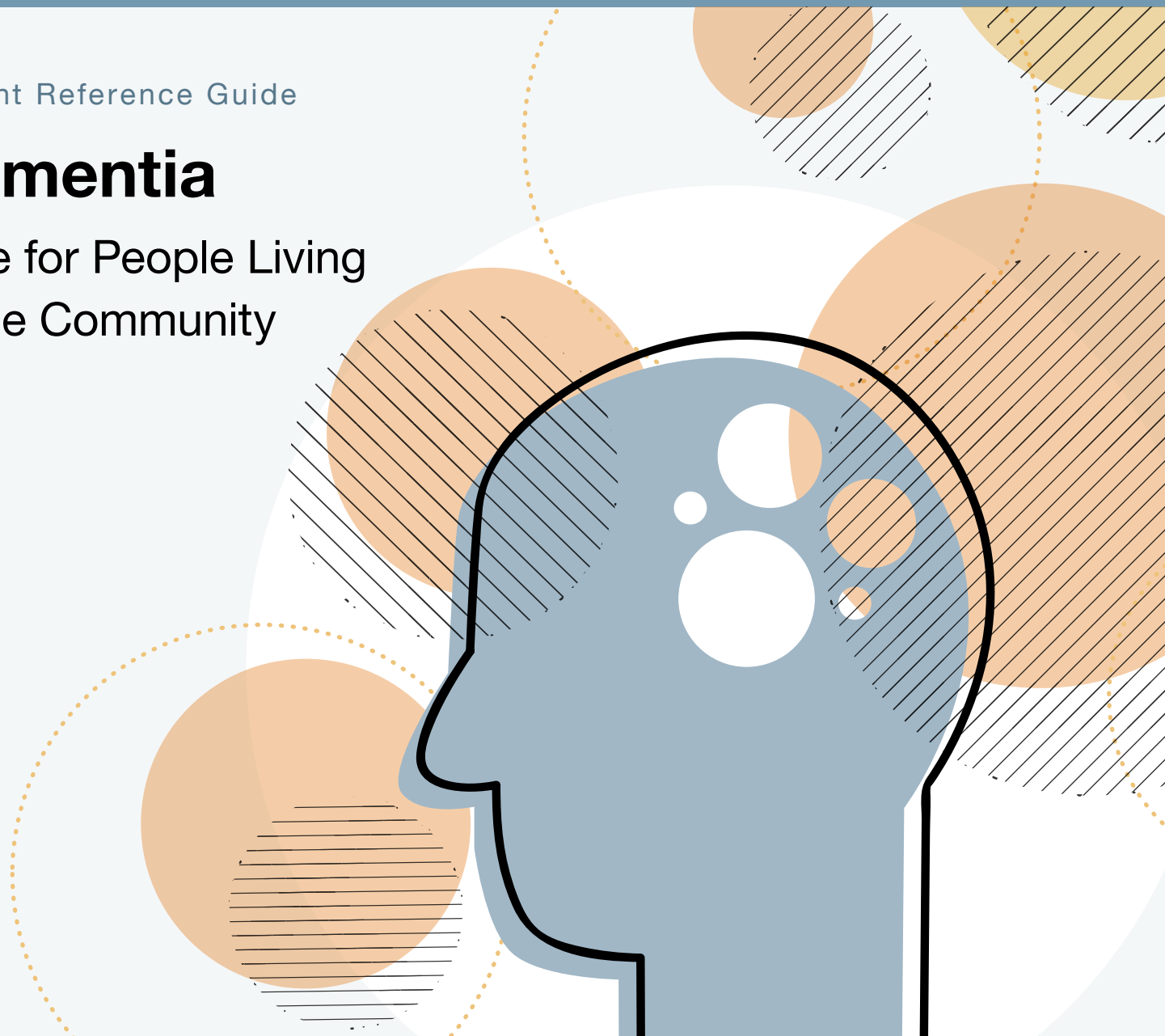


Patient Reference Guide

# Dementia

Care for People Living  
in the Community



Quality standards outline what high-quality care looks like. They focus on conditions or topics where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive.

This guide addresses variations and gaps in care in Ontario that need attention when it comes to caring for people with dementia living in the community. It is based on the best available evidence and was created in partnership with people with dementia, their caregivers, and health care professionals.

**The quality standard, available on our website, contains more information. You can find it at [hqontario.ca](https://www.hqontario.ca).**

In this guide, we use the following term:

- **Caregiver:** refers to an unpaid person who provides care and support to you, such as a family member, friend, or anyone you identify

# This guide is for people with dementia living in the community and your caregivers.

It can help you know what to ask for when receiving treatment and to make sure you receive the highest-quality care.

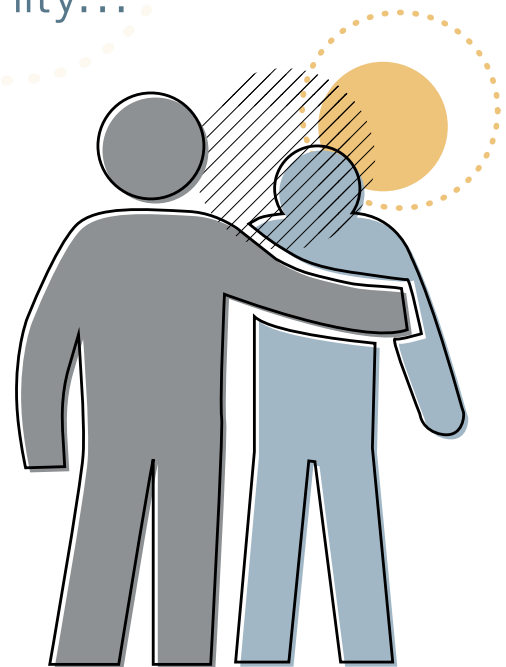
Living with dementia can be difficult, but you and your family don't have to do it alone. The people on your health care team want to build a relationship of trust with you and your family so they can help you live the best life you can. The more they know about you and your goals, the better they can help create a plan with you that meets your needs.

## If you or someone you care for has dementia and is living in the community...

You can use this guide to work with your care providers to make a care plan that works for you, including access to culturally appropriate care. Use this guide to ask informed questions about what types of care and services can help. This guide is for people who live in the community, not people admitted to a hospital or living in a long-term care home.

Care plans can be very different for each person, so it is important to work closely with your care providers.

Here are some things to consider.



## Understanding and Planning Your Care

- When you, your family, or a health care professional first notices changes in your memory or judgment, you should be assessed by a health care professional. This assessment should include questions about your physical health, your medical history, what medications you're taking, and how you're feeling. If you are diagnosed with either mild cognitive impairment or dementia, these assessments should be repeated at regular intervals.
- You should have a family physician or nurse practitioner who sees you regularly and knows your needs. This health care professional should monitor your health, provide care, and link you and your caregivers to other health care providers and support services that meet your changing needs and goals. Examples of support services include assistance with personal care, help around the house, support groups, and transportation services.
- You should have access to a health care team with expertise in dementia care. Your health care team may include doctors, nurses, a social worker, a pharmacist, an occupational therapist, recreational staff, personal support workers, and others.
- Your health care team should provide you with the name and contact information for one or more team members who are coordinating your care on an ongoing basis.
- You, your caregivers, and your health care team should create a care plan together that reflects your needs, concerns, and preferences. A care plan is a written document that describes your goals, the care and support services you should receive, and who will provide them. It should be updated regularly, especially if there is a change in your health or situation.
- You and your caregivers should be treated as important members of your health care team. This means your questions, concerns, observations, and goals are discussed and incorporated into your care plan, and you are supported to play an active role in your own care.



## Support in the Community

- Along with support services, your health care team should provide you and your caregivers with education and training about living with dementia. Your care team can also connect you with groups or organizations in the community who offer education and support. This education will help you understand dementia and how it progresses, your treatment options, and the supports available.
- You should have a safe living environment that meets your needs. Your health care team can help you understand what changes might be needed, such as memory cues or better lighting. Your team can also connect you with services to assess your living environment. Depending on your needs, you may decide to move to a different living environment.

## Caregivers

- Caregiving can be a rewarding experience, but it can also be stressful. If you are a caregiver, you should be assessed on an ongoing basis by a member of the health care team or your own primary care provider to see how you are coping and to help you get the supports you need to help you with your caregiving responsibilities. Supports can include training, support groups, home care, and temporary respite care for the person you are caring for. Respite care can give you a break from the caregiving routine and give you time to take care of yourself.



## Substitute Decision-Maker

- Having a voice in decisions about your health care treatment is important. As your dementia progresses, there will come a time when you won't be able to express your treatment wishes to health care providers, and you will require someone to make those decisions on your behalf. This person will be your substitute decision-maker.
- Make sure you know who your future substitute decision-maker will be, by Ontario law, if you become mentally incapable of making health decisions. Ontario's *Health Care Consent Act* automatically assigns a substitute decision-maker.
- If you would like someone else to be your future substitute decision-maker, prepare a legal document called "Power of Attorney for Personal Care." It is not enough to tell your health care team that you want a different substitute decision-maker.
- Once you have confirmed your substitute decision-maker, talk with them regularly about your wishes, values, and beliefs. This will help them make the right decisions for you, if needed. If your wishes change, keep them informed.
- For more information, excellent resources are available from Speak Up Ontario: [www.speakupontario.ca](http://www.speakupontario.ca)



**Living with dementia can be difficult, but you and your family don't have to do it alone.** Your health care team will work with you and your family to help you live well and as independently as possible.

**Everybody is different, and some options may not apply in your situation.** If you have questions about your care, it is important to speak with your health care professional.



## Looking for More Information?

Please contact us at [qualitystandards@hqontario.ca](mailto:qualitystandards@hqontario.ca) or **1-866-623-6868** if you have any questions or feedback about this patient reference guide.

**The quality standard, available on our website, contains more information. You can find it at [hqontario.ca](http://hqontario.ca).**

## About Health Quality Ontario

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by a single-minded purpose: **Better health for all Ontarians.**

Our quality standards are concise sets of statements outlining what quality care looks like for conditions or topics where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. They are based on the best available evidence and are developed in collaboration with clinical experts from across the province, and patients and caregivers with lived experience with the topic being discussed.

For more information about Health Quality Ontario and our quality standards, visit: [hqontario.ca](http://hqontario.ca).