

# **Behavioural Symptoms** of Dementia

Care for Patients in Hospitals and Residents in Long-Term Care Homes



# **Summary**

This quality standard addresses care for people living with dementia and the specific behaviours of agitation and aggression. The quality standard focuses on care for people 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.

### **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 recommendations 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.

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# **How to Use Quality Standards**

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

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

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by a single-minded purpose: Better health for all Ontarians.

### Who We Are

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

### What We Do

We define the meaning of quality as it pertains to health care, and provide strategic advice so all the parts of the system can improve. We also analyze virtually all aspects of Ontario's health care. This includes looking at the overall health of Ontarians, how well different areas of the system are working together, and most importantly, patient experience. We then produce comprehensive, objective reports based on data, facts and the 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.

# **About This Quality Standard**

### Scope of This Quality Standard

This quality standard focuses on 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. 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.

### 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 15% of Canadians aged 65 and older. In 2011, about 750,000 Canadians were living with dementia; an expected 1.4 million Canadians will be living with dementia by 2031.1

Signs and symptoms of altered perception, thought, mood, or behaviour may occur in people living with dementia; these are known collectively as the behavioural and psychological symptoms of dementia. 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 living with dementia who are living in long-term care homes display symptoms of aggression at some stage of their dementia. 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 living 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. 4-6 Furthermore, they can cause compassion fatigue in families and caregivers of people living with dementia, and are challenging for health professionals.<sup>7,8</sup>

There are important gaps in the quality of care received by people living with dementia in Ontario. For example, the proportion of long-term care home residents prescribed antipsychotic medication varies widely between homes.9 There is also variation between homes in the use of physical restraints. 10 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 living 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 living 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 health care providers and organizations measure their quality of care. Each statement also includes details on how its successful delivery impacts people living with dementia, their caregivers, health care professionals, and health care services at large.

### **Principles Underpinning This Quality Standard**

This quality standard is underpinned by the principle that people living with dementia have the right to receive services that are respectful of their rights and dignity and that promote self-determination.

People living with dementia and symptoms of agitation or aggression are 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.

### **How We Will Measure Our Success**

Early in the development of each quality standard, a small number of health outcomes are chosen as the most important measures of success of the entire standard. The outcomes are mapped to indicators that reflect the goals of the standard. These outcomes and the associated indicators guide the development of the quality standard so that every statement within the standard aids in achieving the chosen outcomes. Each statement is accompanied by process, structure, and/or outcome indicators that measure the successful implementation of the statement.

The following set of outcome indicators has been selected to measure the impact of this quality standard as a whole:

- Percentage of people living with dementia and symptoms of agitation or aggression who experience fewer or less frequent behavioural symptoms
- Percentage of people living 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 long-term care home placement applications that are rejected by a long-term care home owing to an inability to meet client care needs
- Percentage of people living with dementia and symptoms of agitation or aggression who are readmitted within 30 days of hospital discharge
- Rate of emergency room use by people living with dementia and symptoms of agitation or aggression, per 1,000 population
- 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

# **Quality Statements in Brief**

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

People living 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 living with dementia and symptoms of agitation or aggression have an individualized care plan that is developed, implemented, and reviewed on a regular basis with caregivers 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 living 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 living 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 living 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 living 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 living 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: Mechanical Restraint**

People living with dementia are not mechanically restrained to manage agitation or aggression.

### **Quality Statement 9: Informed Consent**

People living 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 living 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: Provider Training and Education**

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

### **Quality Statement 12: Caregiver Training and Education**

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

### **Quality Statement 13: Appropriate Care Environment**

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

# **Comprehensive Assessment**

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

### **Background**

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 living with dementia with symptoms of agitation or aggression. The patient,

family/caregiver, or substitute decision-maker should be included in the assessment. 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.

Sources: American Psychiatric Association, 2007<sup>11</sup> Canadian Coalition for Seniors' Mental Health, 2006<sup>12</sup> Canadian Consensus Conference on the Diagnosis and Treatment of Dementia, 2012<sup>13</sup> National Institute for Health and Care Excellence, 2006<sup>14</sup> Scottish Intercollegiate Guidelines Network, 2006<sup>15</sup> | Sistema Nacional de Salud, 2010<sup>16</sup>



### **For Patients**

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're taking, how you spend your time, and how you're feeling.

### For Clinicians

Perform a standardized, comprehensive assessment (as described in the Definitions section of this statement) when people present to a hospital or long-term care home, or when they transition to another care setting.

### For Health Services

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 Indicators**

### **Process Indicator**

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

- Denominator: total number of people living with dementia and symptoms of agitation or aggression who initially present at a hospital or long-term care home or who transition to another care setting
- Numerator: number of people in the denominator who receive a comprehensive assessment
- Data sources: local data collection, Resident Assessment Instrument Minimum Data Set (RAI-MDS) in long-term care homes

### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### Comprehensive interprofessional assessment

This includes, at a minimum, the following components:

- · Physical health assessment, medical history, and medication review
- Cognitive and functional assessments
- 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 one physician and one other regulated professional who specialize in dementia care are included on the team. Other regulated and unregulated health professionals on the team may include nurses, psychologists, occupational therapists, pharmacists, behavioural support workers, social workers, caregivers, administrative staff, personal support workers, speech-language pathologists, physiotherapists, geriatricians, dietitians, and recreational staff.

# Individualized Care Plan

People living with dementia and symptoms of agitation or aggression have an individualized care plan that is developed, implemented, and reviewed on a regular basis with caregivers 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.

### **Background**

An individualized care plan is essential to coordinate, document, and ultimately guide the care of people living with dementia and symptoms of agitation or aggression. The care plan is agreed upon by providers and caregivers to ensure consistent and coordinated

delivery of care that considers the changing needs of people living 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.

Sources: American Psychiatric Association, 2007<sup>11</sup> Canadian Coalition for Seniors' Mental Health, 2006<sup>12</sup> National Institute for Health and Care Excellence, 2006<sup>14</sup> | Scottish Intercollegiate Guidelines Network, 2006<sup>15</sup> | Sistema Nacional de Salud, 2010<sup>16</sup>



#### **For Patients**

A care plan should be created to meet your individual needs. A care plan is a written statement 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 living with dementia, their caregivers, 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 Health Services

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

### **Quality Indicators**

### **Process Indicators**

Percentage of people living with dementia and symptoms of agitation or aggression who have an individualized care plan

- · Denominator: total number of people living with dementia and symptoms of agitation or aggression who have had a comprehensive assessment
- Numerator: number of people in the denominator who have an individualized care plan
- Data source: local data collection

### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### 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.

#### Caregivers

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 caregiver may or may not also be the person's substitute decision-maker.

#### Individualized Care Plan CONTINUED FROM PAGE 11

#### **Process Indicators** CONTINUED

Percentage of people living with dementia and symptoms of agitation or aggression who have an individualized care plan that has been implemented

- · Denominator: total number of people living with dementia and symptoms of agitation or aggression who have an individualized care plan
- Numerator: number of people in the denominator who receive care in concordance with their individualized care plan
- Data source: local data collection

Percentage of people living with dementia and symptoms of agitation or aggression who have an individualized care plan that has been reviewed on a regular basis

- Denominator: total number of people living with dementia and symptoms of agitation or aggression who have an individualized care plan
- Numerator: number of people in the denominator who have an individualized care plan that has been reviewed on a regular basis (at least once each month in the inpatient setting; at least once every 3 months in long-term care)
- Data source: local data collection

### Structural Indicator

Availability of an electronic system that captures information about individualized care plans, including the plan itself and care associated with the plan

Data source: local data collection.

# Individualized Nonpharmacological Interventions

People living 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.

### **Background**

There are a variety of nonpharmacological interventions that can be effective in managing symptoms of agitation or aggression in people living 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.

Sources: American Psychiatric Association, 2007<sup>11</sup> Canadian Coalition for Seniors' Mental Health, 2006<sup>12</sup> National Institute for Health and Care Excellence, 2006<sup>14</sup> | Scottish Intercollegiate Guidelines Network, 2006<sup>15</sup> | Sistema Nacional de Salud, 2010<sup>16</sup>

### **For Patients**

Non-drug treatments should be tried first.

#### For Clinicians

Before considering drug therapies, offer people at least three nonpharmacological interventions (described in the Definitions section of this statement) for managing their symptoms. Tailor nonpharmacological therapies to people's needs, symptoms, preferences, and history, as documented in their individualized care plan.

### For Health Services

Ensure that hospitals and long-term care homes have the systems, processes, and resources in place to offer a variety of nonpharmacological interventions (described in the Definitions section of this statement).

### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### Nonpharmacological interventions

Effective nonpharmacological interventions may include the following:

- Aromatherapy
- Multisensory therapy
- Music therapy
- Dance 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.



### **Quality Indicators**

### **Process Indicators**

Percentage of people living with dementia and symptoms of agitation or aggression who are offered nonpharmacological interventions

- Denominator: total number of people living with dementia and symptoms of agitation or aggression
- Numerator: number of people in the denominator who are offered at least three nonpharmacological interventions
- Data source: local data collection

Percentage of people living with dementia and symptoms of agitation or aggression who receive nonpharmacological interventions as specified in their individualized care plan

- Denominator: total number of people living with dementia and symptoms of agitation or aggression who have an individualized care plan
- Numerator: number of people in the denominator who receive nonpharmacological interventions as specified in their individualized care plan
- Data source: local data collection.

### Structural Indicator

Availability of three or more evidence-based nonpharmacological interventions to manage the symptoms of agitation and aggression in people living with dementia

Data source: local data collection

# **Indications for Psychotropic Medications**

People living 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.

### **Background**

Because of their potential for adverse events, psychotropic medications should not be considered first-line therapy for people living with dementia. In particular, the use of antipsychotics is cautioned for people living with dementia as it is associated with an increased risk of serious adverse events. such worsening cognition, parkinsonism, diabetes,

sedation, cerebrovascular disease, and premature death. Nonpharmacological interventions should be considered first-line therapy for people living with dementia, and psychotropic medications should be used only when people pose a risk of harm to themselves or others or are in severe distress.

Sources: American Psychiatric Association, 2007<sup>11</sup> Canadian Coalition for Seniors' Mental Health, 2006<sup>12</sup> Canadian Consensus Conference on the Diagnosis and Treatment of Dementia, 2012<sup>13</sup> National Institute for Health and Care Excellence, 2006<sup>14</sup> Sistema Nacional de Salud, 2010<sup>16</sup>



#### **For Patients**

Medications should be used only if you are in severe distress or if there is a concern you might harm yourself or someone else.

#### For Clinicians

Only prescribe psychotropic medications to reduce agitation or aggression in people living 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 caregivers 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.

### For Health Services

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 living with dementia and their caregivers when psychotropic medications are prescribed.

### **Quality Indicators**

### **Process Indicator**

Percentage of people living 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

- Denominator: total number of people living with dementia with symptoms of agitation or aggression who are prescribed a psychotropic medication typically used to reduce distress
- Numerator: number of people in the denominator who are prescribed the psychotropic medication without clear documentation that they are in severe distress or pose a risk of harm to themselves or others
- Data source: local data collection.

### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### Psychotropic medications

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

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

# **Titrating and Monitoring Psychotropic Medications**

People living 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.

### **Background**

People living with dementia are usually elderly, often with 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.

Sources: American Psychiatric Association, 2007<sup>11</sup> National Institute for Health and Care Excellence, 2006<sup>14</sup> Sistema Nacional de Salud, 2010<sup>16</sup>



### **For Patients**

If they are used, medications 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 Health Services

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

### **Quality Indicators**

### **Process Indicator**

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

- Denominator: total number of people living with dementia and symptoms of agitation or aggression who are prescribed a psychotropic medication
- Numerator: number of people in the denominator whose target symptoms are monitored and documented
- Data source: local data collection

### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### **Psychotropic medications**

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

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

# **Switching Psychotropic Medications**

People living 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.

### **Background**

Psychotropic medications should be switched after a maximum of 8 weeks for people living 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.

Source: Expert consensus



#### **For Patients**

Your team of health care professionals should help you find the right medication to fit your needs.

#### For Clinicians

When people living 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 Health Services

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 Indicators**

### **Process Indicator**

Percentage of people living 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

- Denominator: total number of people living with dementia and symptoms of agitation or aggression who continuously receive a psychotropic medication and whose symptoms do not improve after 8 weeks
- Numerator: number of people in the denominator who have their psychotropic medication discontinued and are switched to an alternative psychotropic medication
- Data source: local data collection

### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### **Psychotropic medications**

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

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

# **Medication Review for Dosage Reduction** or Discontinuation

People living 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.

### **Background**

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 these types of medications, people living 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. However, it is important to consider the risk for relapse in behavioural symptoms during or after the withdrawal of medication.

Sources: American Psychiatric Association, 2007<sup>11</sup> Canadian Coalition for Seniors' Mental Health, 2006<sup>12</sup> Canadian Consensus Conference on the Diagnosis and Treatment of Dementia, 2012<sup>13</sup> National Institute for Health and Care Excellence, 2006<sup>14</sup> Scottish Intercollegiate Guidelines Network, 2006<sup>15</sup> | Sistema Nacional de Salud, 2010<sup>16</sup>



### **For Patients**

There should be a regular review of your medications to see if the dosage can be reduced or the medications 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 Health Services

Ensure there are systems, processes, and resources in place in hospitals and longterm 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.

### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### 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.

#### **Psychotropic medications**

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

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



### **Quality Indicators**

#### **Process Indicators**

Percentage of people living with dementia and symptoms of agitation or aggression who are on psychotropic medications 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)

- Denominator: total number of people living with dementia and symptoms of agitation or aggression who are receiving a psychotropic medication
- Numerator: number of people in the denominator 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)
- Data source: local data collection

Percentage of people living 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

- Denominator: total number of people living with dementia and symptoms of agitation or aggression who are receiving a psychotropic medication and have undergone a medication review
- Numerator: number of people in the denominator who have their psychotropic medications tapered or discontinued during a medication review
- Data source: local data collection

# **Mechanical Restraint**

People living with dementia are not mechanically restrained to manage agitation or aggression.

### **Background**

Mechanical 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 living with dementia. Through the proper

management of behavioural symptoms, it is possible to avoid the use of mechanical restraints. Hospitals and long-term care homes should move toward zero use of mechanical restraints.

Source: Expert consensus



#### **For Patients**

You should not be physically restrained.

#### For Clinicians

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

#### For Health Services

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

### **Quality Indicators**

### **Process Indicator**

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

- Denominator: total number of people living with dementia and symptoms of agitation or aggression
- Numerator: number of people in the denominator who are placed in mechanical restraints for symptoms of agitation or aggression
- Data sources: local data collection; proxy measures could be calculated based on data currently collected for restraint use in acute mental health care (Ontario Mental Health Reporting System, provided by the Canadian Institute for Health Information) and for daily physical restraints in long-term care (Continuing Care Reporting System, provided by the Canadian Institute for Health Information)

#### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### Mechanical 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. Mechanical 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 mechanical restraint or a safety device.

## **Informed Consent**

People living 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.

### **Background**

The law requires that providers obtain capable, informed, and voluntary consent prior to initiating a treatment, as stated in the Health Care Consent Act, 1996.<sup>17</sup> In addition, people living 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, 1992.18 Treatment may be initiated without consent in the event of an emergency situation, where people living 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.<sup>19</sup> In either case, the provider must document justification of the treatment, and the patient's values and wishes must always be considered when making a medical decision.

Source: National Institute for Health and Care Excellence, 2006<sup>14</sup>



#### **For Patients**

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 caregivers, 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 Health Services

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 Indicators**

### **Process Indicator**

Percentage of people living 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

- Denominator: total number of people living with dementia and symptoms of agitation or aggression who are receiving a medical treatment
- Numerator: number of people in the denominator whose informed consent (directly or by substitute decision-maker) is documented prior to initiation of the treatment
- Data source: local data collection.

### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### 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.

# Specialized Interprofessional Care Team

People living 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.

### **Background**

The needs of people living with dementia and symptoms of agitation or aggression are multifactorial and complex. Individualized management from providers 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.

Sources: American Psychiatric Association, 2007<sup>11</sup> Canadian Coalition for Seniors' Mental Health, 2006<sup>12</sup> National Institute for Health and Care Excellence, 2006<sup>14</sup> | Sistema Nacional de Salud, 2010<sup>16</sup>



### **For Patients**

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

#### For Clinicians

Ensure that people who have dementia with symptoms of agitation or aggression are cared for by an interprofessional team specialized in the behavioural and psychological symptoms of dementia.

#### For Health Services

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 Indicators**

### Structural Indicator

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

Data source: local data collection

### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### Specialized interprofessional care team

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

# **Provider Training and Education**

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

### **Background**

People living with dementia and symptoms of agitation or aggression have complex needs and should receive individualized care by providers with comprehensive training and education 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. Training and education materials or programs should be tailored specifically to providers' roles and responsibilities.

Sources: American Psychiatric Association, 2007<sup>11</sup> Canadian Coalition for Seniors' Mental Health, 2006<sup>12</sup> National Institute for Health and Care Excellence, 2006<sup>14</sup> | Sistema Nacional de Salud, 2010<sup>16</sup>



#### **For Patients**

You should receive care from a team of health care professionals who have been trained to treat symptoms of agitation and aggression.

### For Clinicians

Ensure that you have the training and education required to effectively provide care for people living 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 Health Services

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

### **Quality Indicators**

### **Process Indicator**

Percentage of providers who care for people living with dementia who have received training and education in the assessment and management of dementia and its behavioural symptoms

- Denominator: total number of health care providers who care for people living with dementia
- Numerator: number of people in the denominator who have received training and education in the assessment and management of dementia and its behavioural symptoms
- Data source: local data collection

### Structural Indicator

Providers who care for people living with dementia have access to staff with training and education in the assessment and management of dementia and its behavioural symptoms

Data source: local data collection

### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### Provider training and education

These should include at minimum the following skills and information:

- Comprehensive assessment of people living 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
- Communication with patients, residents, and caregivers
- Coordination of multidisciplinary care
- Impacts of dementia on patients, caregivers, 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, residents, and caregivers with available resources

# **Caregiver Training and Education**

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

### **Background**

Caregivers of people living 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 living with dementia helps reduce occurrences of agitation or aggression and may also reduce caregiver stress and burden.

Sources: American Psychiatric Association, 2007<sup>11</sup> Canadian Coalition for Seniors' Mental Health, 2006<sup>12</sup> National Institute for Health and Care Excellence, 2006<sup>14</sup> | Scottish Intercollegiate Guidelines Network, 2006<sup>15</sup> | Sistema Nacional de Salud, 2010<sup>16</sup>

#### **For Patients**

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 caregivers comprehensive training and education programs on dementia and its associated behavioural symptoms.

#### For Health Services

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

### **Quality Indicators**

### **Process Indicators**

Percentage of caregivers of people living with dementia and symptoms of agitation or aggression who are offered access to comprehensive training and education on dementia and its associated behavioural symptoms

- Denominator: total number of caregivers of people living with dementia and symptoms of agitation or aggression
- Numerator: number of people in the denominator who have access to comprehensive training and education on dementia and its associated behavioural symptoms
- Data source: local data collection

### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### Caregivers

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 caregiver may also be the person's substitute decision-maker.

#### Caregiver training and education

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
- · 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
- Sources of financial and legal advice and advocacy

#### **Process Indicators** CONTINUED

Percentage of caregivers of people living with dementia and symptoms of agitation or aggression who receive comprehensive training and education on dementia and its associated behavioural symptoms

- Denominator: total number of caregivers of people living with dementia and symptoms of agitation or aggression
- Numerator: number of people in the denominator who receive comprehensive training and education on dementia and its associated behavioural symptoms
- Data source: local data collection

#### Structural Indicator

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

• Data source: local data collection

# **Appropriate Care Environment**

People living 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.

## **Background**

Once people living 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.

Source: Expert consensus



## **What This Quality Statement Means**

#### For Patients

If needed, 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 Health Services

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**

#### **Process Indicator**

Percentage of people living 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

- Denominator: total number of people living with dementia and symptoms of agitation or aggression whose behavioural symptoms have been successfully treated
- Numerator: number of people in the denominator who are transitioned to the most appropriate environment as soon as possible
- Data source: local data collection

#### Structural Indicator

Availability of appropriate environments to which people living with dementia and symptoms of agitation or aggression can be transitioned once their behavioural symptoms have been successfully treated

Data source: local data collection

#### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### 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.

## **Transitions in Care**

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

## **Background**

Transitions between settings can pose problems in continuity of care for people living with dementia. Untimely or uncoordinated transition processes may delay treatment and increase the risk of behavioural symptoms being triggered. People living with dementia and their caregivers 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 providers. A provider 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.

Sources: Canadian Coalition for Seniors' Mental Health, 2006<sup>12</sup> National Institute for Health and Care Excellence, 2006<sup>14</sup> Scottish Intercollegiate Guidelines Network, 2006<sup>15</sup> | Sistema Nacional de Salud, 2010<sup>16</sup>

## **What This Quality Statement Means**

#### **For Patients**

You should have a smooth transition between care environments.

#### For Clinicians

Ensure that people moving between providers or care settings have a person or team responsible for coordinating their care and transferring information among providers. Keep people living with dementia and their caregivers involved in and informed about their transition process.

#### For Health Services

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

#### **DEFINITIONS USED WITHIN** THIS QUALITY STATEMENT

#### Information

The following should be communicated to the patient, family, caregivers, and receiving providers 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 providers

## **Quality Indicators**

#### **Process Indicators**

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

- Denominator: total number of people living with dementia and symptoms of agitation or aggression who transition to a new facility
- Numerator: number of people in the denominator for whom complete and accurate transmission of information is received by the new facility prior to their transition
- Data source: local data collection

Percentage of people living with dementia and symptoms of agitation or aggression whose information is incomplete or inaccurate when received by the new facility

- Denominator: total number of people living with dementia and symptoms of agitation or aggression who transition to a new facility that has received information regarding their care and treatment
- Numerator: number of people in the denominator whose care and treatment information is incomplete or inaccurate during the transition process
- Data source: 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:

#### Ilan Fischler (co-chair)

Medical Director. Clinical Informatics and 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, Regina Gardens Long Term Care Residence

#### 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

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#### **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

www.hqontario.ca



# **Behavioural Symptoms** of Dementia

Care for Patients in Hospitals and Residents in Long-Term Care Homes

