

Non-Pharmacological Assessment and Management of Behavioural and Psychological Symptoms of Dementia in Primary Care

At some point in their disease, most people with dementia will demonstrate behavioural and psychological symptoms, also known as responsive behaviours, such as: agitation, wandering, aggression, etc. The term responsive behaviour was created to stress the fact that these behaviours are not just random meaningless behaviours, but in fact may relate to different factors in either the person's condition and/or their specific environment. The challenges are determining what the triggers are and that most of these behaviours do not respond to pharmacological treatment. In addition, many older adults with dementia will present with atypical symptoms from common conditions (e.g. urosepsis, dehydration, constipation, pain, etc.) Therefore, when addressing behavioural symptoms, one must always consider assessment and investigations for physical disorders associated with behavioural disturbance.

In this guide we will provide insight into the meanings and causes behind responsive behaviours in dementia and provide guidance in how to conduct an assessment and/or facilitate a discussion regarding behaviours to support caregivers at home. Caregivers identify BPSD/responsive behaviours as one of the most challenging and distressing aspects of care and the presence of BPSD, especially physical aggression, can often be the “deal breaker” leading to LTC admission. These behaviours can have an immense impact on the quality of life of both the patient and his/her caregiver.

Behaviours and Potential Causes

Changes in behaviour stem from multiple causes. **Progressive neurologic damage** from the underlying dementia is the root of much BPSD. In addition, concomitant **sensory deficits** (visual, auditory), **physiologic deficits** (e.g. dehydration, electrolyte changes) and **medical illness** must also be considered when behavioural changes occur.

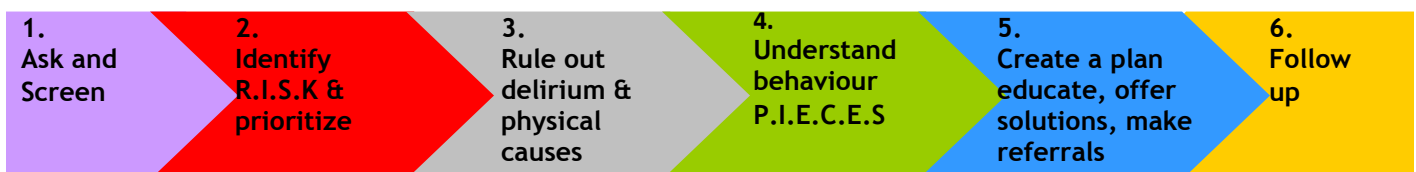
Changes in behaviour can also be caused from the **adverse effects of prescribed and OTC medication (including alcohol)**; this is more likely to occur in the presence of multiple medications with increased potential for adverse interactions.

The **environment** also plays a key role in behavioural change. For example, the patient is more likely to behave differently due to recently moving into a new environment; from overstimulation due to a noisy and busy environment; or from boredom in an environment that does not provide sufficient and appropriate stimulation.

Frustrating Interactions can also change behaviour, as a patient may lash out due to the inability to communicate effectively or a perceived threat. This often occurs during personal care.

ADDRESSING BEHAVIOURS

Follow these simple steps:



1. Ask and Screen

Most caregivers will not ask for assistance or report behaviours until they have become a crisis - perhaps from embarrassment, fear of being perceived as unable to cope or due to lack of knowledge and understanding of the behaviours. In order to avoid crisis it is imperative to be proactive in routinely screening /asking about behavioural symptoms of dementia.

Once a patient has been diagnosed with dementia, instruct your receptionist/office assistant to have the patient or caregiver complete a brief behaviour assessment tool while waiting to be seen (recommended every 3-6 months). The tool recommended is the **Healthy Aging Brain Care Monitor (HABC Monitor)** developed by the University of Indianapolis, for the following reasons:

- This tool can be filled out quickly (within 2 - 5 minutes) in the waiting room.
- No writing is required, mostly check marks
- It asks about both patient symptoms and caregiver burden
- It provides an immediate visual division of the symptoms into four different categories that will help you easily identify an area of focus, i.e., Behaviour, Mood, Cognitive or Functional Status.

(For more details visit this [link](#) or see forms attached in toolkit).

**** It is also recommended to use the general Dementia Management Form (attached) to guide you through the questioning regarding specific behaviours and other challenges related to dementia.**

2. Identify Risk and Prioritize

- We can only deal with one behaviour at a time especially in the primary care environment where time for each visit is limited. Therefore it is imperative to identify which behaviour is putting the patient at highest risk or is the most distressing for the patient and their caregiver.
- Ask the patient (if possible) and the caregiver what is most concerning to them.
- Use the **R.I.S.K.S** acronym to identify the potential risks of the behaviour/s.
 - **R**oaming, wandering, getting lost, etc'
 - **I**mminent physical harm such as: fire, falls, firearms, frailty (e.g. delirium)
 - **S**uicide ideation
 - **K**inship/relationship - i.e. risk of harm to others/by others including neglect/avoidance.
 - **S**elf-neglect /Safe driving/Substance abuse
- Together with the caregiver, choose the behaviour of highest priority.

3. Rule out Delirium and Physical Causes

Delirium is an acute state of confusion that is often missed in patients with dementia but is in fact an indication of an acute physical condition. There is a 30 % risk of mortality in older adults if delirium is not spotted in time.

- **Start by asking:**
 1. What has changed in the behaviour/symptoms?
 2. When did the change occur and how quickly?
 3. How frequent is the behaviour? Is it stable or does it fluctuate?
 4. When is the behaviour most likely to show up?

****If onset is abrupt suspect delirium** - Use the delirium causes screen or the Confusion Assessment Method (CAM) tool attached.

- **Perform an appropriate physical exam and use targeted investigations based on risk factors and common causes of delirium to identify physiologic/physical etiology**
- **If no physical cause detected move to next stage.** Consider asking the caregiver to track behaviour on a behaviour tracking sheet (see attached) towards your next meeting.

4. Understand Behaviours - P.I.E.C.E.S Framework

Offering solutions without exploring meanings and causes is like 'shooting in the dark' and can turn into a tedious task of trial and error that can be both time consuming and frustrating for the caregiver, the patient and the clinician.

Models of understanding behaviours:

Unmet Needs theory - A person may present behaviours when their needs are not met. Intervention will be based on understanding the need that is not met (physiological, emotional, psychological, intellectual, etc.) and intervene by meeting that need.

ABC theory - Antecedent - Behaviour - Consequence - This theory focuses on the triggers for the behaviours, trying to understand what they are and modifying the environment and interaction accordingly.

Low Threshold theory - Due to the progressive nature of dementia as the disease progresses a patient may gradually have decreased capacity to tolerate stress and to cope. This model focuses on removing/reducing cumulative stressors from the environment. V.1. March, 2013

Biomedical theory - Neurological changes in the brain cause brain dysfunction that manifests in behavioural changes. The focus will be on treating reversible causes, educating caregivers and developing strategies that emerge from awareness to the person's condition.

P.I.E.C.E.S.

P.I.E.C.E.S.: Physical, Intellectual, Emotional, Capability, Environment and Social - areas to explore as possible causes for behaviours.

The P.I.E.C.E.S method is a framework created to help screen and assess behaviours in an efficient yet comprehensive way. This framework will allow you to better understand the causes behind the behaviour and to draw a more accurate and effective intervention plan.

In this guide we are using a component of the P.I.E.C.E.S. approach to assist with behaviour assessment process. The Ontario College of Family Physicians offers a 4-hour MAINPRO C accredited P.I.E.C.E.S. training program for family physicians including a handbook specifically targeting family physicians. To inquire about further training in P.I.E.C.E.S. contact your Psychogeriatric Resource Consultant or the OCFP (see contact details at the end of this guide or in this [link](#)).

When meeting with patients and caregivers consider the different domains of P.I.E.C.E.S. and explore possible causes (use the attached behaviour cause assessment tool).

Here are a few options to consider in each domain:

Physical - as specified in section 3 use results of your physical testing, observation of patient and collateral information from caregiver to check for physical causes such as: Pain, constipation, dehydration, hypoxia, hypotension, hunger, infection, disease, illness, drug-related side effects, etc.

Intellectual - Dementia is a neurological condition that changes the way the patient may perceive or respond to his/her environment and affects his/her functional ability. Consider the following:

The 7 A's of Dementia

The 7A's is a tool used to understand the common effects of Dementia on the person's function and behaviour.

THE 7 A's	MEANING	Potential Affect on Behaviour
ANOSOGNOSIA	<ul style="list-style-type: none"> ▪ “The person doesn't know that he/she doesn't know”. ▪ Poor insight into their challenges leading to poor judgement, i.e. not knowing they are not safe to drive or that they need support to transition to the bath. 	Can cause resistance to care, aggression, and/or irritability.
AMNESIA	Memory loss, initially short-term then progressively long-term.	Repeatedly asks the same questions, misplaces items, asksto eat even if they just did, loses time orientation, etc. , leading to caregiver frustration
APHASIA	Problems with use of language, both speech and comprehension	<ul style="list-style-type: none"> ▪ Can cause withdrawal from social interactions due to shame and frustration. ▪ May lead to misunderstandings and conflicts due to inability to communicate needs. ▪ Often people revert to their primary language.

AGNOSIA	<ul style="list-style-type: none"> ▪ Inability to recognize and attach objects, faces, smells, tastes, etc. to meaning. ▪ Inability to recognize everyday objects such as a toilet, brush, razor, cutlery, etc. ▪ May confuse other people's objects as their own or vice versa. 	<ul style="list-style-type: none"> ▪ May use wrong objects for simple tasks. ▪ This may also put a person at a safety risk by using objects inappropriately (e.g., brushing teeth with a razor). ▪ The person may also be suspicious of friends and family members due to not being able to recognize them.
APRAXIA	Loss of the ability to plan, initiate and sequence purposeful movement.	<ul style="list-style-type: none"> ▪ Difficulty with simple daily tasks like dressing and eating. May confuse the sequence in which they do things such as putting a shirt backwards or putting on shoes before socks. ▪ Confusion with directions or problems in following instructions. May be perceived as "being difficult" by their caregivers as they fail to do simple tasks that they were able to not long ago.
ALTERED PERCEPTION	Changes in perception that may occur due to changes in the brain that occur in dementia. For example changes in Visuospatial perception, challenges in understanding the concept of time.	<ul style="list-style-type: none"> ▪ Surfaces perceived as much deeper than they actually are i.e. a bath/toilet may be perceived as very deep/scary to transition to. ▪ Seeing /hearing object/sound and misinterpret it for another e.g. seeing a coat hanging, thinking it's a person ▪ Seeing shadows/lights and being confused about what they are ▪ Hearing the TV/radio and thinking it is a real person talking ▪ Seeing a shiny spot on the floor and thinking it's a water stain or misperceiving a dark spot as a hole in the ground. ▪ Struggling with perception of space bumping into things.
APATHY	Loss of drive to initiate activities.	<ul style="list-style-type: none"> ▪ Remaining in one place without initiating movement or an activity for a length of time even when they might verbalize that they are interested. ▪ Often confused with depression however a person with depression may refuse to engage even when encouraged to and will usually report feeling sadness while a person with apathy will usually be able to engage if he/she is being prompted to initiate the movement/activity.

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Emotional

- Consider reactions of frustration, grief and loss, loneliness, depression.
- Consider mood disorders such as depression, personality disorders, adjustment disorder, and delusions such as paranoid delusions of being poisoned or followed, delusions of being cheated on, etc. (Some delusions may require pharmacological treatment.)

Capabilities - compare the patient's functional ability in ADLs /IADLs and language skills in relation to the demands of the environment such as the level of activity and complexity, amount of time required to focus, level of cognitive understanding (complex planning requirement, level of communication, abstract vs. concrete, etc') .

- Low demand - may trigger frustration, boredom or anger
- High demand - may trigger feelings of frustration, anxiety, avoidance or helplessness.

Environment - Look at both the human and non-human environment.

- Does the environment meet the needs of the patient according to physical, emotional needs and capabilities?
- Has there been any changes in the human or non-human environment? For example changes in caregiver.
- Explore the lighting, distractions, sounds, noises, smells, temperature and physical space
- Can the person be distracted/irritated due to too much glare or lights? Are they cold or warm? Is there something in the environment that can trigger the behaviour or cause discomfort?

5. Create a Plan

Based on the P.I.E.C.E.S. scan what in your opinion could be the main cause/causes behind the behaviour?

** Use the Meanings and Solutions for Behaviours in Dementia Inventory to help with brainstorming and suggesting solutions.

1. Identify knowledge gaps regarding the causes of the behaviour and about dementia then educate the caregiver/family members accordingly.
2. Encourage caregiver/family to brainstorm with your support. Suggest possible solutions to try at home. Encourage a sense of teamwork so that caregivers do not feel helpless and alone.
3. Instruct caregivers/family in the use of a behaviour tracking sheet and have them record behaviours in a regular manner, to review at next visit (see tracking sheet attached).
4. Give clear instructions for when caregivers should contact you or another resource (as suggested below in section 6) if the home situation is worsening/escalating into dangerous behaviour.
5. Consider instructing another member of the care team (or yourself if you have the time) to follow-up proactively with the caregiver at home to support and "tweak" the plan
6. Leverage the help of others - Consider the following referrals:
 - **Alzheimer Society of Toronto** for information, resources and emotional support (i.e. group support and counselling) T: 416-322-6560; F: 416322-6566;
www.alzheimertoronto.org.

- **CARERS program at Mount Sinai Hospital Reitman Centre** to allow the caregiver to learn and acquire skills in managing dementia related behaviours at home. T: 416-586-4800 EXT. 5192; F: 416-586-3231; carers@mtsinai.on.ca (link).
- **Geriatric Psychiatry Specialty clinic** (Ask PRC-PC for a directory). For home bound patients where there are challenges around behaviour management refer to **Community Psychogeriatric Outreach Team** (Ask PRC- PC for a directory).
- **Community Behaviour Support Outreach Team** - community outreach clinicians who have behavioural support expertise. These clinicians work in partnership with health-care providers to support individuals and caregivers to manage responsive behaviour at home and in the community. T: 416-785-2500 ext. 2005; F: 416-785-4211; behavioursupport@baycrest.org;
- In cases where all the above mentioned methods and resources have been tried and when behaviour cannot be managed in the current setting refer to the **Behaviour Support Units (Centralized Access Senior Beds)** located in TRI, CAMH and Baycrest, for a short term admission in a behaviour support specialized clinic to help assess and stabilize the behaviour and transition the patient back to his/her home environment. Referral is done through the CCAC at: T: 416-217-3827 ext. 3827
- If there is a crisis that demands immediate intervention in the home consider calling the **Senior Access Crisis Line (SCAL)**. They will send a crisis team for a short term intervention to your patient's home according to the urgency of the case. Give the SCAL number to your patients and their families so they could call this number in case of crisis at T: 416-619-5001.

Remember while we as clinicians may see the patient once a week or less, the caregiver is there 24/7. The best way to support your patient and the key in managing dementia care in the home is a well supported, educated and skilled caregiver.

6. Follow Up

- Schedule a follow up visit to review progress and behaviour tracking sheet. If the intervention is successful, continue to follow regularly. Caregiver stress is lessened when they know that they will have access if things at home change for the worse. If the behaviour intervention plan was not successful, review what worked/didn't work and adjust the plan accordingly.
- Remember that due to the progressive nature of dementia a solution that may have worked today may not work tomorrow and so the plan should be readjusted. Caregivers need education to know that this is inevitable and not an indication of their failure.
- Monitor caregiver burden and intentionally inquire with the caregiver about how they are coping and about their health and well being.

BEHAVIOUR ASSESSMENT TOOL

(Based on information from Collins J., Harris D., LeClair K., (2010). Putting the PIECES Together, The PIECES Collaboration office¹.)

Behaviour description:		
Date first noticed:		Frequency:
What has changed recently?		
Main concern:		
Any known triggers:		
P.I.E.C.E.S	Current state	Areas of concern/ possible triggers
P- Physical Medication, pain, constipation, BP, dehydration, inflammation, oxygen, sleep, fatigue, etc.		
I- Intellectual Consider the 7 A's of dementia		
E-Emotional Mood, loss, grief, depression, etc.		
C-Capabilities Ability vs demands too low/too high		
E- Environment Lighting, temperature, colours, noise, accessibility, new/old, etc.		
S- Social/cultural Previous social habits vs now, social interaction, specific cultural aspects		
Possible triggers/causes identified :	<hr/> <hr/>	
Intervention plan/recommendations: _____ _____ _____		
Referrals made (If applicable): _____ _____		
Follow up meeting date:		

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DEMENTIA MANAGEMENT FORM

Date of visit:	
Medication change/adjustment:	
Cognitive Ax score	MOCA_____ MMSE_____ Other (specify): _____ - _____
Driving:	<p>Is the patient driving? <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Problem/concern: <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>If yes was patient reported to the ministry? <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Driving safety Assessment done: <input type="checkbox"/> Yes <input type="checkbox"/> No (Use the 10 item checklist)</p> <p>Assessment results: <input type="checkbox"/> Safe <input type="checkbox"/> Unsafe <input type="checkbox"/> Unsure</p>
Function: Any problem with the following activities?	IADL: <input type="checkbox"/> Banking <input type="checkbox"/> Shopping <input type="checkbox"/> Laundry <input type="checkbox"/> Using the phone <input type="checkbox"/> Using devices <input type="checkbox"/> Housekeeping <input type="checkbox"/> Follow Directions <input type="checkbox"/> Using Transportation
	ADL: <input type="checkbox"/> Bathing <input type="checkbox"/> Feeding <input type="checkbox"/> Dressing <input type="checkbox"/> Mobility/transfers <input type="checkbox"/> Sleep problems <input type="checkbox"/> Fall risk
	Communication: <input type="checkbox"/> Verbal <input type="checkbox"/> Non verbal Understands spoken language: <input type="checkbox"/> Yes <input type="checkbox"/> No Language spoken: _____ Understands simple instructions/gestures? <input type="checkbox"/> Yes <input type="checkbox"/> No
Any behaviour/safety concerns in the following:	<p>Behavioural concern: <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Onset of behaviour: <input type="checkbox"/> progressive <input type="checkbox"/> abrupt (suspect delirium/physical cause)</p> <p>Check mark the relevant concern:</p> <p><input type="checkbox"/> Apathy <input type="checkbox"/> Agitation <input type="checkbox"/> Restlessness/pacing <input type="checkbox"/> Wandering <input type="checkbox"/> Repetition</p> <p><input type="checkbox"/> Aggression <input type="checkbox"/> Resistance to care <input type="checkbox"/> Verbal accusations</p> <p><input type="checkbox"/> Sexually Inappropriate <input type="checkbox"/> Threat to self <input type="checkbox"/> Threat to other</p> <p><input type="checkbox"/> Verbally inappropriate <input type="checkbox"/> Psychotic symptoms <input type="checkbox"/> Delusions/Hallucinations</p> <p><input type="checkbox"/> Other_____</p>
Depression	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>GDS score:_____ Other score: _____</p>
Caregiver burden	<p>Main concerns: <input type="checkbox"/> Information <input type="checkbox"/> home help <input type="checkbox"/> coping skills <input type="checkbox"/> respite</p> <p><input type="checkbox"/> emotional support <input type="checkbox"/> Medical : _____ Other:_____</p>
Capacity issues	<p>Concerns: <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Type of capacity decision issue: <input type="checkbox"/> Health care <input type="checkbox"/> Finances/property</p> <p>Power of Attorney: <input type="checkbox"/> Healthcare <input type="checkbox"/> Finances and property</p> <p>Name and relationship: _____</p> <p>Substitute Decision Maker (SDM) assigned? <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Name of SDM: 1. _____ 2. _____ (if more than one)</p> <p>Advance care plan: <input type="checkbox"/> Discussed <input type="checkbox"/> prepared</p>
Items discussed:	<p>1. _____</p> <p>2. _____</p> <p>3. _____</p>
Care Plan/referrals:	

USEFUL WEBSITES

- GiiC website:
 - GiiC toolkit for primary care: <http://giic.rgps.on.ca/toolkit-libraries>
 - Dementia at Home manual: http://giic.rgps.on.ca/files/AtHomeDementia_manual.pdf
- Meanings and solutions for Behaviours in Dementia Inventory: <http://www.rgpeo.com/media/51096/behaviours%20and%20dementia%20inventory.pdf>
- Alzheimer Society of Toronto : <http://www.alzheimertoronto.org/>
- Chaplain Dementia Network - toolkit for physicians - behaviour management in dementia: <http://physicians.champlainedmentianetwork.org/en/physicians-home/education-for-professionals/behavioural-problems-.aspx>

** For additional information please contact your Psychogeriatric Resource Consultant for Primary Care (PRC-PC) at: T: 416-586-4800 ext. 5251; F: 416-586-3231; prc-pc@mtsinai.on.ca .

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