Dementia - behaviour changes

Summary

- Dementia can lead to behaviour changes, which may cause distress for the person with dementia and place added pressure on family and carers.
- Understanding why someone is behaving in a particular way can help families and carers to cope.
- Problems with sleeping are common for people with dementia.
- Discuss your concerns about behaviour changes with the family doctor.
- Physical and environmental changes may help with some changed behaviours.
- Always remember that the behaviour is not deliberate.

Dementia can cause changes in the behaviour of friends and loved ones. Such changes are very common, but they can place enormous stress on families and carers. Understanding why someone is behaving in a particular way may help families and carers to cope.

There are many reasons why a person’s behaviour may change. Dementia is a result of physical changes in the brain, and these can affect the person’s memory, mood and behaviour. Sometimes, behaviour may be related to these changes, but at other times, the behaviour may be triggered by changes in the person’s environment, health or medication.

Understanding the cause will help you to decide which strategies may be helpful. Some carers find that keeping a log or diary helps them to see a pattern of behaviour that may be developing, and this helps them to identify the cause of the changes.

Always discuss concerns about behaviour changes with your family doctor, who will be able to check for the presence of a physical illness or discomfort. The doctor will also be able to advise if there is an underlying psychiatric illness.

The Dementia Behaviour Management Advisory Service (DBMAS) is a national telephone advisory service for families, carers and care workers who are concerned about the behaviour of people with dementia.

Sleeping problems in dementia

Problems with sleeping are common for people with dementia. Some people sleep during the day and are awake and restless at night. Some are no longer able to tell the difference between night and day, while others are simply not as active as they used to be and so need less sleep.

Problems with sleeping or late evening agitation are often a stage in dementia that eventually passes. Many people with dementia sleep more during the later stages of the illness.

Sleep problems are among the most difficult dementia symptoms for carers. Families and carers must be able to get adequate sleep themselves. Plan regular periods of rest and regular breaks for yourself, as well as for the person with dementia.

Medical causes of sleeping problems in dementia

Sleeping problems may be caused by physiological or medical causes including:
• brain damage (caused by the dementia) that affects the ‘biological clock’ in the brain that directs our sleep patterns
• illness such as angina, congestive heart failure, diabetes or ulcers
• pain caused by conditions such as arthritis
• urinary tract infections that cause a frequent need to urinate
• leg cramps or ‘restless legs’, which can indicate a metabolic problem
• depression that causes early morning wakening and an inability to get back to sleep
• side effects of medication, such as antidepressants and diuretics
• snoring and sleep apnoea
• ageing that causes sleep patterns to change so that some people need more sleep and some need less.

Things you can try include:

• Discuss with the doctor the possibility of stopping or changing diuretic medication (which makes a person urinate), because this may be contributing to the problem.
• Arrange a medical check-up to identify and treat physical symptoms.
• Treat pain with an analgesic (pain-relieving medication) at bedtime if the doctor agrees.
• Discuss with the doctor whether sedatives may be contributing to the problem.
• Ask the doctor whether an assessment for depression may be necessary.
• Ask the doctor about possible side effects of medication.
• In some situations, it may be necessary to consider discussing with the doctor the appropriateness of either using tranquillising medication or sleeping medication. Sleeping medication may be helpful in the short term to establish a better sleep cycle, but both types of medication can have negative effects, such as increased confusion.

Environmental causes of sleeping problems in dementia

The environment of the person with dementia can cause sleeping problems in a number of ways including:

• The bedroom may be too hot or too cold.
• Poor lighting may cause the person to become disoriented.
• The person may not be able to find the bathroom.
• Changes in the environment, such as moving to a new home or having to be hospitalised, can cause disorientation and confusion.

Things you can try include:

• Keep the environment as consistent as possible.
• Check whether the person is too hot or cold when they wake up, because dementia can affect the body’s internal thermostat.
• Provide adequate lighting if shadows, glare or poor lighting are contributing to agitation and hallucinations.
• Move the mirror in the bedroom if the person becomes confused when they do not recognise their own reflection or the reflection of others in the room.
• Install night-lights that might help cut down on confusion at night and may help the person to find the bathroom.
• Place a commode next to the bed if finding the bathroom is a problem.
• Make sure the bed and bedroom are comfortable and familiar, because familiar objects may help to orient the person.
• Avoid having daytime clothing in view at night, because this may make the person think it is time to get up.
• Make sure that the person is getting enough exercise – try taking one or two walks each day.

Other causes of sleeping problems in dementia

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Other causes of sleeping problems may include:

- going to bed too early
- sleeping too much during the day
- overtiredness, causing tenseness and inability to fall asleep
- not enough exercise, so the person does not feel tired
- too much caffeine or alcohol
- feeling hungry
- agitation following an upsetting situation
- disturbing dreams.

Managing sleeping problems with food and drink

Some suggestions include:

- Cut down on caffeine (coffee, cola, tea, chocolate) during the day and cut them out altogether after 5 pm.
- Cut down on alcohol and discuss the effects of alcohol and medication with the doctor.
- If you think the person may be hungry at night, try a light snack just before bed or when they wake up during the night.
- Herbal teas and warm milk may be helpful.

Managing sleeping problems through daily routine

Some suggestions include:

- Try not to do any tasks in the late afternoon that may be upsetting to the person.
- If the person refuses to go to bed, try offering alternatives such as sleeping on the sofa.
- In some situations, it may be necessary to consider discussing the appropriateness of either using sedative medication or sleeping medication with the doctor. If the person wanders at night, consider allowing this, but check that the house is safe.
- Try a back rub before bed or during a wakeful period.
- Try a radio beside the bed that softly plays music.
- Gently remind the person that it is the evening and time for sleep.

Hoarding in dementia

People with dementia may often appear driven to search for something that they believe is missing and to hoard things for safekeeping.

Some causes of hoarding behaviours include:

- isolation – when a person with dementia is left alone or feels neglected, they may focus completely on themselves. The need to hoard is a common response
- memories of the past – events in the present can trigger memories of the past, such as living with brothers and sisters who took their things, or living through the Depression or a war with a young family to feed
- loss – people with dementia continually lose parts of their lives. Losing friends, family, a meaningful role in life, their income and a reliable memory can increase a person’s need to hoard
- fear – a fear of being robbed is another common experience. The person may hide something precious, forget where it has been hidden and then blame someone for stealing it.

Managing hoarding

Things that you can do to help manage hoarding behaviour in dementia include:

- Learn the person’s usual hiding places and check these first for missing items.
• Provide a drawer full of odds and ends for the person to sort out, as this can satisfy the need to be busy.
• Make sure the person can find their way about – an inability to recognise the environment may be adding to the problem of hoarding.

Repetitive behaviour in dementia

People with dementia may say or ask things repeatedly. They may also become very clinging and shadow the person caring for them, even following them to the toilet. These behaviours can be very upsetting and irritating for families and carers.

Managing repetitive behaviour

Things that you can do to help manage repetitive behaviour in dementia include:
• If an explanation doesn’t help, distraction sometimes works. A walk, food or doing a favourite activity might help.
• It may help to acknowledge the feeling expressed. For example, ‘What am I doing today?’ may mean that the person is feeling lost and uncertain, and a response to this feeling might help.
• Do not remind the person that they have already asked the question.
• Repetitive movements may be reduced by giving the person something else to do with their hands, such as a soft ball to squeeze or clothes to fold.

Wandering in dementia

Wandering is quite common among people with dementia and can be very worrying for those concerned for their safety and wellbeing. The person’s failing memory and declining ability to communicate may make it impossible for them to remember or explain the reason they wandered.

Develop an action plan for when a person with dementia wanders, such as noting the clothing they were wearing, and contacting neighbours and the police.

Reasons that a person with dementia might wander include:
• changed environment
• loss of memory
• excess energy
• searching for the past
• expressing boredom
• confusing night with day
• continuing a long-held habit
• agitation
• discomfort or pain
• believing they have a job to perform.

Managing wandering

Things that you can do to help manage wandering in dementia include:
• Get a physical check-up for the person to help identify whether illness, pain or discomfort has triggered the wandering.
• Discuss the side effects of medication with the doctor – try to avoid medication that may increase confusion, and cause drowsiness and possibly incontinence.
• Consider the psychological causes of wandering to try to determine if the person is anxious, depressed or frightened.
- Make sure that the person carries some form of identification that includes their current address, if travelling
- Use identification cards available from Alzheimer's Australia.

Sundowning in dementia

People with dementia may become more confused, restless or insecure late in the afternoon or early evening. This is known as sundowning and these behaviour changes can become worse after a move or a change in routine.

The person with dementia may become more demanding, restless, upset, suspicious, disoriented and even see, hear or believe things that aren’t real, especially at night. Attention span and concentration can become even more limited. Some people may become more impulsive, responding to their own ideas of reality, and this may place them at risk.

Visit the doctor for a check-up and a review of medication. There are a number of physical and environmental changes you can make to restrict stimulating activities to the morning and promote relaxation in the afternoon and evening.

Where to get help

- Your doctor
- Your local council
- Your local community health centre
- Dementia Behaviour Management Advisory Service (DBMAS) Tel. 1800 699 799 – for 24-hour telephone advice for carers and care workers
- National Dementia Helpline – Alzheimer’s Australia Tel. 1800 100 500
- Aged Care Assessment Services Tel. 1300 135 090
- My Aged Care (Australian Government information line) Tel. 18000 200 422
- Cognitive Dementia and Memory Service (CDAMS) clinics Tel. 1300 135 090
- Carers Victoria Tel. 1800 242 636 (also know as Carers Advisory and Counselling Service)
- Commonwealth Carelink and Respite Centres Tel. 1800 052 222
- Severe Behaviour Response Team (SBRT). Tel. 1300 014 424

Things to remember

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