

Palliative Care Guide for Patients and Caregivers



This guide explains how palliative care can help to support you and your caregivers. It answers commonly asked questions and can be referred to when you need help.

**Mississauga Halton
Palliative Care
Network**

Ontario 

Introduction

Every patient is unique, and palliative care aims to treat you with dignity and respect. Palliative care helps you meet your personal wishes for care now and in the future (goals of care). We hope this booklet gives you the information you need to start thinking about questions you might have for your health care team.

What is Palliative Care?

It's a type of care that helps to improve your quality of life or live better when you have a serious illness. It can make you be more comfortable by giving you and your family support. It is NOT just about dying... it is about helping you to live your best possible day, each day. (Atul Gawande, *Being Mortal: Medicine and What Matters in the End*, pg. 229).

What Are the Goals of Palliative Care?

- To help you talk about your wishes and make choices about your health
- To help with your symptoms like pain, shortness of breath and others
- To connect you with information and services that you may need now or in the future, like home care or hospice

What Does the Word *Palliative* Mean?

The word palliative comes from the Latin verb *palliare*, which means 'to cloak'. Palliative care aims to 'cloak' patients and families in care and support when dealing with an advanced, life-limiting illness.

Why Do Symptoms Matter?

You can experience symptoms at any time. These symptoms can have a big impact on how you feel. Symptoms might include pain, shortness of breath, nausea, vomiting, fatigue, feeling sad or worried.

Starting to manage symptoms early makes them easier to control. Early symptom control helps to keep you at your best for as long as possible.

Members of your health care team will ask you about symptoms a lot, to see how well they are treating them. They may change doses, add new medications, or stop medications that are no longer needed.

Tell your health care provider early if you have any symptoms or if they are getting worse



What is Advance Care Planning?

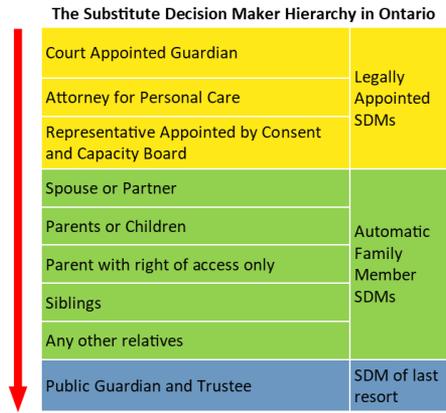
Advance care planning is different from making plans for your finances, property, will, or funeral. Advance care planning includes two key things:

1. Identifying Your Substitute Decision Maker(s) for Personal Care

Your Substitute Decision Maker is often called your SDM. Your SDM is the person(s) who will make health care decisions for you if you are too sick to make your own decisions. Your health care team will use the hierarchy from The Health Care Consent Act (see above) to determine your SDM. If you wish to choose someone else for your SDM, such as a friend or any other person you trust, you must complete a Power of Attorney document.

2. Telling Your Substitute Decision Maker(s) Your Wishes

Discussing your values, wishes, and preferences will not make your illness worse. It helps your SDM know and respect your wishes if you are too sick to make your own decisions. Knowing this may give you peace of mind. It may also reduce stress for those close to you who are asked to make decisions on your behalf.



Ontario's Health Care Consent Act, 1996



For more information on advance care planning visit www.speakupontario.ca

What are Goals of Care?

Goals of Care are your personal wishes for care now and in the future. Your health care team will help you understand what supports are



available based on these wishes. Your health care team will also guide you about tests and treatments that respect your goals.

Examples of Wishes and Goals

- Being pain free
- Not being a burden to others
- Live as long as possible
- Avoid unnecessary trips to the emergency room
- Not being kept alive on a machine or with tubes

Tell Your Care Team:

- What is important to you
- What you value and hope for
- How the care team can support you
- Any limits you want to set on the kinds of medical tests, procedures and treatments you want to receive now and in the future

What Other Planning is Important to Think About?

It's important to plan what to do when your illness gets worse. Planning can be about receiving home care services, getting equipment, or even deciding where else you could go to be cared for if things become more difficult to manage at home.

Although home care services is often the first step, ask your health care team about other places to stay like:

- Temporary short stay care (Respite)
- Retirement Homes
- Long Term Care Homes
- Residential Hospices
- In-hospital palliative care

Being informed about choices and resources available to you early, often relieves stress and worry for you and your loved ones.



Who is Your Health Care Team?

Your health care team may include many people. Some of these people will provide care for you in a clinic, at the hospital, in a hospice. Others will meet you in your home and provide care there.



The Roles of Your Health Care Team

Family Doctor

- Remains a key part of your health care team throughout your illness
- Helps with your ongoing health care needs to manage conditions like blood pressure, diabetes, coughs and colds
- Provides emotional support and may help with many of your palliative care needs
- Refers you to the palliative care team for more support, if needed

Palliative Care Doctor

- Helps your health care team manage more complex symptoms and situations as needed
- Works alongside your family doctor where applicable

Specialist Doctor

- Helps with the management of a specific illness such as heart disease, diabetes or cancer

Palliative Care Nurse

- Provides regular medical assessments and care in clinic, home or hospital
- Knows about your medical needs and communicates with your health care team
- Provides you and your caregivers with emotional support and helps you to access the resources you need

Palliative Care Nurse Practitioner

- Provides medical assessments and follows up as needed
- Works with your health care team to manage your needs as they change
- Helps you manage your symptoms and medications

Home & Community Care Palliative Care Coordinator

- Provides you with relevant community resources and supports
- Helps you and your caregiver to navigate the health care system
- Organizes home care services such as home care nurses, personal support workers and other health care professionals

Social Worker

- Helps you and your caregivers cope with the emotional, practical, and psychological impact of your illness
- Helps guide you through the health care and community systems
- You may meet with social workers on your own, with other family members or with your health care team

Personal Support Worker (PSW)

- Helps with personal care, like getting dressed, bathing or showering, and going to the washroom

Respiratory Therapist

- Helps with breathing and may check to see if you need oxygen at home

Speech-Language Pathologist (SLP)

- Recommends ways to help you swallow safely, eat more comfortably, and communicate more clearly

Dietitian

- Helps you adjust your food to meet your needs
- Provides education and support about changes in what you are eating that your illness may bring

Occupational Therapist

- Gives you advice on ways to complete your daily tasks safely and to the best of your ability
- Recommends equipment such as a cane, walker, wheelchair, hospital bed, commode (bedside toilet), bath chairs, or other assistive devices

Physiotherapist

- Checks your safety to get up and moving
- Recommends exercises to strengthen your muscles and to save energy

Spiritual Care Practitioner

- Offers a safe and confidential space to explore thoughts and feelings during end-of-life, including bereavement
- Provides support in discussing the purpose, meaning of life and what is important to you
- Helps you answer questions such as: “Why is this happening to me?”, “Why now?”, “How will I be remembered?”

Community Hospice

- Helps you, your family and your caregivers to cope with all the emotions and the impact of your illness
- Provides spiritual and bereavement support
- Hospice Counsellors can link you to resources, help you navigate the health care system and help with planning for your wishes

In addition to your formal health care team, there are many community organizations, volunteers and church groups who provide extra support. Talk to your health care team to learn more.



What are the key messages to take home?

- You are not alone
- Your symptoms matter
- Plan now for the future
- Talk to your loved ones about your goals, values and wishes
- Talk to your health care team about how we can best support you

Talk to your family doctor, nurse or anyone on your care team for more information. Additional information can also be found by visiting the Mississauga Halton Palliative Care Network website at www.mhpcn.net

Mississauga Halton Palliative Care Network www.mhpcn.net

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