occur and so changing how you behave towards the person with dementia may make things easier. If you can do this it can help you to feel more in control.

It is often very useful to get help or advice on how to deal with a behavioural problem. You may be in contact with a community psychiatric nurse, psychiatrist or occupational therapist. They will all have experience of helping with behavioural difficulties caused by dementia.

For specific problems, you and the person with dementia may be referred to a clinical psychologist if there is one in your area who will be able to offer specialist help. Your GP may also be able to help, and can refer you to any of these people.

Pain

Older people in general tend to experience more pain due to medical conditions. While

Behaviour that challenges

each person feels pain differently, sometimes people with dementia are unable to describe their pain in words.

Someone in the later stages of dementia may be unable to say that they are in pain but instead communicate their pain through their behaviour. The person may:

- make unexplained/different noises e.g. groaning, crying?
- pace about or rock back and forth
- hit out when someone touches them or tries to help them get dressed or undressed
- appear irritable or stressed
- change their habits – not eating or sleeping; refusing to get out of bed.

It can be very easy to blame the person's worsening dementia for any changes in behaviour but it is important to consider pain as a possible explanation and have it treated appropriately.

Anti-psychotic drugs

Anti-psychotics are now regularly used for the treatment of restlessness, aggression and psychiatric symptoms common in people with dementia, although steps are now being taken to reduce the level of prescribing of these drugs.

Guidance for medical staff now stresses that people developing distressing behavioural symptoms should first be offered an assessment to try to establish any reasons for what is happening and that anti-psychotics should not be used as a "first resort" treatment option, except where there is severe distress or immediate risk of harm to the person or others.

For more information on anti-psychotics, see Alzheimer Scotland's information sheet *Anti-psychotic drugs: what to do if you are worried*.

Available to download at:

www.alzscot.org/pages/info/anti-psychotic-drugs-what-to-do-if-you-are-worried.htm

or from the Dementia Helpline on 0808 808 3000.

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Find us on the internet at
www.alzscot.org



The logo features a stylized icon of a person's head and shoulders in profile, with a smaller figure inside, representing a person with dementia. Below the icon, the text reads "Dementia Alzheimer Scotland Action on Dementia". The word "Helpline" is written in a large, bold, sans-serif font, with "24 HOUR" in a smaller font inside a square box to its right. Below this, the freephone number "0808 808 3000" and the email address "Email: helpline@alzscot.org" are displayed.