MEANING AND SOLUTIONS FOR BEHAVIORS IN DEMENTIA INVENTORY

This document outlines a list of solutions that may be helpful with managing specific dementia-related behaviors. It is important to remember that every individual is different, and that a solution that works for one individual may not work for another. It is also important to understand this is a progressive disease and a solution that may work today may need to be modified or changed in the future. In addition, this tool emphasizes that behavior has meaning. It is important to investigate possible causes of the behaviour prior to implementing solutions, in order to choose the most appropriate strategy. Jumping to a solution without investigating the cause of the behaviour may lead to a long and tiring process of trial and error. This chart covers many causes and solutions, and serves as a basis for discussion and brain-storming with the caregiver. Keep in mind that there may be other causes and solutions that are not mentioned below.

As a general guideline: think about atypical presentations, avoid assumptions, and rule out physical causes.

BEHAVIOURS EXHIBITED	POSSIBLE CAUSES/MEANING	POSSIBLE SOLUTIONS
AGITATION (emotional state of restlessness)	Agitation has many potential causes and it is usually due to a gap between the person's capacity and the demands presented. Cognitive changes and decrease in function can contribute to feelings of agitation due to misperception of reality, uncertainty and fear. Other causes may be: needing to go to the washroom, constipation, pain or discomfort, sensitivity to noise or light, over-stimulation, boredom, inadequate lighting, Inability to communicate needs, being overwhelmed by stimulation or conversation, etc. It could also relate to something that is happening in the person's life, coping with the progression of the disease 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 can also be a cause for agitation.	- Adhere to a routine to reduce uncertainty. - Play soft music (reduce stress and create a calming environment). - Reduce noise and clutter. - Keep a calm tone and remain warm and supportive. - Use short simple sentences to communicate. Most people with dementia find it hard to process multiple words at a time. - Avoid asking questions - Use none verbal method of calming such as touch.
VERBAL /PHYSICAL AGRESSION	- Many individuals who have dementia, have poor impulse control. Therefore, internal thoughts may be expressed without them being filtered first. - Frustration often occurs among individuals with dementia, as they feel unable to articulate what they want to communicate. This translates to a sense of lost independence and a loss of control over the environment. - Individuals with dementia may not understand the need for help/care and therefore feel their personal space is being invaded (anosognosia – don't know that they don't know). - They may not recognize people around them and feel scared (amnesia or agnosia).	- Be aware of your body language, tone of voice and facial expressions, as people with dementia due to having aphasia are more attuned to non-verbal cues and signals. - Keep calm and remain warm and supportive. - If possible, give the person some space and try to approach them again at a later time. - Refrain from arguing or correcting the person's perception of reality, as this will just aggravate their behavior. Instead, validate their emotions (i.e." I can see that this is upsetting") and offer to help. Then, if necessary, distract from there. - Use short simple sentences. For most people with dementia it is hard to process multiple words at a time.

SUSPICION / PARANOIA	**- This behaviour is often due to a** combination of memory loss and disorientation. -Unrealistic fear or concern that harm is imminent. -Suspicion can be due to failing memory, an inability to recognize people, and the need to make sense of what is happening around them.- - Some forms of dementia such as Lewy Body, cause hallucinations. In addition individuals may suffer from delusions, altered perception(illusions), where they see something and perceive it as something else.	- Adhere to a routine. -Remain calm, provide reassurance and do not argue. -If the individual believes objects are being stolen, try to keep duplicates of items assumed stolen (wallet. glasses. keys, etc). - Help the individual look for stolen or missing items and then try to distract them with other activities (eating meals, coffee, activities they enjoy). - Be aware of TV shows in the background – these can trigger fear or paranoia due to altered perception. - Use a behavior log to identify triggers.
PACING/FIDGETING	- Pacing may indicate the individual needs to use the washroom and are unable to tell you. - Restlessness may be caused by them trying to tell you something (eg: they are hungry, thirsty, or in pain). -Other possibilities may be that they are bored, angry, distressed/anxious or worried about something. - They lack exercise and fresh air. - Sometimes pacing can be spontaneous and purposeless , a sign of agitation often propitiated by the dementia itself.	-Adhere to a routine and add new activities to the routine. - Prepare a 'fidget kit' which includes items of different textures and materials. - Provide more day-to-day activities to increase the feeling of purpose and decrease hopelessness (eg: safe aspects of meal preparation, cleaning, folding laundry). - Provide stimulating games and activities to distract and occupy. These could include word searches, singing, and looking at photos. - Build activities according to strengths and personal preferences. - Take them out for regular walks.
WANDERING/EXIT SEEKING	- This behaviour may be goal orientated yet unrealistic (eg: thinking they are going to work or home). -Non-goal orientated (stimulus bound) behaviour may be an impulsive reaction to seeing the door. - May be associated with unrealistic worrying about someone and wanting to go and check on them. - Not understanding that they cannot function on their own (impaired insight i.e. anosognosia- not knowing they don't know) - This behaviour may also be caused by boredom due to lack of appropriate stimulation.	-Adhere to a routine. -Register the individual with MedicAlert + Alzheimer's Society Safely Home program. The patient will be required to wear a bracelet or necklace with contact information. -Inform neighbors and local police. -Keep doors locked, add a keyed deadbolt, or keypad to the doors. Also consider putting up a stop sign to discourage person from exiting. - Use sophisticated door knobs (can be placed on top of the old ones at low cost) . - Hide exits with curtains, or paint a black circle on the floor. Often the individual will think it is a hole and will not exit. -Install a chime that will trigger when the door opens. - Camouflage the door knob with material of roughly the same colour as the door. Cover any windows on the door. This can remove the 'trigger' point (the door knob), and prevent an impulsive reaction to open the door.

REPETITION	- Often linked to memory - individuals with dementia often do not remember that they have just asked the same question or told a certain story. - It may reflect anxiety about fearing they have forgotten something - It can be a sign of fear, insecurity or worry, and often requires reassurance. -This behaviour may signify the person is looking for something comforting and familiar. -Repetition is something the individual may feel they have control over.	-Look for the reason as well as emotion behind the behavior (eg: 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. - Do not tell the person that they have previously asked the same question, as they will likely not remember. Instead, answer the question and then redirect to another activity. - If it is a question about an upcoming appointment or when you are going to do something, write it down on a cue card and instead of answering the question repeatedly, ask the person to read the information on the card. For example, "George look at your card". Sometimes George will start to look at this card automatically – this involves using procedural memory. This strategy can be applied to other areas - you can write a new card every day with simple reminders of what time an event will happen, the answer to a specific repetitive question, etc.
HALLUCINATIONS /ILLUSUNARY ALTERED PERCEPTION	-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. Examples include altered depth perception that affects transfers to bathtub, negotiating stairs, being startled by their own reflection in the mirror (also related to agnosia – not recognizing their own face) , confusing a hanging coat for a person, confusing a shiny spot on the floor for a water stain or a hole in the floor, etc. -It is also common for people with some forms of dementia to have visual hallucinations. With Lewy Body dementia, it is common to have hallucinations related to children and animals.	-Try to understand what the person is looking at and what might be causing the misperception. - Eliminate clutter (this can help with reducing confusion). - TV and radio can be confusing and be mistakenly 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 (avoid shadows). -Colour rooms differently so individuals are able to distinguish a room by its colour. -Label room purposes with symbolic pictures (i.e. toilet for the bathroom).
HOARDING	- Tends to occur in early and middle stages. -Can be a response to isolation. -Can be a response to loss of control of memory, friends or a meaningful purpose in life. - Often associated with the anxiety of knowing you might lose something.	- Remove items gradually. Try to negotiate with the patient if they have insight and ability to understand, and try to obtain their consent. Keep in mind this can cause a catastrophic reaction and must be done slowly and with compassion. - Don't try and use logic – many patient's who suffer from dementia have a hard time understanding things logically. - Re-organize and clear paths in the case of an emergency.

INAPROPRIATE BEHAVIOUR -Disrobing. - Masturbation in public. -Verbally inappropriate. -Hyper sexuality.	- Impaired control of impulses, especially but not limited to frontal lobe dementia. -Disrobing may occur due to the individual being unable to communicate that they are hot/cold, tired or uncomfortable. -Hyper sexuality may be the result of an under-stimulating environment, misinterpretation of cues seen on TV, etc. - Can be a psychological factor such as depression and mania. - Behaviour may be due to altered perception/delusions/hallucinations.	-For inappropriate behavior in public, the Alzheimer's organization has *Pardon My Companion Cards* to save you the stress of explaining their behavior. Some find this useful others benefit from coaching on how to respond- 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 appropriate physical attention. - 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	- A common symptom caused by the dementia itself - Dementia may be affecting the individual's circadian rhythm, which is the body's natural timing system. Difficulty sleeping can contribute to other behavioral issues such as agitation, disorientation, and repetition. - Sometimes this may be due to a breathing problem (sleep apnea).	-Adhere to a routine – encourage regular waking and sleeping times. -Create a transitional item (blanket, clothing), that may only be used at night time. Creating a bed time ritual may also help. -Limit caffeinated and alcoholic beverages, as well as tobacco. -Keep TV exposure to a minimum, especially before bed. - Light therapy or exposure to natural light helps regulate sleep. - Avoid excessive napping during the day. - Monitor when this behaviour does and doesn't occur. What is different at the time it does not occur? - Avoid over-stimulating situations close to bed time, such as large family gatherings and trips to the mall at busy times.
SAFETY ISSUES: **FIRE HAZARD** **FALLS** **MISSUSE OF OBJECTS**	Patients with dementia are vulnerable to injuries due to their physical and mental state. Fires are often caused by patients suffering from amnesia and distractibility (i.e. not remembering they left the stove on or getting distracted by a phone call while cooking). Due to poor balance, altered perception and possible vision problems, patients are in danger of falling around the house or when transferring to the bath. Patients with dementia may lose the ability to recognize objects (anosognosia) and may therefore use them inappropriately, causing harm to themselves unintentionally. For example, using a razor as a toothbrush.	Fire safety – disconnect the stove and oven, and use a stove guard device that stops electricity in the case of a fire. Within the limits of their ability, allow the person to cook with supervision. In the case of accidental falls, it is best to refer to occupational therapist home safety assessments through CCAC. Some devices such as toilet seats, grab bars, bath chairs, non-slip mats and removal of carpets and clutter can help with fall safety as well as using walking devices such as a walker. Lock away sharp objects like scissors, razors, knifes, etc.
SUNDOWNING (Agitation and confusion)	- This becomes apparent in the late afternoon and early evening. It results in increased confusion and an inability to manage stress.	- Play soft music, or music that is enjoyable for that individual. - Assign a room for relaxation. - Reduced distractions or unplanned activities. - Keep the room well lit until bedtime.

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Acknowledgment to Dr. Joel Sadavoy Director of the Cyril & Dorothy, Joel & Jill Reitman Center for Alzheimer's Support and Training; Head of Geriatric Psychiatry; Sam and Judy Pencer Chair in Applied General Psychiatry, and to the Community Behaviour Support Outreach Team, Baycrest for their input in developing this tool and to Robyn Hoiting (volunteer) for her assistance in creating this tool.

References:

- Guerriero M. (2012). Aging Brain Care Medical Home: Replication Manual, University of Indianapolis.
- Hamilton P., Harris D., Le Clair J.K., Cllins J. (2010). Putting the P.I.E.C.E.S. together-A Model for Collaborative Care and Changing Practice, P.I.E.C.E.S. Resource Guide. 6th Edition.
- Kutsumi, M et al (2009) Management of behavioral and psychological symptoms of dementia in long-term care facilities in Japan. Psychogeriatrics 9(4) 186-195
- Ryan D.P. (2012). Approach to Management of Behavioural Disturbances in LTC. RGP program of Toronto.
- Sadavoy J., Lanctot K., Shoumitro D. (2008). Management of Behavioural and Psychological Symptoms of Dementia and Acquired Brain Injury. Cambridge Textbook for Effective Treatments in Psychiatry. Cambridge University press.
- Sadowsky C.H., Galvin J.E. (2012). Guidelines for the Management of Cognitive and Behavioural Problems in Dementia,*JABFM*, Vol. 25/3.