Quality Standards

Dementia
Care for People Living in the Community

May 2017
Summary

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

For a quality standard that addresses care for people living 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*. 
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About Quality Standards

Health Quality Ontario, in collaboration with clinical experts, patients, residents, and caregivers across the province, is developing quality standards for Ontario.

Quality standards are concise sets of statements that will:

- Help patients, residents, families, and caregivers know what to ask for in their care
- Help health care professionals 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

The statements in this quality standard do not override the responsibility of health care professionals to make decisions with patients, after considering each patient’s unique circumstances.

How to Use Quality Standards

Quality standards inform clinicians and organizations about what high-quality health care looks like. They are based on the best available evidence.

They also include indicators to help clinicians and organizations assess the quality of care they are delivering, and to identify gaps and areas for improvement. These indicators measure process, structure, and outcomes.

In addition, tools and resources to support clinicians and organizations in their quality improvement efforts accompany each quality standard.

For more information on how to use quality standards, contact qualitystandards@hqontario.ca.
About This Quality Standard

Scope of This Quality Standard

This quality standard addresses care for community-dwelling people living with dementia, including the assessment of people suspected to have dementia or mild cognitive impairment. The quality standard focuses on care provided by primary care, specialist care, hospital outpatient services, home care, and community support services. It also provides guidance on support for caregivers of people living with dementia. This quality standard does not apply to the care provided in an emergency department or hospital in-patient setting; nor does it apply to people living in long-term care homes.

For a quality standard that addresses care for people living 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.

Terminology Used in This Quality Standard

In this quality standard, “caregiver” refers to an unpaid person who provides care and support, such as a family member, friend, or anyone identified by the person living with dementia.

In making this decision, the lived experience advisors in our Quality Standard Advisory Committee considered a number of terms currently being used to describe this role locally, provincially, and internationally. These included “caregiver,” “care partner,” “informal caregiver,” “family caregiver,” “carer,” and “primary caregiver.”

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

In this quality standard, “health care professionals” 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 “providers” 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.

Why This Quality Standard Is Needed

Dementia is 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.1,2

It is estimated that in 2016, about 564,000 Canadians aged 65 and older were living with dementia; an expected 937,000 million Canadians will be living with dementia by 2031.3 Dementia affects about 15% of Canadians aged 65 and older.4 Age is the primary risk factor for dementia: the risk doubles every 5 years after age 65.5 Notwithstanding this increased risk in
older people, nearly 7% of people diagnosed with dementia in Ontario are younger than age 65.\textsuperscript{6,7}

People living with dementia want to live well and independently and to participate in care decisions with their health care professionals and community service providers for as long as possible. However, the stigma associated with dementia often shifts the focus of others to 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.\textsuperscript{8} The stigma can also cause people to delay acknowledging symptoms and seeking help.\textsuperscript{8}

Recognizing and supporting people throughout the stages of dementia is important. This includes\textsuperscript{6,8}:

- Being proactive in engaging people in decisions about their care and activities of interest
- Accessing care and services that meet individuals’ needs and preferences
- Providing opportunities for them 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 living with dementia and their caregivers and families, as well as a considerable economic impact on the Canadian health care system and society. In Canada in 2008, the total annual economic burden of dementia, including direct costs, indirect costs, and caregiver opportunity costs, was estimated to be $14.9 billion.\textsuperscript{1}

As Canada’s aging population continues grow, and as the number of people living with dementia increases, so too will the demand for health care services and community support services. In 2008, about 55% of Canadians with dementia (aged 65 and older) lived in their own homes; it is estimated this will increase to 62% by 2038.\textsuperscript{1} People living 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.

Being a caregiver for a person living with dementia can be a rewarding experience.\textsuperscript{10,11} However, the role can also be physically, emotionally, and financially demanding and is associated with high levels of stress, strain, and social isolation.\textsuperscript{1} In comparison with caregivers of people without dementia, caregivers of people living with dementia provide 75% more care and experience about 20% higher stress levels.\textsuperscript{12} These caregiving demands tend to increase as the dementia progresses. If families and caregivers 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 community-dwelling people living with dementia in Ontario. Data suggest there are variations in this care across regions. In 2014/15, the percentage of people living with dementia in the community who received home care services ranged from 59% to 83% across the local health integration networks (LHINs). Of those who received these services, the average number of contacts for personal support and homemaking services in 2014/15 ranged from 87 to 165 across the LHINs.\textsuperscript{13} Province-wide, feelings of distress were reported by nearly half of the caregivers of people living with dementia receiving long-stay home care.\textsuperscript{14} More than 60% of caregivers of people exhibiting challenging behaviours felt distressed.\textsuperscript{14}

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

**Principles Underpinning This Quality Standard**

Community-dwelling people living with dementia and their caregivers should receive services that are respectful of their rights and dignity and that promote self-determination.

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

People living with dementia and their caregivers should be provided service that is respectful of their gender, sexual orientation, socioeconomic status, housing, age, background (including self-identified cultural, ethnic, and religious backgrounds), and disability. Services should be provided in their preferred language.

**How We Will Measure Our Success**

A limited number of overarching objectives are set for this quality standard; these objectives have been mapped to performance indicators to measure the success of this quality standard as a whole:

- Percentage of people living with dementia and their caregivers who each have optimized quality of life
- Percentage of people living with dementia and their caregivers who each have increased their knowledge and skills about dementia care
- Percentage of people living with dementia and their caregivers who are confident with the dementia care they provide for themselves and others
- Percentage of people living with dementia and their caregivers who reported being satisfied or very satisfied with the care and services received in the community
- Rate of emergency department visits related to behavioural symptoms for people living with dementia
- Rate of hospitalizations related to behavioural symptoms for people living with dementia
- Rate of emergency department visits related to co-morbidities for people living with dementia
- Rate of hospitalizations related to co-morbidities for people living with dementia
- Percentage of people living with dementia who could be cared for in the community but instead transitioned to a long-term care home
- Percentage of people living with dementia who could be cared for in the community but who applied to live in a long-term care home
- Rate of emergency department visits for people living with dementia
- Rate of hospitalizations for people living with dementia
- Average length of stay in hospital for people living with dementia
- Alternative-level-of-care days for people living with dementia
In addition, each quality statement within this quality standard is accompanied by one or more indicators to measure the successful implementation of the statement.
Quality Statements in Brief

Quality Statement 1: Comprehensive Assessment
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.

Quality Statement 2: Interprofessional Care Team
People living with dementia have access to community-based dementia care from an interprofessional team with expertise in dementia care, of which the person living with dementia and their caregivers are integral team members.

Quality Statement 3: Individualized Care Plan
People living with dementia have an individualized care plan that guides their care. The plan identifies their individual needs, those of their caregivers and includes 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 living with dementia and their caregivers have one or more named providers on the interprofessional care team who serve as a point of contact to facilitate care coordination and transitions across settings.

Quality Statement 5: Education and Training for People Living With Dementia and Their Caregivers
People living with dementia and their caregivers have access to education and training on dementia and available support services.

Quality Statement 6: Education and Training for Health Care Providers
Health care providers delivering care and services to people living with dementia receive education and training in dementia care.

Quality Statement 7: Access to Support Services
People living with dementia and their caregivers have access to support services that are individualized and meet their goals and needs.

Quality Statement 8: Caregiver Assessment and Support
Caregivers of people living with dementia are assessed on an ongoing basis and offered supports to address their individual needs.

Quality Statement 9: Safe Living Environment
People living 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 a Primary Care Provider
People living with mild cognitive impairment or dementia have regular visits to a primary care provider who provides effective primary care that meets both their general health care needs and their needs related to cognitive impairment or dementia.
Quality Statement 1: Comprehensive Assessment

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.

Background

A comprehensive assessment ensures an accurate diagnosis and the collection of baseline information to track changes in a person’s status. 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. Given the ongoing cognitive decline associated with dementia and the increased risk of people with mild cognitive impairment developing dementia, a comprehensive assessment should be performed when a person first exhibits signs and on a regular basis afterwards. The person, family, caregivers, and/or substitute decision-makers should be included in the assessment.


Definitions Used Within This Quality Statement

Comprehensive assessment
This includes, at a minimum, the following components:

- Medical history
- Medication review (including over-the-counter and alternative medications)
- Physical and functional status examinations
- Cognitive assessment, which includes the use of validated instruments
- Assessment of potential medical and psychiatric co-morbidities or potential contributing factors (e.g., delirium, depression) to cognitive signs and symptoms
- Assessment of social history and psychosocial functioning
- Relevant laboratory tests

Collateral history from family and caregivers should be obtained whenever possible.

The assessment should be culturally sensitive—respectful of diverse cultural, ethnic, and spiritual backgrounds—and in the person’s preferred language.

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

A person living 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).
What This Quality Statement Means

For People Living With Mild Cognitive Impairment or Dementia
You should be assessed by a health care professional when you, your family, or a health care professional first notices changes in your memory or judgment. The assessment should include questions about your physical health, your medical history, what medications you’re taking, and how you’re feeling. If you have mild cognitive impairment or dementia, these assessments should be repeated at regular intervals.

For Clinicians
Perform a comprehensive assessment (as described in the Definitions section of this statement) when people first show signs of mild cognitive impairment or dementia. People diagnosed with either condition should be assessed on a regular basis afterwards.

For Health Services
Ensure there are systems, processes, and resources for clinicians and health care teams to carry out comprehensive assessments of people with suspected or confirmed mild cognitive impairment or dementia.

Quality Indicators

Process Indicators

Percentage of people suspected to have mild cognitive impairment or dementia who receive a comprehensive assessment when signs are first identified by a health care provider

- Denominator: number of people suspected to have mild cognitive impairment or dementia
- Numerator: number of people in the denominator who receive a comprehensive assessment
- Data source: local data collection

Percentage of people living with mild cognitive impairment who receive a comprehensive reassessment every year, or sooner according to clinical need

- Denominator: number of people living with mild cognitive impairment
- Numerator: number of people in the denominator who receive a comprehensive reassessment within 1 year of their last assessment
- Data sources: Residential Assessment Instrument—Home Care or local data collection

Percentage of people living with dementia who receive a comprehensive reassessment every 6 to 12 months, or sooner according to clinical need

- Denominator: number of people living with dementia
- Numerator: number of people in the denominator who receive a comprehensive reassessment within 6 to 12 months of their last assessment
- Data sources: Residential Assessment Instrument—Home Care or local data collection
Quality Statement 2: Interprofessional Care Team

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

Background

The needs of people living with dementia are dynamic and complex. Individualized management from providers of various disciplines with expertise in dementia care is necessary. The team’s composition should be flexible and adapt to the person’s changing health, social circumstances, needs, and goals. 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 living with dementia and of their caregivers. People living with dementia and their caregivers are an integral part of the team and should participate in decisions about their own care.

Sources: National Institute for Health and Clinical Excellence, 2006 | Sistema Nacional de Salud, 2010

Definitions Used Within This Quality Statement

Interprofessional team
This consists of:

- At least one physician or nurse practitioner and one other regulated health care professional trained in dementia care
- Other regulated and unregulated providers, which may include family physicians, nurses, nurse practitioners, psychologists, occupational therapists, pharmacists, behavioural support workers, social workers, caregivers, administrative staff, personal support workers, speech-language pathologists, physiotherapists, geriatricians, neurologists, geriatric psychiatrists, dietitians, recreational staff, and spiritual care staff

What This Quality Statement Means

For People Living With Dementia
You should receive care from a team of health care providers with expertise in dementia care.

You and your caregivers should be treated as important members of the 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
Ensure that people living with dementia are cared for by an interprofessional team with expertise in dementia care. Involve people living with dementia and their caregivers in decisions about their own care.

For Health Services
Ensure that systems, procedures, and resources are in place for people living with dementia to receive care from an interprofessional team with expertise in dementia care.
Quality Indicators

Process Indicators

Percentage of people living with dementia who receive community-based dementia care from an interprofessional team with expertise in dementia care

- Denominator: number of people living with dementia
- Numerator: number of people in the denominator who receive community-based dementia care from an interprofessional team including at least one physician or nurse practitioner and at least one other health care provider, all with expertise in dementia care
- Data source: local data collection

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

- Denominator: number of people living with dementia who receive community-based dementia care from an interprofessional team with expertise in dementia care
- Numerator: number of people in the denominator and their caregivers who feel they are integral team members
- Data source: local data collection
Quality Statement 3: Individualized Care Plan

People living with dementia have an individualized care plan that guides their care. The plan identifies their individual needs, those of their caregivers and includes 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.

Background

An individualized care plan is essential to coordinate, document, and ultimately guide the care of people living with dementia. The care plan is developed by and implemented in collaboration with the person living with dementia, caregivers, and providers to ensure consistent and coordinated delivery of care that considers the changing needs and goals of people living with dementia. Care plans need to be communicated to and accessible to the person’s health care providers. Ongoing review of the care plan supports revisiting goals of care and allows for the assessment of evolving needs and preferences and the person’s treatment responses to interventions.


Definitions Used Within This Quality Statement

Individualized care plan
This is based on an assessment of the life history, social and family circumstances, and preferences and needs of the person living with dementia. It is also based on their physical and mental health needs and current level of functioning and abilities. Developed and reviewed with the person living with dementia and their caregiver, the care plan should be flexible, to accommodate fluctuating abilities, and include:

- The results of the comprehensive assessment (see Quality Statement 1)
- The person’s individual needs, preferences, and goals, and those of their caregiver
- A plan to minimize relocations and retain a familiar environment for as long as possible
- Assessments of activities of daily living and instrumental activities of daily living, as well as care-planning advice
- 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 safety plan, including crisis and emergency management
- Advance care planning
- At least one named point of contact—this is the provider who facilitates care coordination and transitions across settings for the person living 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 caregiver.

**What This Quality Statement Means**

**For People Living With Dementia**
You, your caregivers, and your health care professionals 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 services you receive, and who provides them. It should be updated regularly and is based on your regular assessments.

**For Clinicians**
Work with people living with dementia and their caregivers 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 Health Services**
Ensure 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**

**Process Indicators**

**Percentage of people living with dementia who have an individualized care plan that guides their care**

- Denominator: number of people living with dementia
- Numerator: number of people in the denominator who have an individualized care plan that guides their care
- Data source: local data collection

**Percentage of people living with dementia who have an individualized care plan that has been reviewed at least once a year, or sooner according to clinical need**

- Denominator: number of people living with dementia who have an individualized care plan
- Numerator: number of people in the denominator who have an individualized care plan that is reviewed at least once annually
- Data source: local data collection
Quality Statement 4: Named Point of Contact

People living with dementia and their caregivers have one or more named providers on the interprofessional care team who serve as a point of contact to facilitate care coordination and transitions across settings.

Background

It can be difficult and frustrating to navigate the health system and know whom to contact when health issues or concerns arise. A point of contact on the interprofessional dementia care team 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 primary care
- Is involved in the care and understands the current needs and care goals of the person living with dementia and their caregivers
- Is able to address the needs of the person living with dementia or connect the person with the most appropriate provider to address their needs

The point of contact on the interprofessional dementia care team is an essential component of person-centred dementia care.\(^\text{21}\)

Source: Advisory committee consensus

Definitions Used Within This Quality Statement

Point of contact
The point of contact:

- Is one or more named members of the interprofessional team
- Supports communication and information sharing among health care professionals, community service providers, and the person living with dementia and their caregivers
- Facilitates care coordination and transitions across care settings and providers

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

What This Quality Statement Means

For People Living With Dementia and Caregivers
You should have the name and contact information of one or more members of your health care team who coordinate your care with the other care providers and services, and between health care locations (such as your home, your primary care provider’s office, and the hospital).

For Clinicians
Ensure that people living with dementia and their caregivers have the name and contact information of one or more members of the care team responsible for coordinating their care and transferring information among providers.
For Health Services
Ensure that systems, processes, and resources are in place for care providers to serve as a point of contact for people living with dementia, their caregivers, and other providers involved in their care.

Quality Indicators

Process Indicator

Percentage of people living with dementia who have at least one named provider on their interprofessional care team who serves as their point of contact

- Denominator: number of people living with dementia who receive care from an interprofessional care team
- Numerator: number of people in the denominator who have at least one named provider on their interprofessional care team who serves as their point of contact
- Data source: local data collection
Quality Statement 5: Education and Training for People Living With Dementia and Their Caregivers

People living with dementia and their caregivers have access to education and training on dementia and available support services.

Background

Dementia is a complex condition that has a substantial impact on the lives of people living with dementia as well as their caregivers and families. Education and training to help people better understand dementia and its progression, treatment options, and available supports will enable them to make decisions about their care and plan for the future. Written and verbal information should be provided throughout the care journey and align with their evolving needs and the person’s stage of dementia.

Sources: American Psychiatric Association, 2007\(^{17}\) | European Federation of Neurological Societies and European Neurological Society, 2012\(^{18}\) | National Institute for Health and Clinical Excellence, 2006\(^{16}\) | Registered Nurses’ Association of Ontario, 2016\(^{19}\) | Sistema Nacional de Salud, 2010\(^{20}\)

Definitions Used Within This Quality Statement

**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 strategies
- 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 to use during times of stress
- Functions of different providers and health care settings
- Medical-legal issues, including driving
- Financial and legal planning for the person’s eventual incapacity
- Advance care planning
- Processes to resolve disagreement around the person’s care
- Available support services and groups and how to access them
- Sources of financial and legal advice and advocacy

Information should be provided in both written and verbal forms.
What This Quality Statement Means

For People Living With Dementia and Caregivers
You should be offered education and training about living with dementia. These will help you understand dementia and how it progresses, your treatment options, and the supports available.

For Clinicians
Offer education and training to people living with dementia and their caregivers. This should align with their needs and the stage of dementia.

For Health Services
Ensure that providers and teams are able to offer education and training on dementia and local supports services to people living with dementia and their caregivers.

Quality Indicators

Process Indicators

Percentage of people living with dementia who are offered education and training on dementia and available support services

- Denominator: number of people living with dementia
- Numerator: number of people in the denominator who are offered education and training on dementia and available support services
- Data source: local data collection

Percentage of caregivers of people living with dementia who are offered education and training on dementia and available support services

- Denominator: number of caregivers of people living with dementia
- Numerator: number of people in the denominator who are offered education and training on dementia and available support services
- Data source: local data collection

Percentage of people living with dementia who receive education and training on dementia and available support services

- Denominator: number of people living with dementia
- Numerator: number of people in the denominator who receive education and training on dementia and available support services
- Data source: local data collection

Percentage of caregivers of people living with dementia who receive education and training on dementia and available support services

- Denominator: number of caregivers of people living with dementia
- Numerator: number of people in the denominator who receive education and training on dementia and available support services
- Data source: local data collection
Draft—do not cite. Report is a work in progress and could change following public consultation.

**Structural Indicator**

Availability of education and training on dementia and available support services for people living with dementia and their caregivers
Quality Statement 6: Education and Training for Health Care Providers

Health care providers delivering care and services to people living with dementia receive education and training in dementia care.

Background

People living with dementia have complex needs and should receive individualized care from providers with education and training in dementia care. With the knowledge and skills required to effectively provide care for people living with dementia, providers 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 providers’ roles and responsibilities.

Sources: American Psychiatric Association, 2007\(^{17}\) | National Institute for Health and Clinical Excellence, 2006\(^{16}\) | Sistema Nacional de Salud, 2010\(^{20}\)

Definitions Used Within This Quality Statement

Education and training

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

- Comprehensive assessment of people living with dementia and an assessment of caregivers’ needs
- Dementia signs and symptoms and disease progression
- Specific subtypes of dementia
- Person-centred care
- Early identification of behavioural risks and safety issues
- Appropriate use of nonpharmacological and pharmacological treatments
- Strategies for responding to challenging behaviours
- How to communicate with people living with dementia and their caregivers
- How to coordinate multidisciplinary care
- Impacts of dementia on people living with dementia, caregivers, families, and social networks
- Outreach strategies to connect people living with dementia and their caregivers to available resources
- Ethical and medical-legal considerations
- Detection of and strategies to manage abuse
- Advance care planning and palliative and end-of-life care, as appropriate

What This Quality Statement Means

For People Living With Dementia

Your team of providers should be trained to care for people living with dementia.
For Clinicians
Ensure you have the education and training required to effectively provide care for people living with dementia, in accordance with your roles and responsibilities.

For Health Services
Ensure the availability of education and training in dementia care for providers caring for people living with dementia.

Quality Indicators

Process Indicator

Percentage of providers who care for people living with dementia who have received education and training in dementia care

- Denominator: number of providers who care for people living with dementia
- Numerator: number of people in the denominator who have received education and training in dementia care
- Data source: local data collection

Structural Indicator

Providers who care for people living with dementia have access to staff with education and training in dementia care
Quality Statement 7: Access to Support Services

People living with dementia and their caregivers have access to support services that are individualized and meet their goals and needs.

Background

People living 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. As such, they and their caregivers 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. They need access to the right services, at the right time, and in the right place to help them in their journey.


Definitions Used Within This Quality Statement

Support services

A variety of flexible and accessible home care services and community support services are needed to support community-dwelling people living with dementia, as well as their caregivers. Services should be responsive to people’s goals and tailored to their changing physical, psychological, and social needs. Support services include:

- Health professional services, such as nursing, occupational therapy, 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)
- Respite care—this provides caregivers with temporary relief from their caregiving duties. Examples include adult day programs, in-home respite, overnight care, and short stays in a long-term care home (see Quality Statement 8)
- 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 living with dementia and their caregivers should have up-to-date verbal and written information about local services and how to access them.
What This Quality Statement Means

For People Living With Dementia and Caregivers
You should have access to support services that are designed to meet your goals and needs. Examples include assistance with personal care, help around the house, support groups, and transportation services.

For Clinicians
Offer support services to people living with dementia and their caregivers to help them meet their goals and needs. Advise them on available services and how to access them.

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

Quality Indicators

Process Indicators

Percentage of people living with dementia who have access to support services
- Denominator: number of people living with dementia
- Numerator: number of people in the denominator who have access to support services
- Data source: local data collection

Percentage of caregivers of people living with dementia who have access to support services
- Denominator: number of caregivers of people living with dementia
- Numerator: number of people in the denominator who have access to support services
- Data source: local data collection

Percentage of people living with dementia who have support services that are individualized and meet their goals and needs
- Denominator: number of people living with dementia
- Numerator: number of people in the denominator who have support services that are individualized and meet their goals and needs
- Data source: local data collection

Percentage of caregivers of people living with dementia who have support services that are individualized and meet their goals and needs
- Denominator: number of caregivers of people living with dementia
- Numerator: number of people in the denominator who have support services that are individualized and meet their goals and needs
- Data source: local data collection
Draft—do not cite. Report is a work in progress and could change following public consultation.

**Structural Indicator**

Local availability of a comprehensive range of respite services for caregivers of people living with dementia that meet the needs of both the caregiver and the person living with dementia.
**Quality Statement 8: Caregiver Assessment and Support**

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

**Background**

Caregivers play a critical role in supporting the health, well-being, and functional independence of people living 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 caregivers.

While caregiving can be a rewarding experience, it is often described as stressful and can result in considerable physical, psychological, social, and financial impacts. For example, caregivers 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). Caregivers also have to balance their caregiving with other responsibilities, such as their careers, family obligations, and own health needs.

Caregivers 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. Supports such as transportation or respite care services should be provided for caregivers to enable them to participate in services or activities.

**Sources:** National Institute for Health and Clinical Excellence, 2006 | Sistema Nacional de Salud, 2010

**Definitions Used Within This Quality Statement**

**Caregiver assessment**

Caregivers of people living 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.

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

**Supports**

Caregivers 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 living 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
caring for the caregiver (in terms of location, flexible timing and duration, and timeliness) and the person living with dementia (in terms of involving meaningful and therapeutic activities and being in an environment that meets their needs).

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

**What This Quality Statement Means**

**For Caregivers**
You should be assessed on an ongoing basis to see how you are coping. If needed, you should be offered services such as training, peer support, and temporary respite care for your loved one so you have a break from the caregiving routine.

**For Clinicians**
Ensure that you assess caregivers 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 Health Services**
Ensure systems, processes, and resources are in place for providers and teams to assess caregivers. Ensure supports are available to address caregivers’ needs.

**Quality Indicators**

**Process Indicators**

**Percentage of caregivers of people living with dementia who receive an assessment**

- Denominator: number of caregivers of people living with dementia
- Numerator: number of people in the denominator who receive an assessment
- Data source: local data collection

**Percentage of caregivers of people living with dementia who have received an assessment and are offered supports to address their individual needs**

- Denominator: number of caregivers of people living with dementia who have received an assessment
- Numerator: number of people in the denominator who are offered supports to address their individual needs
- Data source: local data collection
Quality Statement 9: Safe Living Environment

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

Background

People living 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 peoples’ ability to interact with and make sense of their environment. Environments that are familiar, home-like, and easy to understand are important.

Over the course of a person’s dementia, living environments need to be modified to help the person manage their surroundings, support their independence, and reduce their feelings of confusion and stress. Design modifications may include non-slip floor coverings, handrails in the shower and beside the toilet to provide support and balance, heat and smoke sensors, and memory cues.

When people living 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, if necessary, a long-term care home. Although people living with dementia may eventually require long-term care, access to the right types of housing and supports can maximize the length of time they are able to live in the community.

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

Source: National Institute for Health and Clinical Excellence, 2006

Definitions Used Within This Quality Statement

Safe living environment
A living environment that helps the person living with dementia navigate their place of residence and supports their caregivers 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). Needs should be assessed and informed by the individualized care plan.

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:

- Lighting
- Surfaces to minimize reflections and glare
- Floor coverings
- Doorways, to widen them
• 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:  
  
• 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

What This Quality Statement Means

For People Living With Dementia
You should have a safe living environment that meets your needs. This may involve changes such as better lighting or memory cues. It may also include moving to a living environment that better meets your needs.

For Clinicians
Ensure housing is safe and meets the needs of the person living with dementia and their caregivers.

For Health Services
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 Indicators

Process Indicator

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

• Denominator: number of people living with dementia
• Numerator: number of people in the denominator who reside in a safe living environment that meets their specific needs
• Data source: local data collection
Quality Statement 10: Access to a Primary Care Provider

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

Background

Primary care plays a critical role in managing the complex health needs of people living 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 caregivers’ health care needs.

More than 90% of community-dwelling seniors with dementia in Ontario have two or more coexisting chronic medical conditions, 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. Conditions that are often manageable can become de-stabilized and exacerbated when a person has dementia. This results in:

- Increased visits to the emergency department, hospitalizations, and hospital readmissions
- Deconditioning (muscle loss owing to inactivity)
- Earlier institutionalization

To address these challenges, people living with dementia or cognitive impairment and their caregivers need access to primary care that:

- Is person-centred (rather than disease-focused)
- Is continuous and comprehensive for most health needs
- Is coordinated and links to other health care professionals and resources across the health care system, as needed
- Addresses individual needs and aligns with the person’s goals of care

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 to link to and get support from specialists in dementia care, such as geriatricians, geriatric psychiatrists, neurologists, and psychogeriatric specialists.

Source: Advisory committee consensus

Definitions Used Within This Quality Statement

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

**Primary care provider**
This is a primary care physician or nurse practitioner.

**Effective primary care**
Primary care is the person’s first contact with the health system. It is effective when it:\(^{34,35}\):

- 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 health care professionals or home and community support services is required
- Continues over time
- Links to and gets support from specialists, as needed

**What This Quality Statement Means**

**For People Living With Mild Cognitive Impairment or Dementia**
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, coordinate your care, and link you and your caregiver to other health care providers and services.

**For Clinicians**
Ensure that people living with dementia or mild cognitive impairment have access to a primary care provider to visit regularly. This individual will provide person-centred, comprehensive, and coordinated care to meet their needs.

**For Health Services**
Ensure the availability of and access to a primary care provider. Ensure the system can accommodate the provision of effective primary care to support the dynamic needs of those living with dementia.

**Quality Indicators**

**Process Indicators**

**Percentage of people with mild cognitive impairment who have visited their primary care provider in the past 12 months**

- Denominator: number of people living with mild cognitive impairment
- Numerator: number of people in the denominator who have visited their primary care provider in the past 12 months
- Data sources: Health Care Experience Survey or local data collection
Percentage of people with dementia who have visited their primary care provider in the past 6 months

- Denominator: number of people living with dementia
- Numerator: number of people in the denominator who have visited their primary care provider in the past 6 months
- Data sources: Health Care Experience Survey or local data collection
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Advisory Committee

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**Linda Lee (co-chair)**
Family Practice Physician and Director, Centre for Family Medicine Memory Clinic, Schlegel Research Chair in Primary Care for Elders, Schlegel-UW Research Institute for Aging, Associate Clinical Professor, McMaster University

**Lori Lawson**
Director of Community Support Services, St. Joseph’s Home Care, St. Joseph’s Healthcare Hamilton

**Jane McKinnon Wilson (co-chair)**
Director, Regional Geriatric Program Central, Hamilton Health Sciences

**Sandy Linseman**
Pharmacist, Grand River Hospital Corporation

**Gillian Barrie**
Occupational Therapist, Adult Physical Medicine and Geriatric Health Clinical Lead, VHA Rehab Solutions

**Carrie McAiney**
Associate Professor, McMaster University

**Nirmala Bowman**
Lived Experience Advisor

**Scott McKay**
Family Practice Physician, London Health Sciences Centre, Associate Chair, Department of Family Medicine, Western University

**Beryl Cable-Williams**
Lived Experience Advisor

**Kelly Milne**
Director, Regional Geriatric Program of Eastern Ontario, The Ottawa Hospital

**Jo-Anne Clark**
Geriatrician, North East Specialized Geriatric Centre, Health Sciences North

**Rakhi Mistry**
Care Coordinator, Mississauga Halton Community Care Access Centre

**Phyllis Fehr**
Lived Experience Advisor

**Frank Molnar**
Geriatrician, Medical Director, Regional Geriatric Program of Eastern Ontario, The Ottawa Hospital

**Jami Finlay**
Manager, Support Services, Alzheimer Society of Elgin–St. Thomas

**Craig O’Brien**
Nurse Practitioner, Lakelands Family Health Team

**Carol Holmes-Kerr**
Lived Experience Advisor

**Dawn Robinson**
Psychogeriatric Resource Consultant, Alzheimer Society of Peel

**Kelly Kay**
Executive Director, Seniors Care Network

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Geriatric Psychiatrist, Providence Care, Assistant Professor, Queen’s University

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Neurologist, Toronto Western Hospital

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Manager, Community Programs, Region of Waterloo
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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.**

Who We Are

We are a scientifically rigorous group with diverse areas of expertise. We strive for complete objectivity, and look at things from a vantage point that allows us to see the forest and the trees. We work in partnership with health care providers and organizations across the system, and engage with patients themselves, to help initiate substantial and sustainable change to the province’s complex health system.

What We Do

We define the meaning of quality as it pertains to health care, and provide strategic advice so all the parts of the system can improve. We also analyze virtually all aspects of Ontario’s health care. This includes looking at the overall health of Ontarians, how well different areas of the system are working together, and, most importantly, patient experience. We then produce comprehensive, objective reports based on data, facts, and the voices of patients, caregivers, and those who work each day in the health system. As well, we make recommendations on how to improve care using the best evidence. Finally, we support large scale quality improvements by working with our partners to facilitate ways for health care providers to learn from each other and share innovative approaches.

Why It Matters

We recognize that, as a system, we have much to be proud of, but also that it often falls short of being the best it can be. Plus certain vulnerable segments of the population are not receiving acceptable levels of attention. Our intent at Health Quality Ontario is to continuously improve the quality of health care in this province regardless of who you are or where you live. We are driven by the desire to make the system better, and by the inarguable fact that better has no limit.
Quality Standards

Looking for more information?
Visit our website at hqontario.ca and contact us at qualitystandards@hqontario.ca if you have any questions or feedback about this guide.

Health Quality Ontario
130 Bloor Street West, 10th Floor
Toronto, Ontario
M5S 1N5

Tel: 416-323-6868
Toll Free: 1-866-623-6868
Fax: 416-323-9261
Email: QualityStandards@hqontario.ca
Website: hqontario.ca

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