QUALITY STANDARDS

Behavioural Symptoms of Dementia

Care for People in Hospitals and Long-Term Care Homes

2024 UPDATE



Scope of This Quality Standard

This quality standard focuses on care for people with dementia and the specific behaviours of agitation or aggression who are in an emergency department, admitted to a hospital, or in a long-term care home. It also provides guidance on the care given when a person is transitioned between these settings; for example, when someone is discharged from a hospital to a long-term care home.

For a quality standard that addresses care for people with dementia in the community, refer to Dementia: Care for People Living in the Community.¹

What Is a Quality Standard?

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

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

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

For more information, contact QualityStandards@OntarioHealth.ca.

Quality Statements to Improve Care: Summary

These quality statements describe what high-quality care looks like for people with dementia and the specific behaviours of agitation and aggression.

Quality Statement 1: Comprehensive Assessment

People with dementia and symptoms of agitation or aggression receive a comprehensive interprofessional assessment when symptoms are first identified and after each transition in care.

Quality Statement 2: Individualized Care Plan

People with dementia and symptoms of agitation or aggression have an individualized care plan that is developed, implemented, and reviewed on a regular basis with care partners and agreed upon by substitute decision-makers. Ongoing review and update of care plans includes documentation of behavioural symptoms and the person's responses to interventions.

Quality Statement 3: Individualized Nonpharmacological Interventions

People with dementia and symptoms of agitation or aggression receive nonpharmacological interventions that are tailored to their specific needs, symptoms, and preferences, as specified in their individualized care plan.

Quality Statement 4: Indications for Psychotropic Medications

People with dementia are prescribed psychotropic medications to help reduce agitation or aggression only when they pose a risk of harm to themselves or others or are in severe distress.

Quality Statement 5: Titrating and Monitoring Psychotropic Medications

People with dementia who are prescribed psychotropic medications to help reduce agitation or aggression are started on low dosages, with the dosage increased gradually to reach the minimum effective dosage for each patient, within an appropriate range. Target symptoms for the use of the psychotropic medication are monitored and documented.

Quality Statement 6: Switching Psychotropic Medications

People with dementia who are prescribed psychotropic medications to help reduce agitation or aggression have their medication discontinued and an alternative psychotropic medication prescribed if symptoms do not improve after a maximum of 8 weeks. Ineffective medications are discontinued to avoid polypharmacy. The reasons for the changes in medication and the consideration of alternative psychotropic medications are documented.

Quality Statement 7: Medication Review for Dosage Reduction or Discontinuation

People with dementia who are prescribed psychotropic medications to help reduce agitation or aggression receive a documented medication review on a regular basis to consider reducing the dosage or discontinuing the medication.

Quality Statement 8: Physical Restraint

People with dementia are not physically restrained to manage symptoms of agitation or aggression.

Quality Statement 9: Informed Consent

People with dementia and symptoms of agitation or aggression are advised of the risks and benefits of treatment options, and informed consent is obtained and documented before treatment is initiated. If a person with dementia is incapable of consenting to the proposed treatment, informed consent is obtained from their substitute decision-maker.

Quality Statement 10: Specialized Interprofessional Care Team

People with dementia and symptoms of agitation or aggression have access to services from an interprofessional team that provides specialized care for the behavioural and psychological symptoms of dementia.

Quality Statement 11: Education and Training for Clinicians

People with dementia and symptoms of agitation or aggression receive care from clinicians with education and training in the assessment and management of dementia and its behavioural symptoms.

Quality Statement 12: Education and Training for Care Partners

Care partners of people with dementia and symptoms of agitation or aggression have access to comprehensive education and training on dementia and its associated behavioural symptoms. This education and training includes management strategies that are consistent with people's care plans.

Quality Statement 13: Appropriate Care Environment

People with dementia and symptoms of agitation or aggression whose behavioural symptoms have been successfully treated are transitioned to an appropriate care environment as soon as possible.

Quality Statement 14: Transitions in Care

People with dementia and symptoms of agitation or aggression who transition between settings have a health care team or clinician who is accountable for coordination and communication. This team or clinician ensures the transmission of complete and accurate information to the family, care partners, and receiving health care team prior to the transition.

Table of Contents

Scope of This Quality Standard	2
What Is a Quality Standard?	2
Quality Statements to Improve Care: Summary	3
2024 Summary of Updates	6
A Note on Terminology	7
Why This Quality Standard Is Needed	9
Measurement to Support Improvement	9
Quality Statement 1: Comprehensive Assessment	11
Quality Statement 2: Individualized Care Plan	13
Quality Statement 3: Individualized Nonpharmacological Interventions	16
Quality Statement 4: Indications for Psychotropic Medications	18
Quality Statement 5: Titrating and Monitoring Psychotropic Medications	20
Quality Statement 6: Switching Psychotropic Medications	22
Quality Statement 7: Medication Review for Dosage Reduction or Discontinuation	24
Quality Statement 8: Physical Restraint	26
Quality Statement 9: Informed Consent	28
Quality Statement 10: Specialized Interprofessional Care Team	30
Quality Statement 11: Education and Training for Clinicians	32
Quality Statement 12: Education and Training for Care Partners	34
Quality Statement 13: Appropriate Care Environment	37
Quality Statement 14: Transitions in Care	39
Appendix 1: About This Quality Standard	41
Appendix 2: Glossary	43
Appendix 3: Values and Guiding Principles	44
Acknowledgements	46
References	48
About Us	51

2024 Summary of Updates

In 2024, we completed a review of the evidence to capture new or updated clinical practice guidelines and health technology assessments published since the original release of this quality standard in 2016. This update aligns the quality standard with the most recent clinical evidence and with current practice in Ontario. Below is a summary of changes to the overall quality standard:

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

Below is a summary of changes to specific quality statements:

- Quality statement 1: Revised the rationale to include the use of validated instruments
- Quality statement 2: Added a definition for individualized care plan
- Quality statement 3: Revised the rationale to remove dance therapy as a type of nonpharmacological treatment
- Quality statement 4: Revised the rationale to address indications for psychotropic medication
- Quality statement 7: Revised the rationale to add decision to reduce or discontinue medication
- Quality statement 11: Revised the definitions to address de-escalation strategies that promote individuals' freedom of movement
- Quality statement 12: Revised the definitions to address psychoeducation and skills training for care partners and self-care strategies

A Note on Terminology

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

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

Substitute decision-maker: This refers to a person who makes care and treatment decisions on another person's behalf if or when that person becomes mentally incapable of making a decision for themselves.² The substitute decision-maker should be involved in ongoing discussions with the person about their goals of care, wishes, values, and beliefs so that the substitute decision-maker is empowered to participate in the health care consent process, if required. The substitute decision-maker makes decisions based on their understanding of the person's wishes, or, if these are unknown or not applicable, makes choices that are consistent with the person's known values and beliefs and in their best interests.

Ontario's *Health Care Consent Act* outlines a hierarchical list of people who would automatically be considered a substitute decision-maker when a person is incapable of making decisions about their own care.³ 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." 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.²

Capacity or mental capacity: Under Ontario's *Health Care Consent Act*, a person is capable with respect to a health care decision if they have the ability to understand the information that is needed to make a decision and have the ability to appreciate the consequences of the decision or lack of decision.³ Capacity is issue- or task-specific.² 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.³ 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.³

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

Dementia: This is defined as a chronic and progressive decline in cognitive ability that interferes with daily functioning. Signs and symptoms of dementia include changes to memory, reasoning and

judgement, 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.^{5,6}

Behavioural symptoms of dementia: This refers to a range of changing symptoms such as agitation and aggression experienced by many people with dementia as their condition progresses. These symptoms can be attributed to a range of cognitive, psychosocial, environmental, and medical factors. Symptoms can range from mild, moderate, to severe. People with dementia may react to feelings of distress by shouting, pushing, hitting, or throwing objects. The changes may also lead to behaviours such as pacing, fidgeting, and becoming irritable with surroundings. Not everyone with dementia will exhibit symptoms in the same manner.

Why This Quality Standard Is Needed

Dementia is a chronic and progressive decline in cognitive ability that interferes with daily functioning. It can be caused by disease or injury. Dementia affects about 8.4% of Canadians aged 65 years and older. As of 2024, about 733,040 people in Canada are living with dementia.

Signs and symptoms of altered perception, thought, mood, or behaviour may occur in people with dementia; these are known collectively as the behavioural and psychological symptoms of dementia.⁸ Among these symptoms, agitation and aggression are two of the most common, with complex causes that can be biological, social, or psychological. It has been estimated that 80% of people with dementia who are living in long-term care homes display symptoms of aggression at some stage of their dementia.⁹ Both nonpharmacological interventions and pharmacological interventions can be used to manage agitation or aggression in dementia.

Agitation and aggression in dementia pose care and safety issues for people with dementia and for those who care for them. Unlike the cognitive and functional deficits of dementia that decline over time, the episodic nature of agitation and aggression contributes to the complexity of their prevention and management. These symptoms are a major cause of hospitalizations and transfers to long-term care homes. ¹⁰⁻¹² Furthermore, they can cause compassion fatigue in families and care partners of people with dementia, and are challenging for health professionals. ^{13,14}

There are important gaps in the quality of care received by people with dementia in Ontario. For example, the proportion of long-term care home residents prescribed antipsychotic medication varies widely between homes. ¹⁵ There is also variation between homes in the use of restraints and confinement. ¹⁶ With the incidence and prevalence of dementia growing with Ontario's aging population, there is a need for a provincial quality standard focusing on the care of people with dementia and symptoms of agitation or aggression.

Based on evidence and expert consensus, this quality standard addresses key areas identified as having significant potential for quality improvement in the care of people with dementia and symptoms of agitation or aggression in Ontario. The 14 quality statements that make up this standard each provide guidance on high-quality care, with accompanying indicators to help clinicians and organizations measure their quality of care. Each statement also includes details on how its successful delivery impacts people with dementia, their care partners, clinicians, and health care services at large.

Measurement to Support Improvement

The Behavioural Symptoms of Dementia Quality Standard Advisory Committee identified 6 indicators to monitor the progress being made toward improving care for people with dementia and the specific behaviours of agitation or aggression in Ontario.

Indicators That Can Be Measured Using Provincial Data

- Percentage of people in long-term care homes with dementia and symptoms of agitation or aggression who experience fewer or less frequent behavioural symptoms
- Percentage of people in complex continuing care with dementia and symptoms of agitation or aggression who experience fewer or less frequent behavioural symptoms
- Percentage of people in inpatient mental health beds with dementia and symptoms of agitation or aggression who experience fewer or less frequent behavioural symptoms
- Percentage of people with dementia and symptoms of agitation or aggression who are admitted to mental health beds in hospital under the Mental Health Act (Form 1)
- Percentage of people with dementia who are readmitted to hospital within 30 days of hospital discharge
- Rate of emergency department use by people with dementia, per 1,000 emergency department visits

Indicators That Can Be Measured Using Only Local Data

- Number of incidents in hospitals and long-term care homes related to symptoms of aggression in dementia: patient-on-patient or patient-on-staff incidents
- Percentage of long-term care home placement applications that are rejected by a long-term care home owing to an inability to meet client care needs

Quality Statement 1: Comprehensive Assessment

People with dementia and symptoms of agitation or aggression receive a comprehensive interprofessional assessment when symptoms are first identified and after each transition in care.

Sources: American Psychiatric Association, 2007¹⁷ | American Psychiatric Association, 2016¹⁸ | Canadian Coalition for Seniors' Mental Health, 2006¹⁹ | Canadian Consensus Conference on the Diagnosis and Treatment of Dementia, 2020²⁰ | National Institute for Health and Care Excellence, 2018²¹ | Scottish Intercollegiate Guidelines Network, 2023²² | Sistema Nacional de Salud, 2010²³

Definitions

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

- Physical health assessment (e.g., blood and urine tests), medical history, and medication review
- Cognitive and functional assessments offered in multiple languages and cultural contexts
- Psychiatric and behavioural assessments for other conditions (e.g., depression, suicidality, danger to self and others, potential for aggression)
- Psychosocial assessment (e.g., for abuse or neglect, inadequate supervision, poor communication, interpersonal conflict, lack of engagement or activities, personal social history)
- Physical environment assessment (e.g., for overcrowding, lack of privacy)
- Investigation and treatment of potential contributing factors to symptoms of agitation or aggression (e.g., pain, discomfort, delirium)

Interprofessional care team: At least 1 physician and 1 other regulated professional who specialize in dementia care are included on the team. Other regulated and unregulated health professionals on the team may include psychologists, occupational therapists, pharmacists, behavioural support workers, social workers, care partners, administrative staff, personal support workers, speech-language pathologists, physiotherapists, geriatricians, dietitians, and recreational staff.

Rationale

A comprehensive assessment ensures an accurate diagnosis and the collection of baseline information. The assessment allows for the identification of potential underlying conditions or issues

(e.g., physical, cognitive, functional, psychiatric, psychosocial, and environmental factors) that may be causes of behavioural and psychological symptoms, and thus informs care for people with dementia with symptoms of agitation or aggression. Clinicians should use a standardized assessment tool to gather information on the type, frequency, severity, pattern, and timing of dementia symptoms. The patient, family/care partner, or substitute decision-maker should be included in the assessment process. The assessment also provides the opportunity to establish likely factors (or "triggers") that may contribute to future occurrences of agitation or aggression. Comprehensive assessments should be performed at a person's initial presentation to a health care setting as well as at transitions between care settings.

What This Quality Statement Means

For People With Dementia

You should receive an examination and full assessment every time you arrive at or leave a hospital or long-term care home. An assessment means that your care team will want to learn more about you to understand how best to help you. It should include questions about your physical health, your medical history, what medications you are taking, how you spend your time, and how you are feeling.

For Clinicians

Perform a standardized, comprehensive assessment when people present to a hospital or long-term care home, or when they transition to another care setting.

For Organizations and Health Services Planners

Ensure hospitals and long-term care homes have comprehensive assessment tools, systems, processes, and resources in place to assess people at presentation and discharge.

Quality Indicator: How to Measure Improvement for This Statement

 Percentage of people with dementia and symptoms of agitation or aggression who receive a comprehensive assessment at first presentation or after a transition in care

Measurement details for this indicator, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u>.

Quality Statement 2: Individualized Care Plan

People with dementia and symptoms of agitation or aggression have an individualized care plan that is developed, implemented, and reviewed on a regular basis with care partners and agreed upon by substitute decision-makers. Ongoing review and update of care plans includes documentation of behavioural symptoms and the person's responses to interventions.

Sources: American Psychiatric Association, 2007¹⁷ | American Psychiatric Association, 2016¹⁸ | Canadian Coalition for Seniors' Mental Health, 2006¹⁹ | National Institute for Health and Care Excellence, 2018²¹ | Scottish Intercollegiate Guidelines Network, 2023²² | Sistema Nacional de Salud, 2010²³

Definitions

Individualized care plan: This is a plan based on an assessment of the life history, social, cultural, and family circumstances, and preferences and needs of the person with dementia. It is also based on their physical and mental health needs and current level of functioning and abilities. Developed and reviewed with the person with dementia and their care partners and substitute decision-maker, the care plan should be flexible to accommodate changes in the person's health status, function, and abilities. The care plan should be coordinated across all services the person with dementia is receiving and across all health care settings. Ensure that the people with dementia, their families, and their care partners feel safe and respected, and their individual goals of care are considered in the plan. Consider providing information about the individualized care plan in multiple languages and literacy levels.

Reviewed on a regular basis: The care plan is reviewed at least once a month in a hospital inpatient setting and every 3 months in a long-term care setting, or sooner according to clinical need.

Care partners: These are paid or unpaid people who help a family member, friend, or another person in need of assistance or support with daily living. In the case of a person with dementia, a care partner may or may not also be the person's substitute decision-maker.

Rationale

An individualized care plan is essential to coordinate, document, and ultimately guide the care of people with dementia and symptoms of agitation or aggression. The care plan is agreed upon by the health care team and care partners to ensure consistent and coordinated delivery of care that considers the changing needs of people with dementia. Ongoing review of the care plan supports the tracking of behavioural triggers and symptoms and allows for the assessment of treatment responses to interventions.

What This Quality Statement Means

For People With Dementia

A care plan should be created to meet your individual needs. A care plan is a written document that describes the care you receive, who provides it, and what medications you are on. It is based on your full assessment.

For Clinicians

Work with people with dementia, their care partners, and substitute decision-makers to create an individualized care plan that documents behavioural symptoms and responses to interventions. For people in hospital inpatient settings, review and update care plans at least once each month. For people in long-term care homes, review and update care plans at least once every 3 months. Also update care plans every time there is a significant change in people's health or care arrangements.

For Organizations and Health Services Planners

Ensure that hospitals and long-term care homes have standardized templates for developing care plans for people with dementia. Ensure there are systems, processes, and resources in place to create and regularly update care plans.

Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with dementia and symptoms of agitation or aggression who have an individualized care plan
- Percentage of people with dementia and symptoms of agitation or aggression who have an individualized care plan that has been implemented
- Percentage of people with dementia and symptoms of agitation or aggression who have an individualized care plan that has been reviewed on a regular basis
- Availability of an electronic system that captures information about individualized care plans, including the plan itself and care associated with the plan

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u> .	

Quality Statement 3: Individualized Nonpharmacological Interventions

People with dementia and symptoms of agitation or aggression receive nonpharmacological interventions that are tailored to their specific needs, symptoms, and preferences, as specified in their individualized care plan.

Sources: American Psychiatric Association, 2007¹⁷ | Canadian Coalition for Seniors' Mental Health, 2006¹⁹ | National Institute for Health and Care Excellence, 2018²¹ | Scottish Intercollegiate Guidelines Network, 2023²² | Sistema Nacional de Salud, 2010²³

Definition

Nonpharmacological interventions: Effective nonpharmacological interventions may include the following:

- Aromatherapy
- Multisensory therapy
- Music therapy
- Pet-assisted therapy
- Massage therapy
- Reminiscence therapy
- Recreational activities
- Physical activity

This list is not intended to be exhaustive. Other nonpharmacological interventions may also be effective for some individuals.

Rationale

There are a variety of nonpharmacological interventions that can be effective in managing symptoms of agitation or aggression in people with dementia. Treatment approaches should include a combination of nonpharmacological interventions that are individualized based on the person's needs, symptoms, preferences, and history. Nonpharmacological interventions may be oriented to the senses (e.g., aromatherapy, multisensory therapy) or cognition (e.g., reminiscence therapy) and should have demonstrated effectiveness in improving behavioural and psychological symptoms of

dementia. Recreational activities and exercise may also improve a person's ability to function and their quality of life.

What This Quality Statement Means

For People With Dementia

Your clinician should offer nondrug treatments first. These are treatments that do not involve taking medication. Nondrug treatments include different types of therapies and activities to help you deal with your symptoms. Your clinician should offer different options to help you decide which nondrug treatment is best for you.

For Clinicians

Before considering drug therapies, offer people at least 3 nonpharmacological interventions for managing their symptoms. Tailor nonpharmacological therapies to people's needs, symptoms, preferences, and history, as documented in their individualized care plan.

For Organizations and Health Services Planners

Ensure that hospitals and long-term care homes have the systems, processes, and resources in place to offer a variety of nonpharmacological interventions.

Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with dementia and symptoms of agitation or aggression who are offered nonpharmacological interventions
- Percentage of people with dementia and symptoms of agitation or aggression who receive nonpharmacological interventions as specified in their individualized care plan
- Availability of 3 or more evidence-based nonpharmacological interventions to manage the symptoms of agitation and aggression in people with dementia

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u>.

Quality Statement 4: Indications for Psychotropic Medications

People with dementia are prescribed psychotropic medications to help reduce agitation or aggression only when they pose a risk of harm to themselves or others or are in severe distress.

Sources: American Psychiatric Association, 2007¹⁷ | American Psychiatric Association, 2016¹⁸ | Canadian Coalition for Seniors' Mental Health, 2006¹⁹ | European Academy of Neurology, 2020²⁴ | National Institute for Health and Care Excellence, 2018²¹ | Sistema Nacional de Salud, 2010²³

Definition

Psychotropic medications: These categories of psychotropic medications are typically used for reducing symptoms of agitation and aggression in people with dementia:

- Antipsychotics
- Antidepressants
- Mood stabilizers
- Benzodiazepines
- Other hypnotics

Rationale

Because of their potential for adverse events, psychotropic medications should not be considered first-line therapy for people with dementia. In particular, the use of antipsychotics is cautioned for people with dementia as it is associated with an increased risk of serious adverse events, such as worsening cognition, parkinsonism, diabetes, sedation, cerebrovascular disease, and premature death. Psychotropic medications should be used only when a person with dementia poses a risk of severely harming themselves or others, or if they are experiencing agitation, hallucinations, or delusions that cause them severe distress. Nonpharmacological interventions should be considered first-line therapy for people with dementia.

What This Quality Statement Means

For People With Dementia

Medication to reduce agitation or aggression should be used only if you are in severe distress or if there is a concern you might harm yourself or someone else. You may choose to continue other nondrug treatments and activities while taking medication.

For Clinicians

Only prescribe psychotropic medications to reduce agitation or aggression in people with dementia when they pose a risk of harm to themselves or others or are in severe distress. If psychotropic medications are prescribed, provide information to people and their care partners about the risks and side effects of the medication, the rationale for prescribing it, and the plan for reviewing and reducing or discontinuing its use. Continue to offer nonpharmacological interventions to manage people's symptoms while they are taking psychotropic medications and after they have discontinued their use.

For Organizations and Health Services Planners

Ensure that hospitals and long-term care homes have systems, processes, and resources in place to document the rationale, plan for review, and provide information to people with dementia and their care partners when psychotropic medications are prescribed.

Quality Indicator: How to Measure Improvement for This Statement

Percentage of people with dementia and symptoms of agitation or aggression who are prescribed
a psychotropic medication typically used to reduce distress, without clear documentation that
they are in severe distress or pose a risk of harm to themselves or others

Measurement details for this indicator, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u>.

Quality Statement 5: Titrating and Monitoring Psychotropic Medications

People with dementia who are prescribed psychotropic medications to help reduce agitation or aggression are started on low dosages, with the dosage increased gradually to reach the minimum effective dosage for each patient, within an appropriate range. Target symptoms for the use of the psychotropic medication are monitored and documented.

Sources: American Psychiatric Association, 2007^{17} | American Psychiatric Association, 2016^{18} | National Institute for Health and Care Excellence, 2018^{21} | Sistema Nacional de Salud, 2010^{23}

Definition

Psychotropic medications: These categories of psychotropic medications are typically used for reducing symptoms of agitation and aggression in people with dementia:

- Antipsychotics
- Antidepressants
- Mood stabilizers
- Benzodiazepines
- Other hypnotics

Rationale

People with dementia are usually elderly, often have comorbid conditions, and may be at increased risk for adverse effects from pharmacological agents. To reduce the risk of adverse events, initial low dosages of medications are suggested, with slow titration to reach the optimal tolerated therapeutic dosage. Frequency of monitoring is dependent on individual factors including symptoms, the onset of action, and risks associated with the medications provided. To learn more about safety considerations when taking medication, refer to the quality standard *Medication Safety: Care in All Settings*.²⁵

What This Quality Statement Means

For People With Dementia

If you are taking medication, it should be started at a low dosage and gradually increased until your symptoms improve.

For Clinicians

When prescribing psychotropic medication, start with a low dosage and gradually increase it to reach the minimum effective dosage for the person, within an appropriate range. Regularly monitor and document the person's target symptoms.

For Organizations and Health Services Planners

Ensure there are systems, processes, and resources in place in hospitals and long-term care homes for appropriately introducing and adjusting the use of psychotropic medications and monitoring people's target symptoms.

Quality Indicator: How to Measure Improvement for This Statement

 Percentage of people with dementia and symptoms of agitation or aggression receiving psychotropic medications who have their target symptoms monitored and documented

Measurement details for this indicator, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u>.

Quality Statement 6: Switching Psychotropic Medications

People with dementia who are prescribed psychotropic medications to help reduce agitation or aggression have their medication discontinued and an alternative psychotropic medication prescribed if symptoms do not improve after a maximum of 8 weeks. Ineffective medications are discontinued to avoid polypharmacy. The reasons for the changes in medication and the consideration of alternative psychotropic medications are documented.

Source: Expert consensus

Definition

Psychotropic medications: These categories of psychotropic medications are typically used for reducing symptoms of agitation and aggression in people with dementia:

- Antipsychotics
- Antidepressants
- Mood stabilizers
- Benzodiazepines
- Other hypnotics

Rationale

Psychotropic medications should be switched after a maximum of 8 weeks for people with dementia and symptoms of agitation or aggression if there has been no clinical improvement in the target behavioural symptoms. An alternative type or class of medication may be considered for trial instead. The medications should not be combined in an attempt to improve effectiveness, except in very special circumstances such as augmentation for a partial drug response. Multiple medications can lead to issues of polypharmacy and the increased likelihood of drug—drug interactions and adverse events.

What This Quality Statement Means

For People With Dementia

Your health care team should help you find the right medication to fit your needs. They should monitor any changes you experience after using the medication to see if there are any improvements. The medication should be stopped if your symptoms do not improve after 8 weeks.

For Clinicians

When people with dementia are taking psychotropic medications to treat agitation or aggression, switch them to an alternative psychotropic medication if their symptoms do not improve after a maximum of 8 weeks. Discontinue ineffective medications before switching to avoid polypharmacy. Document your reasons for the change in medication and considerations of alternative psychotropic medications.

For Organizations and Health Services Planners

Ensure there are systems, processes, and resources in place in hospitals and long-term care homes for switching psychotropic medications in people who do not respond after 8 weeks, and for documenting the reasons for the change in medications as well as consideration of alternative medications.

Quality Indicator: How to Measure Improvement for This Statement

 Percentage of people with dementia and symptoms of agitation or aggression receiving psychotropic medications who have their psychotropic medication discontinued and are switched to an alternative psychotropic medication if symptoms have not improved after 8 weeks

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

Quality Statement 7: Medication Review for Dosage Reduction or Discontinuation

People with dementia who are prescribed psychotropic medications to help reduce agitation or aggression receive a documented medication review on a regular basis to consider reducing the dosage or discontinuing the medication.

Sources: American Psychiatric Association, 2007^{17} | American Psychiatric Association, 2016^{18} | Canadian Coalition for Seniors' Mental Health, 2006^{19} | Canadian Consensus Conference on the Diagnosis and Treatment of Dementia, 2020^{20} | European Academy of Neurology, 2020^{24} | National Institute for Health and Care Excellence, 2018^{21} | Scottish Intercollegiate Guidelines Network, 2023^{22} | Sistema Nacional de Salud, 2010^{23}

Definitions

Psychotropic medications: These categories of psychotropic medications are typically used for reducing symptoms of agitation and aggression in people with dementia:

- Antipsychotics
- Antidepressants
- Mood stabilizers
- Benzodiazepines
- Other hypnotics

Medication review: This is performed at least once a month in a hospital inpatient setting or every 3 months in a long-term care setting, or sooner according to clinical need. To learn more about safety considerations when taking medication, refer to the quality standard <u>Medication Safety: Care in All Settings</u>.²⁵

Rationale

Evidence for the effectiveness of psychotropic medications to treat behavioural symptoms in dementia is usually based on short-term trials (e.g., 12–20 weeks long); the benefit of long-term (i.e., maintenance) medication therapy is unclear. Because of the risk of severe adverse events from antipsychotic medications, people with dementia and symptoms of agitation or aggression who are prescribed psychotropic medications should be considered for regular dosage reductions or medication discontinuation by an interprofessional team once the behavioural symptoms have stabilized or when there are no clear beneficial responses. The decision to reduce or discontinue

medication should be made after a discussion with the person with dementia and their care partners, or their substitute decision-maker. It is important to consider the risk for relapse in behavioural symptoms during or after the withdrawal of medication.

What This Quality Statement Means

For People With Dementia

Your clinician should talk with you about your treatment plan, what medications you are taking and why, and whether your medication is working. They should discuss how to prevent or reduce the risk of side effects or errors. Your clinician should regularly review your list of medications with you to see if the dosage can be reduced or if the medications should be stopped altogether.

For Clinicians

If prescribing psychotropic medications to a person with dementia, conduct and document a medication review at least once a month in hospital or every 3 months in long-term care to determine whether the dosage can be reduced or discontinued.

For Organizations and Health Services Planners

Ensure there are systems, processes, and resources in place in hospitals and long-term care homes to conduct regular documented medication reviews for people who are prescribed psychotropic medications. These reviews should occur at least once a month in hospital or every 3 months in long-term care.

Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with dementia and symptoms of agitation or aggression who are on psychotropic medications and who have had a medication review (within the past month in an inpatient setting or within the past 3 months in a long-term care home)
- Percentage of people with dementia and symptoms of agitation or aggression who are on psychotropic medications and who have their psychotropic medications tapered or discontinued during a medication review

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u>.

Quality Statement 8: Physical Restraint

People with dementia are not physically restrained to manage symptoms of agitation or aggression.

Source: Expert consensus

Definition

Physical restraints: These are devices that restrict people's freedom of movement in emergency situations and are attached to, adjacent to, or worn by people involuntarily when they pose an imminent risk of harm to themselves or others. Physical restraints are different from safety restraints – such as bed rails, geri-chairs, or mitts – that are used in nonemergency situations to enhance people's safety, mobility, or quality of life. The intent of the device use determines whether it is a physical restraint or a safety device.

Rationale

Physical restraints are associated with serious injury and increased mortality, and do not provide any clinical benefit for the management of agitation or aggression in people with dementia. Through the proper management of behavioural symptoms, it is possible to avoid the use of physical restraints. Hospitals and long-term care homes should move toward zero use of physical restraints.

What This Quality Statement Means

For People With Dementia

You should not be physically restrained or confined by anyone, including members of your health care team.

For Clinicians

Avoid the use of physical restraints for managing agitation or aggression in people with dementia. Always use alternative strategies.

For Organizations and Health Services Planners

Ensure that hospitals and long-term care homes have systems, processes, and resources in place to support health care teams in achieving zero use of physical restraints for managing agitation or aggression in people with dementia. Examples include appropriate staffing and access to clinicians with specialized training.

Quality Indicator: How to Measure Improvement for This Statement

 Percentage of people with dementia and symptoms of agitation or aggression who are placed in physical restraints for agitation or aggression

Measurement details for this indicator, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u>.

Quality Statement 9: Informed Consent

People with dementia and symptoms of agitation or aggression are advised of the risks and benefits of treatment options, and informed consent is obtained and documented before treatment is initiated. If a person with dementia is incapable of consenting to the proposed treatment, informed consent is obtained from their substitute decision-maker.

Source: National Institute for Health and Care Excellence, 2018²¹

Definition

Incapable: In this context, being incapable is a person's inability to make appropriate decisions. Capacity is always considered with respect to the proposed treatment that requires consent. A person's capacity can fluctuate depending on the proposed treatment and timing. A person can be capable with respect to some proposed treatments, but incapable for others. Similarly, capacity can be present for a proposed treatment at one time but absent at another time.

Rationale

The law requires that clinicians obtain capable, informed, and voluntary consent prior to initiating a treatment, as stated in the *Health Care Consent Act*, 1996.³ In addition, people with dementia may be assessed for decision-making capacity. If it is determined they do not have the capacity to make decisions with respect to the proposed treatment, a legal substitute decision-maker may be appointed; this is outlined in the *Substitute Decisions Act*, 1992.⁴ Treatment may be initiated without consent in the event of an emergency situation, where people with dementia and symptoms of agitation or aggression are at risk of causing serious bodily harm to themselves or others or are experiencing severe suffering. According to legislation, "treatment may be continued only for as long as reasonably necessary" to obtain consent from the substitute decision-maker, or from the person with dementia if they regain the capacity to make their own decision.²⁶ In either case, the clinicians must document justification of the treatment, and the patient's values and wishes must always be considered when making a medical decision.

What This Quality Statement Means

For People With Dementia

No changes should be made to your treatments until you have been given information about their benefits and harms and have agreed to these changes. In very rare circumstances, where

someone is at risk of being hurt, you might be treated first and then provided with information as soon as possible.

For Clinicians

Provide information on and discuss the risks and benefits of different treatment options with patients, their care partners, or substitute decision-makers. Always obtain and document informed consent before initiating or stopping a treatment. If a person is unable to consent, obtain informed consent from their substitute decision-maker.

For Organizations and Health Services Planners

Ensure that all important information on people's capacity to consent and their substitute decision-makers (if applicable) is documented and accessible in hospitals and long-term care homes.

Quality Indicator: How to Measure Improvement for This Statement

 Percentage of people with dementia and symptoms of agitation or aggression receiving a medical treatment whose informed consent (obtained directly or from the substitute decision-maker) is documented prior to the initiation of the treatment

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

Quality Statement 10: Specialized Interprofessional Care Team

People with dementia and symptoms of agitation or aggression have access to services from an interprofessional team that provides specialized care for the behavioural and psychological symptoms of dementia.

Sources: American Psychiatric Association, 2007^{17} | Canadian Coalition for Seniors' Mental Health, 2006^{19} | National Institute for Health and Care Excellence, 2018^{21} | Sistema Nacional de Salud, 2010^{23}

Definition

Specialized interprofessional care team: At least 1 physician and 1 other regulated professional who specialize in dementia care are included on the team. Other regulated and unregulated health professionals on the team may include psychologists, occupational therapists, pharmacists, behavioural support workers, social workers, care partners, administrative staff, personal support workers, speech-language pathologists, physiotherapists, geriatricians, dietitians, and recreational staff.

Rationale

The needs of people with dementia and symptoms of agitation or aggression are multifactorial and complex. Individualized management from clinicians of various disciplines who are specialized in dementia care is necessary. This interprofessional team allows for the delivery of specialized care for behavioural symptoms through a multifaceted approach, and the development and implementation of an individualized care plan to prevent these symptoms.

What This Quality Statement Means

For People With Dementia

You should receive care from a health care team who have been trained to care for people with dementia.

For Clinicians

Connect people who have dementia with symptoms of agitation or aggression to an interprofessional team that specializes in the behavioural and psychological symptoms of dementia.

For Organizations and Health Services Planners

Ensure that hospitals and long-term care homes have timely access to an interprofessional team that specializes in care for the behavioural and psychological symptoms of dementia.

Quality Indicator: How to Measure Improvement for This Statement

 Access to an interprofessional team that provides specialized care for the behavioural and psychological symptoms of dementia; it consists of at least 1 physician and 1 other regulated professional

Measurement details for this indicator, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u>.

Quality Statement 11: Education and Training for Clinicians

People with dementia and symptoms of agitation or aggression receive care from clinicians with education and training in the assessment and management of dementia and its behavioural symptoms.

Sources: American Psychiatric Association, 2007¹⁷ | Canadian Coalition for Seniors' Mental Health, 2006¹⁹ | National Institute for Health and Care Excellence, 2018²¹ | Scottish Intercollegiate Guidelines Network, 2023²² | Sistema Nacional de Salud, 2010²³

Definition

Education and training for clinicians: These should include at minimum the following skills and information:

- Comprehensive assessment of people with dementia
- Dementia symptoms and disease progression
- Specific subtypes of dementia
- Early identification of behavioural risks
- Appropriate use of pharmacological and nonpharmacological treatment options
- De-escalation strategies for challenging behaviours that promote freedom of movement and that do not use physical restraints
- Communication with patients and care partners
- Coordination of multidisciplinary care
- Impacts of dementia on patients, care partners, families, and social networks
- Ethical and medical legal considerations
- Detection of and strategies to manage abuse and neglect
- Palliative care
- Outreach strategies to connect patients and care partners with available resources

Rationale

People with dementia and symptoms of agitation or aggression have complex needs and should receive individualized care from clinicians with comprehensive education and training in dementia and its behavioural and psychological symptoms. Identification and knowledge of the triggers for behavioural symptoms and the relevant treatment options allow for appropriate treatment and care strategies that meet people's needs and help reduce the occurrence of symptoms. Education and training materials or programs should be tailored specifically to clinicians' roles and responsibilities.

What This Quality Statement Means

For People With Dementia

You should receive care from clinicians who have been trained to treat symptoms of agitation and aggression.

For Clinicians

Ensure that you have the education and training required to effectively provide care for people with dementia and symptoms of agitation and aggression, in accordance with your professional role. This includes identifying and avoiding triggers for behavioural symptoms, and developing strategies for managing these symptoms if they occur.

For Organizations and Health Services Planners

Ensure clinicians caring for people with dementia in hospitals and long-term care homes have education and training in managing dementia and associated behavioural symptoms.

Quality Indicators: How to Measure Improvement for This Statement

- Percentage of clinicians who care for people with dementia who have received education and training in the assessment and management of dementia and its behavioural symptoms
- Clinicians who care for people with dementia have access to staff with education and training in the assessment and management of dementia and its behavioural symptoms

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u>.

Quality Statement 12: Education and Training for Care Partners

Care partners of people with dementia and symptoms of agitation or aggression have access to comprehensive education and training on dementia and its associated behavioural symptoms. This education and training includes management strategies that are consistent with people's care plans.

Sources: American Psychiatric Association, 2007^{17} | American Psychiatric Association, 2016^{18} | Canadian Coalition for Seniors' Mental Health, 2006^{19} | National Institute for Health and Care Excellence, 2018^{21} | Scottish Intercollegiate Guidelines Network, 2023^{22} | Sistema Nacional de Salud, 2010^{23}

Definitions

Care partners: These are paid or unpaid people who help a family member, friend, or another person in need of assistance or support with daily living. In the case of a person with dementia, a care partner may also be the person's substitute decision-maker.

Education and training for care partners: This should include at minimum the following skills and information:

- Dementia symptoms and disease progression
- Prognosis and care plan strategy and monitoring
- Benefits and risks of pharmacological and nonpharmacological treatment options
- Detection of behavioural risks and de-escalation and management techniques
- Causes of behavioural and psychological symptoms of dementia
- Adaptive communication skills during times of stress and other stress reduction strategies
- Functions of different professionals and health care settings
- Medical-legal issues
- Financial and legal planning for the person's eventual incapacity
- Advance care planning
- Disagreement resolution processes for the person's health care

- Sources of local support services and groups
- Tailored psychoeducation and skills training on problem solving and crisis management
- Sources of financial and legal advice and advocacy
- Self-care strategies, including access to mental health, emotional, and spiritual support

Rationale

Care partners of people with dementia and symptoms of agitation or aggression should be provided with the information and support services required to provide adequate care. In particular, they need to understand how to identify triggers for the person's behaviours and how to use de-escalation techniques to help manage these behaviours. Understanding how to identify the needs of people with dementia helps reduce occurrences of agitation or aggression and may also reduce care partner stress and burden.

What This Quality Statement Means

For People With Dementia

Support and information should be provided to your family and other people who care for you so they can help you in the best possible way.

For Clinicians

Offer families and care partners comprehensive education and training programs on dementia and its associated behavioural symptoms.

For Organizations and Health Services Planners

Ensure that hospitals and long-term care homes are able to offer families and care partners comprehensive education and training programs on dementia and its associated behavioural symptoms.

Quality Indicators: How to Measure Improvement for This Statement

- Percentage of care partners of people with dementia and symptoms of agitation or aggression who are offered access to comprehensive education and training on dementia and its associated behavioural symptoms
- Percentage of care partners of people with dementia and symptoms of agitation or aggression who receive comprehensive education and training on dementia and its associated behavioural symptoms

 Availability of comprehensive education and training programs on dementia and its associated behavioural symptoms for care partners

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u>.

Quality Statement 13: Appropriate Care Environment

People with dementia and symptoms of agitation or aggression whose behavioural symptoms have been successfully treated are transitioned to an appropriate care environment as soon as possible.

Source: Expert consensus

Definition

Appropriate care environment: This is an environment that prevents the retriggering of behavioural symptoms for the person with dementia by minimizing factors that may contribute to the symptoms.

Rationale

Once people with dementia have been successfully treated for symptoms of agitation or aggression, they should be moved to an appropriate environment that is calm with minimal potentially disturbing stimuli. This helps prevent retriggering of behavioural symptoms related to the physical environment (e.g., overcrowding, lack of privacy, loud noise levels). This also benefits other service users who might experience violence or harm when witnessing the behavioural symptoms of the person with dementia.

What This Quality Statement Means

For People With Dementia

Once your symptoms are resolved, you should be transferred to an environment that is calm with minimal noise or activity that disturbs you.

For Clinicians

Once a person with dementia's behavioural symptoms are successfully treated, move the person as soon as possible to an appropriate care environment that is calm, with minimal potentially disturbing stimuli, and that ensures the safety of other service users.

For Organizations and Health Services Planners

Ensure that there are environments that are calm with minimal potentially disturbing stimuli available in hospitals and long-term care homes to avoid triggering behavioural and psychological symptoms of dementia.

Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with dementia and symptoms of agitation or aggression whose behavioural symptoms have been successfully treated and who are transitioned to the most appropriate environment as soon as possible
- Availability of appropriate environments to which people with dementia and symptoms of agitation or aggression can be transitioned once their behavioural symptoms have been successfully treated

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u>.

Quality Statement 14: Transitions in Care

People with dementia and symptoms of agitation or aggression who transition between settings have a health care team or clinician who is accountable for coordination and communication. This team or clinician ensures the transmission of complete and accurate information to the family, care partners, and receiving health care team prior to the transition.

Sources: Canadian Coalition for Seniors' Mental Health, 2006¹⁹ | Scottish Intercollegiate Guidelines Network, 2023²² | Sistema Nacional de Salud, 2010²³

Definition

Information: The following should be communicated to the patient, family, care partners, and receiving health care team prior to the transition:

- Approaches to care
- Updated care plan
- Treatment history, including treatment options that have failed
- Potential triggers for behavioural symptoms
- Contact information for discharging and receiving health care teams

Rationale

Transitions between settings can pose problems in continuity of care for people with dementia. Untimely or uncoordinated transition processes may delay treatment and increase the risk of behavioural symptoms being triggered. People with dementia and their care partners should be involved in the transition preparation process so their needs and questions are addressed. When they are aware of what will happen during the transition, they are empowered to play an active role. In addition, the most up-to-date information should be documented in the care plan by all clinicians. A clinician or team should be accountable to ensure the accurate and timely transition of information to the proper recipients, to achieve a seamless transition process. Ultimately, transitions should be limited to only those that are beneficial or necessary. To learn more about transitioning between hospital and home, refer to the quality standard <u>Transitions Between Hospital and Home: Care for People of All Ages</u>.²⁷

What This Quality Statement Means

For People With Dementia

You should have a smooth transition between care environments. You should have a person in your health care team that is responsible for your transition plan. This person will work with you and your care partner to make sure you know what will happen when you change care settings or environments. The information about your transition plan should be written down or printed for you and your care partners. Your clinician should also make sure information about your care plan is shared with all health care team members who are involved in your care.

For Clinicians

Connect people moving between clinicians or care settings to a person or team responsible for coordinating their care and transferring information among clinicians. Keep people with dementia and their care partners involved in and informed about their transition process.

For Organizations and Health Services Planners

Ensure that hospitals and long-term care homes have systems, processes, and resources in place to enable smooth transitions between care settings for people with dementia.

Quality Indicators: How to Measure Improvement for This Statement

- Percentage of people with dementia and symptoms of agitation or aggression whose information is received by the new facility prior to their transition
- Percentage of people with dementia and symptoms of agitation or aggression whose information is incomplete or inaccurate when received by the new facility

Measurement details for these indicators, as well as overarching indicators to measure improvement for the goals of the entire quality standard, are available in the <u>technical specifications</u>.

Appendix 1: About This Quality Standard

How to Use This Quality Standard

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

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

For People With Dementia

This quality standard consists of quality statements. These describe what high-quality care looks like for people with dementia and symptoms of agitation or aggression.

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

In addition, you may want to download this accompanying <u>patient guide</u> on the behavioural symptoms of dementia to help you and your family have informed conversations with your clinicians. Inside, you will find information and questions you may want to ask as you work together to make a plan for your care.

For Clinicians and Organizations

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

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

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

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

Our <u>patient guide</u> on the behavioural symptoms of dementia, which you can share with patients
and families to help them have conversations with you and their other clinicians. Please make the
patient guide available where you provide care

- Our <u>measurement resources</u>, including the technical specifications for the indicators in this
 quality standard, the "case for improvement" slide deck to help you to share why this standard
 was created and the data behind it, and our measurement guide containing supplementary
 information to support the data collection and measurement process
- Our <u>placemat</u>, which summarizes the quality standard and includes links to helpful resources and tools
- Our <u>Getting Started Guide</u>, which includes links to templates and tools to help you put quality standards into practice. This guide shows you how to plan for, implement, and sustain changes in your practice
- Quorum, an online community dedicated to improving the quality of care across Ontario. This is a
 place where clinicians can share information and support each other, and it includes tools and
 resources to help you implement the quality statements within each standard

How the Health Care System Can Support Implementation

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

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

Appendix 2: Glossary

Term	Definition
Care partner	An unpaid person who provides care and support in a nonprofessional capacity, such as a family member, friend, or anyone else identified by the person with dementia. Other terms commonly used to describe this role include "caregiver," "informal caregiver," "family caregiver," "carer," and "primary caregiver."
Clinicians	Regulated professionals who provide care to patients or clients. Examples are nurses, nurse practitioners, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, social workers, and speech-language pathologists.
Culturally appropriate care ²⁸	Care that incorporates cultural or faith traditions, values, and beliefs; is delivered in the person's preferred language; adapts culture-specific advice; and incorporates the person's wishes to involve family or community members.
Family	The people closest to a person in terms of knowledge, care, and affection; this may include biological family or family of origin, family through marriage, or family of choice and friends. The person defines their family and who will be involved in their care.
Health care team	Clinicians, as well as people in unregulated professions, such as administrative staff, behavioural support workers, child life specialists, patient transport staff, personal support workers, recreational staff, spiritual care staff, and volunteers.
Home	A person's usual place of residence. This may include personal residences, retirement residences, assisted-living facilities, long-term care facilities, hospices, and shelters.
Long-term care	Care provided in long-term care homes.
Substitute decision-maker	A person appointed to make decisions on behalf of another under a "Power of Attorney for Personal Care."
Transitions in care	These occur when patients transfer between different care settings (e.g., hospital, primary care, long-term care, home and community care) or between different clinicians during the course of an acute or chronic illness.

Appendix 3: Values and Guiding Principles

Values That Are the Foundation of This Quality Standard

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

These values are:

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

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

Guiding Principles

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

Acknowledging the Impact of Colonization

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

French Language Services

In Ontario, the *French Language Services Act* guarantees an individual's right to receive services in French from Government of Ontario ministries and agencies in <u>26 designated areas</u> and at government head offices.²⁹

Social Determinants of Health

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

Chronic Disease Self-Management

People with dementia and their families, care partners, and personal supports should receive services that are respectful of their rights and dignity, and that promote shared decision-making and self-management.³² Further, people should be empowered to make informed choices about the services that best meet their needs.³³ People with dementia should engage with their clinicians in informed, shared decision-making about their treatment options. Each person is unique and has the right to determine their own path toward mental health and well-being.³²

Acknowledgements

Advisory Committee

Ontario Health thanks the following individuals for their generous, voluntary contributions of time and expertise to help create this quality standard (credentials at the time of initial development in 2016):

Ilan Fischler (co-chair)

Medical Director, Clinical Informatics; Geriatric Psychiatrist, Ontario Shores Centre for Mental Health Sciences

Tarek Rajji (co-chair)

Chief of Geriatric Psychiatry, Centre for Addiction and Mental Health

Carrie Acton

Administrator, Muskoka Landing – Jarlette Health Services

Saima Awan

Director, Integrated Care Pathways Program, Centre for Addiction and Mental Health

Amer M. Burhan

Associate Professor and Chair of Geriatric Psychiatry, Schulich School of Medicine, Western University

Barry Joseph Goldlist

Professor, Department of Medicine, University of Toronto, Mount Sinai Hospital, University Health Network

K. Jennifer Ingram

Divisional Lead, Geriatric Medicine, Peterborough Regional Health Centre, Kawartha Regional Memory Clinic

Krista L. Lanctôt

Senior Scientist, Hurvitz Brain Science Program, Sunnybrook Research Institute; Professor, University of Toronto

Denise Malhotra

Decision Support Analyst, Erie St. Clair Community Care Access Centre

Kathy McGilton

Senior Scientist, Toronto Rehabilitation Institution – University Health Network

Ashley Miller

Administrator, Chartwell Retirement Residences, LiUNA Local 837

Sandi Lynn Robinson

Lived Experience Advisor; Caregiver Education Coordinator, Acclaim Health – Alzheimer Services

Dallas Seitz

Assistant Professor, Division of Geriatric Psychiatry, Queen's University

Richard W. Shulman

Service Medical Director, Seniors Mental Health Services, Trillium Health Partners; Assistant Professor, Division of Geriatric Psychiatry, University of Toronto

Vincci Tang

Deputy Chief Financial Officer and Director of Information Technology and Decision Support, Ontario Shores Centre for Mental Health Sciences

Margaret Weiser

Psychologist, Private Practice; Lived Experience Advisor

Lori Whelan

Occupational Therapist, St. Michael's Hospital

Evelyn M. Williams

President, Ontario Long Term Care Clinicians; Head, Division of Long Term Care, Sunnybrook Health Science Centre

Ken Wong

Full-Time Caregiver; Lived Experience Advisor

References

- (1) Ontario Health. Dementia: care for people living in the community [Internet]. Toronto (ON): King's Printer for Ontario; 2024 [cited 2024 Apr 24]. Available from: https://www.hqontario.ca/Evidence-to-Improve-Care/Quality-Standards/View-all-Quality-Standards/Dementia
- (2) Ontario Palliative Care Network. Key palliative care concepts and terms [Internet]. Toronto (ON): The Network; 2017 [cited 2017 Oct 23]. Available from: https://www.ontariopalliativecarenetwork.ca/
- (3) Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A, (1996).
- (4) Substitute Decisions Act, 1992, S.O. 1992, c. 30, (1992).
- (5) Alzheimer Society of Canada. Rising tide: the impact of dementia on Canadian society [Internet]. Toronto (ON): The Society; 2010 [cited 2017 Apr]. Available from: https://alzheimer.ca/sites/default/files/documents/Rising-tide Alzheimer-Society.pdf
- (6) 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 Demential nCanada-WEB e.pdf
- (7) Alzheimer Society of Canada. Dementia numbers in Canada [Internet]. 2024 [cited 2024 Apr 24]. Available from: https://alzheimer.ca/en/about-dementia/what-dementia/dementia-numbers-canada
- (8) Finkel SI, Costa e Silva J, Cohen G, Miller S, Sartorius N. Behavioral and psychological signs and symptoms of dementia: a consensus statement on current knowledge and implications for research and treatment. Int Psychogeriatr. 1996;8(Suppl 3):497-500.
- (9) Brodaty H, Draper B, Saab D, Low LF, Richards V, Paton H, et al. Psychosis, depression and behavioural disturbances in Sydney nursing home residents: prevalence and predictors. Int J Geriatr Psychiatry. 2001;16(5):504-12.
- (10) O'Donnell BF, Drachman DA, Barnes HJ, Peterson KE, Swearer JM, Lew RA. Incontinence and troublesome behaviors predict institutionalization in dementia. J Geriatr Psychiatry Neurol. 1992;5(1):45-52.
- (11) Wancata J, Windhaber J, Krautgartner M, Alexandrowicz R. The consequences of non-cognitive symptoms of dementia in medical hospital departments. Int J Psychiatry Med. 2003;33(3):257-71.
- (12) Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, Dane K, et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. JAMA. 2002;287(16):2090-7.
- (13) Matsumoto N, Ikeda M, Fukuhara R, Shinagawa S, Ishikawa T, Mori T, et al. Caregiver burden associated with behavioral and psychological symptoms of dementia in elderly people in the local community. Dement Geriatr Cogn Disord. 2007;23(4):219-24.
- (14) Clyburn LD, Stones MJ, Hadjistavropoulos T, Tuokko H. Predicting caregiver burden and depression in Alzheimer's disease. J Gerontol B Psychol Sci Soc Sci. 2000;55(1):S2-13.

- (15) Health Quality Ontario. Looking for balance: antipsychotic medication use in Ontario long-term care homes [Internet]. Toronto (ON): Queen's Printer for Ontario; 2015 [cited 2016 Apr 8].

 Available from: http://www.hqontario.ca/portals/0/Documents/pr/looking-for-balance-en.pdf
- (16) Health Quality Ontario. Long-term care sector performance: quality indicators [Internet].

 Toronto (ON): Queen's Printer for Ontario; 2016 [cited 2016 Apr 8]. Available from:

 http://www.hqontario.ca/System-Performance/Long-Term-Care-Sector-Performance/Quality-Indicators
- (17) Work 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 2015 Mar 30]. Available from: http://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/alzheimer_watch.pdf)
- (18) Reus VI, Fochtmann LJ, Eyler AE, Hilty DM, Horvitz-Lennon M, Jibson MD, et al. The American Psychiatric Association practice guideline on the use of antipsychotics to treat agitation or psychosis in patients with dementia. Am J Psychiatry. 2016;173(5):543-6.
- (19) Canadian Coalition for Seniors' Mental Health. The assessment and treatment of mental health issues in long term care homes (focus on mood and behaviour symptoms) [Internet]. Toronto (ON): Canadian Coalition for Seniors' Mental Health; 2006 [cited 2016 Jan 15]. Available from: http://www.ccsmh.ca/pdf/guidelines/NatlGuideline_LTC.pdf. (Updated 2014; available from: http://www.ccsmh.ca/pdf/guidelines/2014-ccsmh-Guideline-Update-LTC.pdf)
- (20) Ismail Z, Black SE, Camicioli R, Chertkow H, Herrmann N, Laforce Jr R, et al. Recommendations of the 5th Canadian Consensus Conference on the diagnosis and treatment of dementia. Alzheimers Dement. 2020;16(8):1182-95.
- (21) National Institute for Health and Care Excellence. Dementia: assessment, management and support for people living with dementia and their carers. NICE guideline [NG97] [Internet]. London: The Institute; 2018 [cited 2022 Jul 13]. Available from: https://www.nice.org.uk/guidance/ng97
- (22) Scottish Intercollegiate Guidelines Network. Assessment, diagnosis, care and support for people with dementia and their carers [Internet]. Edinburgh, Scotland: The Network; 2023 [cited 2024 April 24]. Available from: https://www.sign.ac.uk/media/2157/sign-168-dementia.pdf
- (23) 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 2015 Mar 25]. Available from: http://www.guiasalud.es/GPC/GPC 484 Alzheimer AIAQS comp eng.pdf
- (24) Frederiksen KS, Cooper C, Frisoni GB, Frölich L, Georges J, Kramberger MG, et al. A European Academy of Neurology guideline on medical management issues in dementia. Eur J Neurol. 2020;27(10):1805-20.
- (25) Ontario Health. Medication safety: care in all settings [Internet]. Toronto (ON): Queen's Printer for Ontario; 2021 [cited 2024 April 24]. Available from: https://www.hqontario.ca/evidence-to-improve-care/quality-standards/view-all-quality-standards/medication-safety
- (26) Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A, ss. 25(6)-(7), (1996).

- (27) Ontario Health. Transitions between hospital and home: care for people of all ages [Internet]. Toronto (ON): Queen's Printer for Ontario; 2020 [cited 2024 April 24]. Available from: https://www.hqontario.ca/evidence-to-improve-care/quality-standards/view-all-quality-standards/transitions-between-hospital-and-home
- (28) Diabetes Canada Clinical Practice Guidelines Expert Committee, Sherifali D, Berard LD, Gucciardi E, MacDonald B, MacNeill G. Diabetes Canada 2018 clinical practice guidelines for the prevention and management of diabetes in Canada. Self-management education and support. Can J Diabetes. 2018;42(Suppl 1):S36-S41.
- (29) Ministry of Health, Ministry of Long-Term Care. French Language Health Services: The French Language Services Act (FLSA) [Internet]. Toronto (ON): Queen's Printer for Ontario; 1986 [cited 2024 May 6]. Available from: https://www.ontario.ca/page/french-language-services-ministry-health
- (30) Keleher HM, Armstrong RL. Evidence-based mental health promotion resource. Report for the Department of Human Services and VicHealth, Melbourne [Internet]. Melbourne (Australia): State of Victoria, Department of Human Services; 2006 [cited 2017 Dec]. Available from:

 https://www2.health.vic.gov.au/Api/downloadmedia/%7BC4796515-E014-4FA0-92F6-853FC06382F7%7D
- (31) Health Quality Ontario. Taking stock: a report on the quality of mental health and addictions services in Ontario [Internet]. Toronto, ON: Queen's Printer for Ontario; 2015 [cited 2024 May 6]. Available from: https://www.hqontario.ca/Portals/0/Documents/pr/theme-report-taking-stock-en.pdf
- (32) Mental Health Commission of Canada. Recovery [Internet]. Ottawa (ON): The Commission; 2017 [cited 2024 May 10]. Available from: http://www.mentalhealthcommission.ca/English/focus-areas/recovery
- (33) Mental Health Commission of Canada. Changing directions, changing lives: the mental health strategy for Canada [Internet]. Calgary (AB): The Commission; 2012. Available from: https://mentalhealthcommission.ca/resource/mental-health-strategy-for-canada/

About Us

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

Equity, Inclusion, Diversity, and Anti-Racism

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

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

For more information about Ontario Health, visit OntarioHealth.ca.

Looking for More Information?

Visit hqontario.ca or contact us at QualityStandards@OntarioHealth.ca if you have any questions or feedback about this quality standard.

Ontario Health 500–525 University Avenue Toronto, Ontario M5G 2L3 Toll Free: 1-877-280-8538 TTY: 1-800-855-0511

Email: QualityStandards@OntarioHealth.ca

Website: hqontario.ca

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

Document disponible en français en contactant info@OntarioHealth.ca

ISBN 978-1-4868-8266-3 (PDF) © King's Printer for Ontario, 2024