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**Coping with
challenging
dementia-related
behaviours**

Summary

Caregivers of individuals with dementia know that care can be difficult as the disease progresses. This is often because people in the late stages of dementia show challenging behaviours that can cause situations which are difficult to handle.

These changes in behaviour are caused by neurological changes in the brain as a result of the disease, but certain personal characteristics and environmental factors can also intensify the behaviour. Challenging behaviours can also reflect unmet needs such as personal care, stimulation, or fun activities with others. These needs are often misinterpreted or go unnoticed, which can make individuals with dementia restless or even aggressive. By providing the right kind of structured, organised activities that are both stimulating and enjoyable, challenging dementia-related behaviours can often be reduced or even prevented altogether.

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1. What are challenging dementia-related behaviours and what makes them problematic?

Dementia can often make a person exhibit challenging behaviours and psychological symptoms that can be upsetting for everyone involved in their care. From other care home residents, to caregivers and loved ones.

Challenging behaviour can manifest itself in many different ways, such as:

- anger
- restlessness
- irritation or even aggression
- being easily distracted
- the need to look for something but not being able to explain what they're looking for

1.1 Common terminology in dementia-related behaviour

Challenging behaviours are part of a wide range of behaviours that are common in people living with dementia. They are often described as 'problem behaviours' because they're experienced as problematic or difficult by those who care for the individuals in question. However, this says nothing about what actually causes them. That's why the preferred terms are 'dementia-related behaviours' or 'behavioural and psychological symptoms of dementia' (BPSD).

However, the range of BPSD is so broad that the term 'BPSD' itself is limiting. Many researchers have tried to categorise BPSD into clusters, and doing so may help to find solutions for reducing BPSD. Unfortunately, there's still a lot of disagreement about this¹. Some researchers categorise BPSD into two main clusters - behavioural and psychological symptoms - and others group them into three or more.^{1,2} Below is an example of five clusters of symptoms that were recently published by researchers Dr. Cloak and professor Khaliki:¹

1. Cognitive/perceptual (e.g. hallucinations)
2. Motoric (e.g. repetitive movements)
3. Emotional (e.g. anxiety)
4. Verbal (e.g. yelling)
5. Vegetative (e.g. sleep disturbances)

"Their motor functions can be restless. In the way that they talk - even their facial expressions change. Their reaction is usually irritation or to ignore you."

Movement therapist

"I can often see it in their eyes on a morning when they're restless and uncomfortable. They also walk back and forth."

Welfare and activities professional for two residential group homes

Neuropsychiatric symptoms (NPS) is also a common term used in reference to dementia-related behaviour. These include:³

- delusions
- hallucinations
- agitation/aggression
- depression/dysphoria
- anxiety
- euphoria/elation
- apathy/indifference
- disinhibited behaviour
- irritability/lability
- aimlessly repetitive behaviour
- nocturnal agitation/sleep disturbances
- appetite/changes in eating behaviour

1.2 The negative effects of challenging dementia-related behaviours on quality of life

In combination with physical limitations, challenging dementia-related behaviour has an incredibly negative effect on the quality of life of those living with dementia.⁵⁻⁶ This is difficult and sometimes distressing for family members, other residents, and caregivers who are on the receiving end of the behaviour.⁷ The impact that this has on these informal caregivers is often what leads to admission into a care facility or care home.⁷⁻⁸

The effects of dementia-related challenging behaviours can also have a significant effect on staff wellbeing and job satisfaction. This is why it is important that solutions for tackling these behaviours are known and readily available to care professionals.

Did you know?

That up to 97% of people living with dementia experience at least one behavioural and psychological symptom of dementia. The most common are apathy, depression, irritability, agitation, and anxiety.⁴

Did you know?

That the majority of care home residents with dementia (61%) exhibit more than one neuropsychiatric symptom?³

2. What causes challenging dementia-related behaviours?

One of the main challenges when it comes to dementia-related behaviours is that it is often difficult to figure out what is causing them. In some cases, these causes change over time, just like the needs of the person living with dementia do.

There are many scientific theories out there that explain what causes challenging dementia-related behaviour.⁹ One of the more widely supported ones is the **Need-driven Dementia-Compromised Behaviour (NDB)** theory.¹⁰⁻¹² It suggests that challenging dementia-related behaviour is the result of unmet needs.

Unmet needs can come about for a number of reasons. For example, it could be because of dementia-related difficulties with verbal communication that make it hard for people to express what they need.

Some of the needs of people in the later stages of dementia are:¹³

- fewer or more stimuli in their environment
- interaction with others
- personal approach and care
- attention
- being in the company of others
- open communication about their needs and desires

If these needs go unnoticed or are misinterpreted, it can lead to the onset of **challenging behaviour**. This can of course have negative consequences for the individual in question, as well as care workers, fellow residents and loved ones.¹¹

Often when people with dementia display challenging behaviour, they're actually communicating that something is wrong. That's why the most important part of reducing challenging dementia-related behaviours is to first identify what's causing them. There may not be a one-size-fits-all approach or quick fix, but by collaborating with family members and loved ones, you can take steps towards getting to the source of the problem. This can be achieved by interpreting and understanding the behaviour. From these insights, you can then build a tailored approach based on the personal needs of the individual.

2.1 The needs of people with dementia

As much as the symptoms of dementia can be similar, people's individual needs are very different. These needs may be closely related to personal interests, cultural background, or the way that carers interact with their residents.

A lot of what has been written about the needs of people with dementia can be traced back to professor Thomas Kitwood - a pioneer in dementia care - and his 'positive person work' concepts.¹⁴ Kitwood's framework looks at which specific carer behaviours meet the needs of people with dementia and which behaviours undermine them.

Examples of behaviours that meet the needs of people with dementia are: giving recognition, negotiating, working together, playing, accepting the reality of the other person, and lastly, creating and facilitating a safe environment. This is ultimately the basis for the concept of **person-centred care**: a philosophy built around the needs of an individual and based on knowing them through a personal relationship in order to provide the best care.



3. Preventing or reducing challenging dementia-related behaviours

There are several methods based on scientific research which have been proven effective in reducing or preventing challenging dementia-related behaviours.¹⁵⁻¹⁷ All of these methods focus on one core concept: identifying and responding to individual needs.

When looking to determine the cause of dementia-related behaviour, the parties involved first check for physical signs of pain, hunger, or thirst. The next step is considering social or environmental factors as a possible cause of the behaviour, before looking for a solution. The goal is always to find a sustainable solution that is based on the unique needs of the individual.

Most protocols for reducing challenging behaviours in people living with dementia follow these steps:

1. Identifying the behaviour
2. Establishing a connection and reassuring the individual
3. Determining the cause of the behaviour
4. Eliminating, or distracting from, the cause
5. Offering medication if non-drug solutions do not work

3.1 Non-drug interventions

When it comes to dealing with challenging behaviour in people living with dementia, care providers are always advised to first consider solutions that do not involve medicine. These are also known as non-drug interventions. This is because medication is not always effective and can often have negative side effects.¹⁸ Some examples of non-drug interventions used to treat challenging behaviour include multisensory stimulation, massage, and psychosocial interventions.

3.2 Psychosocial interventions

Research shows that using psychosocial interventions systematically can reduce both challenging behaviours as well as the use of medication.¹⁵

Psychosocial interventions are approaches that aim to reduce emotional and social difficulties.

Many methods use psychosocial interventions to meet the needs of people living with dementia.

More and more research shows the positive effects they have on reducing challenging behaviours.¹⁸

Examples of psychosocial interventions are reminiscence therapy, music therapy, and meaningful activities.⁹ The **Tovertafel**, for example, is a form of psychosocial intervention.

4. Experiences from the field

Mandy Choy, a Health and Life Sciences student at the VU University in Amsterdam, the Netherlands, conducted a study into how healthcare workers deal with restless behaviour in care facility residents living with dementia.¹⁹ She interviewed 11 professionals in various roles in order to collect valuable insights on the topic.

An important insight from her research was the need to recognise restless behaviour in time so that the ‘undesirable’ behaviour can be reversed. It states that to do that, it is important to know residents well because they may behave in a number of different ways which are unique to them. For example, this could be yelling or walking away, and for someone else, it could be a facial expression.

All of the care professionals that took part in Choy’s research stated that they make contact with their residents and that it could take a while before they are successful in doing so. They also noted that staying patient and calm is crucial. Once having made contact, it’s important to reassure the resident, identify the cause of the unrest and remove it. Sometimes, this can be really simple.

If it’s difficult to determine what the cause of the restless behaviour is, the care professionals in Choy’s study suggest taking the resident to a more quiet environment and distracting them with an activity. When choosing a suitable activity, health care professionals take into account the resident’s personal background (e.g. country of origin or previous profession), as well as their interests and abilities. This includes their physical and cognitive capacities (including the stage of dementia) but also what they can still see and hear.

Another insight from the study highlights the importance of properly documenting your experiences with residents and sharing them with colleagues. What provokes restless behaviour in a specific resident? What helps to reduce the behaviour and what should you absolutely not do? By sharing experiences, you can recognise restless behaviour earlier and possibly even prevent it.

“It could be music which is irritating, or another resident. This is common in residents with dementia. It’s easy for the irritation to flare up.”

Movement therapist

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5. Using the Tovertafel as a tool for managing and reducing restless behaviour

The Tovertafel is a psychosocial intervention tool that can help reduce restless behaviour. It works by projecting interactive lights onto flat surfaces in the form of serious games. The Tovertafel provides care professionals with a simple way to provide what many of their residents in the later stages of dementia need: stimulating, enjoyable, relaxing, social activities.

The care professionals who took part in Mandy Choy's study explained that the Tovertafel's games were instrumental in helping them provide personal care that really made a difference. They emphasised that it is very important to know residents well on an interpersonal level and to gather information from friends and family members about their hobbies, interests, former professions, and more to support these efforts.

The Tovertafel also allows you to take any visual, auditory, or motor limitations of players into account by selecting games that focus on the senses that function better than others. Three participants in Choy's study indicated that they always opt for physical games such as 'Beach Ball' with residents who are physically restless and who make it clear that they would like to go somewhere. For residents who are sad, they choose games with bright colours or music, such as 'Flowers' or 'Sheet Music'.

It's important with a tool like the Tovertafel that it's used structurally, on a regular basis, in order to be a sustainable solution for reducing restless behaviour. A great way to do this is to set a specific time for its use.

If the restless behaviour at hand is primarily caused by physical needs such as pain or hunger, the Tovertafel will be less effective, however, it may provide some welcome distraction.



“One resident loves gardening and playing the game with the leaves. I often ask one of my more active residents: Shall we go to the beach? Grab the beach ball.”

Founder of a company that supports care workers and informal caregivers

5.1 What evidence do we have for this?

Several studies show that playing with the Tovertafel is associated with a reduction in restless behaviour for those in the later stages of dementia.

The first study indicates that playing with the Tovertafel reduces restless and tense behaviour among care home residents with dementia by 21 to 32%.²⁰ The same effect was also confirmed by another three studies.²⁰⁻²²

How does this work? Firstly, the Tovertafel games contain components of psychosocial intervention treatments that are known to be effective in reducing challenging behaviours such as reminiscence, music and meaningful activities.

The Tovertafel's wide range of games are specifically designed and developed to fulfill the needs of care facility residents in various stages of dementia. They can be tailored to their abilities, so you can choose the right game to match the **cognitive capacities, personal interests, needs** and **emotions** of the resident.

For example, care professionals or supervisors can choose from different types of games (*cognitive, physical, social* and *sensory*), levels and themes (such as *music, daily activities, nature* and *words*). This is especially helpful when it comes to managing and reducing challenging dementia-related behaviours.

The Tovertafel's menu makes it easy to select games for specific purposes and difficulty levels, to ensure there's a perfect match between the games and players. The difficulty levels are directly related to stages of dementia, meaning they're based on the extent to which the games appeal to certain cognitive skills. The Tovertafel's games are designed to ensure players won't be confronted with their inabilities by 'losing'. Instead, they provide positive reinforcement and boost confidence by focusing on their existing abilities.

This is all achieved through a method called **co-design**. The Tovertafel games are developed in close collaboration with the target group and care professionals. Only games that align with the abilities and needs of the target group, and that provoke the intended reactions in the players, will be considered for the Tovertafel.

The Tovertafel's unique characteristics make it a great tool for groups and stimulating social activity to combat challenging dementia-related behaviours, but it can also be used one on one to aid in person-centred care.

“Later in the day, as a result of sundowning, residents get anxious or restless. The Tovertafel works very, very well during these difficult moments as a tool to distract and calm them.”

Activity supervisor in a
psychogeriatric department

Conclusion

As a care professional, challenging dementia-related behaviours can be incredibly confronting and difficult to deal with. However, by understanding what these behaviours are and where they stem from, you are already one step closer to understanding how to reduce them.

By taking the time to understand the personal needs of individuals and developing a tailored approach based on these, a sustainable solution can help reduce and even prevent challenging behaviours. Using the right kind of (group) activities on a regular basis such as the Tovertafel can provide a way to manage these behaviours and improve your clients' quality of life. Which in turn has a positive impact on your wellbeing, quality of care and the overall happiness of your team.

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