Quality
Standards

Dementia

Care for People Living in the Community

Health Quality
Ontario

Let's make our health system healthier

Ontario
Health Quality Ontario

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 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.

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 Health Quality Ontario's quality standard *Behavioural Symptoms of Dementia: Care for Patients in Hospitals and Residents in Long-Term Care Homes*.

Table of Contents

TABLE OF CONTENTS CONTINUED

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 for aspects of care that have been deemed a priority for quality improvement in the province. 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 processes, structures, 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 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 care provided in an emergency department or hospital in-patient setting or to people living in long-term care homes. Nor does it address specific aspects of palliative care for 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 Health Quality Ontario's quality standard *Behavioural Symptoms of Dementia: Care for Patients in Hospitals and Residents in Long-Term Care Homes*.

For a quality standard that addresses palliative care, refer to Health Quality Ontario's quality standard *Palliative Care: Care for Adults With a Progressive, Life-Limiting Illness*.

Terminology Used in This Quality Standard

In this quality standard, the term "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 choosing this term, the lived experience advisors on our Quality Standard Advisory Committee also considered a number of other terms currently being used to describe this role locally, provincially, and internationally. These included "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, "substitute decision-maker" 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.[1] 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.

The Ontario *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.[2] 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."[3] 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.[1]

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.[2] Capacity is issue- or task-specific.[1] 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.[2] 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.[2]

In this quality standard, the term "health care professional" 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 "provider" 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 living with dementia and people living with mild cognitive impairment.

"Dementia" 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.[4,5]

"Mild cognitive impairment" is defined as a decline in memory, judgement, thinking, or language that is greater than the cognitive changes associated with aging and that does not interfere notably with activities of daily living.[6,7] While mild cognitive impairment is not a diagnosis of dementia, people with this condition are at greater risk of developing dementia.[6]

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 2015, about 175,000 people in Ontario were estimated to be living with dementia.[8] Dementia affects about 15% of Canadians aged 65 and older.[9] Age is the primary risk factor for dementia: the risk doubles every 5 years after age 65.[10] Notwithstanding this increased risk in older people, dementia also affects younger people: nearly 7% of people diagnosed with dementia in Ontario are younger than age 66.[8,11]

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 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.[12] This stigma can also cause people to delay acknowledging symptoms and seeking help.[12]

Recognizing and supporting people throughout the stages of dementia is important. This includes[12,13]:

- 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 living with dementia and their caregivers and families, as well as a considerable economic impact on the Canadian health care system and society more broadly. 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.[4]

As Canada's population ages, the number of people living with dementia increases and so too grows the demand for dementia-related health care 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.[4] 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.[14,15] However, the role can also be physically, emotionally, and financially demanding and is associated with high levels of stress, strain, and social isolation.[4] 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.[16] 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 and their caregivers in Ontario. Across the province, nearly half of people living with dementia receiving long-stay home care had caregivers who were distressed.[17] More than 60% of people exhibiting behavioural symptoms of dementia had caregivers who felt distressed.[17] Data also suggest there are variations in the kind of care provided to people living with dementia across regions. In 2015/16, the percentage of people living with dementia in the community who received home care services ranged from 52% to 62% across Ontario's 14 local health integration networks (LHINs). Of those who received these services, the average number of hours for personal support and homemaking services ranged from 93 to 179 across the 14 LHINs.[18] These gaps and variations highlight the need for a quality standard for the care of people living with dementia 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 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

People living with dementia should receive care and services that are respectful of their human rights and dignity and that promote shared decision-making.[19]

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. Language, a basic tool for communication, is an essential part of safety of care and needs to be considered throughout a person's health care journey. For example, in predominantly Anglophone settings, services should be actively offered in French and other languages.

Care providers should be aware of the historical context of the lives of Canada's Indigenous peoples and be sensitive to the impacts of intergenerational trauma and the physical, mental, emotional, and social harms experienced by Indigenous people, families, and communities.

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

How Success Can Be Measured

The Quality Standard Advisory Committee identified a small number of overarching goals for this quality standard. These have been mapped to indicators that may be used to assess quality of care provincially and locally.

How Success Can Be Measured Provincially

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

How Success Can Be Measured Locally

You may want to assess the quality of care you provide to people living with dementia in the community. You may also want to monitor your own quality improvement efforts. It may be possible to do this using your own clinical records, or you might need to collect additional data. We recommend the following list of potential indicators, some of which cannot be measured provincially using currently available data sources:

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

In addition, each quality statement within the standard is accompanied by one or more indicators. These indicators are intended to guide the measurement of quality improvement efforts related to the implementation of the statement.

Quality Statements in Brief

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 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 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 ongoing 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 Primary Care

People living 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.

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.

Background

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.[20] 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

BACKGROUND CONTINUED

clinical practice guideline, structural imaging (e.g., CT and/or MRI) isn't 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).[21]

Given the ongoing cognitive decline associated with dementia and the increased risk of people with mild cognitive impairment developing dementia,[6] 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 afterwards. The person and ideally their family, caregivers, 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.

Sources: American Psychiatric Association, 2007[22] | European Federation of Neurological Societies and European Neurological Society, 2012[23] | National Institute for Health and Clinical Excellence, 2006[6] | Registered Nurses' Association of Ontario, 2016[24] | Sistema Nacional de Salud, 2010[25]

What This Quality Statement Means

For People Living With Mild Cognitive Impairment or Dementia

When you, your family, or a health care professional first notice changes in your memory or judgment, you should be assessed by a health care professional. This assessment should include questions about your physical health, your medical history, what medications you're taking, and how you're feeling. If you are diagnosed with either mild cognitive impairment or dementia, these assessments should be repeated at regular intervals.

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 reassessed on a regular basis afterwards.

For Health Services

Ensure 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.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Comprehensive assessment

This clinical assessment should be conducted by skilled health care professionals 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, falls
- Relevant laboratory tests

Collateral history from family and caregivers should be obtained.

Quality Indicators

Process Indicators

Percentage of people suspected to have mild cognitive impairment or dementia who receive a comprehensive assessment

- 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 received a comprehensive reassessment within the past year

- Denominator: number of people living with mild cognitive impairment
- Numerator: number of people in the denominator who received a comprehensive reassessment within the past year
- Data source: local data collection

Percentage of people living with dementia who received a comprehensive reassessment within the past year

- Denominator: number of people living with dementia
- Numerator: number of people in the denominator who received a comprehensive reassessment within the past year
- Data source: local data collection

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

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).

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. 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. The care team's composition should be flexible and adapt to the person's changing health, social circumstances, needs, and goals.[26] 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[6] | Sistema Nacional de Salud, 2010[25]

What This Quality Statement Means

For People Living 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 caregivers should be treated as important members of your health care team. This means your questions, concerns, observations, and goals are discussed and incorporated into your care plan, and you are supported to play an active role in your own care.

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.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Interprofessional team

This includes at least one physician or nurse practitioner and one other regulated health care professional trained in dementia care. Other regulated and unregulated providers on the team 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, therapeutic recreation staff, and spiritual care staff.

Quality Indicators

Process Indicators

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

- Denominator: number of people living with dementia in the community
- 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

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 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, goals, values, and preferences of people living with dementia.[6,24] Care plans need to be communicated to and accessible to the person living with dementia, members of the interprofessional care team, and caregivers or substitute decision-makers. 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.

Older adults living with dementia are at high risk for adverse drug events.[27] Medication optimization is an important aspect of care for people living with dementia. Considerations include medication

BACKGROUND CONTINUED

adherence, appropriate treatment targets for comorbid conditions (e.g., hypertension, diabetes), appropriate use and monitoring of cognition-enhancing medications (e.g., donepezil, galantamine, rivastigmine, memantine), and optimized use of medications with potentially adverse cognitive effects (e.g., minimizing to the lowest dose necessary or eliminating all inappropriate or unnecessary use of medications including, but not limited to, anticholinergic drugs, benzodiazepines and other sedative-hypnotics, antipsychotics, and opioids).[28,29] The decision to continue or discontinue a medication should be individualized and based on regular reassessment of both benefits and harms.

Sources: American Psychiatric Association, 2007[22] | National Institute for Health and Clinical Excellence, 2006[6] | Registered Nurses' Association of Ontario, 2016[24] | Sistema Nacional de Salud, 2010[25]

What This Quality Statement Means

For People Living With Dementia

You, your caregivers, and your health care team should create a care plan together that reflects your needs, concerns, and preferences. A care plan is a written document that describes your goals, the care and support services you should receive, and who will provide them. It should be updated regularly, especially if there is a change in your health or situation.

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.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Individualized care plan

This is a plan 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.[6] Developed and reviewed with the person living with dementia and their caregiver, the care plan should be flexible to accommodate changes in the person's health status, function, and abilities. The plan should include the following components:

- The results of the comprehensive assessment (see Quality Statement 1)
- The person's individual needs, preferences, and goals of care, and those of their caregiver
- 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

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 is reviewed annually

- 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 annually
- Data source: local data collection

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Individualized care plan (continued)

- 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 includes the capable person living with dementia confirming a future substitute decision-maker (see Terminology Used in This Quality Standard 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 themself (for more information on advance care planning, please refer to Health Quality Ontario's quality standard on palliative care: *Palliative Care: Care for Adults With a Progressive, Life-Limiting Illness*)
- At least one named point of contact on the care team—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.

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 for people living with dementia and their caregivers to navigate the health system and know whom 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 living with dementia's primary care team
- Is involved in the care of the person living with dementia and understands their current needs and care goals, as well as those of their caregiver
- 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.[26]

Source: Advisory committee consensus

What This Quality Statement Means

For People Living With Dementia and Their Caregivers

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

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

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).

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 on their caregivers 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.

Sources: American Psychiatric Association, 2007[22] | European Federation of Neurological Societies and European Neurological Society, 2012[23] | National Institute for Health and Clinical Excellence, 2006[6] | Registered Nurses' Association of Ontario, 2016[24] | Sistema Nacional de Salud, 2010[25]

What This Quality Statement Means

For People Living With Dementia and Their Caregivers

Your health care team should provide you and your caregivers with education and training about living with dementia. Your care team can also connect you with groups or organizations in the community who offer education and support. This education will help you understand dementia and how it progresses, your treatment options, and the supports available.

For Clinicians

Offer education and training to people living with dementia and their caregivers. This should align with the person's stage of dementia and their current needs.

For Health Services

Ensure that providers and teams are able to offer education and training on dementia and available support services to people living with dementia and their caregivers.

Quality Indicators

Process Indicators

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

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 for both people living with dementia and for their caregivers
- 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
- Functions of different providers and health care settings
- Medical-legal issues, including driving

PROCESS INDICATORS CONTINUED

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

Structural Indicator

Local availability of education and training on dementia for people living with dementia and their caregivers

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Education and training (continued)

- 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.

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[22] | National Institute for Health and Clinical Excellence, 2006[6] | Registered Nurses' Association of Ontario, 2016[24] | Sistema Nacional de Salud, 2010[25]

What This Quality Statement Means

For People Living With Dementia and Their Caregivers

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 role and responsibilities.

For Health Services

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

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Education and training

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

- Comprehensive assessment of people living with dementia and an assessment of caregivers' needs
- Dementia signs, symptoms, and disease progression
- Specific subtypes of dementia
- Approaches to diagnostic uncertainty in persons with complex conditions
- Person-centred care
- Development of care plans that meet the goals, preferences, values, and cultural expectations of care of people living with dementia and their caregivers
- 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

Quality Indicators

Process Indicator

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

- Denominator: number of health care 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

Local availability of health care providers who have received education and training in dementia care

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Education and training (continued)

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

7

Access to Support Services

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

Background

People living 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 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.[25,30] They need access to the right services, at the right time, and in the right place to help them in their journey.

Sources: American Psychiatric Association, 2007[22] | National Institute for Health and Clinical Excellence, 2006[6] | Sistema Nacional de Salud, 2010[25]

What This Quality Statement Means

For People Living With Dementia and Their Caregivers

Your health care professional 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 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 individualized support services

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

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Support services

These are 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 preferences and tailored to their changing physical, psychological, and social needs. Support services include:

- Health professional 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)

PROCESS INDICATORS CONTINUED

Percentage of caregivers of people living with dementia who have access to individualized support services

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

Percentage of people living with dementia who have received support services that met their needs

- Denominator: number of people living with dementia
- Numerator: number of people in the denominator who have received support services that met their needs
- Data source: local data collection

Percentage of caregivers of people living with dementia who have received support services that met their needs

- Denominator: number of caregivers of people living with dementia
- Numerator: number of people in the denominator who have received support services that met their needs
- Data source: local data collection

Structural Indicator

Local availability of support services for people living with dementia and their caregivers

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Support services (continued)

- 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.

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.[14,15,31-34] 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).[31-36] 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.[6,24] Supports such as transportation or respite care services should be provided for caregivers to enable them to participate in services or activities.[6]

Sources: National Institute for Health and Clinical Excellence, 2006[6] | Sistema Nacional de Salud, 2010[25]

What This Quality Statement Means

For Caregivers

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 provider to see how you are coping and to help you get the supports you need to help you with your caregiving responsibilities. Supports can include training, support groups, home care, and temporary respite care for the person you are caring for. Respite care can give you a break from the caregiving routine and give you time to take care of yourself.

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.

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

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

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

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Supports (continued)

- 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 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.

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 people's ability to interact with and make sense of their environment. Environments that are familiar, home-like, and easy to understand are important.[37]

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.[6] 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 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 a long-term care home.

BACKGROUND CONTINUED

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[6]

What This Quality Statement Means

For People Living 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

Ensure connection with service providers who can help ensure that 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 a make people's living environments safe and to address individual needs. This includes appropriate design modifications and housing options offering more supported living environments.

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 their community and that 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). 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[6,37]:

- Lighting
- Surfaces to minimize reflections and glare
- Floor coverings
- Colour schemes and contrasts

Quality Indicators

Process Indicator

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

- Denominator: number of people living with dementia in the community
- Numerator: number of people in the denominator who reside in a safe living environment that meets their specific needs
- Data source: local data collection

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Design modifications (continued)

- 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[6,37]:

- 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

10

Access to Primary Care

People living 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.

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,[38] 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.[39] 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.[38-41]

BACKGROUND CONTINUED

To address these challenges, people living with dementia or mild cognitive impairment and their caregivers need timely 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[42,43]
- 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 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.

Source: Advisory committee consensus

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, provide care, and link you and your caregivers to other health care providers and support services that meet your changing needs and goals.

For Clinicians

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

For Health Services

Ensure that people living with dementia have 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: Ontario Health Insurance Plan (OHIP) Claims Database or local data collection

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.

Effective primary care

Primary care is the person's first contact with the health system. It is effective when it[42,43]:

- 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

PROCESS INDICATORS CONTINUED

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: Ontario Health Insurance Plan (OHIP) claims database or local data collection

Acknowledgements

Advisory Committee

Health Quality Ontario thanks the following individuals for their generous, voluntary contributions of time and expertise to help create this quality standard:

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

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

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

Nirmala Bowman
Lived Experience Advisor

Beryl Cable-Williams
Lived Experience Advisor

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

Phyllis Fehr
Lived Experience Advisor

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

Carol Holmes-Kerr
Lived Experience Advisor

Kelly Kay
Executive Director, Seniors Care Network

Donna Kearney
Nurse Practitioner, Cottage Country Family Health Team–Muskoka

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

Sandy Linseman
Pharmacist, Grand River Hospital Corporation

Carrie McAiney
Associate Professor, McMaster University

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

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

Rakhi Mistry
Care Coordinator, Mississauga Halton Community Care Access Centre

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

Craig O'Brien
Nurse Practitioner, Lakelands Family Health Team

ADVISORY COMMITTEE CONTINUED

Dawn Robinson
Psychogeriatric Resource Consultant,
Alzheimer Society of Peel

Dallas Seitz
Geriatric Psychiatrist,
Providence Care, Assistant
Professor, Queen's University

Deana Stephen
Community Support
Services—System Navigation,
Canadian Red Cross

Carmela Tartaglia
Neurologist,
Toronto Western Hospital

Natalie Warrick
Senior Research Associate,
Dementia Capacity Planning
Team, Ontario Renal Network,
Cancer Care Ontario

Julie Wheeler
Manager, Community Programs,
Region of Waterloo

References

1. Ontario Palliative Care Network. Key palliative care concepts and terms [Internet]. Toronto (ON): Ontario Palliative Care Network; 2017 [updated 2017; cited 2017 Oct 23]. Available from: www.ontariopalliativecarenetwork.ca

2. Health Care Consent Act [Internet]. Toronto (ON): Government of Ontario; 1996 [updated 1996; cited 2017 Oct 23]. Available from: www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm

3. Substitute Decisions Act [Internet]. Toronto (ON): Government of Ontario; 1992 [updated 1992; cited 2017 Nov 29]. Available from: https://www.ontario.ca/laws/statute/92s30

4. Alzheimer Society of Canada. Rising tide: the impact of dementia on Canadian society [Internet]. Toronto (ON): The Society; 2010 [cited 2017 April]. Available from: http://www.alzheimer.ca/en/Get-involved/Raise-your-voice/Latest-info-stats/Rising-Tide

5. Standing Senate Committee on Social Affairs, Science and Technology. Dementia in Canada: a national strategy for dementia-friendly communities [Internet]. Ottawa (ON): Senate of Canada; 2016 [cited 2017 Mar]. Available from: https://sencanada.ca/content/sen/committee/421/SOCI/Reports/SOCI_6thReport_DementiaInCanada-WEB_e.pdf

6. National Institute for Health and Clinical Excellence, Social Care Institute for Excellence. Dementia: supporting people with dementia and their carers in health and social care [Internet]. London (UK): British Psychological Society and Gaskell; 2006 [cited 2017 Feb]. Available from: http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf

7. Alzheimer Society of Canada. Mild cognitive impairment [Internet]. 2016 [cited 2017 Jun]. Available from: http://www.alzheimer.ca/on/~/media/Files/national/Other-dementias/other_dementias_MCI_e.pdf

8. Mental Health Commission of Canada. Turning the key. Assessing housing and related supports for persons living with mental health problems and illness. Ottawa (ON): The Commission; 2012.

9. Alzheimer Society of Canada. Dementia numbers in Canada [Internet]. Toronto (ON): The Society; 2016 [updated 2015 Apr 6; cited 2017 Mar]. Available from: http://www.alzheimer.ca/en/About-dementia/What-is-dementia/Dementia-numbers

10. World Health Organization. Dementia: a public health priority [Internet]. Geneva, Switzerland: The Organization; 2012 [cited 2017 April]. Available from: http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf

11. Ng R, Maxwell CJ, Yates EA, Nylen K, Antflick J, Jetté N, et al. Brain disorders in Ontario: prevalence, incidence and costs from health administrative data [Internet]. Toronto (ON): Institute for Clinical Evaluative Sciences; 2015 [cited 2017 Mar]. Available from: http://www.ices.on.ca/~/media/Files/Atlases-Reports/2015/Brain-Disorders-in-Ontario/Full-Report.ashx

12. Batsch NL, Mittelman MS. World Alzheimer report 2012. Overcoming the stigma of dementia. London, UK: Alzheimer's Disease International; 2012.

13. National Institute for Health and Clinical Excellence. Dementia: independence and wellbeing [Internet]. London (UK): The Institute; 2013 [cited 2017 Mar]. Available from: https://www.nice.org.uk/guidance/qs30

14. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. Int J Geriatr Psychiatry. 2002;17(2):184-8.

15. Smale B, Dupuis SL, for the Ontario Dementia Caregiver Needs Project. In their own voices: a profile of dementia caregivers in Ontario. Stage 1: survey results. Waterloo (ON): Murray Alzheimer Research and Education Program; 2004.

16. Alzheimer Society of Ontario. A profile of Ontario's home care clients with Alzheimer's disease or other dementias. Toronto (ON): The Society; 2005.

17. Health Quality Ontario. The reality of caring: distress among the caregivers of home care patients [Internet]. Toronto (ON): Queen's Printer for Ontario; 2016 [cited 2017 Mar]. Available from: http://www.hqontario.ca/Portals/0/documents/system-performance/reality-caring-report-en.pdf

18. Dementia Capacity Planning Project – CCO. Analysis for Dementia Capacity Planning Clinical Advisory Committee. 2017.

19. Dementia Alliance International. The human rights of people living with dementia: from rhetoric to reality [Internet]. Ankeny (IA): The Alliance; 2016 [cited 2017 July]. Available from: https://www.dementiaallianceinternational.org/wp-content/uploads/2016/05/Human-Rights-for-People-Living-with-Dementia-Rhetoric-to-Reality.pdf

20. Prince M, Bryce R, Ferri CP. World Alzheimer report 2011: the benefits of early diagnosis and intervention [Internet]. London, UK: Alzheimer's Disease International; 2011 [cited 2017 Mar]. Available from: https://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf

21. Gauthier S, Patterson C, Chertkow H, Gordon M, Herrmann N, Rockwood K, et al. Recommendations of the 4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD4). Can Geriatr J. 2012;15(4):120-6.

22. Working Group on Alzheimer's Disease and Other Dementias. Practice guideline for the treatment of patients with Alzheimer's disease and other dementias [Internet]. Arlington (VA): American Psychiatric Association Publishing; 2007 [cited 2017 Feb]. Available from: http://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/alzheimers.pdf

23. Sorbi S, Hort J, Erkinjuntti T, Fladby T, Gainotti G, Gurvit H, et al. EFNS-ENS guidelines on the diagnosis and management of disorders associated with dementia. Eur J Neurol. 2012;19(9):1159-79.

24. Registered Nurses' Association of Ontario. Delirium, dementia, and depression in older adults: assessment and care. Toronto (ON): The Association; 2016.

25. Development Group of the Clinical Practice Guideline on the Comprehensive Care of People With Alzheimer's Disease and Other Dementias. Clinical practice guideline on the comprehensive care of people with Alzheimer's disease and other dementias [Internet]. Madrid, Spain: Spanish Ministry of Science and Innovation; 2010 [cited 2017 Feb]. Available from: http://www.guiasalud.es/GPC/GPC_484_Alzheimer_AIAQS_comp_eng.pdf

26. American Geriatrics Society Expert Panel on Person-Centered Care. Person-centered care: a definition and essential elements. J Am Geriatr Soc. 2016;64(1):15-8.

27. Kanagaratnam L, Drame M, Trenque T, Oubaya N, Nazeyrollas P, Novella JL, et al. Adverse drug reactions in elderly patients with cognitive disorders: a systematic review. Maturitas. 2016;85:56-63.

28. Lee L, Rojas-Fernandez C, Heckman G, Gagnon M. Cognitive enhancing drugs in dementia: tips for the primary care physician. Can Geriatr Soc J CME. 2011;1(1):5-9.

29. Lee L, Patel T, Molnar F, Seitz D. Optimizing medications in cognitively-impaired older adults: considerations for primary care clinicians. Can Fam Physician. Forthcoming 2018.

30. Dawson A, Bowes A, Kelly F, Velzke K, Ward R. Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. BMC Geriatr. 2015;15:59.

31. Wolfs CA, Kessels A, Severens JL, Brouwer W, de Vugt ME, Verhey FR, et al. Predictive factors for the objective burden of informal care in people with dementia: a systematic review. Alzheimer Dis Assoc Disord. 2012;26(3):197-204.

32. Pinquart M, Sorensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. J Gerontol B Psychol Sci Soc Sci. 2003;58(2):P112-28.

33. Brodaty H, Donkin M. Family caregivers of people with dementia. Dialogues Clin Neurosci. 2009;11(2):217-28.

34. Sorensen S, Conwell Y. Issues in dementia caregiving: effects on mental and physical health, intervention strategies, and research needs. Am J Geriatr Psychiatry. 2011;19(6):491-6.

35. Mahoney R, Regan C, Katona C, Livingston G. Anxiety and depression in family caregivers of people with Alzheimer disease: the LASER-AD study. Am J Geriatr Psychiatry. 2005;13(9):795-801.

36. Schulz R, Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. Am J Geriatr Psychiatry. 2004;12(3):240-9.

37. Canadian Mortgage and Housing Corporation. Housing options for people living with dementia [Internet]. Ottawa (ON): The Corporation; 2015 [cited 2017 Mar]. Available from: https://www.cmhc-schl.gc.ca/odpub/pdf/60967.pdf?fr=1421178129190

38. Gill SS, Camacho X, Poss JW. Community-dwelling older adults with dementia: tracking encounters with the health system In: Bronskill SE, Camacho X, Gruneir A, Ho MM, editors. Health system use by frail Ontario seniors: an in-depth examination of four vulnerable cohorts. Toronto (ON): Institute for Clinical Evaluative Sciences; 2011. p. 47-69.

39. Phelan EA, Borson S, Grothaus L, Balch S, Larson EB. Association of incident dementia with hospitalizations. JAMA. 2012;307(2):165-72.

40. Elliott RA, Goeman D, Beanland C, Koch S. Ability of older people with dementia or cognitive impairment to manage medicine regimens: a narrative review. Curr Clin Pharmacol. 2015;10(3):213-21.

41. Jankowska-Polanska B, Katarzyna L, Lidia A, Joanna J, Dudek K, Izabella U. Cognitive function and adherence to anticoagulation treatment in patients with atrial fibrillation. J Geriatr Cardiol. 2016;13(7):559-65.

42. World Health Organization, editor. Proceedings of the Declaration of Alma-Ata: International Conference on Primary Health Care; 1978 Sep 6-12; USSR. Geneva, Switzerland: The Organization; 1978.

43. Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. Milbank Q. 2005;83(3):457-502.

About Health Quality Ontario

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by this 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 voice 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.

Notes

Notes

Notes

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

ISBN 978-1-4868-1413-8 (Print)
ISBN 978-1-4868-1423-7 (PDF)

Ontario
Health Quality Ontario