

How to Handle Challenging Behaviours in People with Dementia

A guide for caregivers and family members

This is an outline of some solutions that you may use to manage specific dementia-related behaviors that your family member may show. This chart covers many causes and solutions for challenging behaviours. You can also use this tool to start a conversation and brainstorm with other members of your family & support network. Keep in mind that there may be other causes and solutions that are not mentioned below.

It is important to remember & understand:

- Every person is different, and options that works for one person may not work for another.
- Dementia is a progressive disease and options that work today may need to be adapted or changed in the future.
- This tool highlights that behavior has meaning. So it is important to look for possible causes of the behaviour before trying to change things. This will help you choose the most suitable option.
- **As a general guideline:** Make sure there is no physical cause, think about what is different and avoid making assumptions

BEHAVIOURS YOU MIGHT ENCOUNTER	POSSIBLE CAUSES/MEANING	POSSIBLE STRATEGIES
<p>AGITATION Or Emotional Restlessness</p>	<p>Agitation has many possible causes including:</p> <ul style="list-style-type: none"> • A gap between the person’s ability and what they are expected to do or understand at that moment. • Cognitive changes and decreases in function • Changes in how she/he understands reality, and feelings of insecurity and fear. <p>Other causes may be:</p> <ul style="list-style-type: none"> • A need to use the washroom or constipation • Pain or discomfort • Over-stimulation such as sensitivity to noise or light • Too much or not enough lighting in the room • Not able to communicate needs • Being overwhelmed by stimulation or conversation • Boredom • Coping with their dementia getting worse and feeling hopeless, sad or frustrated, as well as unreasonable worrying about family members, etc. • Environmental changes such as transitions, changes in social environment, caregiver, etc. 	<ul style="list-style-type: none"> • Stick to a routine to reduce feelings of uncertainty. • Speak in a calm tone and try to be warm and supportive. • Use short, simple sentences to communicate. Most people with dementia find it hard to understand long sentences • Avoid asking questions • Keep eye contact when you are talking. • Use comforting touch; e.g. a light touch on the arm or a hug if that is OK by the other person. • Create a calming environment for example: play soft music, reduce noise and clutter or other ways to reduce stress

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VERBAL /PHYSICAL AGRESSION	<p>People with dementia can have poor impulse control. This means that they will say and do things without thinking about the consequences. They might:</p> <ul style="list-style-type: none"> • Feel frustrated because they are unable to express or communicate what they want • Feel & understand that they are losing their independence and a loss of control over the environment • Not understand why different support services are coming into the house. They might feel their personal space or privacy is being invaded. This may be due to Anosognosia – a term that refers to the fact that the individual doesn't know that he/she don't know • They may not recognize family, friends or other people they know and feel scared; which is amnesia or agnosia. 	<ul style="list-style-type: none"> • Keep calm and remain warm and supportive. • If possible, give the person some space and try to approach them again at a later time. • Be aware of your body language, tone of voice and facial expressions. People with dementia may have aphasia (challenges understanding spoken language) and are more attuned to non-verbal cues and signals. • Validate their emotions, for example, "I can see that this is upsetting for you." • Ask if you can help them & suggest a specific action. For example, "Do you want me to help you? I can turn the TV down." • Try not to argue or correct the person's perception of reality. Arguing & correcting will just aggravate their behavior. • After trying other options, try to distract or redirect their attention to something else that is more pleasant or acceptable. • Use short, simple sentences. For most people with dementia, it is hard to pay attention to long sentences
PACING/FIDGETING	<p>Restlessness may be caused by the person trying to tell you something, but they are unable to communicate such as:</p> <ul style="list-style-type: none"> • They are hungry, thirsty, need to go to the washroom or in pain <p>Other causes may include:</p> <ul style="list-style-type: none"> • Boredom • Anger • Being distressed/anxious or worried about something • A need for more exercise and fresh air <p>In some people, agitation may be caused by the dementia itself, and it will be spontaneous and purposeless.</p>	<ul style="list-style-type: none"> • Pay attention to physical needs such as pain, hunger, washroom, etc. • Stick to a routine and add new activities to the routine. • Prepare a 'fidget kit' which includes items of different textures and materials. • Have them help with more day-to-day activities. This will help them to feel a sense of purpose and involved. And can decrease hopelessness – e.g. safe aspects of meal preparation, cleaning, folding laundry. • Provide stimulating games and activities to distract and occupy their time. These could include word searches, singing, and looking at photos • Take them out for regular walks <p>When choosing activities, keep in mind their strengths and personal preferences.</p>

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WANDERING/EXIT SEEKING	<p>Wandering can have many causes. It may be:</p> <ul style="list-style-type: none"> • Goal-oriented yet unrealistic – e.g. thinking they are going to work or home. • An impulsive reaction to seeing the door • Linked with unrealistic worrying about someone and wanting to go and check on them • A lack of understanding that they cannot function on their own – e.g. impaired insight, anosognosia (not knowing they don't know) • Boredom and/or lack of stimulation 	<ul style="list-style-type: none"> • Stick to a routine as much as possible • Register the individual with MedicAlert, and Alzheimer's Society Safely Home program. The patient will need to wear a bracelet or necklace with contact information. • Tell neighbors and local police • Lock doors, add a keyed deadbolt, or keypad to the doors • Consider putting up a stop sign to discourage person from exiting. Use safety covers on door knobs. These can be placed on top of the old ones at low cost. Hide doors with curtains, or paint a black circle on the floor. Often the individual will think it is a hole and will not exit. • Camouflage the door knob with material of roughly the same colour as the door. This can remove the 'trigger' point (the door knob) and prevent an impulse to open the door • Cover any windows on the door. <p>Attention: <u>Do not</u> conceal/block the door or use sophisticated locks/door knobs when person is left alone as they may not be able to escape in case of an emergency.</p> <ul style="list-style-type: none"> • Install a chime that will ring or sound when the door opens. • For more technological solutions follow this link or search online for smart alarm/GPS/Amber Alert devices.

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REPETITION	<p>People with dementia often do not remember that they have just asked the same question or told a certain story. It may be due to:</p> <ul style="list-style-type: none"> • Anxiety or fear they have forgotten something • A sign of fear, insecurity or worry and often they need comfort and support • The person is looking for something comforting and familiar. • The individual may want to have something to control. 	<ul style="list-style-type: none"> • Look for the reason as well as emotion behind the behavior (e.g. if the person asks about his grandchild, talk about the grandchild and look at pictures together). • If the repetition is a form of action – make an activity for it. • Avoid telling the person that they have previously asked the same question, as they might not remember. • Answer the question and then redirect to another activity. <p>When repetitive questions are about an upcoming appointment activity or event:</p> <ul style="list-style-type: none"> • Write it down on a cue card and instead of answering the question repeatedly, ask the person to read the information on the card (if they are able). Sometimes he/she will start to look at the cue card automatically – this involves using procedural memory • This strategy can be used for other tasks; e.g. you can write a new card every day with simple reminders of what time an event will happen, the answer to a specific question, etc
HALLUCINATIONS /ILLUSIONARY ALTERED PERCEPTION	<p>Illusions are sensory experiences that seem real to the individual with dementia and are often confused with hallucinations. They are a result of altered perception and can affect:</p> <ul style="list-style-type: none"> • Transfers due to problems with depth perception e.g. transfers to the bathtub, negotiating stairs. • Being startled by their own reflection in the mirror (also related to agnosia – not recognizing their own face) • Confusing a coat hanging on a hook for a person • Confusing a shiny spot on the floor for a water stain or a hole in the floor, etc <p>It is common for people with some forms of dementia to have visual hallucinations. In Lewy Body dementia, it is common to have hallucinations related to children/animals</p>	<ul style="list-style-type: none"> • Try to understand what the person is looking at and what might be causing the misperception. • Eliminate clutter as it can help to reduce confusion • TV and radio can be confusing and might be perceived as real people talking. • Install railings for safe transfers. • Place a colourful non-slip mat in the bathtub or by the bed to help with depth perception. • Increase lighting in active areas of the house. This also reduces areas with shadows. • Paint or design rooms differently so individuals are able to distinguish a room by its colour. • Label room purposes with symbolic pictures - i.e. toilet/ bathroom.

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HOARDING	<p>Tends to occur in early and middle stages and can be:</p> <ul style="list-style-type: none"> • A response to isolation • A response to loss of control of memory, friends or a meaningful purpose in life • Linked to anxiety of knowing you might lose something. 	<ul style="list-style-type: none"> • Remove items gradually. Try to obtain their consent. • Negotiate with them if they have insight and ability to understand. • Keep in mind this can cause a catastrophic reaction and must be done slowly and with compassion. • Avoid using logic – many patients who suffer from dementia have a hard time understanding things logically. • Re-organize and clear paths in the case of an emergency.
INAPPROPRIATE BEHAVIOUR:	<p>Inappropriate behaviours such as disrobing, masturbation in public, verbally inappropriate, hyper-sexuality can be common in people with dementia. These behaviours may be caused by:</p> <ul style="list-style-type: none"> • Less control of impulses, especially in frontal lobe dementia. Also possible in other kinds of dementia. • The individual is not able to communicate that they are hot/cold, tired or uncomfortable (disrobing) • An under-stimulating environment or routine, misunderstanding of cues seen on TV, etc (hyper sexuality) • Psychological factor such as depression and mania. • Altered perception/delusions/hallucinations 	<ul style="list-style-type: none"> • For inappropriate behavior in public, the Alzheimer’s organization has <i>Pardon My Companion Cards</i> to save you the stress of explaining their behavior. • Some people prefer coaching on how to talk to people in public, e.g. quietly tell them he has dementia which causes this behavior. • Don’t take it personally and try to avoid reacting. • Try increasing the level of physical attention, or activity. • Provide personal space if possible and come back when they are calmer. • Distract and re-direct. • Keep an active and regular schedule to avoid boredom. Allow the individual to masturbate in a private area.
DISRUPTIVE SLEEP PATTERN	<p>This is a common symptom caused by dementia, which can:</p> <ul style="list-style-type: none"> • Affect the natural timing system of the individual’s body (circadian rhythm) • Be a factor in other behavioral issues such as agitation, disorientation, and repetition. • Be due to a breathing problem called sleep apnea 	<ul style="list-style-type: none"> • Stick to a routine, encourage regular waking/sleeping time. • Choose a security/comfort item (blanket, clothing) that may only be used at night time. Creating a bed time ritual may also help. • Limit caffeinated and alcoholic beverages, and tobacco. • Reduce TV before bed – especially very dramatic shows • Light therapy or time in natural light helps adjust sleep. • Avoid excessive napping during the day. • Monitor when sleep issues do and don’t happen. This can help you to find some triggers. • Avoid over-stimulating situations close to bed time, such as large family gatherings and trips to the mall at busy times.

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SAFETY ISSUES: FIRE HAZARD FALLS MISUSE OF OBJECTS	<p>People with dementia are at risk to injuries due to their physical and mental state.</p> <ul style="list-style-type: none"> • Fires are often caused when people are distracted or have memory issues - i.e. not remembering they left the stove on, or getting distracted by a phone call while cooking. • Falls generally occur due to poor balance, altered perception, possible vision problems. Risks of falls are more likely in the home when transferring to the bath, from the bed, and if there is clutter. • People with dementia may lose the ability to recognize objects (anosognosia). They may use these objects incorrectly, causing harm to themselves by accident. For example, using a razor as a toothbrush 	<p>Fire safety</p> <ul style="list-style-type: none"> • Disconnect the stove and oven, and use an automatic stove turn off device (link) that stops electricity in case of a fire • If possible, allow the person to cook with supervision <p>Falls</p> <ul style="list-style-type: none"> • Ask CCAC for a home safety assessment by an occupational therapist • Install devices such as raised toilet seats, grab bars, bath chairs, non-slip mats • Remove carpets and clutter • Encourage the use of walking devices such as a walker. • Lock away sharp objects like scissors, razors, knives, etc. <p>Misuse of objects</p> <ul style="list-style-type: none"> • Lock away sharp objects like scissors, razors, knives, et
SUNDOWNING Agitation and confusion	<ul style="list-style-type: none"> • Happens mainly in the late afternoon and early evening • There may be an increase in confusion and an inability to manage stress 	<ul style="list-style-type: none"> • Reduce distractions or unplanned activities • Keep the environment well lit until bedtime • Play soft music, or music that is enjoyable for that person • Choose a room for relaxation

My Notes & Questions:

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