

Exploring Your Options for Palliative Care

A guide for patients and families



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What is palliative care?

Palliative care is care by a team of healthcare professionals for people living with a serious illness and their families.

Palliative care:

- Cares for the whole person, including their physical, emotional, social and practical needs
- Supports their right to make decisions about their healthcare, based on their wishes and choices
- Can be part of the care you are already receiving

The goals of palliative care are to:



- **Relieve suffering due to pain and other symptoms
To prevent new symptoms from occurring**
- **Provide support for the patient and family
throughout the illness**
- **Improve the quality of life**

Palliative care can help people:

- ✓ At any age
- ✓ At any point in their illness, not just at the end of life
- ✓ Whether or not their illness can be cured
- ✓ Whether or not they have cancer
- ✓ Wherever they need it — in their home or a healthcare centre

When should I receive palliative care?

Palliative care may be right for you if you need:

- Help to manage symptoms and prevent new ones from occurring
- Help to plan your future care
- Support for yourself and your caregivers

Where can I receive palliative care?

Palliative care is available wherever you live. Services can be provided in your home or at a health care centre.

If you are staying in a health care centre, care is available 24 hours a day.

A medical or surgical unit in a hospital	<ul style="list-style-type: none">• A medical or surgical team is responsible for your care.• They can arrange for you to have palliative care services while you are being treated in the hospital.• The hospital's palliative care team (doctors and nurses) will come to the unit to provide palliative care services to you and your family.
A palliative care unit in a hospital	<ul style="list-style-type: none">• A palliative care team is responsible for your care.• You and your family will receive palliative care in a unit designed for this type of care.
A residential hospice in the community	<ul style="list-style-type: none">• A hospice team (doctors and nurses) will be responsible for your care.• You and your family will receive palliative care in a home-like setting, not in a hospital.
A long-term care home	<ul style="list-style-type: none">• A long-term care team is responsible for your care, which can include palliative care services.

If you are living in your home, a retirement or assisted living residence, care is not usually available 24 hours a day. The services you receive will depend on:

- Your healthcare needs
- The resources available where you live
- Your personal and financial resources (for additional services)

<p>A palliative care clinic in a hospital</p>	<ul style="list-style-type: none"> • Your doctor may refer you to a palliative care clinic in a hospital. • You will make appointments and come to the clinic for palliative care services. • These services are covered by the Ontario Health Insurance Plan (OHIP).
<p>Home visiting by a palliative care team</p>	<ul style="list-style-type: none"> • If you are unable to come to a palliative care clinic, your doctor may arrange for a palliative care doctor or nurse to visit you at home. • These services are covered by the Ontario Health Insurance Plan (OHIP).
<p>Home and Community Care</p>	<ul style="list-style-type: none"> • You may qualify for home care services provided by your Local Health Integration Network (LHIN). • A LHIN Care Coordinator will determine if you are eligible for services such as nursing visits, personal support (for example, help with bathing), occupational therapy and physiotherapy. • These services are covered by the Ontario Health Insurance Plan (OHIP).
<p>Home hospice services</p>	<ul style="list-style-type: none"> • Home hospices are non-profit organizations that train volunteers to provide support and services in your home. • Many services are available at no cost to you. • To learn what help they provide and find it in your community, ask your health care provider or search Hospice Palliative Care Ontario at www.hpco.ca/search.

Who provides palliative care?

Your illness affects all aspects of your life, so you will need a team to provide palliative care. You and your family are the most important team members. Your needs and goals determine the need for other members of your palliative care team.

Your main team members may include:

Team member	What they do
Doctor	<ul style="list-style-type: none">• Explores your wishes and preferences for care• Coordinates your plan of care with you, your family and other team members.• Helps manage your symptoms with or without medicines.• Works with your family doctor and other medical specialists.
Nurse	<ul style="list-style-type: none">• Monitors your symptoms and health care needs.• Helps you to manage pain and other symptoms.• Provides emotional support for you and your family.
Social Worker	<ul style="list-style-type: none">• Helps you and your family cope with your illness.• Offers counseling for emotional, social or practical matters like finances.
Occupational Therapist	<ul style="list-style-type: none">• Helps you do daily activities safely, such as sitting up in a chair or taking a shower.• Helps you and your family do other activities that are meaningful to you.• Helps you to stay as independent as possible.
Physio-therapist	<ul style="list-style-type: none">• Helps you to move about safely and as independently as possible.• Recommends equipment that will help you, such as a cane, walker or bath chair.

Team member	What they do
Pharmacist	<ul style="list-style-type: none"> • Helps you learn how to take your medications safely and manage your medicines at home.
Spiritual Care Provider	<ul style="list-style-type: none"> • Helps you explore the meaning of illness and its impact your life. • Helps you meet your spiritual needs through prayer, reflection or meditation. • Supports you and your family through all stages of illness and at the end of life.

Other team members may include:

Team member	What they do
Dietitian	<ul style="list-style-type: none"> • Helps you and your family plan a healthy diet or adjust what you eat and drink to give you better nutrition. • Helps you manage side effects related to your treatment or disease.
Psychiatrist or Psychologist	<ul style="list-style-type: none"> • Provides counseling and therapy to help you and your family cope with your illness. • Helps you learn to reduce stress and improve your emotional well-being.
Music Therapist	<ul style="list-style-type: none"> • Uses music to help your emotional well-being and help you cope with symptoms. • Music therapy is available at Princess Margaret Cancer Centre and Kensington Hospice.
Respiratory Therapist	<ul style="list-style-type: none"> • Provides help and treatment if you have trouble breathing. • Helps you get home oxygen if needed.
Speech Language Pathologist	<ul style="list-style-type: none"> • Provides help if you have trouble swallowing so you can enjoy your food safely. • Assesses and treats speech problems. • Offers you and your family tips so you can communicate more easily.

Team member	What they do
Volunteer	<ul style="list-style-type: none"> • Provides you and your family with comfort, companionship and practical help (such as wayfinding in hospital or help with personal care at home).
Home and Community Care Coordinator	<ul style="list-style-type: none"> • Assesses your condition and living situation to see what home care services you are eligible to receive. • Arranges the home care services you are eligible for. This may include services from nurses and personal support workers (who help with bathing, for example).

How can I get palliative care?

If you are staying in the hospital, ask your health care team to refer you to the Palliative Care Program.

If you are living in your own home, a retirement or assisted living residence:

- Talk with your family doctor or primary health care provider, or
- Call Home and Community Care Services at your Local Health Integration Network (LHIN). For the Toronto Central LHIN, call 416-506-9888 or toll-free 1-866-243-006.

How can I plan the care I will need?

Your decisions about your care in the future will be guided by your values, wishes and goals for care (see examples on the next page).

The process of thinking about these things and telling others how you want to be cared for in the future is called Advance Care Planning.



To learn more about Advance Care Planning go to: www.advancecareplanning.ca/

Use their free, online workbook to create a plan that you can print, download or share with others.

A step-by-step guide to Advance Care Planning

1. **Think about what makes your life meaningful.** What are your values, wishes and goals of care?

Some examples of 'Goals of care':

"I want to stay at home as long as possible."

"I am hoping to go to my relative's wedding in the summer."

"I'd like to stay pain-free."

"I want to continue chemotherapy treatment as long as it helps me."

"I don't want to die at home."

2. **Discuss your values, wishes and goals with your family** and others who are important to you. You may want to do this at a family meeting.

Family meetings

- Family meetings can be held at home, at a clinic visit or during your stay in the hospital.
- You can invite family, friends or anyone you want to be involved in your care.
- Your health care team may suggest a family meeting to find out how to help you best.

- 3. Talk with your healthcare team.** Make sure you understand your illness and what may happen with your health. Share your values, wishes and goals.
- 4. Make decisions for your future care** based on your values, wishes and goals and conversations with your family and health care providers.

The two main decisions are:

- What treatment and care would you want and not want?
- Who do you trust to make decisions for you (according to your wishes and values) if you are unable to speak for yourself?

Who will speak on your behalf?

- In Ontario everyone has an automatic substitute decision maker (SDM). They are the person or persons who would make health care decisions for you if you were not capable of making your own decisions. It is important for you to know who your automatic SDM would be.
- If you do not want your automatic SDM to make your health care decisions you can create a legal document naming someone as your Power of Attorney (POA) for Personal Care to speak on your behalf.

For more information ask for the UHN handout 'Substitute Decision Makers and Naming a Power of Attorney for Personal Care' or read it online at www.uhn.ca

- 5. Record your wishes and decisions.** Write down anything that would help others understand and support your future healthcare or end-of-life care. This plan will guide your care in the future if you become unable to communicate your wishes to others.

Make plans flexible

Talk with your health care team about any applications you need and keep your plans flexible. It is a good idea to have a back-up plan.

For example: You wish to receive end-of-life care at home, but you fill out an application for hospice care now, in case you are unable to stay at home in the future.

Where can I get more information?

Our hospital libraries and websites are a good place to start:

University Health Network – Patient and Family Education

- www.uhn.ca/PatientsFamilies/Health_Information/Patient_Family_Education

University Health Network Palliative Care

- www.uhnpalliativecare.ca
- This website describes palliative care at University Health Network and provides links to other resources.

University Health Network Inpatient Hospice Palliative Care Directory

- www.theprincessmargaret.ca/HPCOntario
- This directory includes information and the location of palliative care units, residential hospices, and palliative care beds at local hospitals.

Mount Sinai Hospital – Patient Education Resources

- www.mountsinai.on.ca/patients/patient-education-resources

Other resources we recommend:

Canadian Virtual Hospice

- <http://virtualhospice.ca>
- This website provides support and information about palliative and end-of-life care.

Canadian Hospice Palliative Care Association

- www.chpca.net
- This website has information about palliative care across Canada.

Hospice Palliative Care Ontario

- www.hpco.ca
- This website provides links to palliative care services in your community.

Speak Up

- www.advancecareplanning.ca
- This website has a workbook and other resources to help you with advance care planning.

Ministry of the Attorney General

- www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf
- This booklet helps you complete the form to name your Power of Attorney (POA) for Personal Care. This is a legal document that allows someone you trust to make decisions about your personal care, if you become incapable.

Visit www.uhnpatienteducation.com for more health information.

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