

QUALITY STANDARDS

Dementia

A guide for people
with dementia living
in the community

2024 UPDATE

Ontario Health is committed to improving the quality of health care in the province in partnership with patients, clinicians, and other organizations.

To do that, Ontario Health develops quality standards. These are documents that outline what high-quality care looks like for conditions or processes where there are large differences in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. These quality standards set out important steps to improve care. They are based on current evidence and input from an expert committee that includes patients, care partners, clinicians, and researchers.

This patient guide accompanies the quality standard on [dementia](#). It outlines the top 10 areas where clinicians can take steps to improve care for people with dementia living in the community. The patient guide also includes suggestions on what to discuss with your clinicians, as well as links to helpful resources.

In this guide, we use the following terms:

Care partner: Someone who provides unpaid essential and ongoing care and support for you, such as a family member, a friend, and anyone else you identify. Your care partner's role may change over time as your condition progresses.

Clinician: A health care professional who provides care to patients, including a doctor, nurse, nurse practitioner, occupational therapist, pharmacist, physiotherapist, psychologist, social worker, and registered dietitian.

Health care team: A group of health care providers who work together to care for you. Your health care team may include doctors, nurses, social workers, volunteers, and personal support workers.

Summary of the top 10 areas to improve care for people with dementia

Quality Statement 1: Comprehensive Assessment and Diagnosis



What the standard says

People suspected to have mild cognitive impairment or dementia receive a comprehensive assessment when signs are first identified. If diagnosed with either condition, they are then reassessed on a regular basis or when there is a significant change in their condition.



What this means for you

When you, your family, or a clinician first notice changes in your memory or judgment, you should be assessed by a clinician. 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.

What is the difference between mild cognitive impairment and dementia?

Mild cognitive impairment causes a slight impact on your memory and other abilities that involve language, thinking, and judgment. It is not as severe as dementia and is unlikely to cause problems with your daily activities and functioning. Although not everyone with mild cognitive impairment will have dementia, it does increase your overall chance of developing dementia. Dementia is the gradual loss of memory, reasoning, and judgment that interferes with your daily living. Dementia often affects your ability to complete certain tasks, work, and live independently. However, with the right support, you can continue to be in control of your own life and care.

Quality Statement 2: Interprofessional Care Team



What the standard says

People with dementia have access to community-based dementia care from an interprofessional team with expertise in dementia care, of which the person with dementia and their care partners are integral team members.



What this means for you

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. You and your care partners 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.

You and your care team

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.

Quality Statement 3: Individualized Care Plan



What the standard says

People with dementia have an individualized care plan that guides their care. The plan identifies their individual needs, those of their care partners, and goals of care. The plan is reviewed and updated on a regular basis, including documentation of changing needs and goals and the person's response to interventions.



What this means for you

You, your care partners, 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.

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 your health care team, and you will need 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.

Quality Statement 4: Named Point of Contact



What the standard says

People with dementia, their family, and their care partners have 1 or more named interprofessional care team members who serve as a point of contact to facilitate care coordination and transitions across settings.



What this means for you

Your health care team should provide you with the name and contact information for 1 or more team members who are coordinating your care on an ongoing basis.

Quality Statement 5: Education and Training for People With Dementia and Their Care Partners



What the standard says

People with dementia and their care partners have access to education and training on dementia and available support services.



What this means for you

Your health care team should provide you and your care partners 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.

Quality Statement 6: Education and Training for the Health Care Team



What the standard says

People with dementia receive care and services from health care team members who have education and training in dementia care.



What this means for you

Your health care team should be trained to care for people with dementia.

Quality Statement 7: Access to Support Services



What the standard says

People with dementia and their care partners have access to support services that are individualized and meet their ongoing goals and needs.



What this means for you

Your clinician should link you with support services that meet your changing goals and needs. Examples of support services include assistance with personal care, help around the house, support groups, and transportation services.

Quality Statement 8: Care Partner Assessment and Support



What the standard says

Care partners of people with dementia are assessed on an ongoing basis and offered supports to address their individual needs.



What this means for you

Caregiving can be a rewarding experience, but it can also be stressful. You should be assessed on an ongoing basis by a member of the health care team or your own primary care clinician 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.

Quality Statement 9: Safe Living Environment



What the standard says

People with dementia have access to a safe living environment that meets their specific needs, including design modifications and a range of housing options.



What this means for you

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.

Quality Statement 10: Access to Primary Care



What the standard says

People with mild cognitive impairment or dementia have regular visits with a primary care physician or nurse practitioner who provides effective primary care that meets both their general health care needs and their specific needs related to cognitive impairment or dementia.



What this means for you

You should have a family physician or nurse practitioner who sees you regularly and knows your needs. Your health care team should monitor your health, provide care, and link you and your care partners to other health care and support services that meet your changing needs and goals.

Suggestions on what to discuss with your health care team

Ask your health care team:

- Are there any support groups, programs, or services available for me?
- What can I expect will happen in the future as my symptoms continue to progress?
- What changes can I make to my lifestyle to help me manage my symptoms?
- How often should I follow up with my clinician or specialist?
- Are there any medications I should be taking to manage my symptoms?
- What nondrug treatment options are available for me?
- Are there any tips or strategies to help me remember my daily tasks and activities (for example, memory aids)?
- Who can I call for help?

Share with your health care team:

- If you notice changes in your symptoms such as worsening memory or ability to complete tasks
- If you have any concerns about your condition
- Information about your lifestyle (for example, your sleeping patterns, any exercises you are doing, your diet)
- If you need help at home with completing daily activities

If you are a care partner

You might have your own questions. It can help to identify yourself as the patient's care partner to their health care team. This will make sure they know and respect your questions and concerns.

- Let them know what your role will be in helping the patient manage their condition
- Let them know if you need help

Learn more

The [Alzheimer Society](#) provides tools and resources to help you manage your symptoms of dementia. Information is available in [multiple languages](#), including Traditional Chinese and Punjabi. Resources include:

- [10 warning signs of dementia](#)
- [First Link](#), a program for people with dementia and their care partners that connects newly diagnosed people to local clinicians
- [Finding Your Way](#), a program that helps people with dementia and their care partners be prepared for incidents of going missing
- [Other programs and services](#)

The [Canadian Coalition for Seniors' Mental Health](#) has helpful resources for people with dementia and their care partners, including:

- Why [self-care](#) is essential for care partners
- Resources to support [Indigenous Peoples](#) with dementia
- Resources to support [2SLGBTQIA+ people](#) with dementia

The [Centre for Addiction and Mental Health](#) and the [Alzheimer's Association](#) each provide a list of cognitive assessment tools to identify people who may need additional evaluation for dementia.

[Advance Care Planning Ontario](#) provides information about substitute decision-makers.

Need more information?

If you have any questions or feedback about this guide, please contact us at QualityStandards@OntarioHealth.ca or 1-877-280-8538 (TTY: 1-800-855-0511).

Need this information in an accessible format? 1-877-280-8538, TTY 1-800-855-0511, info@OntarioHealth.ca

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