



QUALITY STANDARDS

Behavioural Symptoms of Dementia

A guide for patients in hospitals and
residents of long-term care homes

2024 UPDATE

Ontario Health is committed to improving the quality of health care in the province in partnership with patients, clinicians, and other organizations.

To do that, Ontario Health develops quality standards. These are documents that outline what high-quality care looks like for conditions or processes where there are large differences in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. These quality standards set out important steps to improve care. They are based on current evidence and input from an expert committee that includes patients, care partners, clinicians, and researchers.

This patient guide accompanies the quality standard on the [behavioural symptoms of dementia](#). It outlines the top 14 areas where health care teams can take steps to improve care for patients in hospitals and residents of long-term care homes with behavioural symptoms of dementia. The patient guide also includes suggestions on what to discuss with your health care team, as well as links to helpful resources.

In this guide, we use the following terms:

Care partner: Someone who provides unpaid essential and ongoing care and support for you, such as a family member, a friend, and anyone else you identify. Your care partner's role may change over time as your condition progresses.

Clinician: A health care professional who provides care to patients in hospitals and residents of long-term care homes, including a doctor, nurse, nurse practitioner, occupational therapist, pharmacist, physiotherapist, psychologist, social worker, and registered dietitian.

Health care team: A group of health care providers who work together to care for you. Your health care team may include doctors, nurses, social workers, volunteers, and personal support workers.

Substitute decision-maker: Someone who makes care and treatment decisions on your behalf if you are mentally incapable of making decisions for yourself.

Patients, residents, families, and clinicians partnered together on this guide to define what the best care should look like for people with dementia who are experiencing behavioural symptoms such as agitation and aggression. The information in this guide has been created to help patients, residents, families, and care partners know what to ask for in their care when treated in a hospital or long-term care home. It is based on the best available research and is designed to help ensure the highest quality care possible.

If you or your loved one is living with dementia and experiencing behavioural symptoms, you can use this guide to help you and your health care team develop a care plan that works for you. You can use this information to become aware of what high-quality care looks like and to ask informed questions about your care. Care plans can be very different for each person, so it is important to work closely with your health care team.

This guide contains some things to consider if you or a loved one is treated in a hospital or long-term care home.

Everybody is different, and some options may not apply in your situation. If you have questions about your care, **it is important to speak with your health care team.**

Summary of the top 14 areas to improve care for people with behavioural symptoms of dementia

Quality Statement 1: Comprehensive Assessment



What the standard says

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.



What this means for you

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.

Behavioural symptoms of dementia

Living with dementia can be challenging. It can impact many aspects of your life, including how you interact with others. Because of the changes happening in your brain, you may occasionally behave in ways that are upsetting to you or your friends and family. You may become frustrated or confused or react negatively to something that is causing you pain or discomfort. You may end up expressing your feelings by shouting, pushing, hitting, or throwing objects. These changes may also cause agitation. You may pace, fidget, and become irritable with your surroundings. Speak with your doctor and ask for support if you or someone you are caring for is experiencing any of these symptoms of dementia.

Quality Statement 2: Individualized Care Plan



What the standard says

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.



What this means for you

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.

Substitute decision-maker

Having a voice in decisions about your health care treatment is important. As your dementia progresses, there will come a time when you won't be able to express your treatment wishes to your health care team, and you will need someone to make those decisions on your behalf. This person will be your substitute decision-maker.

Make sure you know who your future substitute decision-maker will be, by Ontario law, if you become mentally incapable of making health decisions. Ontario's *Health Care Consent Act* automatically assigns a substitute decision-maker.

If you would like someone else to be your future substitute decision-maker, prepare a legal document called "Power of Attorney for Personal Care." It is not enough to tell your health care team that you want a different substitute decision-maker.

Once you have confirmed your substitute decision-maker, talk with them regularly about your wishes, values, and beliefs. This will help them make the right decisions for you, if needed. If your wishes change, keep them informed.

Quality Statement 3: Individualized Nonpharmacological Interventions



What the standard says

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.



What this means for you

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.

Nondrug treatments

Examples of nondrug treatments include:

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

There may be other nondrug treatments not mentioned in this list that may be helpful to you.

Quality Statement 4: Indications for Psychotropic Medications



What the standard says

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.



What this means for you

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.

What are psychotropic medications?

Psychotropic medications are drug treatments that affect mood and behaviour. They can reduce symptoms of agitation and aggression in people with dementia. Examples of psychotropic medications include:

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

Quality Statement 5: Titrating and Monitoring Psychotropic Medications



What the standard says

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.



What this means for you

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

Quality Statement 6: Switching Psychotropic Medications



What the standard says

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.



What this means for you

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.

Quality Statement 7: Medication Review for Dosage Reduction or Discontinuation



What the standard says

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.



What this means for you

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.

Quality Statement 8: Physical Restraint



What the standard says

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



What this means for you

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

What are physical restraints?

Physical restraints are devices or equipment used in emergency situations that stop a person from moving freely. A person is not given a choice to be physically restrained. Physical restraints are different from safety restraints, which are devices used to assist you (for example, bed rails, geri-chairs, and mitts). Physical restraints should not be used, as they can cause serious injury.

Quality Statement 9: Informed Consent



What the standard says

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.



What this means for you

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.

Quality Statement 10: Specialized Interprofessional Care Team



What the standard says

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.



What this means for you

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

What is a specialized interprofessional care team?

A team will work together to help you and your care partner(s) manage your symptoms of dementia. This team will include at least 1 medical doctor and 1 other clinician. Other health professionals on the team may include a psychologist, occupational therapist, pharmacist, behavioural support worker, social worker, administrative staff, personal support worker, speech-language pathologist, physiotherapist, geriatrician, dietitian, and recreational staff.

Quality Statement 11: Education and Training for Clinicians



What the standard says

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.



What this means for you

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

Quality Statement 12: Education and Training for Care Partners



What the standard says

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.



What this means for you

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.

Quality Statement 13: Appropriate Care Environment



What the standard says

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.



What this means for you

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

Quality Statement 14: Transitions in Care



What the standard says

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.



What this means for you

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.

Suggestions on what to discuss with your health care team

Ask your health care team:

- What can I expect will happen in the future as my symptoms continue to progress?
- What is my care plan?
- Who will be included in my health care team?
- Are there any medications I should be taking to manage my symptoms?
- What nondrug treatment options are available for me?
- When will I be discharged?
- Who oversees my transition plan?

Share with your health care team:

- What services you are receiving
- If you need extra help taking care of yourself
- Who you want to include in decisions about your care plan
- If you notice changes in your symptoms such as worsening memory or ability to complete tasks
- Any lifestyle changes (for example, changes in your sleeping patterns, any exercises you are doing, your diet)

If you are a care partner

You might have your own questions. It can help to identify yourself as the patient's or resident's care partner to their health care team. This will make sure they know and respect your questions and concerns.

- Let them know what your role will be in helping the person with dementia manage their condition
- Let them know if you need help

Learn more

The [Alzheimer Society](#) provides tools and resources for managing your symptoms of dementia, moving in to [long-term care homes](#), and planning [end-of-life care](#). Information on dementia is available in [multiple languages](#), including Traditional Chinese and Punjabi.

The [Canadian Coalition for Seniors' Mental Health](#) has helpful resources for people with dementia and their care partners, including:

- Why [self-care](#) is essential for care partners
- Resources to support [Indigenous Peoples](#) with dementia
- Resources to support [2SLGBTQIA+ people](#) with dementia

[Advance Care Planning Ontario](#) provides information about substitute decision-makers.

Need more information?

If you have any questions or feedback about this guide, please contact us at QualityStandards@OntarioHealth.ca or 1-877-280-8538 (TTY: 1-800-855-0511).

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

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