Alzheimer’s Disease and Related Dementias

Understanding Behaviours Related to Dementia
A GUIDE FOR CARE WORKERS

UNDERSTANDING DEMENTIA

- Dementia is an umbrella term with many subtypes such as Alzheimer’s disease, vascular dementia and frontal-temporal dementia. The most common type (64%) is Alzheimer’s disease.
- Most dementia is non-reversible and progressive in nature.
- Each person’s journey is different.
- Changes in ability to function and think vary, depending on stage and type.
- Cognitive losses result in:
  - Impaired ability to learn, remember information and concentrate;
  - Decreased ability to solve problems, make decisions and use good judgment;
  - Increased difficulty communicating and reduced ability to care for self independently.

GOALS OF CARE

Care for persons with dementia aims to achieve the same goals whether at home or in residential care:
- Safety of the person, family and caregivers;
- Respect and dignity for the person;
- Maximum independence and ability to function;
- Optimal quality of life for the older adult, including freedom from anxiety, agitation, fear and loneliness.

In the home, ensure a safe environment, create a routine that works for the older person, facilitate rest and respite for family caregivers.

In residential care, design the environment to make the most of quality of life (e.g., safe access to outdoor space); ensure that approaches to care are flexible and person-centred.

COMPLICATIONS OF DEMENTIA

- Dementia affects behaviour and mood. Many persons with dementia will develop “Behavioural and Psychological Symptoms of Dementia” (BPSD).
- The nature of BPSD includes:
  - Symptoms such as anxiety, depression, agitation, reversed sleep patterns, hallucinations;
  - Repetitive behaviours such as repeated questions, rocking, pacing, restlessness, crying, calling out, repeated communication and/or actions (e.g., tapping fingers);
  - Socially difficult behaviours such as screaming, resistance to care and verbal outbursts.
- Behaviours arise from brain damage caused by dementia and can be triggered by unmet needs or the environment. Behaviours are seldom “unpredictable.”

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A NEW WAY TO UNDERSTAND BEHAVIOURS

- In dementia, all behaviour has meaning. When words are lost, communication becomes 
  behavioural. Every behaviour has an underlying cause.
- Behaviours are the older adult’s best attempt to cope with a confusing and threatening 
  environment.
- Words like “aggressive,” “disruptive,” “challenging,” “excessive” and “resistive” are labels 
  that have negative meaning and focus on the behaviour instead of the unmet need. Focus on the 
  underlying cause of the behaviour.
- Recognizing behaviours as “responsive” and “protective” provides guidance for care:
  - Responsive behaviours indicate an unmet need such as hunger, pain, thirst, need to void, 
    boredom, sensory overload or fatigue.
  - Protective behaviours arise from the person’s need to protect him or herself against 
    feelings such as frustration, failure, embarrassment, confusion and fear.
- The care team’s focus is to create an environment in each person’s best interests:
  - This environment includes physical surroundings that support and “prop up” the older 
    adult’s limitations and enable him or her to continue using existing strengths.
  - The facility must also sustain a culture or philosophy of care that enables staff to adapt 
    routines to individual needs.

PREVENTION IS KEY: KNOW THE PERSON

- Responsive and protective behaviours can often be prevented by eliminating environmental 
  stressors. Look for triggers and patterns. Build this knowledge into the individualized care plan.
- Change the environment as needed. It is easier to change the environment than to change a 
  person with dementia. For example, reduce noise or other stimulation, provide a quiet space.
- Learn about the person’s background, usual routine, personality, name they prefer to be called, 
  preferences, dislikes, strengths, fears, and what comforts the person when distressed.

COMMUNICATION APPROACH

- A person-centred philosophy of care includes a communication approach that aims to be positive, 
  with a focus on “connecting” rather than “correcting.”
- Always look friendly. Don’t rush or hurry care—it will take more time in the long run.
- Use a positive tone of voice. Guide rather than control or tell. Distract rather than confront.
- Don’t start sentences with “No” and “Don’t,” as this increases resistance. Never argue or scold.
- Avoid “elderspeak” (e.g., “dear” or “honey”), the childish style of communication that some 
  people use when speaking to older adults with dementia. This makes most people angry.
- Simplify talk and use short sentences. Ask one question at a time and limit choices to ones the 
  person can successfully make.
- Use non-verbal language whenever possible (e.g., smiling, nodding, gesturing, cueing).
- Avoid laughing near a person with dementia who is suspicious, paranoid or delusional—you may 
  be misinterpreted as threatening and this could lead to a negative reaction.
- Communication should enhance a person’s self-respect and decrease uncertainty and anxiety.

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