

# CLEAR Communication Toolkit for People Expecting a Diagnosis

## Compassionate Language and Empathetic Approaches for Respectful Dementia Disclosure

The Alzheimer Society of Canada is excited to share the CLEAR Communication Toolkit. The toolkit is for people who are experiencing possible signs of dementia and are preparing for a diagnosis appointment. It was developed by researchers, topic experts and people living with dementia.

### What the CLEAR Communication Toolkit provides

- Information to help you prepare for your appointment(s) regarding a dementia diagnosis.
- The possible steps your health-care provider will take during the dementia diagnosis appointment(s).
- A list of questions you may want to ask your health-care provider or care team.
- Blank pages for your questions, concerns or any information you would like to save for later.

**Note:** This is YOUR toolkit. Feel free to use it in the order that makes the most sense to you. We also invite you to go through the toolkit with someone you trust such as a family member or friend.

For useful resources, scan the QR codes below with your smartphone or tablet by opening the camera app and hovering the camera over the squares:

Getting a Diagnosis Toolkit  
[alzheimer.ca/diagnosis](https://alzheimer.ca/diagnosis)



First Steps After Diagnosis  
[alzheimer.ca/firststeps](https://alzheimer.ca/firststeps)



Planning for Your Future  
[alzheimer.ca/plan](https://alzheimer.ca/plan)



# CLEAR Communication Toolkit - Checklist

This **checklist** provides information about what you might expect during appointment(s) with your health-care provider. You can use the checklist at the time of your appointment(s).

## Before the appointment(s) my health-care provider might:

If it helps, you can tick the box if your health-care provider has completed this item.

**1** Review my medical records and prepare a summary of information for me.



**2** Gather resources that meet my needs. For example, information about dementia, guidance on living well with dementia, and community supports.

**3** Recommend that I bring a care partner, such as a family member or friend, with me to my appointment(s).

## During the appointment(s) my health-care provider might:

**1** Let me know that the appointment is a collaborative and ongoing process.

**2** Ask how I would prefer to involve my care partner(s) during the appointment(s).

**3** Remind me about my medical history and the reasons for this appointment.

**4** Share my test results and explain their meaning.

**5** Share what they know about my diagnosis, including the type of dementia.

**6** Let me know that everyone experiences dementia differently and that it is a lifelong condition.

**7** Ask about what values, concerns, and cultural beliefs are important to me. (Note: You can write these down on the next page).

**8** Share educational and support-related resources that reflect my values, concerns and cultural beliefs.

**9** Reassure me that this is a continuing conversation, and another appointment will be scheduled.

**10** Summarize the appointment, and let me know that there is hope and that I can live well with dementia.

**11** Make notes about the conversation and share information about my diagnosis with my care team.

**Note:**  
This may occur  
over multiple  
appointments.



## CLEAR Communication Toolkit - Understanding your needs

Your health-care provider may ask you questions to help understand your values, concerns, and cultural beliefs. The following is a list of questions you may want to think about and answer before your appointment(s). There is space to write down your answers.

If my health changes, what is most important to me?

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If I am diagnosed with dementia, my biggest fears and worries about living with dementia are:

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What gives me strength as I think about living with dementia?

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What abilities are so important to my life that I can't imagine living without them?

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How much do my care partner(s) know about my priorities and wishes?

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If I don't bring my care partner(s) to the appointment, do I want to share my diagnosis with them? Or would I like a separate appointment for my health-care provider to share the information?

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Is there anything I would like my health-care provider to understand about my culture or customs to help them support me?

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How can my health-care team support me best? (For example, resources that might be useful).

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## CLEAR Communication Toolkit - Questions to ask

The following pages provide examples of questions you may want to ask at the time of your appointment(s). They also offer space for you to write down answers as you receive them.

### Understanding a dementia diagnosis and what it means

**Check the box.** The type of dementia I have is:

- |  |  |   |                                       |
|--|--|---|---------------------------------------|
| <input type="checkbox"/> Alzheimer's disease | <input type="checkbox"/> Lewy body dementia      | <input type="checkbox"/> Mixed dementia               | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Vascular dementia   | <input type="checkbox"/> Frontotemporal dementia | <input type="checkbox"/> Parkinson's disease dementia | _____                                 |

What changes might I expect during the progression of dementia?

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How fast might these changes happen?

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### Understanding treatment and support options

Are there medications that could help slow down the progression of dementia?

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What are the available treatment options for managing the symptoms of dementia?

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What lifestyle choices will support my well-being and help manage my condition?

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### Impact on daily life

How might dementia impact my daily life and activities? (For example, memory loss, disorientation, communication, mood, etc.)

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How can I maintain my independence for as long as possible?

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### Sharing concerns and asking questions

How can I communicate with my health-care provider (e.g., family physician, nurse practitioner) about my questions, needs and concerns?

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What safety measures should I consider at home and in the community?

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## Challenges and planning for the future

What potential challenges may I experience while living with dementia? How can I manage them?

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What can I do to plan for my future?

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## Memory clinics and services

Are there memory clinics or specialized services that I can access in my community?

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Can you recommend any dementia-specific community resources or organizations?

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## Support groups and resources

Are there support groups available for people living with dementia and care partners?

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Are there any counselling options available for people living with dementia and care partners?

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Are there any resources available to help with legal and financial planning for people living with dementia and care partners?

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Are there any educational resources available for understanding dementia and how to manage it?

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Are there any nutrition or physical activity resources available for people living with dementia and care partners?

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Are there any local community centres or organizations (such as a local Alzheimer Society) that could provide access to more support and resources?

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What kind of follow-up appointments or monitoring will be necessary?

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For a list of terms that might be used during your appointment(s), visit [alzheimer.ca/diagnosis](https://alzheimer.ca/diagnosis)

### **CLEAR Communication Toolkit - Health-care providers script**

The Alzheimer Society of Canada has developed a CLEAR Communication Toolkit for health-care providers. It provides examples of how to share a dementia diagnosis and have respectful conversations about what living with dementia could mean for you and your care partner(s). Your health-care provider might not be familiar with this toolkit. If they haven't seen it before, share it with them, use it together or read it when preparing for your appointment(s). Each step in the communication process should be covered, but each step does not need to occur in a single appointment. **Reading this information may help you better prepare for what to expect at the time of your appointment(s).**

**[alzheimer.ca/ndg](https://alzheimer.ca/ndg)**

**For more information, contact your local Alzheimer Society. Call 1-855-705-4636 or visit [alzheimer.ca/find](https://alzheimer.ca/find).**

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