

# Quality Standards

## Patient Reference Guide

### Palliative Care

Care for Adults

September 2017

DRAFT

**Ontario  
Palliative Care  
Network**

**Health Quality  
Ontario**

*Let's make our health system healthier*

Quality standards outline what high-quality care looks like. They focus on areas where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive.

This guide addresses variations and gaps in care in Ontario that need attention when it comes to palliative care. It is based on the best available evidence and was created in partnership with family and other informal caregivers, and health care providers.

This guide is for people who are living with a serious, life-limiting illness and are considering palliative care.

Palliative care is a philosophy of care that aims to relieve suffering and improve quality of life for people living with a serious, life-limiting illness, and for their families and caregivers. You can receive palliative care while you are being treated for your illness.

Serious illnesses such as cancer, heart failure, chronic obstructive pulmonary disease, and dementia can affect both health and quality of life and can lead to death. Anyone with a serious illness such as this can benefit from a palliative approach to care.

We know that living with this type of illness is hard on you and your family and caregivers, both physically and emotionally. Palliative care addresses all aspects of your well-being, including physical, psychological, social, spiritual, and practical aspects, and it considers your expectations, needs, hopes, and fears.

## **If you or someone you care about is living with a serious, life-limiting illness ...**

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

Here are some things to consider.

### **Your Care Team**

- You should receive care from a knowledgeable team that works together to meet your needs and goals of care.

### **Understanding Palliative Care**

- You, your family, and your caregivers should be given information about palliative care from the care team. You should also be given information about resources and supports, such as hospice volunteers, support groups, and grief counselling.

### **Your Care**

- You and your care team should talk about your illness and how it could progress. You should also talk about your goals and treatment options. Talking about your wishes will help your care team make sure you get the type of care you want.

- You should be assessed to determine what palliative care or supports you need. Your care team will 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.
  - Your care team should assess you for pain and other symptoms. They should manage pain or other symptoms quickly and effectively.
  - Your care team should assess your mental, emotional, social, cultural, and spiritual well-being.
  - Your care team should ask your family members and caregivers about the help they need.
- Your care team should work with you to create a care plan that fits with your values, wishes, and goals. Your care team will use the plan to provide palliative care that meets your needs. This care plan should be updated as often as you need.
- You should be able to get palliative care support whenever you need it, day or night.
- You and your care team should talk about where you would like to be cared for (for example, at home, in a home-like environment called a hospice, or in a long-term care home).
- Your wishes may change over time, so on an ongoing basis, you should discuss your preferences, how your disease impacts your ability to perform normal daily activities, whether you are living with someone who can help you, and whether other help you may need is available.
- You should be given information about care in different locations to help you make the best choices for you, your family, and other informal caregivers.

### **Substitute Decision-Maker**

- The law designates a substitute decision-maker if you do not choose someone else. If there is someone you want to make decisions on your behalf if you aren't able to do so, you should tell your care team as soon as possible. This person will be your substitute decision-maker.
- Your care team should ensure that you know who your substitute decision-maker is, if you have not appointed one yourself.
- You should talk to your substitute decision-maker about your wishes, values, and beliefs so they can make the right decisions for you.

## **When You Change Care Settings or Providers**

- 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 that you and your new care team members have the information you need (such as information about your medication) and that you receive the services you need (such as plans for follow up).

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

## Looking for more information?

Please contact us at [qualitystandards@hqontario.ca](mailto:qualitystandards@hqontario.ca) if you have any questions or feedback about this patient reference guide.

A more detailed version of this quality standard, written for health care professionals, is available on our website. You can find it at [hqontario.ca](http://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.**

Our quality standards are concise sets of statements outlining what quality care looks like for conditions where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. They are based on the best available evidence and are developed in collaboration with clinical experts from across the province, and patients and caregivers with lived experience with the condition being discussed.

For more information about Health Quality Ontario and our quality standards, visit: [hqontario.ca](http://hqontario.ca).

## About the Ontario Palliative Care Network

The Ontario Palliative Care Network is a partnership funded by the Ministry of Health and Long-Term Care and led by CCO, the Local Health Integration Networks, Health Quality Ontario, and the Quality Hospice Palliative Care Coalition of Ontario. It is putting patients and families at the centre of every decision and strengthening hospice palliative care services across Ontario. This work is person-centred, focusing on supporting the provision of quality hospice palliative care for all Ontarians, regardless of their age or disease type. The Ontario Palliative Care Network will help to ensure that hospice palliative care in Ontario is high-quality, sustainable, accessible, continuous, and person-centred.

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