

Dementia can have a profound effect on communication abilities, which can be upsetting and frustrating for the person with dementia and those around them. This information sheet will provide you with information about dementia and communication, including:

- An overview of dementia
- The importance of communication and how we communicate
- How dementia affects communication
- Other factors that could affect communication abilities
- Strategies to make a person-centred approach to communication possible
- Tips and strategies to support communication at every stage of the disease

What is dementia?

Dementia is an overall term for a set of symptoms that is caused by disorders affecting the brain. Symptoms may include memory loss and difficulties with thinking, problem-solving or language, severe enough to reduce a person's ability to perform everyday activities. A person with dementia may also experience changes in mood or behaviour. These dementia symptoms are irreversible, which means that any loss of abilities cannot come back.

Dementia is not a specific disease. Many diseases can cause dementia, including Alzheimer's disease, vascular dementia, Lewy Body disease, frontotemporal dementia and Creutzfeldt-Jakob disease. These conditions can have similar and overlapping symptoms.

There is currently no cure for dementia. However, there are treatment options and lifestyle choices that may slow it down. Researchers continue to look for ways to prevent or stop dementia and to improve care and quality of life for those living with dementia.

How do we communicate?

Communication is an important part of our life; it helps us to express who we are and allows us to relate to one another. When we communicate, we exchange information about our needs, opinions, ideas, beliefs, feelings, emotions, experiences and values. Communication is more than talking and listening; it involves understanding and interpreting.

Communication can happen in many ways, including¹:

- Verbal communication: words we use (7%)
- Non-verbal communication: body language (facial expression, posture and gesture) (55%)
- Para-verbal communication: tone, pacing and volume of our voice (38%)

Because non-verbal communication is so important, negative body language (such as looking at your phone while talking to someone) can be easily picked up by the other person and can feel disrespectful.

¹ Mehrabian, Albert (1981) *Silent Messages: Implicit Communication of Emotions and Attitudes*. 2nd ed. Belmont, CA: Wadsworth

How does dementia affect communication?

Dementia can have a profound effect on the language abilities of people living with the disease. This language deterioration is known as aphasia. Individuals with **aphasia** experience difficulty:

- expressing themselves
- finding the right words
- understanding spoken language
- reading and writing

People with dementia will lose specific communication abilities during the early, middle, and late stages of the disease. As the disease progresses, non-verbal communication will become increasingly important. Despite the changes in communication abilities, it is important to remember that communication remains possible at every stage of the disease.

As the dementia progresses the person with dementia may:

- Create new words for ones that are forgotten
- Repeat or get stuck on a word or phrase (perseveration)
- Curse or use other offensive language
- Revert to the language that was first learned
- Talk less than usual
- Have difficulty following instructions with multiple steps
- Lose their train of thought more often
- Lose their ability to make their speech understandable. Although they might still occasionally speak, their language may not make sense to others
- Become totally mute in some cases

The person with dementia may also experience difficulties:

- Finding a word
- Interpreting facial expressions (like a wink or a nod of the head)
- Finishing sentences
- Explaining or understanding abstract concepts (e.g., "I feel blue")
- Following conversations
- Staying on topic
- Organizing words into logical sentences
- Understanding humour, jokes and fast talk

All of these changes can be upsetting and frustrating for the person with dementia and for those around them. In this information sheet you will learn strategies that you can use to communicate with a person with dementia at every stage of the disease.

For help with communication issues, consider contacting a speech-language pathologist. Speech-language pathologists are specialists in the area of communication and can help diagnose and treat language issues. They can teach the person with dementia strategies to help them communicate.

For individuals diagnosed with primary progressive aphasia, the support of a speech-language pathologist is particularly important, as the person will experience a progressive loss of communication abilities. To find a speech-language pathologist near you, please visit www.sac-oac.ca/find-speech-language-pathologist-or-audiologist-service or ask your doctor to make a referral.

What else could cause communication difficulties?

There are other factors that may cause communication difficulties, including sensory impairments such as hearing and vision loss. Because of this, it is very important that people with dementia have annual hearing and vision evaluations and that they use assistive devices, like hearing aids and eye glasses, as needed.

What is a person-centred approach to communication?

The information presented in this document is based on a person-centred approach to communication. A person-centred philosophy views people with dementia first and foremost as individuals, with unique attributes, personal values and life history.

The following strategies can make a person-centred approach possible:

- ✓ **Learning about dementia, its progression and how it affects individuals:** Learning about dementia can help you have realistic expectations of the person's abilities to communicate throughout the various stages of the disease. Encourage the person to share their feelings and experiences with their family and friends as much as they are able. Let others know that the person with dementia may need more time to express themselves.
- ✓ **Believing communication is still possible and that all behaviour has meaning:** Communication remains possible at all stages of dementia. Although it may become difficult to understand what the person is trying to communicate to us, remember that the person's words and actions always have meaning. In the following example Nadia's mother's behaviour is her way of communicating that she does not want to listen to country music.

Nadia is driving her mother to a family celebration. The car radio is on, playing country music. Suddenly, Nadia's mother starts banging her fist on the dashboard and speaking in an agitated voice. Nadia does not understand what her mother is saying, as her speech is garbled and does not make sense. Nadia takes a moment to try to figure out what her mother is trying to tell her. Why is she suddenly so upset? Nadia remembers that her mother has always disliked country music. Nadia reaches over, changes the channel to music her mother has always enjoyed and says, "That's better. I don't like country music either." Her mother sits back and seems to relax, no longer banging her fists or calling out. Nadia rests her hand on her mother's knee and pats her reassuringly as she smiles.

✓ **Focusing on the person's abilities and skills rather than their deficits:** Although dementia affects certain abilities, the person's need for companionship, purpose and belonging will remain. If the person's speech has become hard to understand, use what you know about them and what you feel they might be trying to say to help you interpret their words. Consider helping the person with dementia to find alternate ways of expression through art, music or gardening to maintain and enhance communication. In the following example focusing on Maria's ability and enjoyment of setting the table helps avoid responsive behaviours.

Maria raised a family of five children. Each evening, as it begins to get dark, she becomes restless, searching through drawers and cupboards, becoming more and more anxious. Her family and caregivers remember that Maria always took pride in providing a multi-course dinner each evening for her family. When Maria is given access to a basket with placemats, serviettes and cutlery, her caregivers support her in setting a table for seven people. Maria hums while she works, enjoying the family activity.

✓ **Meeting the person where they are and accepting their new reality:** With the progression of the disease, a person's perception of reality can become confused. However it is their reality. Try to accept their reality and meet them where they are. Avoid contradicting them or convincing them that what they believe is untrue or inaccurate. Trying to bring them into your reality or disagreeing with them will cause frustration and make things worse. If they say something you know isn't true, try to find creative ways around the situation rather than reacting negatively. In the following example when Ben sees the dog it may trigger a belief that he is back in the concentration camp, causing distress and agitation. To help prevent this, the volunteer should bring a different breed of dog to visit with the residents.

Ben is now living in a long-term care home. Every Friday afternoon, a volunteer brings her gentle German Shepherd dog in to visit with the residents. The dog quietly sits and lets everyone pet him. Many residents talk about their memories of caring for their own pets. When Ben sees the dog, he becomes very agitated, pushing himself frantically down the hall in his wheelchair. The staff know that Ben lived through World War II in Europe but do not know the details of his experience. They learn from his son that he spent one year in a concentration camp, guarded by German Shepherd dogs.

✓ **A special note about delusions:** As the disease progresses, delusions – namely paranoid beliefs or false accusations – may occur. It is common for people with dementia to believe that their food is poisoned or that their belongings have been stolen. Others may believe that someone is spying on them or trying to hurt them. These suspicions or accusations may be due to the person's failing memory or difficulty understanding what is happening around them. Although these accusations can be hurtful, remember that they are a result of the disease. It is important not to argue with a person with dementia or try to convince them that their perception of reality is not correct. It doesn't matter who is right. What is important is that the person's feelings are respected and understood. Delusions can also be caused by a medical condition, such as a urinary tract infection. If the person is experiencing delusions, it is important to see a doctor to rule out a physical cause.

✓ **Planning ahead:** Being informed about the disease and knowing what lies ahead can help you feel more prepared. As the disease progresses, the person will not always be able to communicate their thoughts and wishes. Be sure that someone trustworthy has the legal authority to make financial and healthcare decisions for the person with dementia when the time comes. People with dementia are encouraged to talk about their wishes for the future with trusted friends and family members when they are still able to do so. Advice from lawyers and/or financial consultants can also be helpful.

✓ **Doctor visits:** When visiting the doctor try to book extended appointments, when possible, so the person with dementia doesn't feel rushed. To prepare for a doctor's visit write down symptoms and any questions you may want to ask. You may want to focus particularly on the things that have changed since the last doctor's visit.

Consider having a friend or family member accompany the person to their appointments to help them communicate and clarify information. If needed, ask the doctor to write down instructions for any changes in the care of the person with dementia.

✓ **Non-verbal communication will become increasingly important:** As the disease progresses you will have to rely on non-verbal communication more. The person with dementia may use laughter as a way to communicate to others that they are at ease. Watch for behaviour changes, body language and non-verbal signs that may be used to express a feeling or indicate physical discomfort. If you suspect that the person is in pain or discomfort, contact the person's doctor.

✓ **Communicate through the senses:** As the person approaches end of life they may lose their capacity for verbal communication and may experience the world primarily through their senses. Use the senses to maintain a connection.



- **Touch:** Hold the person's hand. Give a gentle massage to the hands, legs or feet.



- **Smell:** The person may enjoy the smell of a favourite perfume, flower or food, which may bring back happy memories.



- **Vision:** Videos can be relaxing, especially ones with scenes of nature and soft, calming sounds.



- **Hearing:** Reading to the person can be comforting, even if they may not understand the words. The tone and rhythm of your voice may be soothing. What you say is not as important as how you say it. Speak gently and with affection. Your tone can help the person feel safe and relaxed. Read a favourite story or poem. Music is a universal language that promotes wellbeing for most of us. Sing together, play music, especially the type of music the person has enjoyed throughout their life.

Consider spending time outdoors. It makes us all feel better! For more information, please visit the Alzheimer Society of Toronto's website www.alz.to.

Information and support are available. You are not alone.

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Communication tips and strategies

- Reduce distractions:** Communicating is easier if other things are not happening at the same time. For example, if the TV or radio is distracting the person, turn it off.
- Introduce yourself:** Before engaging in conversation, introduce yourself. Tell the person your name and your relation to them, e.g., "My name is Andrea, I am your nurse and I am here to help you get ready."
- Have one-on-one conversations:** Keeping track of conversations in larger groups may become difficult. When possible, try to have one-on-one conversations or conversations in smaller groups.
- Gain attention:** Face the person. Making eye contact with the person will help focus their attention.
- Be aware of your tone and body language:** Remain calm and speak in a relaxed tone of voice to put them at ease. Abrupt or hurried movement, as well as a sharp tone or raised voice, may cause distress.
- Connect don't correct:** Instead of criticizing and correcting, ignore failures and remember to be supportive, positive and encouraging.
- Be clear and concise:** Talk slowly and clearly, using short and simple sentences. Use closed-ended questions which are focused and can be answered with "yes" or "no" or with a choice, e.g., do you want coffee or tea? Avoid open-ended questions. Avoid phrases that can be interpreted literally, such as "up to my eyeballs" which might be confusing.
- Be respectful:** Use the person's preferred name when addressing them. Do not patronise or speak down to the person. Avoid using childish or "elder" talk or any demeaning language. Avoid talking about the person as if they aren't present. Do not talk over the person. They may still understand what is being said even though they have lost the ability to produce the words that are in their mind.
- Listen carefully:** Listen carefully to what the person is saying and observe both verbal and non-verbal communication. Try not to interrupt the person even if you think you know what they are saying. If the person is having difficulty finding the right words, you can offer a guess as long as they appear to want some help.
- Be patient:** The person may need more time to process information, so be patient. Provide reassurance. If they sense you are impatient or agitated, they may feel stressed or frustrated.
- Encourage exchange:** Make your communication a two-way process that engages the person with dementia. Involve them in the conversation. If you don't understand what is said, avoid making assumptions. Check back with them to see if you have understood what they mean.
- Show and talk:** Use actions as well as words. For example, if it is time to go for a walk, point to the door or bring the person's coat or sweater to illustrate what you mean.
- Encourage humour and laughter, respect sadness:** Humour can bring you closer, can release tension and is good therapy. Laughing together over mistakes or misunderstandings can help. If the person seems sad, encourage them to express their feelings, and show you understand.
- Don't forget to account for hearing or vision problems!** Make sure that the person is wearing a working hearing aid and/or clean glasses, if prescribed. Schedule regular checkups and watch for changes in abilities and behaviour.

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