

UNDERSTANDING YOUR PALLIATIVE CARE OPTIONS

INFORMATION FOR OLDER ADULTS, FAMILIES,
AND CAREGIVERS



READ THIS PAMPHLET TO LEARN:

- What Palliative Care Is.
- How to Plan Your Palliative Care.
- About Palliative Care Services at Hospitals, Hospices and at Home.



Sinai Health System

HEALTHY AGEING AND GERIATRICS

WHAT IS PALLIATIVE CARE?

Palliative care is a special area of health care. It focuses on providing the best quality of life for people who are living with an advanced illness. Palliative care teams provide a support system for people. The team will suggest care plans to help

- Relieve pain and symptoms associated with advanced illnesses.
- Support individuals living with an advanced illness and their caregivers to establish their care preferences and goals of care and with planning future care and treatments that are aligned.
- Provide end-of-life care.

The goal of palliative care is to help all patients to live as actively and comfortably as possible until they die.

Palliative care can take place in any setting and can be delivered in a hospital, on a palliative care unit, in a hospice, or at one's home, based on the patient's preference and type of end-of-life care wanted and needed. Palliative care teams in every setting aim to always prevent and ease end-of-life suffering.

PLANNING AHEAD: COMMUNICATING YOUR CARE GOALS, PREFERENCES AND END-OF-LIFE WISHES

Planning the type of care you want to receive is known as advance care planning. **Advance Care Planning** is the process of communicating and reflecting on the type of health and personal care you would want in the future.

Asking yourself the following questions could be helpful for you in determining your care goals and preferences:

- How do I want to live? What are my values? What makes life meaningful for me?
- What sort of care would be acceptable or unacceptable to me and when?
- How important is the physical location of where I die? Would I prefer to do so at home?
- If I am nearing death, what would make it peaceful for me?

Discussing end-of-life preferences can be difficult, but it is an important conversation to have with family members or friends. When having a conversation about end-of-life care with care providers, patients and their caregivers can then communicate their values, which their palliative care team can help them to translate into care and treatment options.

If you were unable to speak for yourself, there are many ways to have others communicate your preferences and wishes, including

- Naming a Substitute Decision Maker “SDM” or Power of Attorney “POA” for Personal Care
- Having discussions around your care preferences with your SDM or POA
- Preparing a Living Will/Advance Directive that outlines your care preferences

For more information on naming substitute decision makers, read our pamphlet “**Naming A Substitute Decision Maker or Power of Attorney for Personal Care.**”

ACCESSING PALLIATIVE CARE SERVICES

HOSPITAL-BASED PALLIATIVE CARE

You may be referred to a hospital's palliative care team if you are currently a patient receiving care from another area within the hospital. This is done through a referral that is made by the physician overseeing your care in hospital.

Palliative care professionals in hospital will work with you and your loved ones and your main physician to make sure your physical, emotional and spiritual needs are being met. For example, they are experts at managing symptoms such as pain or difficulty breathing. If needed, they will also help you and your loved ones make decisions about your future treatment and care.

If you need to receive ongoing palliative care, your palliative care team will help you decide where the best place is to receive your continued care. This includes receiving palliative care at home, in a hospice or nursing home or on a hospital-based palliative care unit. Your palliative care team will work to try to ensure your transition to your new place of care is smooth and seamless.

HOME-BASED PALLIATIVE CARE

You may prefer to receive palliative care in the comfort of your own home. Palliative care teams will work with you and your family to meet your physical, emotional, and spiritual needs at home.

Palliative care services at home can be arranged by your Local Health Integration Network (LHIN) Home Care Program. You can also access additional palliative care services through a number of community-based organizations.

At Mount Sinai Hospital, the Temmy Latner Centre for Palliative Care provides in-home palliative care from palliative care physicians and nurses working in partnership with the Local Health Integration Network's (LHIN) Home Care Program. More information on Temmy Latner Centre for Palliative Care can be found on page 9.

HOSPICE-BASED PALLIATIVE CARE

A hospice is a stand-alone community-based palliative care setting for those who may be facing a life-limiting illness. Hospices can help manage pain and other symptoms so that a person can live as comfortably as possible in a community-based home-like setting. A number of community and health care palliative care organizations offer both hospice-based care as well as in-home palliative care and hospice services.

Hospices typically offer:

- Specialized care from an interprofessional team
- Personal support and caregiver respite
- Friendly visiting by trained volunteers
- Complementary therapies
- Links to other community support programs
- Transportation services

For more information on finding hospices in your area, visit our **Suggested Resources** section on page 10.

PALLIATIVE CARE TEAMS

If you are receiving palliative care, you will have access to a health care team dedicated to making sure you are safe and comfortable.

Members of your palliative care team may include:

Palliative Care Doctor and Nurse

A palliative care doctor and/or nurse will work with your main medical team. They can

- Support you and your caregivers through your illness
- Prescribe treatments to control pain and other uncomfortable symptoms
- Discuss medical decisions with you and your caregivers
- Monitor and manage your care as needed

Nurse

A palliative care nurse provides regular assessments and care. They help you with many daily tasks such as

- Monitoring your pain and symptoms
- Giving you medication as needed
- Assisting with any other medical needs

Social Worker

A palliative care social worker helps you and your caregivers cope with the impact of your illness. They can help you with many types of needs. These include emotional, financial and any practical needs. A social worker can give you

- Individual and family counselling about coping
- Information about practical or financial resources
- Information about hospice and palliative care units in the community and help filling out forms to access these
- Help with talking to your care providers

Information about advance care planning, living wills, powers of attorney, and how to decide who makes decisions when you cannot.

Physical and Occupational Therapists

Palliative care therapists will check to see how well and how safely you move around and function. They may recommend equipment to help you such as

- Wheelchairs/walkers
- Bedside commodes (toilets)
- Bath chairs
- Hospital beds

They may also teach you some exercises you can do to feel better.

Speech and Language Pathologist

A palliative care speech and language pathologist can help if you have trouble eating, drinking and/or communicating. They can make recommendations to:

- Help you swallow better
- Eat more comfortably
- Communicate more clearly

LHIN Care Coordinator

A Local Health Integration Network (LHIN) Palliative Care Coordinator can help organize the services you need at home, including

- Personal support (such as help with bathing)
- Nursing visits
- Caregiver respite
- Equipment
- Physiotherapy and occupational therapy
- Social work

The services funded by the government vary from region to region. A LHIN Care Coordinator will tell you what services are available to you in your home.

Dietitian

- A dietitian helps people with nutritional needs. They will make recommendations to help you keep the safest and most satisfying diet.

Respiratory Therapist

- A respiratory therapist may check to see if you need oxygen at home, and help you obtain it if you do
- If you have a tracheostomy, the respiratory therapist will discuss what your needs are, and recommend equipment that you will need to manage your tracheostomy at home.

Spiritual Care

A spiritual care provider, like a chaplain or priest, can provide spiritual support for you and your family. Spiritual care includes

- Providing encouragement and comfort
- Providing support for loss and grief
- Providing a time for prayer, meditation and reflection
- Linking spiritual and faith-based activities

TEMMY LATNER CENTRE FOR PALLIATIVE CARE

The Temmy Latner Centre for Palliative Care provides palliative care and end-of-life services to patients who are living with an advanced illness. It also provides support to their caregivers and families.

Patients who are discharged from Mount Sinai and other Toronto-based hospitals and transitioning back home in Toronto, North York, York or East York may benefit from the centre's home-based palliative care services run in partnership with the LHIN Home Care Programs.

Doctors from the centre provide specialized palliative care in patients' homes and are available 24 hours a day, seven days a week.

To be referred to the Temmy Latner Centre for Palliative Care, a physician must complete a referral form

Eligible patients must

- Have a valid OHIP Card
- Be diagnosed as needing palliative care
- Live in the Program's catchment area

For more information about the Temmy Latner Centre for Palliative Care and their catchment area, visit their website at www.tlcpc.org, or contact the centre.



Phone: 416-586-4800 ext. 7884



Email: info.tlcpc@sinaihealthsystem.ca

SUGGESTED RESOURCES

ADVANCE CARE PLANNING RESOURCES:

THE CONVERSATION PROJECT

The Conversation Project focuses on helping people talk about their wishes for end-of-life care. Visit their website for more information on having end-of-life conversations.



www.theconversationproject.org

SPEAK UP CANADA

SPEAK UP Canada is part of a larger initiative - Advance Care Planning in Canada. Speak Up offers workbooks and guides on developing your advance care plan.



www.advancecareplanning.ca

EDUCATION TO SUPPORT HEALTHY AGEING

For information on substitute decision makers and powers of attorney for personal care, read our pamphlet:



Naming a Substitute Decision Maker or Power of Attorney for Personal Care

PALLIATIVE AND HOSPICE CARE RESOURCES:

HOSPICE AND PALLIATIVE CARE ONTARIO

Hospice and Palliative Care Ontario (HPCO) offers public education and awareness on Hospice Palliative Care.



www.hpco.ca

LOCAL HEALTH INTEGRATION NETWORK (LHIN)

To arrange palliative care at home, contact your local LHIN for referral and assessments.



310-2222 (No area code required)



www.healthcareathome.ca

CIRCLE OF CARE

Circle of Care provides a number of end-of-life in-home supports including a visiting hospice volunteer program, personal care, homemaking and caregiver relief.



www.circleofcare.com/helping-you-at-home/end-of-life-care/

RELEVANT RESOURCES IN OUR SERIES

- Living Longer, Living Well – Your Guide to Healthy Ageing
- How to Prevent and Manage Delirium
- Recognizing and Managing Hearing Loss
- Safe Medication Use for Older Adults

ADDITIONAL HEALTH RESOURCES IN OUR SERIES:

- Calcium, Vitamin D and Bone Health
- Preventing Falls at Home
- Managing Constipation
- Improving Urinary Incontinence
- Managing Sleep in Older Adults
- Substitute Decision Makers and Powers of Attorney
- Elder Abuse
- Managing Caregiver Stress

ADDITIONAL COMMUNITY RESOURCES IN OUR SERIES:

- Meals on Wheels
- Community Transportation Options
- How to Register for Wheel-Trans
- Driving Assessment Services
- Funding for Mobility Aids from the Assistive Devices Program

Visit www.sinaigeriatrics.ca/healtheducation for additional resources for older adults, families and caregivers.

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