Learning Guide

Dementia: Related behaviours

Name:

Workplace:

23923 Demonstrate knowledge of behaviour presented by people living with dementia in a health or wellbeing setting

Level 4 4 credits
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**Introduction**

This learning guide describes how to understand behaviours related to dementia and how you can better support people living with dementia.

**How to use your learning guide**

This guide supports your learning and prepares you for the unit standard assessment. The activities and scenarios should be used as a general guide for learning.

This guide relates to the following unit standard:

- 23923 Demonstrate knowledge of behaviour presented by people living with dementia in a health or wellbeing setting (level 4, 4 credits).

This guide is yours to keep. Make it your own by writing notes that help you remember things, or where you need to find more information.

Follow the tips in the notes column.

You may use highlight pens to mark important information and ideas, and think about how this information applies to your work.

You might find it helpful to talk to colleagues or your supervisor.

Finish this learning guide before you start on the assessment.

**What you will learn**

This topic will help you to:

- understand behaviours presented by people living with dementia.
- understand factors that trigger and influence behaviour.
- use strategies to positively manage behaviour when supporting a person living with dementia.

*More info*

If you have a trainer, they should give you all the forms that you need for this topic.
Dementia and behaviour

Dementia is an umbrella term used to describe a chronic disorder of mental functioning caused by physical changes in the brain resulting from disease or injury. When these physical changes occur they can lead to a loss of function for some parts of the brain. These changes affect memory, thinking, behaviour and emotions.

Behaviour is the action we take as we respond to a situation. For people living with dementia, the changes in their brain make it more difficult for them to act in the way they have ‘normally’ done in the past. Changes in their environment, health or medication may make it even harder for them to express themselves. Memory loss and the resulting confusion can sometimes cause emotional reactions and behaviour patterns that take a special effort to manage.

The behaviour of a person living with dementia can become very challenging for the people who provide support. Understanding why someone is behaving in a particular way can give some clues to the best way of managing their behaviour.

Behaviour patterns have meaning; the challenge is to understand their significance and why they are happening, so that any unwanted behaviour can be managed, decreased or diverted.

In this guide we will look more closely at common behaviour patterns in people living with dementia and the kinds of behaviour that create challenges for the people who support them. We will see how these behaviour patterns can be triggered and look at some positive ways of managing them.

More info

For more information on dementia refer to the learning guides for unit standards:

23920 Dementia: Support and safe practice
23921 Dementia: Person-centred support
23922 Dementia: Effects of providing support

You can also find additional resources on the Careerforce website:
http://ilearn.career
Dementia-related behaviours

Behaviour is very individual. The way each person sees and reacts to the circumstances of their world will determine their patterns of behaviour.

Terms used to describe difficult or unwanted behaviour include:

- problem behaviour.
- disruptive behaviour.
- challenging behaviour.

Changes in behaviour are very common in people living with dementia. The changes may be related to the condition itself, or to other influences such as:

- other changes in the brain or another part of the body.
- pain, such as a headache or sore neck.
- a response to what is going on in the person’s environment, such as the amount of activity.
- the people around the person and their reactions.

These things are outside the person’s control and can be a very frightening experience for them. People living with dementia do not try to be difficult – it is often their attempts to communicate their feelings, thoughts and frustrations, and their ability or inability to do this, that cause their behaviour to change and/or seem challenging to others.

It is important to assume that there is a purpose to the behaviour. Once the reason for the behaviour is understood, it is usually easier to develop effective ways of working with the person to manage its challenging aspects.

Effective ways of managing behaviour sometimes develop from trial and error and by testing what works and what doesn’t. What works one day may not work the next, so a variety of strategies may be needed. This can be very tiring for those who provide care and support for the person living with dementia, so it is important that carers have time to relax and recharge and also receive support themselves.
Coping with dementia-related behaviour

Behaviour is an issue for the support person rather than for the person living with dementia. How behaviour is perceived will vary from person to person – what is seen as a problem by one person may not be a problem to another.

The effects of dementia-related behaviour can:
- restrict the person from taking part in everyday life.
- put the physical safety of the person at risk.
- put the physical safety of others at risk.
- increase the person’s anxiety and/or aggression.

Positive support for a person living with dementia is important, especially if the person shows aggression.

Positive techniques for managing behaviour include:
- maintaining a calm approach.
- avoiding raising your voice (even if the behaviour is difficult for you to cope with).
- using individualised and creative ways to distract the person from the unwanted behaviour.
- trying not to take the behaviour personally.
- keeping the environment familiar and routines consistent.
- knowing how to get assistance when you need it.
Types of dementia-related behaviour

Some common behaviours that can cause challenges for the person providing support are:

- wandering.
- aggressive behaviour.
- hoarding and rummaging behaviour.
- repetitive behaviour and vocalisation.
- catastrophic reactions.
- sundowning.
- sexually inappropriate behaviour.
- anxiety.
- agitation.
- hallucinations.
- delusions.

Wandering

Wandering is common among people living with dementia and is a cause for concern when their failing memory and difficulty in communicating may make it hard for them to get the help they need to return home.

There are many factors that may cause a person to begin to wander.

- A change in their environment – for example, they may have moved to a new house or a different room.
- Loss of memory – the person may forget where they were going or why, or may they may forget that their carer has gone out for a while and set out in search of them.
- Excess energy may be a symptom of the need for more exercise. Walking or rocking in a rocking chair may help.
- They are searching for a person or an object in their past.
- Boredom or a lack of concentration makes it difficult for them to do activities they previously enjoyed.
- Reversing day and night – sometimes people living with dementia confuse day with night, wake early and are disorientated, or are used to being active at unusual times (for example, if the person was a shift worker). Poor eyesight or hearing loss can mean that shadows or sounds become confusing and distressing.
• Habit – people may be used to walking long distances or think they have a job to do.
• Agitation, restlessness and anxiety.
• Pain or discomfort, tight clothing or the need to go to the toilet.
• Dreams that seem real.

Managing wandering

Helping the person living with dementia to remain safe is the most important part of managing wandering. A person living in their own home near a busy intersection will have different needs from the person who lives in a secure environment such as a dementia facility.

Here are some precautions to prevent wandering.
• Look for an immediate cause – for example, pain, discomfort or medication.
• Ensure that the person wears some form of identity – for example, a bracelet or photo ID showing their name and a contact phone number. Some Alzheimer’s associations have ID cards available.
• Remove from sight items such as jackets, handbags or outdoor clothes that may act as a trigger for going out.
• Use visual barriers – for example, disguise the door, place white strips in front of it or put up ‘stop’ or ‘no exit’ signs.
• Install alarms on doors or pressure mats at exits, to alert carers. An extra lock on the door may also help.
• Keep the garden secure but accessible. Disguise exits whenever possible.
• Tell the neighbours or local shops that the person may wander and may need help to get home. In some situations it may also be useful to advise the local police and provide a photo ID of the person for their records.
• Look for a pattern or reason for the wandering. What kind of wandering is it? For example, is it aimless or does the person believe they are going to work?
• Try to distract the person by introducing another activity.
• Walk with the person for a while and then suggest that they take a rest.
Aggressive behaviour

Aggressive behaviour can be physical (for example, hitting, spitting, biting) or verbal (for example, using abusive language).

Aggressive or altered behaviour may be due to frustration, anger or fear. For example, if the person feels that their personal space has been invaded when you are standing close to them, they may react with anger and confrontation.

Preventing the behaviour by recognising the things that can trigger it can help prevent a situation from developing or becoming worse.

Getting the person to take part in a meaningful activity can help defuse the situation – for example, you might say “Come and help me make the tea”.

It is important to assess an aggressive situation after the event, to decide what may have triggered the unwanted behaviour. Support workers who do not understand the person living with dementia may interact with them in a way that triggers an unwanted response.

Understanding the reasons for the behaviour may suggest additional strategies that support workers can use to reduce the likelihood of it happening again.

Managing aggressive behaviour

There are a number of ways to help manage aggression displayed by a person living with dementia. Here are some useful strategies.

• Talk to the person in a calm, confident and reassuring way. Remain calm at all times.

• Approach the person slowly, making sure they can see you. If the person is known to be aggressive at particular times, approach with two staff members to support you.

• Let the person know that their anger is recognised. Do not respond to anger with anger.

• Use short, clear statements to talk to them – for example, “I’m going to help you put your jacket on”.

• Gently encourage the person to a secluded area well away from others. This avoids others becoming anxious or frightened by the person’s aggressive behaviour. It also allows the support person to devote attention to the angry person and reduces distractions.

• Try to distract the person by talking about things they have enjoyed in the past.

• Always prepare the person by explaining what is going to happen, or where you are going, before you start.
• Avoid putting the person in situations that may produce anxiety, fear, frustration or disorientation.

• When showering or dressing an aggressive person, provide care from the side of the person, not from in front of them. If the person responds negatively to personal care, try giving them a facecloth or towel to hold while you are providing care.

• Try to avoid arguments. It can be better to agree with what the person says or does and then try distraction or humour, or provide friendly help.

• Try to use encouragement, praise and affection rather than criticism, anger or frustration.

• Keeping a diary may help to identify the triggers and circumstances of an aggressive episode, so that the same situation can be avoided in the future.

Dealing with physical aggression
Aggression may get physical. Here are some ways to deal with physical aggression and keep safe.

• If the person is not causing harm to themselves or others, leave the person alone.

• Avoid approaching the person until they have settled down.

• Stay out of reach and try to ensure that the person can’t do any real damage to anyone or anything.

• Keep the environment as safe as possible by moving dangerous objects away.

• Allow plenty of space between you and the person – aggressive people need more space, and personal space promotes feelings of security.

• When walking with a person who is known to be aggressive, walk with them between you and the wall. Don’t walk in between the person and the wall, as this leaves you nowhere to go and may put you at risk.

• Avoid making the situation worse by shouting at the person or abusing or touching them. Speak in a calm voice and use reassuring words.

• Redirect the person to some other activity.

• Never punish the person after the event, as they are unlikely to remember what happened and the punishment won’t have a helpful effect.
Read the following scenario and then answer the questions that follow.

**Lena**

Lena has been married to a caring husband for 40 years and has three supportive children. Sue, the youngest, remembers how her mother started to show symptoms of dementia ten years ago. First there was forgetfulness then confusion, along with a breakdown in the communication skills that had once come so easily to Lena. As Lena’s condition continued to deteriorate the family realised that she might have Alzheimer’s disease.

All of Lena’s family wanted to care for her however they could. They recall the really difficult times when Lena started showing violent behaviour (which was very uncharacteristic of her) and began wandering at night. This brought new challenges for the whole family, including the need to have some relief care when everyone was too tired to cope.

There were special times as well, especially when Sue played the piano for Lena. Lena could no longer recognise the family or communicate with them in words. She would sit silently in a chair next to the piano showing no sign that she was hearing the music. The family noticed, however, that Lena had fewer violent outbursts after she had listened to the music for a while. Her daughter would play song after song and after each one Lena would begin to clap. This was one of the few things that Lena still responded to.

**What behaviour was Lena showing?**

**What did the family do to help manage these behaviour patterns?**

**How did Lena respond to the way the family chose to manage these behaviour patterns?**
Think about a situation when you supported a person living with dementia who showed signs of aggression or was aggressive.

**What were the triggers that caused the aggression?**

**What (if anything) did you do to minimise or eliminate these triggers?**

**What strategies did you use that worked well, and what effect did they have on the person?**

**Were there other strategies you could have used?**
Hoardings and rummaging

A person living with dementia may be driven to search for something they believe is lost or to hoard things for safekeeping. This activity often makes the person feel useful and purposeful.

This kind of behaviour may be caused by isolation – the person may feel alone, bored or neglected. The urge to hoard is a common response to the need for security.

Fear of their possessions being stolen can lead people living with dementia to hoard objects or forget where they have put things. This can lead them to blame others or accuse them of taking the item.

Events in the present will often trigger memories of the past – for example, a sibling may have taken the person’s possessions when they were children or they may have worried about having enough food for the next family meal.

Rummage boxes, containing objects that feel interesting or are related to the person’s past, may help to keep hands occupied. This is an option for excessive hand activity where the person constantly wrings their hands, pulls at their clothes, taps or fidgets or touches themselves inappropriately in public.

Rummaging can obsessive and become an ongoing daily activity. The items chosen may make no sense to others.

Rummaging can provide comfort, pleasure and satisfaction, so it is a worthwhile activity under safe and controlled situations.
Managing hoarding and rummaging

Here are some tips to manage hoarding and rummaging.

- Get to know the places where the person usually puts their treasured items and check there first.
- Keep a spare set of items that are frequently misplaced, such as a purse or their glasses.
- Replace valuable items with look-alikes that have little value. You may need to involve the family in this. If you must remove an item, have something to replace it or ‘trade’ with the person.
- Keep the person busy with a selection of things that need sorting. The type of item should be relevant to the personality and interests of the person – such as sorting socks, wool, laundry, fishing equipment or hardware.
- Provide ‘safe’ rummaging by providing a drawer of items for the person to organise how they wish. Include items that provide comfort as well as items that provide some sensory stimulation.
- Use activity frames or ‘busy boards’ that have moveable parts or things to touch. This helps with boredom and the need to rummage, without leaving items spread around.
- Do not scold the person for losing items or hiding things.
- Redirect the person to other enjoyable activities such as music.
Read the scenario and then answer the questions that follow.

All of her life, my mother was known for sending greeting cards without fail to everyone, even people she barely knew. Although she had always been slightly eccentric, she was also loving and generous. Then a few things started to change. She forgot to send cards, even to the close family. She stopped being excited about Christmas and didn’t do the usual Christmas baking. She asked the same questions over and over again, which drove me crazy. She would think that she had just eaten, or showered, or written letters, or phoned someone, or sent a gift. Sometimes she remembered that she hadn’t, and then she would get really upset and tearful. Somehow she thinks she is a failure. She seems to understand that her mind isn’t what it used to be. She needs to be constantly reassured.

Then recently, when I was helping her tidy up the spare room, I came across boxes full of old newspapers – she said she was keeping them ‘just in case’, but she could not explain what ‘just in case’ meant. I noticed that she was starting to hoard a strange collection of odds and ends in the cupboards. When I asked her why, she told me quite seriously that it was for the children to play with when they came home from school. Then, just the other day, she accused me of stealing an ornament from the bedroom, which really upset me. It certainly wasn’t in its usual place. I then discovered the broken pieces in her usual hoarding place under the stairs. But she still blames me for taking it. I know she can’t help it, but it certainly isn’t nice to be accused of something you haven’t done!”

What are some of the positive things about hoarding and rummaging?

What are some of the negative things about hoarding and rummaging?
Repetitive behaviour and vocalisation

**Repetitive behaviour** means repeating words, doing the same things over and over again and asking the same question over and over, even when it was answered just a few minutes earlier. Sometimes the person will follow you around, or constantly be ‘in your space’. This can cause anger and frustration for the person providing support.

**Vocalisation** means using the voice for expression. Vocally disruptive behaviour includes loud and repetitive verbal utterances, sounds that make no sense, crying and screaming. The person may be vocally disruptive because they are unable to communicate their personal needs, wishes and thoughts.

These behaviour patterns may be related to an unmet physical need such as wanting to go to the toilet, being in an awkward or uncomfortable position or feeling too hot or too cold.

**Psychological distress** is a range of symptoms or experiences that the person finds troubling or confusing. Calling out may be a sign of psychological distress. This may be the only way in which the person is able to communicate sadness, frustration or distress.

**Environmental factors** can cause repetitive behaviour and vocalisation. An overstimulating environment may lead to agitation, irritability, stress and confusion. Repetitive behaviour may also be the result of loneliness and boredom caused by a lack of stimulation or social contact, or not being able to see what is going on.

**Managing repetitive behaviour**

If the behaviour does not bother you, do nothing. Otherwise, here are some ways to manage repetitive behaviour.

- Look for the feeling behind the words and respond to this. For example, the person who constantly asks what is happening next may be feeling lost or uncertain. Talking about this feeling can help.
- Avoid reminding the person that they have already asked the same question before. Instead, try to give a different answer or turn the question into a discussion.
- If the repetitive activity involves the hands, try giving the person something else they can do instead – for example, folding the washing.
- When explanations don’t help, try distractions such as a walk or a favourite food or activity.
- If the person living with dementia can read, use memory aids such as written labels on objects, notes they can use as a memory aid and a whiteboard with a list of the day’s activities and/or schedule.
• Increase social contact and meaningful activity. Know and use the person’s past skills and interests – for example, if the person enjoyed plants and flowers, encourage them to take a walk in the garden.

• Change the level of stimulation according to need. If the person is overstimulated, place them in a quieter environment; if they are understimulated, place them in a communal area such as the lounge room.

• Provide adequate meals, snacks and fluids to prevent hunger and thirst; this is a common problem for people living with dementia.

• Use sensory techniques such as massage, if appropriate.

Catastrophic reactions

Catastrophic reactions are overreactions to ordinary situations that result in responses or outbursts such as shouting, crying, making unreasonable accusations, becoming very agitated or stubborn, crying or laughing uncontrollably and inappropriately or displaying a high level of agitation. This kind of behaviour can result from:

• stress as the person feels out of control.

• frustration from not getting their message across.

• an underlying illness or a change in health.

The behaviour may develop very quickly and make others feel very frightened. Sometimes carers can unwittingly make things worse. The person may become physically violent if they are touched at these times.

Difficult behaviour can sometimes be managed by giving control back to the person or by letting them calm down in a safe environment. Trying to figure out what triggers catastrophic behaviour can sometimes help avoid it in the future.

Managing catastrophic reactions

Catastrophic reactions can often be avoided by keeping to a routine, such as:

• doing a task at the same time each day.

• doing a task in the same way – for example, sitting in the same chair can be reassuring and help the person to orient themselves.

• doing things in the same order each time helps to reduce the stress of the unexpected.

• anticipating the person’s needs helps to avoid frustration.

Keeping a diary or recording incidents in your progress notes can help to identify the circumstances of such behaviour.
Sundowning

People living with dementia are often at their best early in the day. As the day progresses, however, the person’s memory and ability to carry out tasks can deteriorate. **Sundowning** is the term used to describe the increased confusion, restlessness and agitation that people living with moderate to severe stages of dementia may experience in the day and evening and sometimes into the night. It may become more obvious when there has been a change from the usual routine – the person may become less cooperative and be more likely to argue.

Sundowning is thought to be the result of changes in the brain. There is some evidence that it is caused by severe damage to the parts of the brain that control the internal body clock so that the normal urges to sleep when tired and wake when rested (the sleep/wake cycle) are out of balance.

A person’s previous habits, such as closing up a shop, getting ready for the next day or cleaning up before going to bed, may also contribute to sundowning.

There are several possible causes of sundowning.

- **Disrupted sleep** – people living with dementia may experience wakefulness and confusion that last throughout the night. They may also tire more easily and may become more restless when they are very tired.

- **Overstimulation or fatigue during the day** can result in confusion, restlessness and a feeling of insecurity at night. The loss of security together with a reduced understanding of what is going on around them can increase a person’s restless behaviour.

- **Fear of the dark**, which is often caused by the lack of the familiar daytime noises and activities. The behaviour may also occur when there is less sensory stimulation at night, and when cues such as noises, lights and activity are reduced.

- **Some medications** can cause sundowning. The dosage or timing of medications may also be trigger factors.

- **Physical discomfort**, such as pain, hunger or the need to go to the toilet.

- **A drop in blood pressure** during the day or after a meal can take oxygen away from the brain and increase confusion.

- **Changes in glucose levels in the blood** may bring on agitation and confusion, especially if the person also has diabetes.
Managing sundowning

Here are some tips for managing sundowning.

- Check for and deal with any physical discomfort.
- Be flexible in your approach and your expectations of the person. Don’t expect more than the person is capable of doing.
- Maintain familiar routines – for example, setting the table, closing the curtains, or having a pre-dinner drink can be helpful, or other meaningful activities.
- Avoid giving the person drinks containing caffeine in the afternoon and evening.
- Use low-glare lighting and be aware of the effect of bright lights, television and family activity. Try using a nightlight in the person’s bedroom.
- Remain calm and try to be undemanding so that the person feels safe and secure. Remember that a person living with dementia does not have control over their personal behaviour.
- Avoid stimulating activities (such as a shower) at an unusual time of day as this may add to the agitation.
- Meet the physical needs of the person – for example, hunger, thirst or the need to use the toilet.
- Avoid too many naps during the day.
- Focus on morning activity and a rest after lunch.
- Play soothing music for relaxation.
- Suggest a walk outdoors when the person is restless.
- Provide stimulating activity during the day without exhausting the person.

Keep a diary or record in your progress notes the different strategies you have tried and their effectiveness. Over time, this can help you to identify some problems often experienced by the person and the triggers that led to them.

Medication and outside support such as respite care may be required if things become too difficult or the caregiver requires a break.
Sexually inappropriate behaviour

Sexually inappropriate behaviour can be a frustrating, embarrassing and potentially frightening experience for a support worker. These behaviours are connected to damage in the frontal and temporal lobes of the brain so that the person living with dementia may lose their ability to control their responses.

There are a number of reasons for a person living with dementia to act out sexually. These may include:

• emotional stress leading to feelings of inadequacy.
• resentment or anger related to sexual difficulties.
• confusion or disorientation.

When people living with dementia display behaviour that seems to be sexually oriented it is not necessarily related to sex – there is often an innocent explanation. For example, when the person seems to be fidgeting or attempting to masturbate they may actually be trying to loosen their clothing or go to the toilet. In the same way, if they take off their clothes they may appear to be indecently exposing themselves when they may simply be too warm.

Managing sexually inappropriate behaviour

The key thing in managing sexually inappropriate behaviour is to remember, first and foremost, that it is the disease that is at work in these situations.

Here are some tips for managing sexually inappropriate behaviour.

• Remain calm and try to not show shock or irritation.
• Keep a journal of inappropriate sexual behaviours and possible triggers. For example, a woman living with dementia may lift her skirt as an indication that she needs to go the toilet.
• Report these behaviours to your healthcare professional so that they can try to identify causes and possible treatments.
• Distract the person or redirect them to other topics or activities.
• Gently but firmly explain that their behaviour is inappropriate.
• Try to guide the person to a private area.
• Understand that certain stimuli may prompt crude remarks. Educate others about the person’s disease to help avoid misunderstandings or confrontations.
Think about someone living with dementia whom you support and answer the following questions.

What are your organisation’s policies and procedures for the safety of people who are prone to wandering?

What strategies does your organisation use to support a person who experiences sundowning?
Triggers for behaviour

What things can trigger or influence certain behaviours in people living with dementia?

Dementia affects people in different ways, so it is important to understand what the person is experiencing and how it can affect the way they behave.

Changes in the brain

As the brain function deteriorates, the person may be aware that something is ‘not quite right’. This can lead to increased anxiety.

Some types of dementia affect particular parts of the brain. For example, Lewy Body dementia affects the part of the brain that controls thinking and movement. The person may have hallucinations, visual disturbances or symptoms similar to Parkinson’s disease.

Another example is Pick’s disease, which affects the frontal lobe of the brain. This is the part that controls behaviour. The person may show changes in personality – for example, they may become withdrawn or show less control over their actions.

Communication style

As the person living with dementia loses language, they rely increasingly on other communication cues such as body language, tone and pitch of the voice (rather than the words) to understand the world around them. Their behaviour may be an attempt to communicate with others.

Communication is made easier when the person living with dementia is able to concentrate on what is being said. Here are some suggestions.

- When you speak to the person, make sure that you are facing them, that the light is good, and that the person can hear what you say.
- Speak slowly and clearly and talk about one idea at a time.
- Touch can also be a useful way to communicate with the person, convey care and concern and provide reassurance in a confusing world. Make sure that touch is culturally acceptable to the person living with dementia.

Approach used by other people

A respectful and calm approach reduces stress for the person living with dementia and helps to reduce confusion and uncertainty. As a support worker, using a strategy of maintaining routines and consistency will help the person to anticipate events or activities.
Loss of choice

As the person relies increasingly on others for support it is easy for carers to take over. This leaves the person with less choice and may lead them to lose confidence in their own ability to make choices. This in turn will increase their stress, anxiety and frustration.

The environment

The environment plays a major part in the way a person living with dementia behaves. Factors such as noise, activity levels, lighting or large groups can decrease the person’s level of functioning.

Too much stimulation can lead to agitation, while too little can make the person apathetic, unresponsive and frustrated.

Sensory issues

Problems with sight and hearing can affect the person’s ability to communicate. For example, their hearing aid may not be working, their glasses may not be the correct prescription or the person may forget to wear them.

Anxiety

Many aspects of the person’s life can cause them to become anxious. The multiple frustrations of daily activity, feeling unwell, feeling pressured to perform beyond current abilities and being unable to tell you what is wrong can all cause anxiety. Clinging behaviour, such as when the person will not let you out of sight even to go to the toilet, is another sign of anxiety.

Anxiety can be a response to tension or the negative feelings of other people.

Health and medications

Changes in physical health can cause discomfort, anxiety and concern, which in turn may trigger dementia-related behaviour. Some medications can increase the person’s confusion and agitation and alter their body functions – for example, some sleeping tablets can also cause incontinence or urinary retention.

Interactions between medicines can have unexpected and unpleasant results for people living with dementia. Changes of medication can also influence changes in behaviour.
Self-esteem and dignity

A person living with dementia may feel humiliated because of the need to accept help with personal care for functions such as bathing, toileting and dressing.

The person may also feel that their independence and privacy are being threatened. This can lead to negative responses when personal care is suggested.

Loss of independence

The person finds it more difficult to complete tasks they previously found simple and may be aware of their reduced function. This can lead to physical or verbal aggression towards the people who are supporting them.

Attempts to help the person can emphasise their lost abilities. Maintaining the person’s independence whenever possible is a major factor in balancing their frustration levels with a sense of personal achievement.

Service limitations

When only a few people are available to care for the person living with dementia, they may not be able to provide the individualised support that the person requires.

Cultural factors

Knowing the cultural background of the person living with dementia is important in determining the kind of support that will be provided. Culture can affect communication, food preferences, what we celebrate, how we show respect to an older person and what the person enjoys doing.

As dementia progresses, the way a person responds to cultural factors can change. Here are some examples.

- The person may revert to their first language, which can make verbal communication difficult.
- Celebration events can trigger happy memories and help the person to retain contact with others and socialise in a meaningful way.
- Food can trigger pleasant memories and help the person living with dementia relate to past events and times.
- A person experiencing dementia may find meaning in religious activities and events. This can also help to reduce anxiety and increase their sense of security.
**Write**

Think of a person or people living with dementia. What behaviours do they display? Why do you think the behaviour happened? Fill in four behaviours in this table.

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<thead>
<tr>
<th>Description of the behaviour</th>
<th>What was the trigger for the behaviour?</th>
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Strategies for managing behaviour

Supporting a person living with dementia requires good observation, creativity, resourcefulness, patience and understanding. Each person living with dementia is different, but they will all respond to individual attention from people who care about them and have the time and energy to communicate effectively with them. The person may be increasingly bewildered by the world around them, but the ‘original’ person is still there under the dementia. The challenge for the carer is to understand and meet the person’s needs.

Strategies for encouraging positive responses

The way we act when we are supporting a person living with dementia has a direct influence on the way the person responds and behaves. We can adapt our caring styles so as to encourage positive responses from the person living with dementia. If the person resists or is aggressive but is not causing harm to themselves or to others, leave them alone. Give the person time to settle down, and come back later.

We can encourage positive responses by the way we speak and the body language we use, by creating a positive relationship with the person and by treating them with empathy and understanding.

Spoken language

You can show care through your tone of voice and spoken language, by:

- explaining what you are doing.
- simplifying the language you use.
- simplifying tasks.
- reducing the amount of information you give at one time.
- being gentle and using a calm voice and manner.

Body language

You can show care through your body language by:

- making sure the person can see you coming when you approach them.
- trying to be at the person’s eye level when you are talking to them.
- using physical affection when appropriate.
- smiling – the person will take their cue from you and mirror your relaxed and positive body language and tone of voice.
Positive relationships

You can show care by building a positive relationship with the person as an individual.

- Get to know the person’s preferences, routines and dislikes.
- Get to know the person and show an interest in them.
- See the person beyond the disease and understand that the ‘original’ person is still there.
- Believe in and respect the right of the person to make choices within their abilities.
- Really listen to what the person is saying or trying to communicate.
- Be patient and avoid showing any frustration.

Being with the person

You can show care by being with the person and:

- respecting and understanding the realities of what the person is experiencing.
- adjusting your actions to the person’s rhythms.
- slowing down and spending time with the person, even if you have a lot to do.
- being flexible with routines.
- validating the person’s experience.
- empathising with the person.
Steps for managing behaviour

Define the problem

Ask yourself these questions:

- **What is the behaviour?**
  Is it threatening behaviour, verbal abuse, roaming, sexual behaviour, being demanding, asking repetitive questions, or rummaging?

- **Who has the problem?**
  Is it you or is it the person living with dementia? If the person does not have a problem and the behaviour does not bother anyone else, is it a problem at all?

Look for what triggers the behaviour

It is a good idea to keep a record of what triggers certain behaviours.

Consider the following possibilities:

- Medications – are they the right ones and at the right level for the person? Are they necessary or are they making the behaviour problems worse? Has the medication been changed recently?

- Is the person unwell? Are there medical issues that are contributing to the behaviour such as a urinary tract infection or an upper respiratory tract infection?

- Does the person have pain that they may not be able to recognise or communicate adequately?

Other triggers could include anything that impacts on the person’s senses, such as overstimulation, confusion, depression, frustration with communication, loss of personal space, the need to control a situation, anger, grieving, fear, anxiety, boredom, intrusive thoughts, loneliness, a change in routine, a lack of control or the urge to do something.

When does the behaviour occur?

It is good practice to keep a record or behaviour log to identify trends and patterns of when certain behaviour is displayed.

Some of the more common reasons for a change in behaviour are:

- times of the day – for example, sundowning.

- a change of season can trigger a change in living patterns – for example, going out less in winter and more in summer.

- a change in routines.

- a change in the usual cycle – for example, the behaviour follows three nights of erratic sleep.

- a reaction to stimuli – for example, fear or confusion.
Look for warning signs

Non-verbal cues, especially body language, facial expressions, physical movements or using a louder or softer voice, can sometimes be the best indicator that behaviour may change. Look for the meaning behind the behaviour.

What makes the behaviour worse?

Take note of what can make the situation worse. This could be:

- anything that affects the senses, such as confrontation, overstimulation or a change in temperature.
- changes in routine, such as hurrying or making demands that the person is unable to understand or achieve.
- reacting negatively to the person’s behaviour.
- trying to reason with the person or prolonging the argument.
- trying to make the person do something they don’t want to do. Ask yourself “Is it really that important?”

What can make the behaviour better?

Have a range of strategies and learn what works best. This could be:

- shifting the focus away from the behaviour – try a change of subject or activity or arrange a treat.
- keeping decision making at a minimum.
- trying to find purposeful activities or exercise.
- checking the person’s general health and wellbeing.
- validating the person’s feelings.
- keeping a sense of safety by practising consistency and continuity. Don’t try to change the routine or the person’s patterns and allow them to do what makes them content.
- being flexible and not pushing. Back off and try again later.
- allowing plenty of time when you ask people to do tasks.
Things to consider

A useful checklist to use when trying to decide what lies behind the behaviour that you are observing, is to consider the PIECES formula.

**Physical causes**
For example—UTI, flu, constipation, pain or discomfort, hunger.

**Intellectual causes**
For example—Frustration with lack of ability to communicate.

**Emotional causes**
For example—Need for touch, love, grief and loss, boredom.

**Capabilities**
For example—The link between the task and the person’s remaining abilities to carry it out.

**Environment**
For example—Lighting, noise, activity in the environment.

**Social and cultural factors**
For example—Social interactions, style of support, life experiences and culture.

Other strategies

Many of the positive strategies to deal with behaviour have already been discussed in this workbook.

The table on the next three pages provides an overview of some additional ways that you can obtain the information you need to positively support a person living with dementia.
### Strategies

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<th>Description</th>
<th>Example</th>
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<td><strong>Diversion</strong></td>
<td>Use familiar distractions such as:</td>
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| A diversion is a kind of distraction that takes the person’s attention away from the unwanted behaviour. Caregivers often become very skilled at developing strategies to distract the person living with dementia. Often it means having a range of distractions, because the person may not respond to the same tactic each time. The person’s response to the diversion can change according to their level of tiredness, the time of the day or their general health. | • music that the person enjoys.  
• exercise.  
• playing cards.  
• reminiscing.  
• a walk outside.  
• purposeful activities such as making a cup of tea or folding washing. |
| **Individualised service plan**    | The following terms may be used to describe all the ways that the person needs support with their behaviour. |
| Each person will have an individual plan that outlines specific ways to support positive behaviour. The plan will be developed over time after a full assessment. Some people will require a very detailed plan, or it may be a 24-hour plan that reflects the changes in the person’s behaviour throughout the day. There is also likely to be an associated activities plan that adds more information and strategies for social and daily routines. There should be enough information for you to safely provide all the support needed. The plan should be reviewed and updated regularly by the multidisciplinary team. | • activities plan.  
• lifestyle plan.  
• 24-hour plan.  
• behaviour plan.  
• care pathway.  
There may also be a behaviour flowchart that tells you in a picture form which actions to take – for example, if the person becomes very aggressive. |
| **Safe social and physical environment** | Behaviour requiring specialist care may be: |
| Someone living with dementia may need specialist support in a safe environment because of their behaviour. When they cannot be supported at home they may need to enter a specialist residential dementia facility. | • unsafe wandering.  
• screaming and shouting, causing disruption.  
• aggressive behaviour towards others.  
• inappropriate sexual behaviour. |
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<td><strong>Individualised activity plans</strong>&lt;br&gt;These may be the responsibility of a diversional therapist or may be incorporated into the general plan and used by all staff. There will often be an activities coordinator who is responsible for implementing parts of the person’s individual plan.</td>
<td>Activity plans may include:&lt;br&gt;• a leisure programme.&lt;br&gt;• individual one-on-one activities.&lt;br&gt;• group activities.&lt;br&gt;• outings.&lt;br&gt;• day care.</td>
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<td><strong>Avoidance of triggers</strong>&lt;br&gt;The individual plan is likely to identify any particular triggers for unwanted behaviour, but you may notice others. It is important that you report and document anything you observe so that the triggers and strategies can be reviewed and included in the plan. You will need to be alert to activities, noises, smells and people who may distress the person or which could increase the unwanted behaviour.</td>
<td>You need to know the person well. For example, you may observe that the person becomes increasingly agitated when there is loud music in the room. As a result, you might redirect the person before the music starts or seat them away from the music.</td>
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<td><strong>Time out</strong>&lt;br&gt;If people are overloaded with information and other kinds of stimulation, they may be unable to cope and their behaviour may change. Removing them from the environment causing the overload will help them to retain control of their behaviour. They are not restrained and they can return at any time.</td>
<td>A resident you support becomes very vocal during the weekly church service, which upsets those around them. Knowing this, you offer the person an alternative activity in a quieter environment such as in a small lounge nearby, or an individual meeting with the pastor or minister.</td>
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<td><strong>Communication techniques</strong>&lt;br&gt;Communication techniques are the ways in which we exchange information. They may be written, spoken or expressed through gestures and body language. It is especially important that the ways in which we communicate with a person living with dementia are kept simple. As language is lost, the person relies increasingly on other kinds of communication such as body language and the tone and pitch of the voice (rather than words) to understand the world around them.</td>
<td>A calm voice, simple instructions and a low-stress environment help a person living with dementia receive your message clearly. You will need to learn the best way to communicate with each person. Information about this will be in the person’s plan.</td>
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<td><strong>Staff education and training</strong></td>
<td>Education and training may include:</td>
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<td>• in-service sessions.</td>
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<td>• orientation programmes.</td>
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<td>• case conferences.</td>
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<td>• family meetings.</td>
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<td>• clinical sessions.</td>
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**Debriefing**

Debriefing is a kind of interview or meeting in which you are asked about or report back on a task or event after it has ended. It is often used to analyse serious events so that the cause of the problem can be found.

A debriefing would be held after an episode of aggression in which a staff member was hit by a resident.

**Stress management**

This is a way of dealing with stress using physical and psychological techniques. It helps people cope better with strain and anxiety.

Examples may include:
• relaxation.
• exercise.
• meditation.

More info

US 23922 provides detailed information on strategies for stress management.