



A BY US FOR US GUIDE

Enhancing Communication

An inspirational guide
for people living with dementia

SERIES 1

Introduction

This guide discusses the most important tool we have, which is communication. Communication is BOTH verbal and non-verbal. Both means of communication are important, but non-verbal communication becomes an even more valuable tool when dealing with memory changes. Watching other people and their body language helps us understand a conversation better, as so much of our language can have different meanings depending on how it is stated. A hand signal can be used to stop a conversation while thoughts are gathered. A meaningful glance can be used to let others know that help is needed. Body language can tell others that we are uncomfortable or tell us whether someone is truly interested in what we have to say. A warm touch can tell us that you understand and care.

Some people are excellent communicators and find it easy to use this tool in difficult situations, while others find it very difficult to have sensitive conversations. If a strong effort is made to communicate in the beginning, it will benefit all. It is important that care partners remember that asking what would work best is the ideal approach, as everyone is unique in their likes and dislikes, their experiences, and their feelings.

Introduction continued

Memory changes may affect our communication skills, but we can use communication to our advantage. This requires us to be very open and candid with others, and for others to be open and honest with us. This is a very difficult and emotional time, but the rewards of these early conversations will be carried with us throughout our journey. It is important to communicate and document everything now, while you are still able. Don't be afraid to ask for help, as working together in these times will be some of your fondest memories. Vocalize: write letters, poems, songs, or stories; or use videos and pictures to help with this. Don't be afraid to tell others how you are feeling and what your experience is like. Tell people now how much they mean to you and thank them ahead of time for all their future assistance. That way they can remember this on the days that dementia causes you to say or do something inappropriate. Also, we need to be willing to hear from our care partner about how they are feeling and what their experience is like. It is important that all parties listen carefully, respect each other's perspectives, and never judge.

There is great power in saying, **I LOVE YOU! THANK YOU!
CARRY THESE WORDS WITH YOU EVERY DAY OF OUR
JOURNEY TOGETHER!**

– Brenda Hounam, Paris, ON

This By Us For Us guide is dedicated in memory
of a dear friend, **Sharon Smith**

Things we have always wanted to say...

We are so close to our care partners, and we realize how much we rely on them at times, so we do not want to hurt them with our feelings. This is why it is often hard to say what we really want to say, which is....

- ✓ **I need to be open about my experiences and not protect you.** I have always wanted to tell my family members how hard this diagnosis is for me and the problems that go along with it. I have not told them much because I want to keep a positive attitude and I need them to help me. At first, I wanted to protect my family from knowing what may happen to me as the disease progresses because I didn't want them to be scared or feel bad, but I decided that it is more important to be honest with family right from the beginning.
- ✓ **I get frustrated, too.** I know I must frustrate you sometimes, but please know that it is never my intention. Keep in mind that I get frustrated too, and we have to work at not letting small things bother us.
- ✓ **Treat me like an adult.** Don't treat me like a child, do everything for me, speak for me, or smother me. Please ask me what I need and want.
- ✓ **I need your support.** Make me feel part of you and stick with me. Please don't correct me; encourage me instead.
- ✓ **Please don't make assumptions or speak for me.** Listen to me. Hear what I am saying and don't assume you know. Just ask me what would be helpful

Communication challenges with family and friends

I feel discredited and devalued

It hurts when I am second-guessed or when people ignore me and talk to my care partner before talking to me. I do not like being treated like a child or treated as though I am not there. I sometimes do not feel validated, or I feel that I am no longer considered 'an expert' capable of making valid decisions.

Personal solutions

- ✓ Join a support group to talk with people who understand what you are going through.
- ✓ Share your challenges and coping tips with others.
- ✓ Talk with others about how you want to be involved in decision-making.

What others can do

- ✓ Speak directly to me.
- ✓ Really listen to what I am saying and ask questions if you do not understand.
- ✓ Do not talk to me as though you are speaking to a child.

Communication challenges with family and friends continued

What others can do

- ✓ Offer gentle encouragement and “quiet help” when I need it.
- ✓ Please respect me as a person and preserve my dignity.
- ✓ Allow me to try things on my own.
- ✓ Acknowledge that I still have a lot to offer and can still contribute in some way. My life doesn’t stop here.
- ✓ Treat me in the same way you would want to be treated in the same situation.
- ✓ Problem solve as a family.
- ✓ Write reminder notes for me and leave them where you know I will find them.
- ✓ Make a checklist for me or help me use timers as reminders.
- ✓ Don’t be afraid to ask me for help.
- ✓ Give instructions one step at a time.

Communication challenges with family and friends continued

My friends lack understanding or doubt my diagnosis

Friends are often uncomfortable around me, now that I have dementia. It is almost as though they forget that I am still the same person. They tell me they understand, but really, they don't, because they can't. Sometimes, friends and family do not accept that I have Alzheimer's, and as a result, they do not discuss it with me. They even question the diagnosis and they say things like, "You look so well", or "I forget things also". It is hard to communicate about the disease when others do not acknowledge it.

Personal solutions

- ✓ Be open about your diagnosis and share your feelings and experiences with others.
- ✓ Use laughter to communicate to others that you are at ease and it will make them more receptive to what you are sharing.
- ✓ When you accept your diagnosis, and are comfortable talking about it, then others will be comfortable and open as well.
- ✓ Take initiative to ensure that people understand you by asking them if they understand.

Communication challenges with family and friends continued

Personal solutions

- ✓ If friends and family don't phone or visit, call them.
- ✓ If available, use a computer or other device to keep connected.

Notes

“We appreciate your effort to understand what it is like to have dementia, but you really cannot fully understand what the experience is like until you have walked in our shoes. We hope that, through this guide, you can gain a better understanding of our experience and gain tips on how we can all work together to enhance our lives together.”

(Gail Robinet, BA., M.Div., Burford, ON)

Communication challenges with family and friends continued

What others can do

- ✓ Ask me what I am experiencing, how I am feeling, and validate what I am saying.
- ✓ Acknowledge that you do not totally understand but that you are trying.
- ✓ Please listen to me and believe what I am telling you about my experiences.
- ✓ Don't get angry when I repeat myself.
- ✓ Be open with me, even about those things you think will upset me.
- ✓ You can tell me that you are grieving as well, because we are going through this together.
- ✓ Please don't give up on me.

Opening up and asking for assistance is difficult

It is difficult to open up to people, or ask someone to drive me places. It is also hard to request special outings, such as going to hockey games, because I do not want to interfere with others' lives.

Communication challenges with family and friends continued

Personal solutions

- ✓ Explain that you are having difficulties and ask them to be patient with you.
- ✓ Realize that sensitive or personal conversations can be more difficult depending on the topic. Choose to speak to someone with whom you feel comfortable.
- ✓ The sooner you start open dialogue with your loved ones, the easier it becomes.
- ✓ Make a list of your needs and share them with others.
- ✓ Don't be afraid to ask for help.

What others can do

- ✓ Please don't back off after I have exposed my feelings to you, because I will see it as a form of rejection.
- ✓ Try to be comfortable talking to me about difficult topics, such as sexuality.
- ✓ Ask me how you can help.

Communication challenges when in social situations

Sometimes, I am at a loss for words or cannot find the right word

Communication is challenging when I cannot find the right words. My vocabulary gets lost and my mind goes blank. My sentences 'derail', I have difficulty projecting my voice, and sometimes I stutter.

Personal solutions

- ✓ Keep a pen and paper handy and write down notes for reminders.
- ✓ When in a group setting, write down one word that can bring the point back when you get an opportunity to speak.
- ✓ Keep conversations simple and on the light side.
- ✓ Take a few moments, relax, and think about what you want to say, or what people want you to do; the words often come when you feel less pressured.
- ✓ If you cannot remember, simply say so.
- ✓ Be a good friend to yourself.
- ✓ Don't be afraid to tell others if you are having a bad day.
- ✓ Ask people to slow down.

Communication challenges when in social situations continued

What others can do

- ✓ Pay attention to non-verbal cues and body language, such as eyes and hands.
- ✓ Give me reminders and prompts.
- ✓ Tell me your name and remind me of my connection to you.
- ✓ Allow me time to think, find the right word, answer questions, or write down my thoughts.
- ✓ Remember that I have something to say too.
- ✓ Ask me how I would like to be helped.
- ✓ Remind me what we are speaking about.
- ✓ Ask me if I want help with a word, but do not rush in to finish my sentences.

Difficulty maintaining focus and keeping on track, especially in large groups

When talking with friends, I often lose my train of thought. I cannot keep up or on track. People often talk too quickly and do not give me enough time to talk. I have something to say; I just need more time and less distraction.

Communication challenges when in social situations continued

Personal solutions

- ✓ If you can't think of anything to say, ask the other person a personal question. Then pay close attention to the answer and comment on something they said.
- ✓ Listen to your peers and learn what works for them.
- ✓ Do your important communicating when you are rested.
- ✓ Communicate in a quiet environment and minimize distractions.
- ✓ Ask people to speak one person at a time.
- ✓ Make notes before important conversations so you don't get sidetracked.
- ✓ Communicate during mealtimes, while walking, or when working on projects, as these conversations tend to flow more easily.
- ✓ Ask people to slow down and use shorter sentences.
- ✓ Ask people to repeat a question in a different context, or have them provide an example.
- ✓ Try to keep to one-on-one conversations or small groups.

Communication challenges when in social situations continued

What others can do

- ✓ Keep conversations light and simple and talk to me slowly and calmly.
- ✓ Provide me with one suggestion at a time and provide fewer options/choices.
- ✓ Don't avoid talking about something difficult, be direct, specific and open with me.
- ✓ Please don't interrupt me or I'll lose my thoughts.
- ✓ Do not move ahead in a conversation without me because I will not move on in my head. I often repeat myself because I am still thinking about that issue and I don't know that I already spoke about it.
- ✓ Allow me the time I need to process my thought and communicate it to you.

Notes

Communication challenges when in social situations continued

Others forget the range of communication strategies

Many people believe communication involves only the things that we say, when it is really so much more. Communication also incorporates the things that we do not say – the looks we give, the hand gestures we use, or the body language we use. It can include writing, gestures, signs or signals, behaviours, and displays of emotion. The manner in which we say something can clarify a message or provide room for misinterpretation. For example, someone may shout in order to be heard, which may lead to a perception of anger or impatience, even if the words do not reflect these emotions.

Notes

Communication challenges when in social situations continued

Personal solutions

- ✓ Use hand signals. Hold your hand up to stop a conversation or prevent someone from interrupting, or use the 'time out' signal if a question is too long or complicated, or if you lose your concentration.
- ✓ Writing is an easier way for some people to communicate.
- ✓ When you need to start a difficult talk, leave a note for someone saying that you would like to talk about something.
- ✓ The computer is a good tool for writing letters to tell others about your feelings, and you can also use it to help you proofread.
- ✓ Use other visual aids or non-verbal cues. Use your eyes and body language, draw pictures, write notes, or point to photos or pictures.
- ✓ Use a voice recorder for the times when you think of a thought and writing it down may be difficult (like in the middle of the night).
- ✓ Keep lists of things you would like to share with others.

Communication challenges when in social situations continued

What others can do

When in public and I would like my children to step in and help me with what I am trying to communicate, I give my children a look. We joke about it being a ‘Mother’s Look’ – you know, the look a mother gives when her children are misbehaving in public. Now that look means “PLEASE HELP!”

- ✓ Recognize that I rely on your body language.
- ✓ Some conversations are easier in person than over the phone or email.
- ✓ A warm touch can tell me that you care.

Notes

“I like to use the computer to proofread letters and rewrite for feelings and expressions.”

(Clayton Wilson, B.A., M.Ed., Brantford, ON)

Challenges when communicating with health care professionals

I have difficulty remembering, describing, or relaying my experiences

I have difficulty finding the right words or remembering my feelings in order to explain my situation to doctors or other health care professionals. Plus, doctors are always rushed and they do not allow us the time we need to express the issue.

Personal solutions

- ✓ Write down any questions or symptoms you have and prioritize these comments before your appointment, as you might not have time to discuss all your concerns.
- ✓ Ask the doctor to write down any instructions for you, no matter how small, such as going to the lab or making a new appointment.
- ✓ Take a trusted family member or friend with you to a doctor's appointment and ask them to make notes, ask questions, and support you.
- ✓ Be totally open and honest with your doctor about everything that has changed and the things that are not normal for you. Make a list or keep a diary to help you remember.
- ✓ Ask a trusted family member to make a list of changes that they have noticed in you and have them discuss this list with you BEFORE they show it to your doctors.

Challenges when communicating with health care professionals cont.

Personal solutions

- ✓ Book an extended appointment if needed (like 30 minutes instead of 15).

What professionals can do

- ✓ Have patience with me.
- ✓ Give me time to express myself and think. Slow down during my visits.
- ✓ Get to know me beyond the dementia. I am a person first.
- ✓ Encourage me to keep a diary of my experience and allow me to share it with you.
- ✓ Ask me what I have been experiencing.

They lack an understanding of the disease or they deny that something is wrong

Doctors seem to have a misconception of my disease and how it affects me. They may think I am in the late stage already, or they might not think anything is wrong. A short appointment is often not enough time for them to see the extent of my disease, especially if I am articulate or I appear capable.

Challenges when communicating with health care professionals cont.

Personal solutions

- ✓ Realize that doctors are not gods; you are the expert about yourself!
- ✓ Be your own advocate and have confidence in yourself.
- ✓ You know your body more than anyone else so be firm about how you feel and keep persisting!
- ✓ Many issues arise from interactions with your family doctor, so get them to refer you to specialists who will be more likely to understand what you are going through.

What professionals can do

- ✓ Listen! Listen! Listen! Don't assume you know what is best for me.
- ✓ Ask me what I am experiencing and how you can help!
- ✓ Learn as much as you can about dementia, and if you are not sure, please refer me to a specialist.
- ✓ Know what supports are available in the community and refer me to those resources, such as the Alzheimer Society.
- ✓ It's better to say you don't know than to say nothing.

Challenges when communicating with health care professionals cont.

They treat me like I am not there

They think I am less credible than others, so they talk to others instead of me. They assume they know what is best for me.

Personal solutions

- ✓ If you are unhappy with how your doctor treats you, say how you feel or find a new doctor.
- ✓ Ask doctors to explain things to you in simple terms, so you can be involved in the discussion.

What professionals can do

- ✓ Please ask me what I want or how you can help.
- ✓ Speak to me directly, not to the person I am with.
- ✓ Allow me to be involved in decision-making.

We asked the doctor for you

An appointment checklist...

“I have been asked by the By Us For Us participants, as a physician specializing in the care of individuals with cognitive loss, to supply the following checklist for your next doctor’s visit:”

- Did you bring all of your medications, in bottles, including over-the-counter medications like vitamins and herbal medications?
- Did you write down questions or concerns before the appointment?
- Recognize that not all issues can be dealt with at one appointment.
- Did your trusted family members or friends write down observations regarding changes (either good or bad) that they have observed in your behaviour since your last appointment? This will help the doctor to better gauge the progression of the disease (either positive or negative), and to follow any improvement after medication.
- Did you arrange for a trusted family member or friend to accompany you to the appointment to provide information and be a second set of ears?
- Did you keep a list of all doctor or therapy appointments, medical tests, and hospital admissions forms to bring with you to the appointment, to help keep track of important issues?

E. Anne Braun, M.D., M.Sc., F.R.C.P.(C), F.A.C.P.
Associate Clinical Professor Medicine
& Psychiatry McMaster University Geriatrician

What research says

Factors that influence communication

Certain health events (e.g., hearing loss, strokes) can affect communication, and the ability to process information slows with age. People may take medications that have side-effects that change communication. All these things may cause increased isolation, which leads to decreased opportunities for communication.

Communication issues

The impairment of our short-term memory impacts our ability to hold and maintain a conversation. Changes in communication are reflected by losses of vocabulary, word-finding ability, understanding of abstract language, ability to understand messages on the telephone, ability to express ideas, and ability to keep up with the conversation.

People living with dementia are often aware of their communication difficulties and can feel embarrassed, frustrated, or scared. Positive encouragement, helpful cues, or gentle reminders to complete thoughts and sentences will become necessary with time.

People living with dementia may become less aware of their difficulty, but increasingly frustrated and stressed. Please only help us find our words when necessary, and do not correct or insist. You can use pictures or objects to help us remember.

What research says continued

People living with dementia may be unable to communicate with exact words, and may use other ways of communicating. Even though the words or gestures may not make sense to some, they still communicate something. People living with dementia may enjoy non-verbal communication, so use gestures, facial expressions, tone of voice, and caring touch, to help make a connection.

Attitudinal factors influencing communication breakdown

Attitudes and stereotypes of dementia can influence the way people communicate to us, causing them to inappropriately modify their speech, such as using baby talk, shouting, or using demeaning language. This leads us to become disempowered, ignored, and banished from many meaningful opportunities for relationships and personal exchange. This is why it is important for people living with dementia to seek opportunities to express themselves. We all need to focus on a wide range of non-verbal communication techniques, and celebrate strengths and abilities.

“I want to learn more about Alzheimer’s. It helps to remove the fear and denial. I want to learn how to stay healthy longer. I’m not prepared to just fade away.”

(Carl Wilson, Sarnia, ON)

Brenda's story: The inspiration behind the By Us For Us Guides

When Brenda Hounam was diagnosed with Alzheimer's disease at the age of 53, she realized that very little information was available for people living with dementia. The dominant view was that people living with dementia could no longer learn and be involved in their own care. Brenda knew differently. In 2003, she was inspired to address this gap - to develop a series of resources specifically designed by and for people living with dementia. In 2004, she approached two of her peers with her idea and was surprised by the enthusiasm and support they offered. Through Brenda's contacts at the Alzheimer Society of Brant, the Alzheimer Society of St. Thomas, and the Murray Alzheimer Research and Education Program (MAREP), Brenda connected with various people living with dementia from all around Ontario to work on what came to be called, the By Us For Us (BUFU) guides. These guides provide tips and strategies for managing daily challenges and enhancing well-being for themselves and others living with dementia. Since the publication of the first guide, "Memory Workout", the following guides focused on issues raised by people living with dementia. The project has grown to include three series researched and developed in partnership with people living with dementia and care partners. The philosophy of the By Us For Us guides remains committed, placing importance first on the experiences, suggestions, and tips from those directly affected BY dementia, FOR those directly affected. Brenda has been a true inspiration and role model to her peers. Without her determination and perseverance, this project would not exist or have the international recognition that it does.

Resources

Alzheimer Society of Canada

Toll-free telephone: 1-800-616-8816

Email: info@alzheimer.ca

Website: www.alzheimer.ca

Alzheimer's Society UK

Website: www.alzheimers.org.uk

Refer to information on communicating with someone with sensory impairment.

BrainXChange

Website: www.brainxchange.ca

World Health Organization

Website: www.who.int

We also suggest that you check for other local, national and international resources.

Endorsements

As Chief Executive Officer of the Alzheimer Society of Canada, I want to congratulate the 'By Us For Us' team for their continued support to people, like themselves, who are living with early stage memory loss. The innovative ideas and suggestions contained within this Communications Guide are valuable tools for anyone living with the day to day challenges of dementia. Whether you are someone living with the disease, a family member, a friend or health care professional, the 'By Us For Us' guide provides unique insight into how communication, both verbal and non-verbal, can be a powerful tool. Thank you again to everyone involved with this project, as your guidance and inspiration is truly helping to make a difference in the lives of people touched by dementia.

Scott Dudgeon

CEO, Alzheimer Society of Canada

www.alzheimer.ca

This practical guide clearly shows how persons with early-stage memory loss can take steps to maintain satisfying communication and how their conversation partners can learn to listen to them and follow their lead in interactions. These concrete suggestions flow from the same wisdom evident in published memoirs by writers with dementia. The problem-solving format will be very useful for individuals and for group role-play sessions.

Dr. Ellen Ryan

Professor, Gerontology and Psychiatry McMaster University

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About the By Us For Us Guides

The By Us For Us Guides (BUFU guides) are designed to provide people living with dementia/care partners the necessary tools to enhance their well-being and manage daily challenges. What makes these guides unique is that they are created BY people living with dementia/care partners, FOR people living with dementia/care partners. The guides include three unique series:

People Living with Dementia: Series 1

This series is written by people living with dementia and covers their experiences. It includes topics such as tips and strategies for managing daily challenges, memory exercises, and enhancing communication and wellness.

Partnership: Series 2

This series is written by both people living with dementia and care partners and covers the partnership experience. It includes topics such as safety, food and mealtimes, social connections, and coping with loss and grief.

Care Partner: Series 3

This series is written by care partners and covers their experiences of supporting a person living with dementia. This series includes topics such as before diagnosis, young care partners, roles, and health and wellbeing.

**To view other guides or order print copies, please visit the Schlegel-UW Research Institute for Aging website:
www.the-ria.ca**

We welcome your input...

If you are living with dementia or are a care partner and would like to comment on this guide, suggest topics for future guides, or participate in future guides, please contact Murray Alzheimer Research and Education Program (MAREP).

Connect with us!

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