

First Responder Handbook

Alzheimer Society

First Responder Handbook

The purpose of this handbook is to provide you with information on how to recognize, communicate with and respond to someone with Alzheimer's disease or other dementias.

This handbook provides information about dementia and Alzheimer's disease including its symptoms; the impact of the disease on a person's abilities; and strategies that you can use to respond to the needs of someone who is affected. It also provides information about Alzheimer Society and programs and services.

Contact your local Alzheimer Society for more information on educational in-service opportunities and resources available specific to your community. To contact your local Society please visit alzheimer.ca/find.

Remember the Person

This handbook discusses the losses that a person with dementia experiences throughout the progress of the disease; however, it is important to remember that people with dementia want to and do lead active, meaningful lives and have a right as every other citizen to be participants in their communities. Be mindful that each person you interact with is a unique individual with their own values, beliefs, fears, likes and dislikes. By gaining a better understanding about the disease you will be in a better position to communicate and assist people with dementia in your community.

Note: we refer to the person with the disease throughout this handbook as "her" or "she". This does not mean that men do not get the disease. Using one term throughout is simply for ease of reading.

Dementia in Canada at a Glance¹

- The number of Canadians living with cognitive impairment, including dementia, now stands at 771,939.
- More than 70,000 Canadians living with Alzheimer's disease or other dementia are under the age of 65.
- By 2030, nearly 1 million people in Canada could live with dementia.

Encountering individuals with dementia

Given the increasing number of people living with dementia, you as a first responder working in the community are more and more likely to encounter such individuals.

The circumstances under which you come into contact with someone with dementia may range from finding a person who is lost, to someone who has been disturbing the peace or has been involved in a criminal activity such as shoplifting.

People with dementia are often able to maintain their usual level of abilities for some time but will eventually experience changes in all aspects of their life.

- Their mental abilities, emotions and moods, behaviours and physical abilities are all affected.
- They may not remember something they have just done.
- They may be uncoordinated and appear to be intoxicated.
- They may not recognize when their behaviour is wrong or inappropriate.

Understanding Dementia

Dementia is progressive, which means the symptoms will gradually get worse as more brain cells become damaged and eventually die.

Dementia is not a specific disease. Many diseases can cause dementia, the most common being Alzheimer's disease and vascular dementia (due to strokes). Some of the other causes of dementia include dementia with Lewy bodies, frontotemporal dementia, Creutzfeldt-Jakob disease, Parkinson's disease, and Huntington's disease. These conditions can have similar and overlapping symptoms.

Some treatable conditions can produce symptoms similar to dementia, for example, vitamin deficiencies, thyroid disease, sleep disorders, or mental illness. It is therefore important to arrange for a full medical assessment as early as possible.²

A person with dementia may experience symptoms including:

- memory loss that affects day-to-day abilities
- difficulty performing familiar tasks (e.g., preparing a meal)
- problems with language (e.g., forgetting simple words or substituting words)
- misplacing items such as putting an iron in the freezer
- disorientation in time and space such as becoming lost on their own street
- impaired judgment such as wearing heavy clothing on a hot day or not realizing that an item in a store needs to be paid for
- changes in personality (e.g., can become confused, suspicious or withdrawn) such as believing that their partner is trying to poison them

¹ Alzheimer Society of Canada

² www.alzheimer.ca/en/about-dementia/what-dementia

Dementia is not a normal part of aging.

Dementia does not just happen to people over 65. People in their 30's, 40's and 50's can also experience dementia.

Dementia is not limited by gender, ethnic group or economic status.

What are the Effects of Dementia?

As nerve cells in the brain are damaged and the disease progresses, a person will experience changes in their mental, emotional, behavioural and physical abilities. Each person is affected differently. It is difficult to predict what symptoms each person will have, the order in which they will appear or the speed of their progression.

Mental Abilities

The disease affects a person's ability to understand, think, remember and communicate. They may:

- Be unable to do simple tasks.
- Have trouble remembering people's names (including their own); where they are or what they were about to do.
- Have difficulty understanding what is being said and making themselves understood.

People with dementia will, however, still be able to hear, respond to emotions and be aware of touch.

Due to changes in a person's mental abilities, it is critical to get corroborating information from others before making a decision. For example, the person with dementia may describe to you a situation that took place years ago as though it just happened, or report doing something regularly (e.g., making meals), when in fact they haven't done this in a long time.

Emotions and Moods

A person with dementia may have difficulty controlling their moods and emotions. They may:

- Appear sad one moment and angry the next.
- Laugh inappropriately or worry a great deal over small things.
- Be suspicious of the people around them, even family members and others who support them.

These emotions and moods may vary, change rapidly and be difficult to predict.

A person may exhibit defensive behaviour. They may not remember how an incident happened or be suspicious of those around them.

Responsive Behaviours

Due to changes in the brain, a person with dementia may have increasing difficulty communicating verbally and may therefore use actions and gestures to communicate what they are feeling or how they are responding to their current environment (thus "responsive behaviours").

Changes in mental abilities and mood may cause the person with dementia to experience responsive behaviours. These may include:

- pacing
- agitation
- repetitive actions
- hiding things
- constant searching
- undressing or emotional outbursts at inappropriate times

Spatial Perception

A person with dementia may have difficulty judging the environment around them. For example, they may have challenges walking up or down stairs because they are unable to judge the height of the stairs or the distance between them. They may try to walk around a black floor tile as they perceive it to be a hole in the ground.

Physical Abilities

Changes in the brain of a person with dementia also result in decreased physical abilities. Coordination may be affected, as may the ability to move about.

An individual may have difficulty with balance and gait which may be mistaken for intoxication.

Changes to physical abilities can also impact a person's ability to execute actions.

You may be trying to help the person leave a harmful situation (e.g., fire in their house). The person may have heard and understood what you've said but may not know how to follow your directive.

Recognizing Dementia

There are no obvious physical characteristics which can easily identify someone with dementia. There are, however, clues that may suggest that a person is affected by the disease.

Dementia may be a possibility when an individual:

- appears confused and disoriented
- does not understand the current situation or is unable to sort out the obvious, such as her name and current address, where she is, or where she is going
- has no idea about the time of day or how much time has passed since leaving home
- must be told repeatedly who you are and what you want
- appears fearful, agitated, frustrated, angry or is crying
- provides inappropriate responses to simple questions, or does not respond at all
- may have a blank facial expression or one that is inappropriate to the situation
- is dressed inappropriately, perhaps overdressed in the summer or underdressed during cold weather.

For example, a person with dementia is at a store or a bank and is not able to continue the transaction without support but is unable to explain this to the staff. The person may express themselves through their behaviour, appearing angry or agitated.

Common Situations

You may encounter a person with dementia in a variety of circumstances. The following are some of the more common situations:

Abuse

- Abuse is most often defined as, “Single or repeated acts, or lack of appropriate action, occurring within a relationship where there is an expectation of trust, which causes harm or distress to another person.”³ Types of abuse include: financial, physical, sexual, psychological (emotional), neglect, institutional and domestic.
- People with dementia can be vulnerable to all forms of abuse and these concerns should be taken seriously. It is important to investigate any allegation of abuse, neglect or other mistreatment. In situations where domestic abuse is suspected it is important to ensure the safety of the person with dementia as well as the caregiver.

Resources you may find helpful include your local crisis centre and Alzheimer Society.

Auto Accidents

- Disorientation and problems with memory and judgment can make it dangerous for people with dementia to continue driving, even though they may still be physically able.

You may encounter a person driving erratically or failing to obey street signs, traffic signals or speed limits.

Wandering and/or Getting Lost

- People with dementia can become lost very easily, even in their own neighbourhood. Once they feel they are lost, they may panic or continue to walk in a straight line until they are stopped by an obstruction or exhaustion.

- Wandering may occur at any time of the day or night and it may occur on foot or car/public transportation.

See page 10 for more information about reuniting a person with their caregivers after they have gone missing.

Keep in mind: Like all people, people with dementia should have the opportunity to move about as freely as possible but due to changes in the brain they may lack the judgment and reasoning to do so independently and safely. Walking in itself is not harmful when done in a safe environment and can be a healthy outlet for a person with dementia. The balance between risk and safety is a delicate one, as unsafe walking can put the person in danger such as walking into traffic or being inappropriately dressed for the weather.

Alzheimer Society staff can work with individuals and families on strategies to try to reduce the risk of a person going missing. See the listing at the back of this handbook for your local Alzheimer Society's contact information who in turn can connect you with the office in your community.

Making False Accusations Against Others

- The memory losses and confusion of a person with dementia may reduce her trust in both herself and her surroundings. As a result, she may become suspicious of the people around her. She may accuse people of theft, misconduct, or of other improper behaviour directed against her. This is due to an inability to accurately understand and interpret the actions of others or what is happening around them.

For example, a person with dementia may call 911 or their local police station reporting that they have been robbed when in fact they have misplaced the item that they are looking for.

³ Definition source: www.who.int/ageing/projects/elder_abuse/en/

Expressing Inappropriate Behaviour in Public

- The memory loss, confusion and emotional reactions due to dementia can make inappropriate behaviour (such as taking off clothes in public) a possibility.
- Keep in mind that the person with dementia does not understand that their behaviour is unsuitable.

Shoplifting

- Memory loss and confusion may cause a person with dementia to forget to pay for items in a store, or even fail to realize that it is necessary to pay for items before leaving the store.

Appearance of Intoxication

- The confusion, disorientation and lack of physical coordination that accompany dementia can often be mistaken for signs of intoxication.

Medical Emergencies

- The person with dementia may forget to take their medications or how to use medical devices (such as an oxygen machine) which can lead to a medical emergency.
- Keep in mind that it may be challenging for a person in the later stages of the disease to verbally describe any pain they are feeling. Changes in the person's behaviour can be a sign of pain – caregivers can help corroborate differences in the person's behaviour. Review the person's medications for possible interactions.
- Emergency departments are busy and noisy places which can be overwhelming for a person with dementia. If possible, try to take the person to a quieter place – advising staff in the hospital – and try not to leave the person on their own.

Fires

- Due to memory loss and confusion, a person with dementia may be at greater risk of fire hazards in the home.
- A person may not have the insight to realize when they are in danger. Due to this loss of insight, the person may not understand what is happening and be unable to execute the actions needed to evacuate the premises. They may also not comprehend the reasons why a firefighter is taking them away from their home.

A person may leave a pot on the stove or forget to turn off the oven. A person may mix up the seconds and minutes when using a microwave, thus causing an item in the microwave to burn.

Hoarding⁴

- Poor insight and judgment can cause a person to neglect themselves and their home which can lead to increased safety risks and violation of fire codes. This behaviour, commonly referred to as "hoarding", causes the individual to excessively accumulate material possessions of dubious value and quality. This "hoarding" of possessions substantially interferes with an individual's normal social, functional and vocational roles.
- In some cases a Fire Marshall may be required to intervene; however, it may only be after a fire has taken place that you become aware of the person's hoarding behaviour.

Safety risks can be direct (e.g., spoiled food that is not discarded, fire hazard from the accumulation of combustibles, piles toppling onto persons or pathways through home) or indirect (e.g., possessions becoming home to pests and vermin, possessions interfering with the ability to prepare and eat meals, important items such as outstanding bills and medications lost in the clutter).

⁴ Adapted from: Frank C. and Misiaszek B., Approach to hoarding in family medicine. Canadian Family Physician, 58 (2012),1087-91

Communication Strategies

A person with dementia will experience a progressive loss of ability to communicate. The further the disease progresses, the less she will be able to express herself or understand what is being said.

Remember that communication can be both verbal and non-verbal. Your body language, tone and volume of your voice can be just as important as the words you use.

You may find the following strategies helpful when approaching and communicating with a person with dementia.

1. Identify yourself

As you approach the person, state your name and why you are there. You may have to repeat this information.

Hello, my name is Steve and I'm a paramedic. I'm here to help you.

2. Establish a calm, caring atmosphere

If you are approaching an individual who is upset or emotional, your calmness may help to settle the person down.

Keep in mind that your uniform may make the person with dementia feel anxious. Your uniform may also trigger a memory from their past, such as experiences of war or genocide. Removing your cap may help the person feel more comfortable.

3. Reduce distractions

People with dementia may have a short attention span and experience difficulty screening out other noises in the environment, such as traffic, television, or other conversations. Too much activity around the individual also makes it difficult for her to concentrate so it may be necessary to move to a quieter place.

4. Establish and maintain eye contact

Face the person directly when speaking. Move slowly, as sudden movements may startle her.

5. Speak slowly and clearly

Present one idea at a time. You may have to allow the person time to absorb one sentence before moving on to the next.

6. Ask questions requiring simple answers

Simple questions which can be answered by "yes" or "no" may be more successful than open-ended questions.

"Do you know this street?" will be easier to answer than "Where do you live?" Allow plenty of time for a response - it may take a while for the person to gather her thoughts.

7. Back up your words with actions

If you need the person to do something, demonstrate it by using non-verbal communication whenever possible.

If you are asking a person to sit down, point to the chair. It may also be helpful if you sit down next to her.

8. Listen actively

Listen actively and carefully to what the person is trying to say. Respond to the emotional tone of the statement. You may not understand all of the words being said, but you may recognize emotions such as fear or anger. Saying, "You seem afraid" acknowledges the person's emotional state.

9. Watch for non-verbal cues

Do not rely strictly on the person's verbal responses for information. The person may not be able to express herself fully with words. Her actions may tell you more about her needs.

Rubbing a part of the body may indicate pain. Tugging at clothing or attempting to disrobe may indicate a need to go to the bathroom.

10. Repeat/rephrase responses

If you are having difficulty understanding the person, try repeating or rephrasing what she said, asking if you have understood correctly. This may help the person further clarify what she is trying to tell you.

Be Patient

A person with dementia does not have the same ability as you have to be rational and logical. She is not being difficult on purpose and may be feeling frustrated. Being patient and calm will encourage her to keep attempting to communicate with you.

Other Strategies

If the person with dementia seems anxious or under stress, consider using a distraction such as talking about something that is pleasant or familiar to her; this may help her feel secure and comforted. A sense of humour may also help to relieve any stress or tension she may be feeling.

Reuniting the Individual and the Caregiver After a Person has been Found

Returning a person to their home after they have been found can be very traumatic for both the individual with dementia and their caregiver.

The caregiver may have been anxiously waiting and worrying about the person for quite a while which can leave them feeling very stressed. On the other hand the person with dementia may not realize that anything is wrong and may be confused by all the concern. It is also possible the person with dementia may not recognize the caregiver or her own home.

It is important to ensure that both the person with dementia and the caregiver have had an opportunity to de-escalate from the crisis that has occurred. Engaging the support of other family members, staff at your local Alzheimer Society or after-hour community services may be very helpful to the family.

What You Can Do To Help

- In some cases, especially when an individual is feeling agitated, it may be better to bring the family member to the person rather than return the person home.
- Under different circumstances, it may be best to return the individual directly home.
- Regardless of where the reunion takes place, talk to family members or caregivers to ensure that everyone is calm and able to deal with the situation before you leave.
- Encourage family, caregivers and the individual to contact their local Alzheimer Society for information on services and supports available specific to their community (see list of offices on the next page).
- If the person does not already use a locating device or GPS, suggest they consider using a device to help facilitate a safe return should they go missing again. Information is available at: alzheimer.ca/locatingdevices.

Additional resources:

alzheimer.ca

alzheimer.ca/firstresponders

findingyourwayontario.ca

Alzheimer Society

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