

QUALITY STANDARDS

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# Dementia

## Care for People Living in the Community

2024 UPDATE

# Scope of This Quality Standard

This quality standard addresses care for people with dementia living in the community, including the assessment of people suspected to have dementia or mild cognitive impairment. The quality standard focuses on primary care, specialist care, hospital outpatient services, home care, and community support services. It also provides guidance on support for care partners of people with dementia.

This quality standard does not apply to care provided in an emergency department or hospital inpatient setting or to people living in long-term care homes, nor does it address specific aspects of palliative care for people with dementia.

For a quality standard that addresses care for people with dementia and the specific behaviours of agitation or aggression who are in an emergency department, admitted to a hospital, or in a long-term care home, refer to [Behavioural Symptoms of Dementia: Care for People in Hospitals and Long-Term Care Homes](#).<sup>1</sup>

For a quality standard that addresses palliative care, refer to [Palliative Care: Care for Adults With a Serious Illness](#).<sup>2</sup>

## What Is a Quality Standard?

Quality standards outline what high-quality care looks like for conditions or processes 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:

- Help patients, families, and care partners know what to ask for in their care
- Help clinicians know what care they should be offering, based on evidence and expert consensus
- Help health care organizations measure, assess, and improve their performance in caring for patients

Quality standards and their accompanying patient guides are developed by Ontario Health, in collaboration with clinicians, patients, and care partners across Ontario.

For more information, contact [QualityStandards@OntarioHealth.ca](mailto:QualityStandards@OntarioHealth.ca).

# Quality Statements to Improve Care: Summary

These quality statements describe what high-quality care looks like for people with dementia living in the community.

## **Quality Statement 1: Comprehensive Assessment and Diagnosis**

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.

## **Quality Statement 2: Interprofessional Care Team**

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.

## **Quality Statement 3: Individualized Care Plan**

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.

## **Quality Statement 4: Named Point of Contact**

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.

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

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

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

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

## **Quality Statement 7: Access to Support Services**

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

### **Quality Statement 8: Care Partner Assessment and Support**

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

### **Quality Statement 9: Safe Living Environment**

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

### **Quality Statement 10: Access to Primary Care**

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.

# Table of Contents

Scope of This Quality Standard .....	2
What Is a Quality Standard? .....	2
Quality Statements to Improve Care: Summary .....	3
2024 Summary of Updates .....	6
A Note on Terminology .....	7
Why This Quality Standard Is Needed .....	9
Measurement to Support Improvement .....	10
Quality Statement 1: Comprehensive Assessment and Diagnosis .....	12
Quality Statement 2: Interprofessional Care Team.....	15
Quality Statement 3: Individualized Care Plan .....	17
Quality Statement 4: Named Point of Contact .....	20
Quality Statement 5: Education and Training for People With Dementia and Their Care Partners...	22
Quality Statement 6: Education and Training for the Health Care Team .....	25
Quality Statement 7: Access to Support Services .....	27
Quality Statement 8: Care Partner Assessment and Support .....	30
Quality Statement 9: Safe Living Environment .....	33
Quality Statement 10: Access to Primary Care .....	36
Appendix 1: About This Quality Standard .....	39
Appendix 2: Glossary.....	41
Appendix 3: Values and Guiding Principles .....	42
Acknowledgements.....	44
References .....	46
About Us.....	50

# 2024 Summary of Updates

In 2024, we completed a review of the evidence to capture new or updated clinical practice guidelines and health technology assessments published since the original release of this quality standard in 2018. This update aligns the quality standard with the most recent clinical evidence and with current practice in Ontario.

Below is a summary of changes to the overall quality standard:

- Added links to related quality standards where applicable
- Updated links, secondary references, and data sources where applicable
- Updated the data in the “case for improvement” slide deck
- Updated terminology
  - Replaced *health care providers* with *clinicians or health care team*
  - Replaced *caregiver* with *care partner*
  - Replaced *people or person living with dementia* with *people or person with dementia*

Below is a summary of changes to specific quality statements:

- Quality statement 3: Revised the rationale to include delivering culturally appropriate care that considers the goals, values, preferences, and language spoken by the person with dementia, their family, and their care partners
- Quality statement 4: Revised the citations to address recent evidence from updated clinical practice guidelines regarding the role of a point of contact
- Quality statement 5: Revised the definitions to include stress reduction strategies as part of the training care partners receive
- Quality statement 6: Revised the definitions to include additional training practices for clinicians
- Quality statement 7: Revised the definitions to address cultural and language needs of people with dementia and their care partners
- Quality statement 8: Revised the definitions to include practical supports and coping strategies as part of care partner support
- Quality statement 10: Revised the citations to address recent evidence from updated clinical practice guidelines

# A Note on Terminology

**Care partner:** This refers to an unpaid person who provides care and support, such as a family member, friend, or anyone identified by the person with dementia.

We acknowledge that not everyone in this role may identify as a “care partner.” In addition, their role may change over time, especially as the person’s dementia progresses and they require more assistance. Our choice to use “care partner” does not diminish or negate terms that an individual may prefer.

**Substitute decision-maker:** This refers to a person who makes care and treatment decisions on another person’s behalf if or when that person becomes mentally incapable of making a decision for themselves.<sup>3</sup> The substitute decision-maker should be involved in ongoing discussions with the person about their goals of care, wishes, values, and beliefs so that the substitute decision-maker is empowered to participate in the health care consent process, if required. The substitute decision-maker makes decisions based on their understanding of the person’s wishes, or, if these are unknown or not applicable, makes choices that are consistent with the person’s known values and beliefs and in their best interests.

Ontario’s *Health Care Consent Act* outlines a hierarchical list of people who would automatically be considered a substitute decision-maker when a person is incapable of making decisions about their own care.<sup>4</sup> If a person is not satisfied with their automatic substitute decision-maker, they can formally appoint someone else to be their substitute decision-maker using a “Power of Attorney for Personal Care.”<sup>5</sup> A “Power of Attorney for Personal Care” is a legal document in which one person gives another person the authority to make personal care decisions on their behalf if they become incapable.<sup>3</sup>

**Capacity or mental capacity:** Under Ontario’s *Health Care Consent Act*, a person is capable with respect to a health care decision if they have the ability to understand the information that is needed to make a decision and have the ability to appreciate the consequences of the decision or lack of decision.<sup>4</sup> Capacity is issue- or task-specific.<sup>3</sup> A person’s specific capacity to understand information and appreciate the decisions that must be made should be respected so that their mental capacity for a specific health care decision is recognized. A person may be capable with respect to making some health care decisions, but incapable with respect to others.<sup>4</sup> If a person is incapable with respect to making a health care decision, the substitute decision-maker can give or refuse consent on the person’s behalf.<sup>4</sup>

**Clinician:** This refers to regulated professionals, such as nurses, nurse practitioners, pharmacists, physicians, physiotherapists, psychologists, occupational therapists, social workers, and speech-language pathologists. We use the term “health care team” when we are also including people in unregulated professions, such as administrative staff, behavioural support workers, personal support workers, recreational staff, and spiritual care staff.

This quality standard includes statements that refer specifically to people with dementia and people with mild cognitive impairment.

**Dementia:** This is defined as a chronic and progressive decline in cognitive ability that interferes with daily functioning. Signs and symptoms of dementia include changes to memory, reasoning and judgment, language and communication abilities, mood and behaviour, problem-solving ability, and orientation. These may affect a person’s ability to work, live independently, and manage relationships.<sup>6,7</sup>

**Mild cognitive impairment:** This is defined as a decline in memory, judgment, thinking, or language that is greater than the cognitive changes associated with aging and that does not interfere notably with activities of daily living.<sup>8,9</sup> While mild cognitive impairment is not a diagnosis of dementia, people with this condition are at greater risk of developing dementia.<sup>8</sup>

Of note, the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* uses the terms “mild neurocognitive disorder” and “major neurocognitive disorder,” and together these terms include both mild cognitive impairment and dementia.



# Why This Quality Standard Is Needed

In Canada, there are approximately 733,040 people with dementia.<sup>10</sup> Dementia affects about 8.4% of Canadians aged 65 years and older.<sup>10</sup> Age is the primary risk factor for dementia: the risk doubles every 5 years after age 65.<sup>11</sup> Notwithstanding this increased risk in older people, dementia also affects younger people: 2% to 8% of people diagnosed with dementia in Canada are younger than age 65.<sup>10</sup> Dementia remains a growing problem, with the percentage of Canadians over age 65 with dementia projected to increase from 8.4% to 13.2% by 2050.<sup>12</sup>

People with dementia want to live well and independently and to participate in care decisions with their clinicians and health care teams for as long as possible. However, the stigma associated with dementia often shifts the focus of others to the ways dementia impairs a person's ability to do things, rather than the individual's strengths and ability to participate in and enjoy activities and interactions.<sup>13</sup> This stigma can also cause people to delay acknowledging symptoms and seeking help.<sup>13</sup>

Recognizing and supporting people throughout the stages of dementia is important. This includes<sup>13,14</sup>:

- Being proactive in engaging people in decisions about their care and activities of interest
- Offering care and services that meet individuals' needs and preferences
- Providing opportunities for people to participate in their communities and influence the design, planning, evaluation, and delivery of services

The debilitating effects of dementia have substantial personal and economic impacts on people with dementia and their care partners and families, as well as a considerable economic impact on the Canadian health care system and society more broadly. In 2020, the total estimated economic cost of dementia in Canada was \$40.1 billion, including indirect costs on family and care partners through lost productivity.<sup>15</sup> If current trends continue, the annual economic burden could grow to \$110 billion by 2050.<sup>15</sup>

As Canada's population ages, the number of people with dementia increases and so too grows the demand for dementia-related health care and community support services. People with dementia can live independently for some time, but as their condition progresses, they require increasing levels of support to help them remain in their homes and local communities for as long as possible. In 2023, more than 52% of people aged 65 and older with dementia lived outside of long-term care homes, with the majority living at home (Discharge Abstract Database (DAD) and Ontario Health Insurance Plan (OHIP) database, May 1, 2024).

Care partners for people with dementia often experience significant changes in their lives.<sup>16</sup> The role can be physically, emotionally, and financially demanding and is associated with high levels of stress, strain, and social isolation.<sup>16</sup> In comparison with care partners of people without dementia, care partners of people with dementia provide 75% more care and experience about 20% higher stress levels.<sup>16</sup> These caregiving demands tend to increase as the dementia progresses. If families and care

partners are to continue to provide the majority of care to this growing population, training and tailored supports are needed to assist them.

There are important gaps in the quality of care received by people with dementia living in the community and their care partners in Ontario. Across the province, nearly half of people with dementia receiving long-stay home care had care partners who were distressed.<sup>17</sup> More than 60% of people exhibiting behavioural symptoms of dementia had care partners who felt distressed.<sup>17</sup> In 2020, there were over 350,000 people providing support to people with dementia, with most being close family members.<sup>12</sup> On average, these care partners provide 26 hours per week of support and caregiving, which represents an economic worth of over \$7.3 billion.<sup>12</sup> Data also suggest that there are variations in the kind of care provided to people with dementia across regions. People with dementia living in areas with higher income tend to have greater rates of home care and are more likely to live at home than in a long-term care home.<sup>18</sup> These gaps and variations highlight the need for a quality standard for the care of people with dementia living in the community.

Based on evidence and expert consensus, this quality standard addresses key areas identified as having considerable potential for quality improvement in the care of people with dementia living in the community in Ontario. The 10 quality statements that make up this standard each provide guidance on high-quality care, with accompanying indicators to help clinicians and organizations measure their quality of care. Each statement also includes details on how its delivery impacts people with dementia and their care partners, clinicians, health care team, health care services, and community support services at large.

## Measurement to Support Improvement

The Dementia Care in the Community Quality Standard Advisory Committee identified 5 overarching indicators to monitor the progress being made toward improving care for people with dementia living in the community in Ontario.

### Indicators That Can Be Measured Using Provincial Data

- Rate of emergency department visits for people with dementia living in the community
- Rate of hospitalizations for people with dementia living in the community
- Average length of stay in hospital for people with dementia living in the community
- Alternate-level-of-care days for people with dementia living in the community
- Average length of stay in the community for people with dementia

# Indicators That Can Be Measured Using Only Local Data

- Percentage of people with dementia living in the community and their care partners who each have optimized quality of life
- Percentage of people with dementia living in the community who are confident with self-care
- Percentage of care partners of people with dementia living in the community who are confident with their ability to work collaboratively with people with dementia to provide care based on their needs and preferences
- Percentage of people with dementia living in the community and their care partners who reported being satisfied or very satisfied with the care and services received in the community

# Quality Statement 1: Comprehensive Assessment and Diagnosis

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.

Sources: American Psychiatric Association, 2007<sup>19</sup> | European Federation of Neurological Societies and European Neurological Society, 2012<sup>20</sup> | National Institute for Health and Clinical Excellence, 2018<sup>21</sup> | Registered Nurses' Association of Ontario, 2016<sup>22</sup> | Scottish Intercollegiate Guidelines Network, 2023<sup>23</sup> | Sistema Nacional de Salud, 2010<sup>24</sup>

## Definitions

**Comprehensive assessment:** This clinical assessment should be conducted by skilled clinicians and include, at a minimum, the following components:

- Medical history
- Medication review (including over-the-counter and alternative medications) and substance use history
- Physical and functional status examinations, including diet, nutrition, oral health, pain, sleep, and continence
- Cognitive assessment, using a validated instrument
- Assessment of potential medical and psychiatric comorbidities or potential contributing factors (e.g., delirium, depression) to cognitive signs and symptoms
- Assessment of behavioural and psychological symptoms of dementia
- Assessment of social history and psychosocial functioning
- Assessment of safety risks, including driving safety and falls
- Relevant laboratory tests

Collateral history from family and care partners should be obtained.

**Regular basis:** A person with mild cognitive impairment should receive a comprehensive assessment every year, or sooner according to clinical need. A person with dementia should receive a

comprehensive assessment every 6 to 12 months, or sooner according to clinical need. The assessment informs the care plan (see Quality Statement 3).

## Rationale

A comprehensive assessment ensures an accurate diagnosis and the collection of baseline information to track changes in a person's status. Diagnosis should ideally be made by a physician with expertise in diagnosing and treating cognitive disorders such as dementia. An early and accurate diagnosis helps people and their families get timely access to information, advice, and support. It also helps them start treatment earlier, if appropriate, and enables them to plan and make important decisions about their care.<sup>25</sup> If, after the comprehensive assessment, the diagnosis still remains unclear, it is important for the physician to organize a plan to arrive at a diagnosis (such as arranging for further testing or referral to a specialist). Clinically indicated care interventions (such as optimizing medications and coordinating necessary supports) should be initiated during this process and not delayed until diagnosis is achieved. Based on the current Canadian clinical practice guideline, structural imaging (e.g., computed tomography (CT) and/or magnetic resonance imaging (MRI)) is not mandatory in the assessment of a person with cognitive impairment or dementia, but should be obtained if the results would change the clinical management (e.g., if the presence of cerebrovascular disease would result in initiation of specific medications, or where there is suspicion of a mass).<sup>26</sup>

Given the ongoing cognitive decline associated with dementia and the increased risk of people with mild cognitive impairment developing dementia,<sup>8</sup> a comprehensive assessment should be performed when a person first exhibits or experiences changes in cognition, behaviour, mood, or function, and on a regular basis afterward. The person and ideally their family, care partners, and/or substitute decision-makers should be included in the assessment. The assessment should be culturally appropriate – respectful of diverse cultural, ethnic, and spiritual backgrounds – and in the person's preferred language.

## What This Quality Statement Means

### For People With Mild Cognitive Impairment or Dementia

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.

### For Clinicians

Perform a comprehensive assessment when people first show signs of mild cognitive impairment or dementia. People diagnosed with either condition should be reassessed on a regular basis afterward.

## For Organizations and Health Services Planners

Ensure that there are systems, processes, and resources, including standardized assessment instruments, for clinicians and health care teams to carry out comprehensive assessments of people with suspected or confirmed mild cognitive impairment or dementia.

# Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people suspected to have mild cognitive impairment or dementia who receive a comprehensive assessment
- Percentage of people with mild cognitive impairment who received a comprehensive reassessment within the past year
- Percentage of people with dementia who received a comprehensive reassessment within the past year

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 2: Interprofessional Care Team

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.

Sources: National Institute for Health and Clinical Excellence, 2018<sup>21</sup> | Scottish Intercollegiate Guidelines Network, 2023<sup>23</sup> | Sistema Nacional de Salud, 2010<sup>24</sup>

## Definition

**Interprofessional team:** This includes at least 1 physician or nurse practitioner and 1 other clinician trained in dementia care. Other regulated and unregulated health care team members may include family physicians, nurses, nurse practitioners, psychologists, occupational therapists, pharmacists, behavioural support workers, social workers, care partners, administrative staff, personal support workers, speech-language pathologists, physiotherapists, geriatricians, neurologists, geriatric psychiatrists, dietitians, therapeutic recreation staff, and spiritual care staff.

## Rationale

The needs of people with dementia are dynamic and complex. Individualized management from health care team members of various disciplines with expertise in dementia care is necessary. An interprofessional team allows for the delivery of dementia care through a multifaceted and collaborative approach to meet the individualized needs and preferences of each person with dementia and of their care partners. The care team's composition should be flexible and adapt to the person's changing health, social circumstances, needs, and goals.<sup>27</sup> People with dementia and their care partners are an integral part of the team and should participate in decisions about their own care.

## What This Quality Statement Means

### For People With Dementia

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.

### For Clinicians

Connect people with dementia to an interprofessional team with expertise in dementia care. Involve people with dementia and their care partners in decisions about their own care.

### For Organizations and Health Services Planners

Ensure that systems, procedures, and resources are in place for people with dementia to receive care from an interprofessional team with expertise in dementia care.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with dementia living in the community who receive community-based dementia care from an interprofessional team with expertise in dementia care
- Percentage of people with dementia who receive community-based dementia care from an interprofessional team with expertise in dementia care in which they and their care partners are integral team members

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).



# Quality Statement 3: Individualized Care Plan

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.

Sources: American Psychiatric Association, 2007<sup>19</sup> | National Institute for Health and Clinical Excellence, 2018<sup>21</sup> | Registered Nurses' Association of Ontario, 2016<sup>22</sup> | Scottish Intercollegiate Guidelines Network, 2023<sup>23</sup> | Sistema Nacional de Salud, 2010<sup>24</sup>

## Definitions

**Individualized care plan:** This is a plan based on an assessment of the life history; social, cultural, and family circumstances; and preferences and needs of the person with dementia. It is also based on their physical and mental health needs and current level of functioning and abilities.<sup>8</sup> Developed and reviewed with the person with dementia and their care partners, the care plan should be flexible to accommodate changes in the person's health status, function, and abilities. Ensure that the people with dementia, their families, and their care partners feel safe and respected, and their individual goals of care are considered in the plan.

The plan should include the following components:

- The results of the comprehensive assessment (see Quality Statement 1)
- The person's individual needs, values, preferences, culture, and goals of care, and those of their care partners
- A plan to minimize relocations and retain a familiar living environment for as long as possible
- Assessment and care-planning advice about activities of daily living and instrumental activities of daily living
- Details of environmental modifications to help the person function independently and to promote safety; these can include assistive devices and technologies, if available (see Quality Statement 9)
- A plan for physical exercise, with an assessment and advice from a physiotherapist or occupational therapist when needed

- Support for people to participate in meaningful activities at their own pace
- Individualized nonpharmacological and pharmacological interventions, as indicated
- A plan for managing behavioural symptoms associated with dementia, if present
- A nutrition care plan
- A safety plan, including crisis and emergency management
- Advance care planning, which includes the capable person with dementia confirming a future substitute decision-maker (see A Note on Terminology for a more detailed description) who can communicate their wishes, values, and beliefs about future health care, and make care and treatment decisions when that person is no longer mentally capable of doing this for themselves (to learn more about advance care planning, refer to the quality standard [Palliative Care: Care for Adults With a Serious Illness](#))<sup>2</sup>
- At least 1 named point of contact on the care team – this is the care team member who facilitates care coordination and transitions across settings for the person with dementia (see Quality Statement 4)

**Regular basis:** The care plan should be reviewed every 6 to 12 months, or sooner according to clinical need. Reviewing the care plan may require a partial or full reassessment, including revisiting the goals of care with the person and care partner.

## Rationale

An individualized care plan is essential to coordinate, document, and ultimately guide the care of people with dementia. The care plan is developed by and implemented in collaboration with the person with dementia, care partners, and care team members to ensure consistent and coordinated delivery of care that considers the changing needs, goals, values, and preferences of people with dementia.<sup>8,22</sup> Care plans need to be communicated to and accessible to the person with dementia, members of the interprofessional care team, and care partners or substitute decision-makers. Consider providing information about the individualized care plan in multiple languages and literacy levels. Ongoing review of the care plan supports revisiting goals of care and allows for the reassessment of evolving needs, preferences, and the person’s treatment responses to interventions. To learn more about medication safety considerations, refer to the quality standard [Medication Safety: Care in All Settings](#).<sup>28</sup>

## What This Quality Statement Means

### For People With Dementia

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.

## For Clinicians

Work with people with dementia and their care partners to create an individualized care plan that documents care and services and responses to interventions. Review and update care plans every 6 to 12 months, or sooner if there is a considerable change in a person's health or care arrangements.

## For Organizations and Health Services Planners

Ensure that there are systems, processes, and resources in place to support clinicians to develop and regularly update individualized care plans, as well as to communicate care plans to others who provide care to the individual. Resources may include standardized care plan templates.

# Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with dementia who have an individualized care plan that guides their care
- Percentage of people with dementia who have an individualized care plan that is reviewed annually

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 4: Named Point of Contact

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.

Sources: National Institute for Health and Clinical Excellence, 2018<sup>21</sup> | Scottish Intercollegiate Guidelines Network, 2023<sup>23</sup>

## Definition

**Point of contact:** The point of contact:

- Is 1 or more named members of the interprofessional team
- Supports communication and information sharing among clinicians, the health care team, and the person with dementia, their family, and their care partners
- Facilitates care coordination and transitions across care settings and health care teams (Advisory Committee consensus)

This person's name and contact information is provided to the person with dementia and their care partners and is included in the individualized care plan (see Quality Statement 3).

## Rationale

It can be difficult and frustrating for people with dementia and their care partners to navigate the health system and know who to contact when health issues or concerns arise. A point of contact on the interprofessional care team (see Quality Statement 2) makes communication easier and aids continuity of care and transitions across settings. This person should be an active team member who:

- Closely coordinates with or is embedded within the person with dementia's primary care team
- Is involved in the care of the person with dementia and understands their current needs and care goals, as well as those of their care partner
- Is able to address the needs of the person with dementia or connect the person with the most appropriate clinician to address their needs

The point of contact on the interprofessional dementia care team is an essential component of person-centred dementia care.<sup>27</sup> To learn more about transitioning from the hospital to home, refer to the quality standard [Transitions Between Hospital and Home](#).<sup>29</sup>

## What This Quality Statement Means

### For People With Dementia and Their Care Partners

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.

### For Clinicians

Provide people with dementia and their care partners the name and contact information of 1 or more members of the care team responsible for coordinating their care and transferring information among the care team.

### For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place for care team members to serve as a point of contact for people with dementia, their care partners, and other team members involved in their care.

## Quality Indicator: How to Measure Improvement for This Statement

- Percentage of people with dementia who have at least 1 named interprofessional care team member who serves as their point of contact

Measurement details for this indicator, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

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

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

Sources: American Psychiatric Association, 2007<sup>19</sup> | European Federation of Neurological Societies and European Neurological Society, 2012<sup>20</sup> | National Institute for Health and Clinical Excellence, 2018<sup>21</sup> | Registered Nurses' Association of Ontario, 2016<sup>22</sup> | Sistema Nacional de Salud, 2010<sup>24</sup>

## Definition

**Education and training:** Education and training should include, at a minimum, the following information and skills:

- Dementia types, signs and symptoms, prognosis, and details of disease progression
- Care plan strategy and monitoring
- Self-care and stress reduction strategies for both people with dementia and their care partners, including access to mental health, emotional, and spiritual support
- Benefits and risks of nonpharmacological and pharmacological treatment options
- Medication management strategies and aids (e.g., medication reconciliation, dose reminders, marked pillbox)
- Causes of behavioural and psychological symptoms of dementia
- Detection of behavioural risks and techniques for de-escalation and management
- Adaptive communication skills during times of stress
- Functions of different health care team members and health care settings
- Medical-legal issues, including driving
- Financial and legal planning for the person's eventual incapacity, including "Power of Attorney for Personal Care" and "Continuing Power of Attorney for Property"
- Requirement for informed consent
- Advance care planning and the role of the substitute decision-maker

- Processes to resolve disagreement around the person’s care
- Available support services and groups and how to access them, including both locally available services and supports available online
- Sources of financial and legal advice and advocacy

Information should be provided in verbal, printed, and/or multimedia formats.

## Rationale

Dementia is a complex condition that has a substantial impact on the lives of people with dementia, as well as on their care partners and families. Providing evidence-based education and training to help people better understand dementia, its progression, treatment options, and available supports can enable them to make informed decisions about their care and plan for the future. Information should be provided throughout the care journey and align with the person’s stage of dementia and their evolving needs.

## What This Quality Statement Means

### For People With Dementia and Their Care Partners

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.

### For Clinicians

Offer education and training to people with dementia and their care partners. This should align with the person’s stage of dementia and their current needs.

### For Organizations and Health Services Planners

Ensure that clinicians and teams are able to offer education and training on dementia and available support services to people with dementia and their care partners.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with dementia who receive education and training on dementia and available support services
- Percentage of care partners of people with dementia who receive education and training on dementia and available support services

- Local availability of education and training on dementia for people with dementia and their care partners

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).



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

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

Sources: American Psychiatric Association, 2007<sup>19</sup> | National Institute for Health and Clinical Excellence, 2018<sup>21</sup> | Registered Nurses' Association of Ontario, 2016<sup>22</sup> | Scottish Intercollegiate Guidelines Network, 2023<sup>23</sup> | Sistema Nacional de Salud, 2010<sup>24</sup>

## Definition

**Education and training:** Education and training needs to be tailored to the clinicians' scope of practice. This information should include, at a minimum, content related to:

- Comprehensive assessment of people with dementia and an assessment of care partners' needs
- Dementia signs, symptoms, and disease progression
- Specific subtypes of dementia
- Approaches to diagnostic uncertainty in people with complex conditions
- Person-centred care
- Development of care plans that meet the goals, preferences, values, and cultural expectations of care of people with dementia and their care partners
- Early identification of behavioural and psychological symptoms of dementia and techniques for de-escalation and management
- Early identification of behavioural risks and safety issues and techniques for de-escalation
- Appropriate use of nonpharmacological and pharmacological treatments
- Self-care and safety for health care team members
- How to communicate with people with dementia and their care partners, including being able to hold emotionally challenging conversations
- How to coordinate multidisciplinary care
- Impacts of dementia on people with dementia, care partners, families, and social networks
- Outreach strategies to connect people with dementia and their care partners to available resources
- Ethical and medical-legal considerations

- Requirement for informed consent
- Detection of and strategies to manage abuse
- Advance care planning and palliative care

## Rationale

People with dementia have complex needs and should receive individualized care from health care teams with education and training in dementia care. With the knowledge and skills required to effectively provide care for people with dementia, health care teams can offer care strategies and treatments that meet people's needs, optimize their strengths, and help improve or maintain their quality of life and level of functioning. Training and education materials and programs should be tailored to the roles and responsibilities of health care team members.

## What This Quality Statement Means

### For People With Dementia and Their Care Partners

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

### For Clinicians

Ensure that you have the education and training required to effectively provide care for people with dementia, in accordance with your role and responsibilities.

### For Organizations and Health Services Planners

Ensure the availability of education and training in dementia care for health care teams caring for people with dementia.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of health care team members who care for people with dementia and have received education and training in dementia care
- Local availability of health care team members who have received education and training in dementia care

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 7: Access to Support Services

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

Sources: American Psychiatric Association, 2007<sup>19</sup> | National Institute for Health and Clinical Excellence, 2018<sup>21</sup> | Scottish Intercollegiate Guidelines Network, 2023<sup>23</sup> | Sistema Nacional de Salud, 2010<sup>24</sup>

## Definition

**Support services:** These are a variety of flexible and accessible home care services and community support services needed to support people with dementia living in the community, as well as their care partners. Services should be responsive to people's goals, values, and preferences and tailored to their changing physical, psychological, and social needs. Ensure that people with dementia, their families, and their care partners feel safe and respected, and their individual goals are considered when offering support services. If feasible, support services should be offered in multiple languages. Support services include:

- Clinical services, such as nursing, occupational therapy, pharmacy, physiotherapy, social work, speech-language pathology, and dietitian services
- Assistance with personal daily care (e.g., grooming, bathing, dressing)
- Help to maintain a safe and comfortable home (e.g., cleaning, doing laundry, preparing meals)
- Help with minor household repairs and maintenance (e.g., yard work, snow removal)
- Help performing errands (e.g., shopping, banking)
- Social or recreational opportunities and programs (e.g., adult day programs, support groups, exercise programs, friendly visiting programs, cultural programs)
- Respite care – this provides care partners with temporary relief from their care duties. Examples include adult day programs, in-home respite, overnight care, and short stays in a long-term care home (see Quality Statement 8)
- Diverse, culturally safe programs and culturally appropriate information tailored to the needs and preferences of the person with dementia, their family, and their care partners (e.g., addressing religious needs and requirements, providing culturally appropriate service options, offering programs in multiple languages)

- Transportation – help getting to and from medical appointments, adult day programs, social activities, stores, etc. Examples include public transportation, taxis, and assisted or escorted transportation for those unable to take public transportation
- End-of-life care (e.g., pain management, medical supplies, hospice services)

People with dementia and their care partners should have up-to-date verbal and written information about local services and how to access them.

## Rationale

People with dementia can live independently for some time; as their condition progresses, they require increasing levels of support to help them remain in their homes and local communities for as long as possible. As such, they and their care partners need access to a range of services that are timely, responsive, flexible, close to home, and tailored to their individual needs, strengths, capabilities, and choices.<sup>24,30</sup> They need access to the right services, at the right time, and in the right place to help them in their journey.

## What This Quality Statement Means

### For People With Dementia and Their Care Partners

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.

### For Clinicians

Offer support services to people with dementia and their care partners to help them meet their goals and needs. Advise them on available services and how to access them.

### For Organizations and Health Services Planners

Through adequately resourced systems and services, ensure that people with dementia and their care partners can access the support services they need, when they need them. Involve people with dementia and care partners in the design, planning, delivery, and evaluation of services. Ensure that clinicians are aware of and able to connect or refer people to these services.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with dementia who have access to individualized support services
- Percentage of care partners of people with dementia who have access to individualized support services

- Percentage of people with dementia who have received support services that met their needs
- Percentage of care partners of people with dementia who have received support services that met their needs
- Local availability of support services for people with dementia and their care partners

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 8: Care Partner Assessment and Support

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

Sources: National Institute for Health and Clinical Excellence, 2018<sup>21</sup> | Sistema Nacional de Salud, 2010<sup>24</sup>

## Definitions

**Care partner assessment:** Care partners of people with dementia should receive an ongoing assessment of their individual needs and preferences. This includes, at a minimum, assessment of their emotional, psychological, and social needs.

Care partners who experience psychological distress and negative psychological impact should be referred to their primary care clinician or mental health specialist for assessment and treatment.

**Supports:** Care partners of people with dementia should have access to a range of tailored supports. These may include:

- Individual or group psychoeducation and counselling
- Peer support groups, tailored to the needs of individuals, depending on the dementia stage of the person being cared for and other characteristics
- Support and information available by telephone and through the Internet
- Training courses about dementia, services, and communication and problem-solving in the care of people with dementia
- Respite services, including planned and emergency respite, such as adult day programs, overnight care, and short-term residential care. These should meet the needs of both the care partner (in terms of location, flexible timing and duration, and timeliness) and the person with dementia (in terms of involving meaningful and therapeutic activities and being in an environment that meets their needs)
- Healthy coping skills and strategies to manage stress and discomfort

Supports such as transport or respite care services should be provided for care partners to enable them to participate in the services and activities described above.

# Rationale

Care partners play a critical role in supporting the health, well-being, and functional independence of people with dementia. As dementia progresses, cognitive changes interfere with a person's ability to perform everyday activities and manage their personal affairs. They increasingly require more support and assistance from their care partners.

While caregiving can be a rewarding experience, it is often described as stressful and can result in considerable physical, psychological, social, and financial impacts.<sup>31-36</sup> For example, care partners experience high levels of stress and social isolation and have an increased risk of psychological and physical health problems (e.g., depression, anxiety, cardiovascular problems, and lower immunity).<sup>33-38</sup> Care partners also have to balance their care duties with other responsibilities, such as their careers, family obligations, and own health needs.

Care partners should be assessed on an ongoing basis to see how they are managing. They should be offered supports that are responsive to their individual needs and the person's stage of dementia.<sup>8,22</sup> Supports such as transportation or respite care services should be provided for care partners to enable them to participate in services or activities.<sup>8</sup>

## What This Quality Statement Means

### For Care Partners

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.

### For Clinicians

Assess care partners on an ongoing basis to see how they are managing. If needed, offer supports that are responsive to their needs and the person's stage of dementia.

### For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place for clinicians and teams to assess care partners. Ensure that supports are available to address care partners' needs.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of care partners of people with dementia who receive an assessment

- Percentage of care partners of people with dementia who have received an assessment and are offered supports to address their individual needs
- Local availability of a comprehensive range of respite services for care partners of people with dementia that meet the needs of both the care partner and the person with dementia

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).



# Quality Statement 9: Safe Living Environment

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

Sources: National Institute for Health and Clinical Excellence, 2018<sup>21</sup> | Scottish Intercollegiate Guidelines Network, 2023<sup>23</sup>

## Definitions

**Safe living environment:** A living environment that helps the person with dementia navigate their place of residence and their community and that supports their care partners by helping to keep the person safe. The environment should have appropriate stimuli and address potential safety and security hazards inside and outside the residence (e.g., stoves and ovens, unlocked doors, clutter on floors and surfaces, and unfenced yards). A person's living environment needs should be documented in their individualized care plan (see Quality Statement 3).

**Design modifications:** These are tailored to the person's needs and preferences and adapted as needed during the course of their dementia.

Modifications can include changes to<sup>8,39</sup>:

- Lighting
- Surfaces to minimize reflections and glare
- Floor coverings
- Colour schemes and contrasts
- Noise and room acoustics (e.g., locate bedrooms away from, and not adjacent to, high-noise areas; minimize background noise)

Modifications can include the use of<sup>8,39</sup>:

- Signage
- Glass-fronted cupboard doors so people can see what is inside
- Memory cues
- Notice boards

- Assistive technology (e.g., prompts and reminders, orientation devices) and devices (e.g., handrails)
- Safety devices for hazardous items, such as heat and smoke sensors for the stove
- Fencing in yards

**Housing options:** These include:

- The person's own home (independent living)
- Assisted-living facilities or supportive housing, such as seniors' housing, retirement residences, or retirement communities
- Dementia-friendly group homes
- Long-term care homes

## Rationale

People with dementia should have a living environment that is safe and helps them to live as comfortably and independently as possible. As the disease progresses, dementia impacts people's ability to interact with and make sense of their environment. Environments that are familiar, home-like, and easy to understand are important.<sup>39</sup>

Over the course of a person's dementia, living environments need to be modified to help the person navigate their surroundings, support their independence, and reduce their feelings of confusion and stress.<sup>8</sup> Design modifications may include nonslip floor coverings, handrails in the shower and beside the toilet to provide support and balance, heat and smoke sensors, and memory cues.

When people with dementia are no longer able to live safely and independently in their home, they may consider moving to a more supported care setting, such as an assisted-living facility, a dementia-friendly group home, a retirement residence, or a long-term care home.

Housing options for people with dementia should ideally be financially accessible and in close proximity to their care partners and family. They should meet the needs and preferences of both the person and their care partners. Spouses wishing to remain living with each other should have access to environments where this is possible.

## What This Quality Statement Means

### For People With Dementia

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.

## For Clinicians

Connect with health care teams who can help ensure that housing is safe and meets the needs of the person with dementia and their care partners.

## For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place to make people's living environments safe and to address individual needs. This includes appropriate design modifications and housing options offering more supported living environments.

# Quality Indicator: How to Measure Improvement for This Statement

- Percentage of people with dementia living in the community who reside in a safe living environment that meets their specific needs

Measurement details for this indicator, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Quality Statement 10: Access to Primary Care

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.

Sources: European Academy of Neurology, 2020<sup>40</sup> | National Institute for Health and Clinical Excellence, 2018<sup>21</sup>

## Definitions

**Regular visits:** A person with mild cognitive impairment should visit their primary care clinician every 6 to 12 months, or sooner according to clinical need. A person with dementia should visit their primary care clinician every 3 to 6 months, or sooner according to clinical need.

**Effective primary care:** Primary care is the person's first contact with the health system. It is effective when it<sup>41,42</sup>:

- Is person-focused; rather than focusing on the disease or a single condition, it focuses on the whole person
- Is accessible
- Provides comprehensive care for most health needs (in collaboration with specialists, as needed)
- Coordinates and integrates care and services when a referral to other clinicians or home and community support services is required
- Continues over time
- Links to and gets support from specialists, as needed
- Addresses individual needs and aligns with the person's goals of care

## Rationale

Primary care plays a critical role in managing the complex health needs of people with mild cognitive impairment or dementia. This care involves both their general health care needs and their needs related to cognitive impairment or dementia, as well as their care partners' health care needs.

More than 90% of community-dwelling seniors with dementia in Ontario have 2 or more coexisting chronic medical conditions,<sup>43</sup> whose courses are often complicated by dementia. As dementia progresses, people experience challenges with memory, symptom awareness, decision-making, and expressive language, which can make it difficult for them to manage their general health and coexisting chronic conditions. It can be hard to adhere to medication regimens and to monitor themselves and perform the self-care required to effectively manage conditions such as diabetes, heart failure, and chronic obstructive pulmonary disease (COPD).<sup>44</sup> Chronic conditions can become destabilized and exacerbated when a person has dementia, potentially resulting in visits to the emergency department, hospitalizations, deconditioning (muscle loss owing to inactivity), and earlier institutionalization.<sup>43-46</sup>

Primary care also provides a critical link to specialist care and specialty programs, such as specialty dementia care and specialized geriatric services. To address complex medical and behavioural issues, functional complexity, and certain stages of illness, it is important for primary care clinicians to collaborate with and get support from specialists in dementia care, such as geriatricians, geriatric psychiatrists, and cognitive neurologists, as well as community support agencies.

## What This Quality Statement Means

### For People With Mild Cognitive Impairment or Dementia

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.

### For Clinicians

Have regular primary care visits with people with dementia or mild cognitive impairment. Provide person-centred, comprehensive, and coordinated care to meet their needs.

### For Organizations and Health Services Planners

Ensure that people with dementia have access to a primary care clinician. Ensure that the system can accommodate the provision of effective primary care to support the dynamic needs of those with dementia.

## Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with mild cognitive impairment who have visited their primary care clinician in the past 12 months
- Percentage of people with dementia who have visited their primary care clinician in the past 6 months

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the [technical specifications](#).

# Appendix 1: About This Quality Standard

## How to Use This Quality Standard

Quality standards inform patients, clinicians, and organizations about what high-quality care looks like for health conditions or processes deemed a priority for quality improvement in Ontario. They are based on the best evidence.

Guidance on how to use quality standards and their associated resources is included below.

### For People With Dementia

This quality standard consists of quality statements. These describe what high-quality care looks like for people with dementia.

Within each quality statement, we have included information on what these statements mean for you as a patient.

In addition, you may want to download this accompanying [patient guide](#) on dementia to help you and your family have informed conversations with your clinicians. Inside, you will find information and questions you may want to ask as you work together to make a plan for your care.

### For Clinicians and Organizations

The quality statements within this quality standard describe what high-quality care looks like for people with dementia. They are based on the best evidence and designed to help you know what to do to reduce gaps and variations in care.

Many clinicians and organizations are already providing high-quality, evidence-based care. However, there may be elements of your care that can be improved. This quality standard can serve as a resource to help you prioritize and measure improvement efforts.

Tools and resources to support you in your quality improvement efforts accompany each quality standard. These resources include indicators and their definitions, available in the technical specifications. Measurement is key to quality improvement. Collecting and using data when implementing a quality standard can help you assess the quality of care you are delivering and identify gaps in care and areas for improvement.

There are also a number of resources online to help you, including:

- Our [patient guide](#) on dementia, which you can share with patients and families to help them have conversations with you and their other clinicians. Please make the patient guide available where you provide care
- Our [measurement resources](#), including the technical specifications for the indicators in this quality standard, the “case for improvement” slide deck to help you to share why this standard

was created and the data behind it, and our measurement guide containing supplementary information to support the data collection and measurement process

- Our [placemat](#), which summarizes the quality standard and includes links to helpful resources and tools
- Our [Getting Started Guide](#), which includes links to templates and tools to help you put quality standards into practice. This guide shows you how to plan for, implement, and sustain changes in your practice
- [Quorum](#), an online community dedicated to improving the quality of care across Ontario. This is a place where clinicians can share information and support each other, and it includes tools and resources to help you implement the quality statements within each standard

## How the Health Care System Can Support Implementation

As you work to implement this quality standard, there may be times when you find it challenging to provide the care outlined due to system-level barriers or gaps. These challenges have been identified and documented as part of the development of the quality standard, which included extensive consultation with clinicians and lived experience advisors and a careful review of available evidence and existing programs. Many of the levers for system change fall within the purview of Ontario Health, and as such we will continue to work to address these barriers to support the implementation of quality standards. We will also engage and support other provincial partners, including the Ministry of Health or other relevant ministries, on policy-level initiatives to help bridge system-level gaps.

In the meantime, there are many actions you can take on your own, so please read the standard and act where you can.



# Appendix 2: Glossary

Term	Definition
<b>Care partner</b>	An unpaid person who provides care and support in a nonprofessional capacity, such as a family member, friend, or anyone else identified by the person with dementia. Other terms commonly used to describe this role include “caregiver,” “informal caregiver,” “family caregiver,” “carer,” and “primary caregiver.”
<b>Clinicians</b>	Regulated professionals who provide care to patients or clients. Examples are nurses, nurse practitioners, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, social workers, and speech-language pathologists.
<b>Culturally appropriate care<sup>47</sup></b>	Care that incorporates cultural or faith traditions, values, and beliefs; is delivered in the person’s preferred language; adapts culture-specific advice; and incorporates the person’s wishes to involve family or community members.
<b>Family</b>	The people closest to a person in terms of knowledge, care, and affection; this may include biological family or family of origin, family through marriage, or family of choice and friends. The person defines their family and who will be involved in their care.
<b>Health care team</b>	Clinicians, as well as people in unregulated professions, such as administrative staff, behavioural support workers, child life specialists, patient transport staff, personal support workers, recreational staff, spiritual care staff, and volunteers.
<b>Home</b>	A person’s usual place of residence. This may include personal residences, retirement residences, assisted-living facilities, long-term care facilities, hospices, and shelters.
<b>Primary care</b>	A setting where people receive general health care (e.g., screening, diagnosis, and management) from a clinician who the person can access directly without a referral. This is usually the primary care physician, family physician, nurse practitioner, or other clinician with the ability to make referrals, request biological testing, and prescribe medications.
<b>Primary care clinician</b>	A family physician (also called a primary care physician) or nurse practitioner.
<b>Substitute decision-maker</b>	A person appointed to make decisions on behalf of another under a “Power of Attorney for Personal Care.”

# Appendix 3: Values and Guiding Principles

## Values That Are the Foundation of This Quality Standard

This quality standard was created, and should be implemented, according to the [Patient, Family and Caregiver Declaration of Values for Ontario](#). This declaration “is a vision that articulates a path toward patient partnership across the health care system in Ontario. It describes a set of foundational principles that are considered from the perspective of Ontario patients, and serves as a guidance document for those involved in our health care system.”

These values are:

- Respect and dignity
- Empathy and compassion
- Accountability
- Transparency
- Equity and engagement

A quality health system is one that provides good access, experience, and outcomes for all people in Ontario, no matter where they live, what they have, or who they are.

## Guiding Principles

In addition to the above values, this quality standard is guided by the principles outlined below.

### Acknowledging the Impact of Colonization

Clinicians should acknowledge and work toward addressing the historical and present-day impacts of colonization in the context of the lives of Indigenous Peoples throughout Canada. This work involves being sensitive to the impacts of intergenerational and present-day traumas and the physical, mental, emotional, and social harms experienced by Indigenous people, families, and communities, as well as recognizing their strength and resilience. This quality standard uses existing clinical practice guideline sources that may not include culturally relevant care or acknowledge traditional Indigenous beliefs, practices, and models of care.

### French Language Services

In Ontario, the *French Language Services Act* guarantees an individual’s right to receive services in French from Government of Ontario ministries and agencies in [26 designated areas](#) and at government head offices.<sup>48</sup>

## Social Determinants of Health

Homelessness and poverty are 2 examples of economic and social conditions that influence people's health, known as the social determinants of health. Other social determinants of health include employment status and working conditions, race and ethnicity, food security and nutrition, gender, housing, immigration status, social exclusion, and residing in a rural or urban area. Social determinants of health can have strong effects on individual and population health; they play an important role in understanding the root causes of poorer health. People with a mental illness or addiction often live under very stressful social and economic conditions that worsen their mental health,<sup>49</sup> including social stigma, discrimination, and a lack of access to education, employment, income, and housing.<sup>50</sup>

## Chronic Disease Self-Management

People with dementia and their families, care partners, and personal supports should receive services that are respectful of their rights and dignity and that promote shared decision-making and self-management.<sup>51</sup> Further, people should be empowered to make informed choices about the services that best meet their needs.<sup>52</sup> People with dementia should engage with their clinicians in informed, shared decision-making about their treatment options. Each person is unique and has the right to determine their own path toward mental health and well-being.<sup>51</sup>

# Acknowledgements

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Ontario Health thanks the following individuals for their generous, voluntary contributions of time and expertise to help create this quality standard (credentials at the time of initial development in 2018):

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# About Us

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We are an agency created by the Government of Ontario to connect, coordinate, and modernize our province's health care system. We work with partners, providers, and patients to make the health system more efficient so everyone in Ontario has an opportunity for better health and well-being.

## Equity, Inclusion, Diversity, and Anti-Racism

Ontario Health is committed to advancing equity, inclusion and diversity and addressing racism in the health care system. As part of this work, Ontario Health has developed an [Equity, Inclusion, Diversity and Anti-Racism Framework](#), which builds on existing legislated commitments and relationships and recognizes the need for an intersectional approach.

Unlike the notion of equality, equity is not about sameness of treatment. It denotes fairness and justice in process and in results. Equitable outcomes often require differential treatment and resource redistribution to achieve a level playing field among all individuals and communities. This requires recognizing and addressing barriers to opportunities for all to thrive in our society.

For more information about Ontario Health, visit [OntarioHealth.ca](https://OntarioHealth.ca).

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