

You are not
alone.

Living Lessons®

*About quality of life for
the last stages of life.*

You are now confronting a
life-threatening illness.

This is a difficult and perhaps
frightening time, but you
should know that you are not
alone. There is a net of caring
to support you: compassionate,
experienced people who can
ease your pain and help in any
way that is important to you.

Every life must come to an end, yet it requires great courage to know that the end may be imminent, and to face it. No one should have to be alone at this time in their lives. No one should be in pain. Everyone should live the end of their lives with dignity.

This is not about dying: it is about living well to the end of your life. Hospice palliative health care professionals and volunteers can help. Your family doctor will help you to find access to this net of caring.

You are not alone.

YOU DESERVE

- to be a full partner in your own care,
- to live free of pain,
- to have your decisions and choices respected and followed,
- to be treated with openness and honesty, without deception or half-truths,
- to receive quality medical and nursing care, even though its goals may have changed from cure to comfort,
- to be cared for by compassionate, sensitive, and knowledgeable people who will attempt to understand your needs and try to meet them, and
- to live and die in peace and with dignity.

YOUR QUESTIONS

YOU MAY WANT TO KNOW...

What is hospice palliative care?

Hospice palliative care supports people living with life-threatening illnesses. It provides care for patients' every need, and for those of their loved ones, whether medical, psychological, social, spiritual or practical. Physicians, nurses, physio- and occupational therapist, volunteers and counsellors work together with friends and family to ease a difficult life passage. Care can be provided at home, in hospitals, in nursing homes or in free-standing hospices.

Hospice palliative care considers that dying is an important part of living, and that it is essential to manage pain and other symptoms effectively so that those facing death, and their loved ones, can devote their energies not to fighting physical discomfort, but to embracing the time they have left together.

Hospice palliative services vary from place to place in Canada, but they usually include these elements:

- expert medical care to ease pain and other symptoms;
- planning with loved ones for a team approach to care;
- emotional support for patients and their loved ones;
- spiritual support for people of all faiths and beliefs;
- support for at-home care with, for example, help with medication, dressing changes, bathing, and other health services;
- help with home-making, driving, and physical support;
- telephone counselling in crisis situations;
- respite care to give caregivers a break;
- sympathetic listeners who are not afraid to talk about dying; and
- ongoing bereavement support after the death of a loved one.

*What will I experience with regard to...
...the management of my care?*

You deserve to be a full partner in the management of your own care, and you deserve to have your needs and desires respected by all your caregivers, from your family physician, your nurses and therapists, to your family and friends.

Begin a dialogue with your caregivers so that they are always aware of your concerns and wishes, and it will be easier for you to be honest and open as these change.

...my prognosis?

You are a full partner in the team that is caring for you at this stage of your life. You deserve, therefore, to be told as much about your condition and its likely progression as you want to know at any one time. Be honest and open about what – and how much detail – you want to know. Your loved ones can help, too, by attending physician and care meetings and taking notes.

...my feelings?

People experience this transition in an entirely personal and individual way.

You may feel shock, numbness, disbelief, panic, helplessness, or hopelessness.

You may feel angry or frightened, anxious or guilty, or terribly sad.

You may feel all of these things, your mind zigzagging between emotions like lightning bolts, or none of them.

It is all normal. There are no ways that you ‘should’ behave or emotions that you ‘should’ feel, but there are people on the hospice palliative care team who can help you understand and cope with the power of your own feelings.

...pain and other symptoms?

Hospice palliative care understands pain in two ways: It can be both physical pain and ‘soul’ pain, anguish that is in a person’s head and heart. Physical pain and symptoms can be eased with the careful use of medication, a process in which health care teams, patients and their families work together to find the best pain and symptom relief. Hospice palliative care teams include compassionate counsellors who can help patients and their loved ones work through soul pain.

...my death?

Experienced members of the hospice palliative care team can answer your questions about death itself. They aren’t afraid to talk about it, and can respond gently but straightforwardly to anything you want to know.

...I don’t want to be alone at this time in my life. Where can I find hospice palliative care in my area?

The hospice palliative care team works to ensure that you and your loved ones are supported in whatever ways you need. Hospice palliative care is offered in different ways in communities across Canada. Your doctor, hospital discharge planner or local home care organizer can give you a referral. You can also call the Living Lessons® Help Line at: **1-877-203-INFO**, or look on our website for “Groups that can help” at **www.living-lessons.org.**, or visit the **Canadian Hospice Palliative Care Association’s website at: chpca.net**