The Palliative Care Program: What you should know

Information for patients and caregivers

Read this resource to learn:

• What is palliative care

• How can palliative care help me

• Who is part of the palliative care team

• How do I access the palliative care program

• Where to get more information on palliative care

Please visit the UHN Patient Education website for more health information: www.uhnpatienteducation.ca

© 2017 University Health Network. All rights reserved.

This information is to be used for informational purposes only and is not intended as a substitute for professional medical advice, diagnosis or treatment. Please consult your health care provider for advice about a specific medical condition. A single copy of these materials may be reprinted for non-commercial personal use only.
What is palliative care?

Palliative care is an area of health care that focuses on providing the best quality of life for people with advanced illness. People of every age and at any point in their illness can get palliative care. It can be given when a cure is possible, in advanced disease, and at the end of life.

Palliative care looks after people with cancer. Palliative care also looks after people with non-cancer illnesses such as:

- Heart disease
- Lung and kidney disease
- Parkinson’s disease
- Alzheimer’s disease

The goal of palliative care is to ease suffering due to pain or other symptoms. Palliative care aims to treat the pain and symptoms you have now. It also tries to prevent new symptoms from occurring. Palliative care provides a chance for personal and spiritual healing.

How can palliative care help me?

The palliative care team provides a support system for people. The team will work with you to suggest care plans to help:

- manage symptoms
- support you and your caregivers
- plan for the future
Symptom Management

Symptoms may come from your illness or from the treatments that you are getting. Common symptoms include:

- pain
- nausea (feeling of wanting to vomit)
- vomiting (throwing up)
- shortness of breath (having problems with breathing)
- fatigue (feeling very tired)
- loss of appetite (trouble eating)
- trouble sleeping
- constipation (trouble having a bowel movement)

Many of these symptoms can be helped with medicines.

You may also be offered treatments that do not involve taking medicines. This can include:

- nutrition (food)
- physical therapy
- breathing methods
- meditation and relaxation

Psychosocial (emotional, social and practical) support

Dealing with a serious illness can be stressful. You may feel emotions such as sadness, fear and anxiety. Palliative care can help you and your caregivers cope with your illness by:

- providing counseling to help you deal with the emotions you may be feeling
- suggesting support groups and other community resources
- exploring the meaning of your illness and your spiritual beliefs
- making referrals to other psychosocial health experts
Palliative Planning (planning for the future)

The palliative care team can help you explore your goals, wishes and plan for the future. They can help you with some of the following:

- Address concerns about advance care planning, such as getting a power of attorney for personal care.

- Discuss your values (what is important to you) and help you make decisions about your care and treatment.

- Explore options for financial (money) help. For example, help with drug coverage (paying for medicine) and compassionate care benefits.

  Compassionate care benefits are a type of financial help. This help is for family members who have to take time off work to care for an ill family member.

- Link you to community supports such as the community care access centre (CCAC). Also link you to palliative care teams that visit patients in their own homes.
Who is part of the palliative care team?

As patients and caregivers, you are very important members of the team. The list below explains what each team member can do for you:

Core team members:

- **Palliative care doctor**: Focuses on managing your symptoms with or without medications. They will coordinate your care plan with you and other members of the team.

- **Palliative care nurse**: Helps you to manage and cope with your symptoms. They will also help you with psychosocial (emotional and coping) concerns.

- **Social worker**: Helps you and your caregivers cope with your illness. This may include counseling for emotional, social or practical matters (like finances).

- **Occupational therapist**: Helps you to safely do daily activities that have meaning for you and your family. These activities could be things like sitting up in a chair or taking a shower. They help you to stay as independent as possible.

- **Physiotherapist**: Helps you to move about safely and do as much by yourself as possible. They may suggest equipment such as a cane, walker or bath chair.

- **Pharmacist**: Works closely with you and your team to teach you how to take your medicines safely. They will also show you how to manage your medicines at home.

- **Spiritual care provider**: Helps you explore the spiritual meaning of illness, suffering, and life changes. Spiritual care offers support for loss and grief. They also provide a chance to engage in prayer, reflection, and meditation.
Other team members:

Dietitians: Helps you and your caregivers make changes to the foods you eat and drink. Dietitians can help you maintain a balanced diet or help improve your diet. They can also help you manage side effects related to your treatment or disease.

Psychiatrist or Psychologist: Provides counseling and therapy to help you and your family cope with your illness. They can help reduce stress and improve your emotional well-being.

Music therapist: Supports emotional well-being and managing symptoms through the use of music (available at Princess Margaret Cancer Centre).

Respiratory therapist: Provides help and treatment if you have trouble breathing. They can help you get oxygen at home if your doctor thinks you need it.

Speech language pathologist: Provides help if you have trouble swallowing so you can enjoy your food safely. They will also assess and treat speech problems. They can offer you and you caregiver tips so you can communicate more easily.

Volunteer: Provides emotional and practical support such as finding your way around the hospital.

Community Care Access Centre (CCAC) coordinator: Arranges home care services for you.
How do I access the palliative care program?

Ask your health care team to refer you to the palliative care program.

The palliative care program at UHN offers a number of services. Some services are for inpatients. These are patients who stay in hospital for at least one night.

Some services are for outpatients (patients who don’t stay overnight).

**Inpatient palliative care consult**

The inpatient palliative care consult teams are a group of palliative care doctors and nurses. This team will work with your primary health care team to provide you and your caregiver with palliative support.

Each of UHN’s four hospitals has a consult team:
- Princess Margaret Cancer Centre
- Toronto General
- Toronto Western
- Toronto Rehab

**Inpatient palliative care units**

There are 2 inpatient palliative care units at UHN. One is at Princess Margaret Cancer Centre. The other is at Toronto Rehab.

**Harold and Shirley Lederman palliative care unit**

**Princess Margaret Cancer Centre**

This a short term care unit. Patients will get help to manage symptoms including pain. The goal is to help you go home or move to a longer term palliative care unit. You will also get support in planning for end of life care.

**E.W. Bickle Centre**

**Toronto Rehab**

This is a longer term unit where patients can come for end of life care.
Outpatient palliative care clinics

Outpatient palliative care clinics see patients who are referred by their doctor. Patients with a cancer diagnosis would be referred by their doctor at Princess Margaret Cancer Centre. Patients with certain chronic non-cancer diseases would be referred by doctors at Toronto General and Toronto Western Hospitals.

Where can I get more information on palliative care?

University Health Network Palliative Care
Website: www.uhnpalliativecare.ca

University Health Network Inpatient Hospice Palliative Care Directory
Website: www.theprincessmargaret.ca/HPCOntario
This directory includes information and the location of:
- palliative care units
- residential (home-like) hospices
- palliative care beds within local hospitals

Princess Margaret Patient and Family Library
Main floor of the Princess Margaret Cancer Centre
416 946 4501 ext. 5383
Email: patienteducation@uhn.ca

Canadian Virtual Hospice
Website: http://virtualhospice.ca

The Canadian virtual hospice provides support and information about palliative and end of life care. This information is for patients, family members, caregivers and health care providers.

Hospice Palliative Care Ontario
Website: http://www.hpco.ca

The development of patient education resources is supported by the Princess Margaret Cancer Foundation.