



QUALITY STANDARDS

Palliative Care

A guide for
adults with a
serious illness

2024 UPDATE

Ontario
Palliative Care
Network



Ontario
Health

Ontario Health is committed to improving the quality of health care in the province in partnership with patients, health care professionals, 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, health care professionals, and researchers.

This patient guide accompanies the quality standard on [palliative care](#). It outlines the top 13 areas where providers can take steps to improve care for people with a serious illness. The patient guide also includes suggestions on what to discuss with your health care providers, as well as links to helpful resources.

In this guide, we use the following terms:

Family: The people closest to you, including your biological family or family of origin, family by marriage, and friends. You define who your family is and how they will be involved in your care.

Care partner: Someone who provides unpaid essential and ongoing care and support for you, such as family members, friends, and anyone else you identify.

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

This guide is for people who are living with a serious illness. It can help you to know what to ask for when receiving treatment and to make sure you receive the highest-quality care.

Serious illnesses such as cancer, heart failure, chronic obstructive pulmonary disease, and dementia can affect health and quality of life and can lead to death. Anyone with such an illness can benefit from a palliative approach to care. Living with this type of illness can be hard on you and your family and care partners, both physically and emotionally. Palliative care helps by addressing all aspects of your well-being – physical, psychological, social, spiritual, linguistic, cultural, and practical.

This quality standard does not address medical assistance in dying. People who choose medical assistance in dying should receive high-quality palliative care.

If you or someone you care about is living with a serious illness ...

You can use this guide to work with your care team to make a care plan that works for you. We encourage you to use this guide to ask informed questions and to learn how you and your family and care partners can get the supports you need.

Care plans can be very different for each person, so it is important to work closely with your care team to create a care plan that works for you.

What is palliative care?

Palliative care is a philosophy of care that aims to relieve suffering and improve quality of life for people with a serious illness, and for their families and care partners, too. Palliative care can help improve your quality of life at any stage of illness – it is not just for end of life. You can also receive palliative care while you are being treated for your illness.

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 professional.**

Summary of the top 13 areas to improve care for people with a serious illness

Quality Statement 1: Identification and Assessment of Needs



What the standard says

People with a serious illness have their palliative care needs identified early through a comprehensive and holistic assessment.



What this means for you

Your care team should talk with you about your illness and how it could progress. They should also talk with you about your values and goals and your treatment options. These discussions will help you understand your illness, your goals of care, and your treatment options so you can make decisions about your care and provide health care consent.

Your care team should assess what palliative care or supports you need:

- They should ask questions about your physical and mental health, your support system, and any other needs you feel you have, to understand how best to help you
- They should assess your pain and other health concerns, and manage them quickly and effectively
- They should assess your mental, emotional, social, cultural, and spiritual well-being
- They should ask your family members and care partners about the help they need

Quality Statement 2: Timely Access to Palliative Care Support



What the standard says

People with identified palliative care needs have access to palliative care support 24 hours a day, 7 days a week.



What this means for you

Palliative care support should be available for you whenever you need it, day or night.

What is palliative care support?

Palliative care support consists of health advice, resources, treatment, and other assistance provided by the health care team to meet your palliative care needs. Support should be culturally relevant, and it can come in many forms, including a telephone call with a registered nurse, a number to call when pain or other symptoms are not well managed, or a home visit from a primary care or palliative care provider.

Quality Statement 3: Advance Care Planning – Substitute Decision-Maker



What the standard says

People with a serious illness know who their future substitute decision-maker is. They engage in ongoing communication with their substitute decision-maker about their wishes, values, and beliefs, so that the substitute decision-maker is empowered to participate in the health care consent process if required.



What this means for you

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 based on a ranked list.

If the person automatically assigned to be your substitute decision-maker is not the person you want in this role, prepare a legal document called a "Power of Attorney for Personal Care." It is not enough to tell your 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.

For more information, excellent resources are available from [Advance Care Planning Ontario](#).

What is a substitute decision-maker?

A substitute decision-maker is someone who makes care and treatment decisions for you if you are mentally incapable of making decisions for yourself.

What is health care consent?

There are 2 parts to health care consent. First, you and your health care team discuss your condition, treatment options, risks and benefits, side effects, and what would happen without the proposed treatment. Once you understand those things, you decide to give or refuse permission for the treatment.

Quality Statement 4: Goals-of-Care Discussions and Consent



What the standard says

People with identified palliative care needs or their substitute decision-makers have discussions with their interprofessional health care team about their goals of care to help inform their health care decisions. These values-based discussions focus on ensuring an accurate understanding of both the illness and the treatment options so the person or their substitute decision-maker has the information they need to give or refuse consent to treatment.



What this means for you

Your care team should talk with you about your illness and how it could progress. They should also talk with you about your values and goals and your treatment options. These discussions will help you understand your illness, your goals of care, and your treatment options so you can make decisions about your care and provide health care consent.

Quality Statement 5: Individualized, Person-Centred Care Plan



What the standard says

People with identified palliative care needs collaborate with their primary care provider and other health care professionals to develop an individualized, person-centred care plan that is reviewed and updated regularly.



What this means for you

Your care team should work with you to create a care plan that fits your values, wishes, and goals. Your care team should use this plan to provide palliative care that meets your needs. This care plan should be updated as often as you need.

What is a care plan?

A care plan is a written document that describes your health needs and goals and the care that will be provided to meet them. The care plan should include your goals, wishes, treatment decisions, consent to treatment or plan of treatment, preferred care setting, current and future care needs, and the resources needed to meet those needs. A care plan is not the same as a discussion about goals of care, and it is not a treatment plan or a consent to treatment. A care plan is broader than a treatment plan. A treatment plan is associated with a health care decision and requires consent from the patient or substitute decision-maker.

Quality Statement 6: Management of Pain and Other Symptoms



What the standard says

People with identified palliative care needs have their pain and other symptoms managed effectively, in a timely manner.



What this means for you

Your health care team should assess your pain and other health concerns and manage them quickly and effectively.

Quality Statement 7: Psychosocial Aspects of Care



What the standard says

People with identified palliative care needs receive timely psychosocial support to address their mental, emotional, social, cultural, and spiritual needs.



What this means for you

Your care team should assess your mental, emotional, social, cultural, and spiritual well-being. Your needs should be addressed as part of your care plan and according to your wishes, values, and goals of care.

Quality Statement 8: Education for People With a Serious Illness, Substitute Decision-Makers, Families, and Care Partners



What the standard says

People with a serious illness, their future substitute decision-maker, their family, and their care partners are offered education about palliative care and information about available resources and supports.



What this means for you

Your care team should give you, your family, your substitute decision-maker, and your care partners information about palliative care. They should also give you information about resources and supports, such as counselling, hospice volunteers, wellness programs, spiritual care, or support groups. This knowledge can help you understand your treatment and service options, how palliative care can improve your quality of life, and how to connect with available supports.

Quality Statement 9: Care Partner Support



What the standard says

Families and care partners of people with identified palliative care needs are offered ongoing assessment of their needs, and are given access to resources, respite care, and grief and bereavement support, consistent with their preferences.



What this means for you

Caregiving can be a rewarding experience, but it can also be stressful. If you are a care partner, a member of the care team should assess you to see how you are coping and help you get the supports you need. Supports can include training, support groups, home care, and temporary respite care for the person you are caring for. Respite care can give you a break from the caregiving routine and give you time to take care of yourself.

Quality Statement 10: Transitions in Care



What the standard says

People with identified palliative care needs experience seamless transitions in care that are coordinated effectively among settings and health care providers.



What this means for you

When you change care settings or care providers (for example, if you return home after being in hospital), your care team should work with you to make sure you and any new team members have the right information (such as information about your medication). They should also make sure you receive the services you need (such as plans for follow-up).

Quality Statement 11: Setting of Care and Place of Death



What the standard says

People with identified palliative care needs, their substitute decision-maker, their family, and their care partners have ongoing discussions with their health care professionals about their preferred setting of care and place of death.



What this means for you

Your care team should talk with you about where you would like to be cared for throughout your illness and at end of life (for example, at home, in a home-like environment called a hospice residence, in a hospital, or in a long-term care home). They should give you information about the care available in different locations to help you make the best choices for you, your family, and your care partners. Your wishes may change over time, so you should have regular opportunities to discuss them. You may want to talk about:

- Your preferences
- How your disease affects your ability to perform normal daily activities
- Whether you are living with someone who can help you
- Whether other help you may need is available

Quality Statement 12: Interprofessional Team-Based Care



What the standard says

People with identified palliative care needs receive integrated care from an interprofessional team, which includes volunteers.



What this means for you

You should have access to care providers who are knowledgeable about palliative care and who will work together to meet your needs and goals of care.

What is integrated care?

This means managing and delivering health care in a way that is coordinated and that meets people's needs at every stage of life. With integrated care, the different parts of the health system work together throughout a patient's journey, including diagnosis, treatment, care, rehabilitation, and health promotion. Integrated care is more efficient, and it leads to better access, better quality of care, and better patient experiences.

What is an interprofessional team?

An interprofessional team is a group of health care providers with different training and skills, the person with a serious illness, and their care partners. The team works together to provide care based on a person's care plan. Who is on the team varies depending on the needs of the person with the serious illness, but it might include doctors, nurse practitioners, registered nurses, registered practical nurses, social workers, psychologists, spiritual care providers, pharmacists, personal support workers, dietitians, and volunteers.

Quality Statement 13: Education for Health Care Providers and Volunteers



What the standard says

People receive palliative care from health care providers and volunteers who possess the appropriate knowledge and skills to deliver high-quality palliative care.



What this means for you

You should have access to care providers who have the skills and knowledge to provide palliative care and who will work together to meet your needs and goals of care.

Suggestions on what to discuss with your health care providers

Ask the care team:

- How do I know if I need palliative care?
- Who is part of my care team?
- What are my treatment options?
- What palliative care supports are available where I live?
- Where can I get more information and support?
- Who can I contact if I need to speak to someone?
- What should I do in an emergency?

Share with the care team:

- Who you want to include in decisions about your care (for example, a family member or care partner)
- The type of information and support you want from your health care team
- If you do not understand why you are taking a medication or how to take it
- If you are feeling pain or other symptoms
- If there are things that make it hard to take your medication, such as the cost or difficulty using it

If you are a care partner

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

- Let them know what your role will be in helping the patient during their care
- Let them know if you need help

Living with a serious illness can be difficult. Your care team will work with you to ensure your care addresses all aspects of your well-being and is tailored to you.

Learn more

Your local [Home and Community Care Support Services](#) organization can help you access palliative care and provide more information and resources.

[Advance Care Planning](#) is a program provided by Hospice Palliative Care Ontario to help people and their families and care partners plan for palliative care.

The [Canadian Hospice Palliative Care Association](#) has several resources to support families and care partners, including:

- [Living Lessons: A Guide for Caregivers](#)
- [A Caregiver's Guide: A Handbook About End-of-Life Care](#)

[Canadian Virtual Hospice](#) provides information and support on palliative care and end-of-life care to patients, family members, health care providers, researchers, and educators.

[The Ontario Caregiver Organization](#) provides programs and resources for care partners, including a 24/7 Ontario Caregiver Helpline 1-833-416-CARE (2273) and a [caregiver toolkit](#).

[Hospice Palliative Care Ontario](#) has resources for individuals and care partners, including [Caregiver Support Education](#).

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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