

This document is intended to help the person with dementia, and his/her family and caregivers understand how dementia affects communication and provide them with useful strategies to maintain and enhance communication throughout the progression of the disease.

What is Alzheimer's disease and dementia?

Alzheimer's disease is the most common of a large group of disorders known as "dementias". It is a disease of the brain, characterized by deterioration of thinking ability and of memory, caused by the progressive degeneration of brain cells. The disease also affects mood and emotions, behaviour and one's ability to perform activities of daily living. There is currently no cure for Alzheimer's disease nor can its progression be reversed. However, new treatments that will slow down or even stop the disease are expected within the next five to seven years. Moreover, present treatment options and lifestyle choices can often significantly slow the progression of the disease. Related dementias include Vascular Dementia, Frontotemporal Dementia, Creutzfeldt-Jakob Disease and Lewy body Dementia.

Alzheimer's disease typically follows certain stages which will bring about changes in the person's and family's lives. Because the disease affects each individual differently, the symptoms, the order in which they appear and the duration of each stage vary from person to person. In most cases, the disease progresses slowly, and the symptoms of each stage may overlap, often making the move from one stage to another quite subtle. The duration of the disease is usually seven to ten years but may be much longer in some people.

How do we communicate?

Communication is a critical component of our life; it enables us to express who we are and allows us to relate to one another. When we communicate, we convey messages or exchange information to share needs, opinions, ideas, beliefs, feelings, emotions, experiences and values. Communication is more than talking and listening, it involves understanding and interpreting.

Information is conveyed in many ways:

Verbal: words we use

Non-verbal: body language (facial expression, posture and gesture)

Para-verbal: tone, pacing and volume of our voice

When a person has changing abilities as a result of dementia, communication is affected and this can cause misunderstanding and mutual frustration.

How does dementia affect communication?

Although each individual is unique, dementia has a profound effect on the language abilities of people living with the disease and therefore on the way they communicate. This language degeneration is known as aphasia. Individuals with aphasia experience difficulty expressing themselves, finding the right words, understanding the words heard, reading and writing. As the disease progresses, communication can become increasingly challenging. Recognizing those changes will help the person with the disease, their family and friends find ways to communicate more effectively.

What is 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 history.

A successful person-centred approach to communication is based on:

- Learning about dementia, its progression, and how it affects individuals.
- Believing that communication is possible.
- Focusing on the abilities and skills.
- Reassuring the individual with dementia and being positive.
- Meeting people with dementia where they are and accepting their reality.

The quality of life for people with dementia is largely dependent on their connection with others. Maintaining a relationship can be a complex and challenging process, especially when verbal communication is lost.

1. WHAT SHOULD I EXPECT?

People with dementia lose particular communication abilities during the early, middle, and late stages of the disease. As the illness progresses, they will experience a gradual deterioration of their ability to communicate, to express themselves clearly and to understand what others say. *However, communication does remain possible at every stage of the disease.*

Dementia creates distinct challenges in regard to how people express themselves and understand what is being communicated to them.

The following changes are common among people with dementia:

- Difficulty finding a word.
- Creating new words for ones that are forgotten.
- Repeating a word or phrase (perseveration).
- Difficulty organizing words into logical sentences.
- Cursing or using other offensive language.
- Reverting to the language that was first learned.
- Talking less than usual.

Communication challenges that may occur during each stage of Alzheimer's disease:

At the early stage, the person often cannot find the right words – particularly the names of objects. They may substitute an incorrect word, or they may not find any word at all.

At this stage, the person may:

- Have difficulty understanding humour, jokes, and fast talk.
- Have difficulty following multiple step instructions.
- Require increased concentration to follow conversations.
- Have trouble staying on topic.
- Need more time to respond to questions.
- Experience increased frustration.
- Have trouble finding the right word.
- Lose their train of thought more often.

At the middle stage, more and more words are becoming lost, and the person needs to think longer before expressing their thought. The person loses spontaneity, their vocabulary is more and more limited and sometimes they repeat the same word over and over again.

At this stage, the person may:

- Have trouble understanding everyday conversation.
- Often ask the speaker to repeat simple sentences.
- Find it difficult to follow long conversations.
- Have difficulty understanding reading materials.
- Repeat the same word or information over and over (perseveration).
- Not be able to interpret facial expressions (like a wink or the nod of the head).
- Have trouble explaining or understanding abstract concepts (e.g. “I feel blue”).
- Experience decreased speech and ability to raise or lower voice.
- Have difficulty finishing sentences.
- Lose interest in talking.
- Speak in vague and rambling sentences.

At the late stage, individuals appear to lose the capacity for recognizable speech, although words or phrases may occasionally be uttered.

Non-verbal communication will become increasingly important as, at this stage, the person may:

- Be unable to understand the meaning of most words.
- Lose their capacity for recognizable speech, although words or phrases may occasionally be uttered. Language often does not make sense to others.
- Become totally mute in some cases.

2. WHAT SHOULD I TRY?

This section suggests strategies and tips that people with dementia, families and caregivers can use to enhance communication.

A. STRATEGIES FOR THE PERSON WITH DEMENTIA¹:

At the early stage of the disease, you should use communication to your advantage. It is very important for you to communicate while you find it relatively easy to do so. This is a good time to start talking about your wishes and making them known. It is critical to be very open with your caregiver, your family members, your friends and also health professionals.

Learning about the disease and being open about it

Learn as much as you can about dementia, its irreversible and fatal consequences as well as its effects on your expression and communication. Inform your family and friends about these. You can tell them how you want to be involved in decision-making.

Be open with your family and friends about your diagnosis and share your feelings and experiences as much as you are able. Let family and friends know that you may need more time to express yourself and if you are tired or have difficulty communicating, encourage them to speak with you when you are more rested.

Thinking about non-verbal communication

Think about using notes for reminders. Use visual aids or non-verbal cues, draw or point at pictures, use your eyes, gestures and body-language to enhance communication. Use hand signals and body language to communicate.

Laughter is a good way to communicate to others that you are at ease and it will make them more open to what you are sharing.

Maintaining relationships

We all need our friends and relatives to support us. Many of these people will empathize with your situation. Remaining loving, positive and dedicated will help you feel safe, secure and valued. They are here to support you, so do not hesitate to open up to them and ask them for help or assistance when you need it.

And if friends or relatives don't phone or visit you, call them!

¹ Source: By Us For Us guide, Enhancing communication, an inspirational guide for people like us with early-stage memory loss. Murray Alzheimer Research and Education Program, University of Waterloo. This guide has been developed by persons who know better than any of us about the lived experience of dementia, their capabilities and needs, and what works best for them.

Remaining socially active

Sometimes, as the disease progresses and communication skills deteriorate, getting out and meeting people - or even having visitors - can be problematic. Try not to feel intimidated or embarrassed if you cannot find the right word. Take time to relax and think about what you want to say. One-on-one discussions are usually easier than keeping track of conversations in large groups.

When in social situations, ask people to slow down, use short sentences or to repeat what they have said. It can also be very useful to tell people how you would like to be helped. Some people with dementia say they like to have time to find the word or answer they are looking for, while others appreciate if someone fills in the words for them.

Try not to isolate yourself. Contact your local Alzheimer Society for support, information and strategies to remain active. You may also want to join a support group to talk with people who can understand and relate to what you are going through. This will allow you to share your feelings, your challenges and coping strategies with others.

Communicating with your doctor

Try to book extended appointments with your doctor, when possible, so you don't feel rushed. This gives you both enough time to express yourself and talk about your challenges so your doctor can respond. You can prepare for your doctor's visit by writing down symptoms and any questions you may want to ask and you may want to focus particularly on the things that have changed since your last doctor's visit.

Example: You may notice that you find it harder to keep track of your medications than you used to or your wife may be telling you that you now become disoriented when driving.

To feel at ease, you may want to ask a friend or family member to accompany you to help communicate and clarify information. Be honest and open with your doctor about everything that has changed. Be as specific as possible. Ask them to explain things to you in a way you can understand and to write down every instruction for you, no matter how small it is. Ask any questions you want answered. Ask them to talk to you directly. If you are unhappy with the way they treat you, let them know how you feel. Finally, when it comes to your health and your feelings, you are the expert!

Planning ahead

Being informed about the disease and knowing what lies ahead can help you feel more prepared. As the disease progresses, you will not always be able to communicate your thoughts and wishes. Be sure that someone trustworthy has the legal authority to make financial and health care decisions for you when the time comes. Talking about this with trusted friends and family members when you are still able to do so can give you a sense of control over your future and put your family more at ease. Advice from lawyers and/or financial consultants can also be helpful. You can tell them how you want to be involved in decision-making.



It is important to find your own unique ways to speak with others without anxiety.

Different things help different people, so find what works best for you and then communicate it to others.

B. STRATEGIES FOR CAREGIVERS:

As dementia progresses, communication can become more and more challenging. You may find that individuals with dementia have good days and bad days; this can depend on the quality of their sleep, stress level and other medical conditions.

Respectful, sensitive, ongoing communication remains critical, no matter what stage of dementia the person is at and how confused they may appear.

Elements for successful person-centred communication throughout the disease:

Learning

As a caregiver, try to learn as much as you can about the disease to provide the best possible care and support. Learning about the disease, its progression² and how it affects a person will help you be prepared and have realistic expectations of the person's abilities to communicate throughout the various stages of the disease. As the disease progresses and abilities are lost, you can learn to interpret the person's messages by paying attention to both verbal and non-verbal cues. This means putting together the various cues to help you interpret what the person is trying to tell you about how they think and feel.



Communication skills are not learned overnight and require patience and practice.

Example: 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.

Believing communication is still possible and there is always a meaning

Every person, regardless of abilities, maintains a core of self that can be reached. Communication remains possible at all stages of dementia. What a person says or does and how a person behaves has meaning; however, the disease affects their ability to communicate with us in a way that we can always understand. Never lose sight of the person. No matter how the disease affects the individual, it is important to treat them with dignity and respect.



If you find it difficult to understand the person, call upon their past experience and what you know about them.

² The Progression Series can be found at <http://www.alzheimer.ca/english/disease/progression-intro.htm> or by contacting your local Alzheimer Society office.

Focusing on the person's abilities and skills

Although dementia affects certain abilities, the person's emotions and feelings will remain, as will the need for companionship, purpose and belonging. Focusing on the person's abilities and skills will go a long way in adding to their quality of life and will help the person maintain a sense of self. 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. Consider helping the person with dementia to find alternate ways of expression through art, music or gardening to maintain and enhance communication.

Example: Ben is now living in a care facility. Every Friday afternoon, a volunteer brings her gentle German Shepherd dog into 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.

Reassuring and being positive

As a caregiver, it is important to encourage the person in their attempts to express themselves when they have trouble communicating. Instead of criticizing and correcting, ignore failures and remember to be supportive, positive and encouraging. New activities can be stimulating yet confusing for a person with dementia, so use familiar things to create a sense of comfort and reassurance. Laughter and humour are positive ways to help you get through difficult times.

Example: 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 to 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.

Example: Nazir repeats the word "Mama" over and over. His family do not remind him that his mother died fifteen years ago. Instead they talk with Nazir about his mother and have photos of him and his mother on hand to look at together.

Remember to CONNECT not to CORRECT

Consider the following when communicating with a person at the middle stage of dementia:

The middle stage brings a greater decline in the person's cognitive and functional abilities. Not only will they be unable to find the words of objects, they may even forget the names of friends and family. This can be very distressing for the person, however it is a predictable aspect of memory loss associated with dementia.

At this stage, the person with dementia may be trying to interpret a world that no longer makes sense to them because their brain is interpreting information incorrectly. Sometimes the person with dementia and those around them will misinterpret each other's attempts at communication. These misunderstandings can be upsetting and frustrating for the person with dementia and caregivers. However, there are ways to help make sure that you understand each other.

Non-verbal communication will become increasingly important.

Watch for behaviour changes, body language and non-verbal signs that may be used to express a feeling or indicate physical discomfort, in which case you may wish to contact the person's family doctor.

Consider communicating primarily through the senses from the late stage of the disease to end of life:

The person will lose their capacity for recognizable speech, although words or phrases may occasionally be uttered. However, even if the person can no longer communicate verbally or recognize you, they likely will still be able to communicate in other ways and feel your affection and reassurance. At this stage, non-verbal communication will become increasingly important. People in this stage experience the world primarily through their senses, so 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!*

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. And some may even accuse their partner of having an affair.

Remember that these accusations are the result of the disease; they are not willful or intentional. And although they can be hurtful, try not to take them personally.

It is important not to argue with a person with dementia or try to convince them that their perception is not real. Their perception is part of their own reality; try to accept it and meet them where they are.

Living with dementia at any stage can be very challenging. Whether you are the person with the disease or someone who supports them, it is normal to feel a variety of emotions throughout all stages of the disease. It is important to acknowledge your feelings, care for yourself and seek the practical help and emotional support that you need. The Alzheimer Society in your community can provide educational resources to help you learn more about the disease, referrals to help you access the practical support you need, and one-on-one and group support to help cope with the emotional impact of the disease.

We are learning more everyday about dementia and how to best provide support to the person with the disease. Much of what we understand comes from people with the disease or caregivers who find solutions to their challenges and share them with others. You can also exchange ideas by visiting the Alzheimer Society of Canada's Message board on the website www.alzheimer.ca.

For more information, please visit the Alzheimer Society's website www.alzheimer.ca or contact your local Alzheimer Society.

There is information. There is help. You are not alone.

Alzheimer Society

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COMMUNICATION TIPS FOR CAREGIVERS

- ✓ **Reduce distractions:** Communicating is always 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.
- ✓ **Gain attention:** Face the person. Making eye contact with the person will help focus their attention. Get close enough so they can see your facial expressions and any gestures you may use. As some people have problems recognizing family and friends, you might want to introduce yourself and remind them who you are.
- ✓ **Be aware of your tone and body language:** Remain calm and still and speak in a relaxed tone of voice to put them at ease. Brusque or hurried movement as well as a sharp tone or raised voice may cause distress.
- ✓ **Be clear and concise:** Talk slowly and clearly, using short and simple sentences. Use closed-ended questions which are focused and answered using a simple "yes" or "no" instead of open-ended questions, which are time-consuming, may result in unnecessary information, and may require more effort on the part of the person with dementia. Avoid phrases that can be interpreted literally, such as "it's the cat's pyjamas" or "up to my eyeballs" which might be confusing.
- ✓ **Be respectful:** Use the person's name when addressing them to help them retain a sense of identity. 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 form the words that are in their mind.
- ✓ **Listen carefully:** Listen carefully to what the person is saying and observe both verbal and non-verbal communications. 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 the information so be patient. Provide reassurance. If they are having trouble communicating, tell them that it's fine and encourage them to keep trying to put their thoughts into words. 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. Use body movements such as pointing or demonstrating an action to help the person understand what you are saying. Of course, this should be done tactfully so the person does not feel you are treating them as a child.
- ✓ **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 listen for cues to health problems.

WHERE CAN I GET FURTHER INFORMATION?

Please refer to the following resources or contact your local Alzheimer Society:
www.alzheimer.ca

Day-to-day series:

- Bathing
- Toileting
- Personal care
- Meal time
- Locating devices
- Caregiving options: considering long term care
- Adjusting to long term care

Progression series:

- Overview
- Early stage
- Middle stage
- Late stage
- End of life

Alzheimer's disease brochures:

- First steps
- First steps for families
- Ways to help
- What to expect
- Reducing caregiver stress
- Dispelling the myths
- Treatment options

Research series:

- Creutzfeldt-Jakob disease
- Lewy body Dementia and Pick's disease
- Frontotemporal Dementia
- Vascular Dementia
- Down syndrome
- Genetics
- Risk factors

Tough issues:

- Communicating the Diagnosis
- Living Alone
- Decision-making: Respecting Individual Choice
- Quality of life
- Participation in Research
- Genetic Testing
- Restraints
- Intimacy and Sexuality

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