

CLEAR Communication Toolkit for Health Care Providers

Compassionate Language and Empathetic Approaches for Respectful Dementia Disclosure

[The Alzheimer Society of Canada](#) is excited to share with you the CLEAR Communication Toolkit to support health care providers in putting the [National Dementia Guidelines for Disclosing and Communicating a Diagnosis of Dementia](#) into practice. The CLEAR Communication Toolkit is adapted from the Serious Illness Conversation Guide, which we have refined through an iterative, community-engaged process involving researchers, health care providers, and persons with lived experience.

How to Use the CLEAR Communication Toolkit

- The Toolkit should be used before and during the appointment(s) communicating a dementia diagnosis.
- Health care providers are recommended to:
 - Review the flow diagram to understand the steps involved in communicating a dementia diagnosis,
 - Use the script during their appointments to communicate the dementia diagnosis and check-in with the patient regularly to ensure they are comfortable,
 - Read the overview to understand the purpose and structure of the Toolkit.

Useful Resources

The full Guidelines,
education, and resources
guidelines.alzheimer.ca

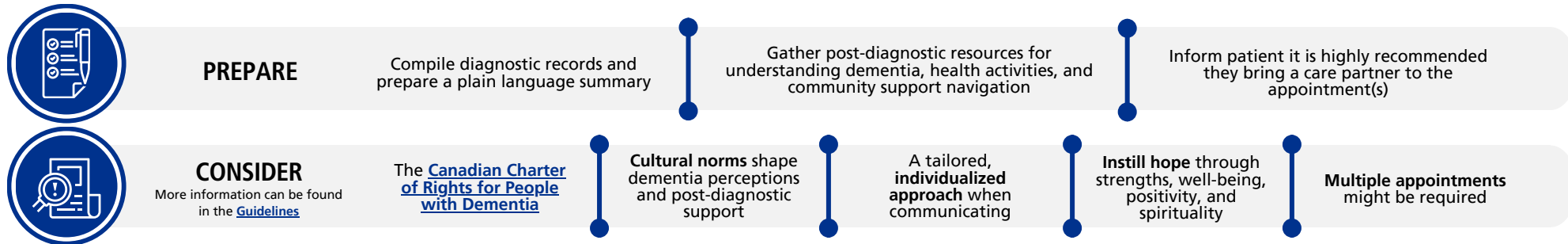


This Toolkit is currently being evaluated by Alzheimer Society of Canada (started January 2024). This Toolkit may be updated. Please check the National Dementia Guidelines website regularly for updates.

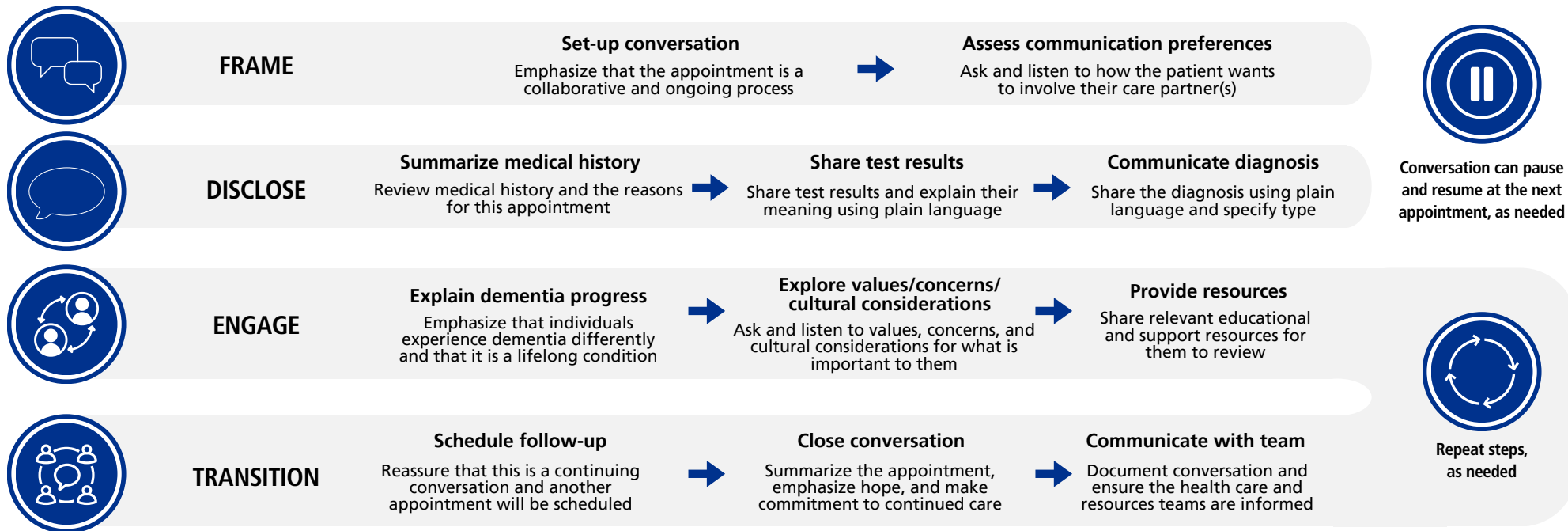
CLEAR Communication Toolkit

This **flow diagram** provides health care providers an overview of the process for communicating a dementia diagnosis with patients and their care partners. This flow diagram can help support earlier, more, and better conversations that are compassionate between health care providers, patients, and their care partners and that can inform future care.

Before the appointment(s)



During the appointment(s)



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This **script** offers health care providers prompts for setting up the conversation, disclosing the diagnosis, engaging in genuine conversation about what the diagnosis means for the patient and their care partner(s), and transitioning from diagnosis to continued care and support. Throughout the appointment(s), it is important to communicate with the patient in-front of you and actively listen to what they need from you now and in the future. Each step in the communication process should be covered but each step does not need to occur in a single appointment.

FRAME	Set-up conversation	"Before we start, I want you know that today's appointment is a collaborative conversation. I'm here to listen and understand how you feel. We'll take it step by step, and I'll make sure you understand everything we discuss, so we might need more than one visit."
	Assess communication preferences	"I want to make sure we're communicating in the best way for you." (Patient alone) "Is there anyone else here you'd like to be involved in our conversation or would you prefer that we talk one-on-one?" (Care partner(s) present) "I will speak directly to you during this appointment. Would you like me to include your care partner or anyone else in this appointment by asking them questions or providing them information as well?"
DISCLOSE	Summarize medical history	"The last time we spoke, we discussed _____ [<i>summarize medical history pertaining to diagnosis</i>]. We did several tests to find the reason for why you are experiencing these symptoms."
	Share test results	"The test results have come back and they confirm our concerns about your _____ [<i>medical history pertaining to diagnosis</i>]." "Based on the test results, we have a diagnosis. Can I discuss this with you now?"
	Communicate diagnosis	"According to the test results you have dementia, specifically _____ [<i>name type, if known</i>]." "I would like to discuss your diagnosis in terms of what is next and any concerns you have at the moment. How do you feel about this?"
ENGAGE	Explain dementia progress	"Dementia is a term which describes a set of symptoms which may include memory loss, changes in mood and behaviour, and difficulties with thinking, vision, movement, problem solving and language. Dementia is a progressive condition, meaning it tends to change over time, but each individual's experience is unique. There isn't a cure but there are treatments and support that can help maintain a fulfilling life." "What more information about your condition, your test results, or treatments would you like, if any?" "What is your understanding of your condition?" "How much information about what is likely to be ahead with your condition would you like from me?" "I would like to know what is important to you moving forward with your condition. How do you feel about this?"

Explore values, concerns, and cultural considerations

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Family
- Cultural considerations

“What are your most important goals if your health changes?”

“What are your biggest fears and worries about the future with your condition?”

“What gives you strength as you think about the future with your condition?”

“What abilities are so critical to your life that you can’t imagine living without them?”

“How much do your care partner(s) know about your priorities and wishes?”

(Patient alone) “Do you have a care partner(s) to help support you? Do you want to share this diagnosis with your care partner(s)? Would you like another appointment with me to share this information or would you like to share the information first?”

“Is there anything you would like me to understand about your culture or customs to help the team support you better?”

“How do we as a team help to support you?”

Provide resources

“I would like to provide you with resources that will help you understand your diagnosis and get more support. How do you feel about this?”

“I’ve heard you say that _____ is really important to you. Understanding what you have shared, and what we know about your condition, I recommend that we _____. This will help _____ [*specifics and value of resource(s)*].”

“I would like to share with you the information for your local Alzheimer Society, which can also help you locate valuable resources and support.”

Schedule follow-up

“I would like to schedule another appointment to discuss _____ [*any questions and concerns or topics not covered*] once you have had a chance to think about everything we’ve discussed. How do you feel about this? Is this something you would like us to book before you leave?”

Close conversation

“Today I’ve confirmed a diagnosis of dementia. I have directed you to support and resources available for you that address the values and concerns you shared with me. Know that you can live well with dementia. You’re not alone. I’m committed to your care, well-being, and working closely with you and your care partner(s) to manage your symptoms and explore all available options for your well-being.”

Communicate with team

For health care providers: It is important to provide a holistic approach to supporting people living with dementia and care partners. Make sure to communicate outcomes of appointments and involve other health care and resources teams in care planning.

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Overview

Purpose and Philosophy

In healthcare, communication is essential, especially when providing care and support to people living with dementia and care partners. The CLEAR Communication Toolkit is designed to build better relationships between health care providers, patients, and their care partners. The CLEAR Communication Toolkit is not just a resource; it will help you provide empathy, compassion, understanding, and clarity for patients and their care partners about dementia and care.

The core philosophy of the CLEAR Communication Toolkit is the belief that every patient deserves a conversation that is as honest as it is compassionate. The CLEAR Communication Toolkit aims to facilitate discussions that honor the patient's values, preferences, and goals, ensuring that health care providers communicate with patients and care partners in a way that expresses respect and instills hope.

Structure and Approach:

The CLEAR Communication Toolkit contains two elements: a flow diagram and a script. The flow diagram offers a visual that summarizes the step-by-step process. An important part of communicating a diagnosis of dementia is adequate preparation and review of key considerations to support more, better, and earlier conversations. Becoming familiar with the [National Dementia Guidelines](#) for Disclosing and Communicating a Diagnosis of Dementia is vital.

The script provides health care providers with patient-tested language and questions that make sure patients are seen, heard, and understood. By using the wording and questions in the script, health care providers do not need to spend valuable time looking for the "right" words or "right" way to communicate the diagnosis. This not only supports more, better, and earlier conversations but helps the conversation fit within the current Canadian healthcare system.

Each step in the communication process should be addressed, but each step does not need to occur in a single appointment. After the diagnosis is communicated, health care providers should collaborate with patients and care partners to work through the remaining steps to enable continued conversation and quality care and support.

Finally, if a person shares information about their cultural understanding of dementia, respect and acknowledge this is understood by the provider(s). Make sure they understand that dementia is a medical condition and that care and support is available to help them maintain their quality of life.