THE TRUTH ABOUT
Hospice Palliative Care:
A GUIDE FOR CANADIAN FAMILY CAREGIVERS
The Truth About Hospice

Let’s face it. Death is a difficult topic. No one wants to think about it. Few are willing to talk about it. However, we’ll all deal with it, eventually. Many will go through the final days with an elderly parent, family member or friend. Some will need to manage the details from afar.

Still, end of life doesn’t need to be so daunting, depressing or dreaded. It can be full of life-affirming moments of compassionate care. Advance care planning is key to help making sure a loved one’s final days are as comfortable and organized as possible. However, even if you’ve already started down that road with a family member or friend and don’t know where you’re headed, it’s not too late to get the information you need to help make smart decisions.

Among the most difficult aspects of hospice palliative care are the pre-conceived ideas about end of life. There are many myths surrounding hospice palliative care. There’s also a fear of death. Facing the truth head-on and taking action could be the best course for you and your family.

In this guide, we’ll address several of the myths surrounding hospice palliative care, and hopefully give you or someone you’re caring for a clearer view of the road ahead.

86% of Canadians have not heard of advance care planning. Only 9% have ever spoken to a healthcare provider about their wishes for care.*

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Receiving hospice palliative care means you’ve “given up”.

In a nutshell, hospice palliative care is a holistic approach to care that neither hastens nor prolongs death. Instead, this concept of care aims to affirm life and face dying as a normal part of living. This approach for families creates a unique care plan where the individual and family caregiver are the center of attention, and may be implemented early in the course of an illness.

Hospice palliative care not only involves an individual who may be receiving medical care, pain management, and emotional, psychological and spiritual support, but also offers support for the family caregiver – who may serve as the primary caregiver – throughout his or her loved one’s illness and typically for at least a year following that individual’s death.

Hospice palliative care aims to promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.\(^2\)

The palliative approach to care is defined as “care that focuses on meeting a person’s and family’s full range of needs – physical, psychosocial and spiritual – at all stages of a chronic progressive illness, not just at the end of life. It reinforces the person’s autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It sees hospice palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging. It provides key aspects of palliative care at appropriate times during the person’s illness, focusing particularly on open and sensitive communication about the person’s prognosis and illness, advance care planning, psychosocial and spiritual support and pain/
OF THOSE CANADIANS THAT HAVE A PREFERENCE OF WHERE THEY DIE,

75% would prefer to die in their home.³


3. A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima’s proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region). Full survey available here: http://www.hpcintegration.ca/media/51032/The%20Way%20Forward%20-%20What%20Canadians%20Say%20-%20Survey%20Report%20Final%20Dec%202013.pdf
symptom management. As the person’s illness progresses, it includes regular opportunities to review the person’s goals and plan of care and referrals, if required, to more specialized palliative care services.”

Hospice palliative care is typically initiated soon after the diagnosis of a serious or terminal illness, and encourages the individual to have frequent conversations with both family and health care professionals about his/her goals of care – adjusting these goals as the disease progresses. This care may complement and enhance disease-modifying therapy or it may become the total focus of care.

Hospice palliative care focuses on helping to improve quality of life and helps individuals to live their final days in comfort. Its goal is to help people complete life’s journey with comfort, dignity and companionship. Pain and symptom management are therefore a major aspect of hospice palliative care.
Even though the family caregiver plays a large role in his/her loved one’s care, a team of professionals – including physicians, nurses, personal support workers, spiritual care providers and more – work together to provide the best possible care and meet the needs of the loved one and the loved one’s family.

Professionals are usually trained by schools or organizations that are governed by specific educational standards. All providers are generally accountable to standards of professional conduct that are set by licensing bodies and/or professional associations.

Volunteers also play a large role in providing comfort to individuals and their family caregivers. Although volunteer training can be thorough, it may vary from province to province.

As a family caregiver, I am all alone on my journey.

Although as a family caregiver you may serve as the primary caregiver for your loved one, you are never alone. You have an expert team to call upon when you need assistance.
An interdisciplinary team-based approach can help families make the most of their time together. A hospice palliative care team typically includes the following members:

**Physician** - The physician’s primary role is to help manage the patient’s pain, symptoms and other medical concerns. This generally involves regular evaluation of comfort and modification of medication as pain and other symptoms may increase.

**Family Caregiver** - The family caregiver is at the center of the hospice palliative care team and may be the primary caregiver on the team, depending on the setting of care. Family caregivers typically provide care their loved one would receive while in a hospital or residential hospice; for example, providing assistance with bathing, toileting, grooming and eating. However, family caregivers also can look to other members of the team for such help and support.

**Nurses** - Nurses generally check in to make sure that a person is comfortable and that his or her physical needs are being met. Nurses also help to educate family members, teaching them techniques for personal care and ways to help keep their loved one comfortable.

**Social Workers** - Once someone is admitted to hospice palliative care, social workers provide pivotal support to both patients and their families. This includes patient advocacy, assessment, care delivery, advance care planning, decision-making, education and research, information sharing, interdisciplinary teamwork, and assistance with self-reflection.

**Spiritual Care Advisor** - A spiritual care advisor or chaplain provides spiritual support to the person in hospice palliative care and his/her family members.
Speech/Physical Therapist – While not typically part of the core hospice palliative care team, the team may need the assistance of a speech therapist to show the patient techniques to communicate with family members and caregivers. A physical therapist may help someone on hospice palliative care learn to move with a disability or a new device.

Volunteers - Volunteers help by providing an individual emotional support and companionship, comfort, practical assistance such as running errands, informational support, respite care, and grief and bereavement support. Hospice palliative care volunteers are usually great listeners and good at coping with the demands associated with caring for the dying.

Personal support workers – Personal support workers may assist with other tasks as required. They are sometimes available for home care visits on an intermittent basis, usually one time a week, for assistance with tasks such as bathing.

Professional Caregivers - Outside caregivers from in-home care companies are available to help as well. They can provide companionship and assistance with personal services, meal preparation and light housekeeping. They can also provide respite help if the family needs time away or has an outside commitment. A caregiver may further support the family’s loved one by providing assistance with laundry, medication reminders and errands.

MYTH NO. 3: You can’t keep your own doctor if you enter hospice palliative care.

Individuals will usually be referred to a hospice palliative care physician by their family physician, who may work closely with the hospice palliative care physician to determine a plan of care. Someone in hospice palliative care can usually keep his/her family physician. However, that person will also typically gain a hospice palliative care physician as part of the care team. In smaller and more rural communities, family physicians may also be trained to provide hospice palliative care.
Hospice palliative care programs are provided in many care settings. This can be the place your loved one calls home. “Home” may be a personal residence, a long term care facility, residential hospice, and even a prison or a shelter. In fact, a recent study discovered that most seniors in Canada would prefer to live at home and want to stay there as long as possible.⁶

An Ontario study found that between 20 and 50 per cent of people on waiting lists for residential long-term care could age safely and cost-effectively at home if some basic services were accessible.⁷ Hospice palliative care services, when combined with treatment, can lead to better outcomes, such as improvement of symptoms, while reducing costs.⁸

The home and community care workforce, which consists largely of nurses and personal support workers, has needed to adapt to a growing demand for home care. Integrated hospice palliative care teams that connect acute care, home care and community care will help to support the aging Canadian population as more and more suffer from multiple chronic and life-limiting illnesses.

Residential hospice palliative care programs are still at least 50 per cent funded by charitable donations, and pass on no costs to the families of those they serve. However, as hospice palliative care is designated as a core service under only a small number of provincial health plans, families must still typically bear part of the cost of dying at home, in a long-term care facility, or almost anywhere else outside a hospital.⁹


Receiving hospice palliative care means that death is imminent.

Hospice palliative care is a process that can be as unique as the individual.

In the past, hospice palliative care was traditionally for people with a prognosis of six months or less to live, after all curative treatments had ceased. Now, a person may be referred to hospice palliative care earlier in his/her disease path, with goals of care reviewed and discussed over time. Some patients may require complex hospice palliative care provided by specialized care teams in residential hospices or hospitals.

The palliative approach to care helps to ensure that everyone who is becoming frail or is diagnosed with a life-limiting illness benefits from hospice palliative care services. A person may benefit from this approach for months or even years prior to his/her death.

This type of care may also enable more people to receive hospice palliative care in the setting of their choice and reduce the fear associated with death. To learn more about the palliative approach to care, please see the resources section of this document.

Once a family member is referred to hospice palliative care, there is no time limit on how long a patient can receive care.
We shouldn’t tell Mom she is dying or has exhausted all treatment options.

It’s important to be honest with a loved one and to remember that people with a life-limiting illness do have a choice. They can continue treatment to try to combat their illness or they can discontinue treatment and seek comfort care. When they discontinue treatment, they may be referred to hospice palliative care, which is a holistic approach designed to help control the pain and manage the symptoms associated with the illness.

They may move from a hospital to a home setting or from a hospital to a long-term care facility or residential hospice. They may also remain in a hospital-based palliative care unit. They must weigh several factors when they make their decision. Deciding what to do can be a process.

Hospice palliative care may make someone feel as though others have given up hope on him or her, so they must be reassured that is not the case. Hospice palliative care is not about giving up hope, but helping to ensure that a person lives his/her final days in quality and free from pain. In fact, some individuals may improve in hospice palliative care for a time. When it is time to go, though, hospice palliative care can help someone die with dignity.

Here are some conversation starters that could help a family caregiver and his/her loved one work through these issues:

“Mom, I wish we had a treatment that could take all this away, but we don’t. I think we should focus on the things that will enable you to have the best quality of life for the longest period of time.”
“What do you think? Do you feel like you’re on your final journey?”

“Did you understand what the doctor said? Can I go over that with you?”

“Do you have questions about what this means?”

“The doctor has suggested hospice palliative care. I think this sounds like a great way to make you more comfortable. Would you like to learn more? I think I would. We can have someone come in and talk with us about hospice palliative care. How does that sound?”

“After we learn more, you can decide what you’d like to do.”

“I’ll be with you every step of the way, Mom. We’ll face this together.”

It is also essential that you have conversations about advance care planning while your family member is still able. Advance care planning is a process to help an individual reflect on his/her values and wishes, and discuss his/her future health and personal care preferences. A substitute decision-maker should be established as well. This is the person who is designated to make decisions should a loved one become incapacitated and unable to do so.
The hospice palliative care philosophy focuses on quality not quantity. The emphasis is on living comfortably and with dignity. It’s not about counting the days, but celebrating the life we’ve lived, and making the most of every moment.”

Dr. Larry W. Parsons,
Hospice and Palliative Care Specialist
THE FAMILY CAREGIVER

The family caregiver plays an integral role in hospice palliative care and often serves as the primary caretaker for a family member or loved one. Having to care for a parent or family member during this time can be physically and emotionally exhausting. The dying process can bring intense emotions that require exceptional coping skills. These emotions can change daily and even hourly as the end nears.

Take time to adjust so that you are comfortable in this new role. Some people never become fully comfortable and feel guilty when they cannot do it. If the role of caregiving is overwhelming you or you don’t have enough support, there is help. It’s also a good time to pull the family together and determine everyone’s roles. Hold regular family conferences and make sure to keep the lines of communication open.

Here are some examples of key roles and challenges of the family caregiver:

**Hands-on caregiving:**

Taking care of the physical needs of a loved one will be a big part of the family caregiver’s responsibilities. You could be called on to help your family member or friend maintain hygiene habits and proper nutrition, alleviate or resolve sleeping issues and provide pain control. Nursing staffs can help teach a family caregiver common caregiving techniques based on their ability.

**Decision-making:**

Caregivers may be called upon to take over daily decisions for their loved ones. This could become more difficult if a family member or friend becomes mentally impaired or has dementia and does not have an advance care plan. If that’s the case, try to put yourself in your loved one’s shoes before the illness and think about what that individual would have wanted.
**Withstanding the ups and downs:**
Caregiving for a loved one at the end of life creates emotional upheavals. Anger is a normal and common reaction to such a situation. There is always room for hope. For their loved ones, caregivers can hope for a life without pain and discomfort, and meaningful time with family and friends.

**Maintaining balance:**
A family caregiver's well-being is crucial. Make a point of getting out of the house periodically. If needed, obtain a substitute caregiver to stay with your loved one while you are away from the house.

**Striving for quality:**
Make sure your loved one is treated with dignity and respect, and strive for quality of life and independence. A set routine can help both of you.

**Communicating:**
Create an atmosphere of give and take. Include your loved one in choices about his or her medical treatment. Be sure to include other family members as well, understanding the role they will play. Try to convey to other family members what you need.

**Getting extra support:**
Remember, you can’t be an effective family caregiver if you don’t have the help you need. Look to other family and friends who could help, or seek respite assistance through a home care company. Don’t feel guilty about asking for help and for going through varied emotions that can be part of the end-of-life process.

Professional and trained caregivers can provide respite, help educate families, provide a consistent familiar face, relay information, build trust, and provide daily updates.

Wherever you or a loved one may be on life’s journey, take comfort that others have traveled this road and are there to help.
NATIONAL RESOURCES

Compassionate Care Benefits
1-800-622-6232 / TTY: 1-800-926-9105
http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

Canadian Hospice Palliative Care Association
www.chpca-acsp.org

Canadian Virtual Hospice
www.virtualhospice.ca

Canadian Home Care Association
http://www.cdnhomecare.ca/

Speak Up: Start the conversation about end-of-life care
www.advancecareplanning.ca

The Way Forward: An Integrated Palliative Approach to Care
www.hpcintegration.ca
PROVINCIAL RESOURCES

Alberta Hospice Palliative Care Association
http://ahpca.ca/

British Columbia Hospice Palliative Care Association
http://www.bchpca.org/

New Brunswick Hospice Palliative Care Association
http://www.nbhpca-aspnb.ca/

Nova Scotia Hospice Palliative Care Association
http://nshpca.ca/

Newfoundland and Labrador Palliative Care Association
http://www.nlpalliativecareassociation.com/

Hospice & Palliative Care Manitoba
http://www.manitobahospice.ca/

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

Saskatchewan Hospice Palliative Care Association
http://www.saskpalliativecare.org/

Hospice Palliative Care Association of Prince Edward Island
http://hospicepei.ca/wordpress/

Réseau de Soins Palliatifs du Québec
http://www.aqsp.org/

The Home Instead Senior Care Network
HomelInstead.com
ABOUT HOME INSTEAD SENIOR CARE
The Home Instead Senior Care® network strives to enhance the lives of aging adults and their families. Founded in 1994 in Omaha, Nebraska, by Lori and Paul Hogan, the Home Instead Senior Care network is the world’s leading provider of non-medical in-home care services for seniors, with more than 1,000 independently owned and operated franchises that provide more than 50 million hours annually of care throughout the United States, Canada, Japan, Portugal, Australia, New Zealand, Ireland, the United Kingdom, Taiwan, Switzerland, Germany, South Korea, Finland, Austria, Italy, the Netherlands, Mexico and China.

Local Home Instead Senior Care offices employ more than 65,000 CAREGivers℠ worldwide who provide basic support services – assistance with activities of daily living (ADLs), personal care, medication reminders, meal preparation, light housekeeping, errands, incidental transportation and shopping – which enable seniors to live safely and comfortably in their own homes for as long as possible. In addition, CAREGivers are trained in the network’s groundbreaking Alzheimer’s Disease or Other Dementias CARE: Changing Aging Through Research and Education® Program to work with seniors who live with these conditions. This world class curriculum is also available free to family caregivers online or through local Home Instead Senior Care offices.

At Home Instead Senior Care, it’s relationship before task, while continuing to provide superior quality service.