

Palliative Care

Hamilton Health Sciences and surrounding communities

What is palliative care?

Palliative care is a way of providing health care that focuses on improving the quality of life for you and your family when you are faced with an illness that may not be cured. The aim of palliative care is to prevent and provide relief from symptoms, and address other matters, such as physical, spiritual, emotional, social, and practical problems that can happen when someone is experiencing a serious illness.

Palliative care:

- Helps you to feel as well as you can by managing your symptoms, such as pain, shortness of breath and fatigue and weakness.
 - Helps you and your family to understand your illness, treatment choices, and how those choices might affect your health.
 - Supports your right to make decisions about your health care which respects your wishes and choices.
 - Supports the wishes of you and your family to be in the setting of your choice (home, hospice, hospital, long term care).
 - May help you and your family avoid unnecessary hospital visits by helping you and your family to know what to expect in the future and have plans to address changes in your health.
 - Helps to prepare you and your family for the dying process.
 - Supports you and your family to cope with loss and grieving.
 - Supports your loved ones during their bereavement.
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Understanding your fears about palliative care

Although death is a natural part of life, the thought of dying frightens many people. Many patients and families worry about involving a palliative care team in their care. Some of those worries are:

- **If we talk about palliative care will my family member lose hope?**
Having a serious life limiting illness can be very frightening to both you and your family. Palliative care teams will ask what is most important to you. They will provide information in a way that respects how much you want to know and when you want to know it. They can support your need for hope by involving you in decisions about your illness and health care.
 - **If I am referred to palliative care does that mean my doctors have given up and I will no longer receive active treatment for my illness?**
No. Palliative care can be provided with any medical care for your illness. The palliative care team will work with your doctors and specialists as part of your health care team.
 - **My doctor has referred me to a palliative care team. Does this mean I am dying?**
Palliative care is often confused with end of life care. End of life care is the care provided in the last few days or weeks of life. Palliative care can start as soon as you are diagnosed and continue throughout your illness. End of life care is only a part of palliative care.
 - **Will palliative care shorten my life?**
Palliative care supports life. It neither speeds up nor delays death. It can help you to understand and manage your symptoms which can help you to live a better life, for a longer time.
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What are the benefits of receiving a palliative approach to care?

There is a growing public awareness that a palliative approach to your care can have many positive benefits for you and your caregivers.

Some of these benefits are:

- 1. Better quality of life** by helping you with your pain and other symptoms to allow you to feel as well as possible for as long as possible.
- 2. Better understanding of your disease and the goals of treatment.** Many people who have a life limiting illness have questions about how their disease will progress and change over time. There is evidence that tells us that people receiving medical care designed to improve their symptoms and prolong their life often believe that the treatment will “cure” their disease. If you and your family have a better understanding of your illness and how suggested treatments will affect you and your illness you may be able to make more informed decisions about your care.
- 2. Fewer invasive treatments at the end of life.** Most people who think about the end of their life do not imagine that they will be in an Intensive Care Unit (ICU) hooked up to machines experiencing many painful procedures. Most people hope to be comfortable and peaceful, surrounded by our family and friends. However, many people have aggressive medical care in the last few weeks, days, and hours of life that has no chance to return them to a meaningful quality of life. This can happen if you have not had the chance to think about what you would want before your health worsens.

3. Less time spent in Emergency Departments and hospitals.

One of the most common things that bring patients to the Emergency Department is unmanaged symptoms. A goal of palliative care is to help you to know what symptoms you might experience now and in the future, and to have a plan in place to manage those symptoms. Once patients and their families know what to expect and have a good plan to manage their symptoms, they are less likely to have the need to seek medical care in the Emergency Department.

4. More likely to have advance care planning discussions with their doctors and loved ones

and assign a Power of Attorney for Personal Care whom they trust to carry out their wishes about resuscitation, levels of investigation and treatment, and plans for end of life care. They are also more likely to have done life closure activities such as making funeral arrangements of their choosing and creating a legal will.

5. Greater patient and family satisfaction with care.

When you understand your illness, treatment options, and you know what to expect in the future you are better able to make decisions about your care that will allow you to focus on things that are important to you. Knowing what to expect in the future may also help you to feel less worry because you are able to have plans in place to help you deal with those changes. This may help you and your family to feel less distress and greater satisfaction with your care.

How can palliative care help me?

Issue	Palliative care can help...
Physical	<ul style="list-style-type: none"> • Pain • Shortness of breath/cough • Fatigue or tiredness • Loss of appetite • Nausea and vomiting • Confusion • Difficulty sleeping • Constipation
Psychological	<ul style="list-style-type: none"> • Emotions (sadness, worry, anger, distress, hopelessness, loneliness, guilt) • Depression, anxiety • Fears (abandonment, being a burden)
Social	<ul style="list-style-type: none"> • Relationships (reconciling difficult relationships; changing roles within family) • Family caregiver support • Financial (disability, Employment Insurance or EI for family caregiver, insurance) • Legal (powers of attorney for property and health, wills)
Spiritual	<ul style="list-style-type: none"> • Find meaning in your life • Talk about questions such as "Why is this happening to me?" "What happens after I die?" • Loss and grief • Rituals • Religious beliefs
Practical help	<ul style="list-style-type: none"> • Nursing visits at home • Obtain help with activities of daily living • Equipment (such as walkers, wheelchairs, hospital bed) • Caregiver support and relief • Volunteer visitors
End of life planning and care	<ul style="list-style-type: none"> • Life closure (completing life tasks, closing relationships, saying goodbye) • Advance care planning • What to expect in the last few days or hours of life • Plan for care at end of life, help to make application to hospice or palliative care unit if desired

Who provides palliative care?

Anyone involved in providing health care to you can take a palliative approach to your care, which means they can:

- help to manage your pain and other symptoms
- provide practical and emotional support for you and
- help you to make decisions about your care now and in the future.

Health team

Palliative care is usually best when it is provided by a group of health professionals working together with you and your family. Often this will involve doctors (including your family doctor and medical specialists), nurses, social workers, occupational therapists, physiotherapists, dietitians, chaplains and spiritual counselors. The members of the team you see will depend on your needs.

Family, caregivers and friends

Family, caregivers and friends are an important part of the team. They are involved in helping you to make decisions about your care. They also are with you throughout the illness and can help to provide information about what is happening now and in the past. They can help health care teams to know what your wishes and goals of care are. As you become weaker they also play an important role in providing care, including monitoring symptoms and giving practical help with personal care and administering medication.

Volunteers

Volunteers also can play an important role. They help by providing:

- companionship,
- caregiver relief so that your family may leave you for a time knowing that someone is sitting with you to help you if you need it,
- transportation to and from your medical appointments.

Your Hamilton Niagara Haldimand Brant Local Health Integrated Network (HNHB LHIN) (previously known as Community Care Access Centre or CCAC) care coordinator or your health care team can help to identify organizations in your region that provide volunteer services and help you to access them.

Specialty teams that provide palliative care

1. Palliative Care Consult Team

Are health care teams that see patients who are admitted to the hospital. Your admitting doctor may refer you to one of these teams if you have symptoms that are difficult to manage or if you need help making decisions about your goals for care now and in the future. There is a team at these Hamilton Health Sciences sites; Juravinski Hospital and Cancer Centre, Hamilton General Hospital, St. Peter's Hospital and West Lincoln Memorial Hospital.

Many other hospitals in the region also have teams. Ask your health care team if you need more information on these resources.

2. Outpatient Palliative/Pain and Symptom Teams

Are teams who see patients with palliative needs in outpatient clinics. You must be well enough to attend clinic appointments and need the care of a specialized palliative team. The availability of these clinics varies across the region. You can ask your health care team whether there is an outpatient palliative clinic in your area. You will need a doctor's referral to be seen.

3. Shared Care Team – HNHB LHIN

This is a specialized team of palliative care doctors, nurse practitioners and clinical nurse specialists who can visit you at home. They work with you, your family doctor and visiting nurse to help you with your symptoms and other needs.

Your family doctor is a key member of the team and will be your contact if you need help while you are at home. You can be referred to this team by your family doctor, medical specialist, HNHB LHIN care coordinator or your visiting nurse.

Where can I receive palliative care?

You can receive palliative care anywhere. The goal of palliative care is to support you so that you can live as normal a life as possible for as long as you are able in the setting of your choice.

Home

For most of the time you will be at home. Being at home may help you to remain involved with your family's day to day life and live as normally as possible. Some people feel that when they are at home they have more control of their care.

Initially if you need help you will be referred to a HNHB LHIN care coordinator.

HNHB LHIN Care Coordinator

You will be assigned a care coordinator who can:

- Arrange for a variety of services to support you at home including: nursing visits, personal support workers, social worker, counselor, occupational therapist, physiotherapist or dietitians.
- Help you to get the equipment you need.
- Make applications to hospice or palliative care units if you need them.

If you are going home from hospital, you can ask your health care team about a referral to HNHB LHIN care coordinator.

If you are already at home you can contact your family doctor for a referral or you can refer yourself by dialing toll-free at **1-800-810-0000**.

What happens if I need more help?

There will be a time towards the end of your life when you will need care 24 hours a day.

Dying at home is possible with support from family and friends. In your last few days of life you will need help with:

- bathing
- managing your bowel and bladder functions
- turning and repositioning
- mouth care
- Taking medications. This may involve giving needles when you are not able to swallow your medications.

The HNHB LHIN nurses will help to teach your family and friends how to look after you and visit to ensure that you are comfortable.

HNHB LHIN can provide some support, but they cannot provide around the clock care.

If you have private health insurance benefits you may have coverage for nursing care in addition to the care HNHB LHIN is able to provide.

Check your policies and contact your providers to find out what coverage you have and what you need to provide them with so that they can cover this additional nursing care.

Dying at home for some people is difficult and/or not where they want to be. Many people think that they will go to hospital. A busy hospital ward is not where most people want to be at the end of life. They are noisy and busy places.

There are places which provide care in the last few weeks of life. If you are already in the hospital and approaching a time when you will need more care than you have at home your team may discuss starting an application to one of the following places while you return home to wait for a bed:

1. Hospice

A hospice is a place where care is provided in a home-like setting when the goals of care focus on comfort and you are expected to live 3 months or less. The usual length of stay is few days to a few weeks.

You will have a private room. Your family is able to stay with you all the time and/or visit whenever they are able.

There are nursing, personal support workers, spiritual/psychosocial counselors and volunteers to help with your care and to support you and your family.

There are hospices in:

Hamilton

- Dr. Bob Kemp Hospice
905-387-2448
- Emmanuel House
905-308-8401, ext. 3222

Brantford

- Stedman Hospice
519-751-7096

Burlington

- Carpenter Hospice
905-631-9994

Grimsby

- McNally House Hospice
905-309-4013

St Catharines

- Hospice Niagara
905-984-8766

Hospices also provide many other programs such as day programs, volunteer visitors at home and bereavement support.

You can learn more by going to their website or calling the hospice.

How do I apply?

If you are in hospital the social worker will help to begin the application to hospice.

If you are at home you can contact your HNHB LHIN care coordinator who will complete the application and let you know about the bed availability.

When should I apply?

There are a limited number of beds. Hospices have difficulty accommodating crisis admissions because they may not have open beds. If you hope to go to hospice we recommend you apply a few weeks before you think you will be ready. A good indication that you are ready to apply is that you are spending $\frac{1}{2}$ to $\frac{3}{4}$ or more of the day in bed.

You can contact your local hospice and arrange a tour to see whether the hospice is somewhere you would feel comfortable at the end of life.

2. Beds/units in community hospitals and complex care hospitals

Many community hospitals have a few beds or a unit for palliative care. Often this is a more hospital like setting. You may be in a private, semi-private or ward room depending on availability and your private health insurance coverage.

St Peter's Hospital

In Hamilton, St. Peter's Hospital, a part of Hamilton Health Sciences, has 60 inpatient palliative care beds which are open to any adult in the later stage of their illness that is expected to live 3 months or less, has chosen to focus their care on comfort and requires an expert palliative care team for symptom management.

How do I apply?

You can ask anyone involved in your care to make a referral to St. Peter's, including your family doctor, medical specialist, visiting nurse, HNHB LHIN care coordinator or social worker.

If you are in hospital, a social worker can help you begin to complete the application forms.

If you are at home you can contact your HNHB LHIN care coordinator who will complete the application and let you know about the bed availability.

When should I apply?

Urgent admissions from home to a St. Peter's Hospital palliative care bed can usually be arranged within 48 hours following a referral.

In smaller communities your family doctor, HNHB LHIN care coordinator or visiting nurse can help you to access a palliative bed if you need one.