



## **You Are Not Alone**

*Courtesy of the Living Lessons, a program of The GlaxoSmith Kline Foundation and the Canadian Hospice Palliative Care Association*

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 group of 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 healthcare professionals and volunteers can help. You are not alone.

### **What is hospice palliative care?**

Hospice palliative care supports people living with a life-threatening illness.

It provides care for your every need – physical, psychological, emotional, social, spiritual or practical. And, it supports families and loved ones to cope.

Physicians, nurses, pharmacists, social workers, therapists, volunteers, dieticians and pastoral/spiritual care professionals work together to ease suffering and bring comfort. Care can be provided at home, in hospitals, in nursing homes or in a Hospice House.

***“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 and the fears and challenges associated with dying, but to embracing the time they have left together.”***

*Hospice is a community healthcare charity.  
Donations make Hospice support possible to the over 800 people who need it every year.*

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Hospice palliative care 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;
- ❑ Trained volunteers to visit and provide emotional 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 grief and bereavement support after the death of a loved one.

### **How will I manage 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.

You deserve to be told as much as you want to know about your condition and its likely progression. Be honest and open about what – and in how much detail – you want to know. Your loved ones can help too by attending physician and care meetings and taking notes.

### **What will I feel?**

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.

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- ◆ You may feel all of these things, your mind zigzagging between emotions like lightening bolts or you may feel 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.

### **What about 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 healthcare teams, patients and their families work together to find the best pain and symptom relief. For 25% of people living with a life-threatening illness, they will experience no physical pain

The hospice palliative care team includes social workers, spiritual and religious care professionals, counsellors and volunteers who can help people and their loved ones work through soul pain.

### **How do I talk about dying?**

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.

### **Where can I find help?**

The hospice palliative care team works to ensure that you and your loved ones are supported in whatever ways you need.

### **Hospice Greater Saint John**

Since 1983, Hospice has been providing free non-medical support services to people living with advanced illness and families coping with caregiving and loss.

Hospice works with your medical team to ease suffering and improve the quality of living and dying. We do this by providing information and comprehensive emotional, social, practical, spiritual and grief support through a number of free programs and services.

Care and support is delivered by professional staff and trained and experienced volunteers who work with your medical and healthcare teams.

### **Extra-Mural Program and Healthcare Team**

The New Brunswick Extra-Mural Program (EMP) is a provincial home/community healthcare program that provides a comprehensive range of services to individuals of all ages in their homes, nursing homes, special care homes and schools.

EMP works to promote, maintain and/or restore health and when necessary to provide services to support quality end-of-life care. If EMP is involved, the nurse can pronounce the death and the body can then go directly to the funeral home.

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Care is delivered by a number of healthcare professionals who work with your physicians and Hospice:

- ❑ Nurses
- ❑ Social Workers
- ❑ Dietitians
- ❑ Physiotherapists
- ❑ Occupational Therapists
- ❑ Respiratory Therapists
- ❑ Speech-Language Pathologists

Extra-mural services are available only upon a referral from your doctor. Talk to your doctor about a consult to the Extra-Mural Program. They can help. You may also visit their website at [www.ahsc.health.nb.ca/extramural](http://www.ahsc.health.nb.ca/extramural)

### **Hospice Palliative Care Outreach Service**

People living at home have access to an experienced hospice palliative care team through a Clinic appointment or a Home Visit.

People attending the clinic will meet with an experienced palliative care physician and nurse. They will work with you to control pain and symptoms and help you and your family cope with the needs, hopes and fears associated with a life threatening illness and death and connect you to other support services, like Hospice. For people who are bedridden, a Home Visit is available in the greater Saint John area only.

This program is available to you through your family physician or specialist or Extra Mural Nurse.

### **Palliative Care Unit**

The Palliative Care Unit at the Saint John Regional Hospital is an eight bed in-patient unit designed to provide comfort and symptom control to terminally ill people who have less than three months to live. People are admitted for the following reasons:

- ❑ Expert pain and symptom management;
- ❑ Respite support;
- ❑ Terminal care.

The Palliative Care Team works closely together to control symptoms and maintain comfort and dignity through compassionate physical, emotional and spiritual care. The team includes:

- ❑ Physicians
- ❑ Nurses
- ❑ Social Workers
- ❑ Dietitians
- ❑ Pastoral Care Professionals
- ❑ Pharmacists
- ❑ Volunteers
- ❑ Hospice

You can contact the Palliative Care Unit at the Saint John Regional Hospital by calling 648-6155

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## **Family Physicians and Specialists**

Your family physician is an important member of your healthcare team. He or she has likely been caring for you for many years and has a keen interest in providing and supporting your quality end-of-life care.

You may also be under the care of a specialist – perhaps an oncologist or radiologist who is providing chemotherapy or radiation treatments to control pain and enhance the quality of your life. Or, you may be under the care of another specialist who is supporting your quality care.

Your family physician or specialist works with the hospice palliative care team. They may suggest a consult to a Palliative Physician who has specialized expertise in pain and symptom management for advanced illness.

## **Working With Your Healthcare Team**

*“A Guide for Caregivers” Courtesy of the Living Lessons, a program of The GlaxoSmith Kline Foundation and the Canadian Hospice Palliative Care Association*

You and your loved ones face a number of choices and questions (some of them unanswerable). You may have to deal with some of them right away, while others will unfold gradually, depending on the nature of the illness and your own situation. You and your loved ones will probably find yourselves asking questions like these:

- *How long will we have?*
- *What will happen to me?*
- *What pain and symptoms will I experience and how will they be managed?*
- *What decisions can we make together that will allow the last stage of life to be lived as well as possible?*
- *What healthcare options are available to me?*
- *Who will help all of us cope, and how will our family live with the loss?*

You will have a team of people who will care for you and support your family on this journey.

Establishing good channels of communication with your healthcare team is vital to achieving physical and emotional comfort for you and your loved ones.

A core principle of hospice palliative care is that the patient is ultimately responsible for decisions about care. Loved ones who serve as primary caregivers may also be involved to help you and your healthcare team make decisions that are right for you and your family.

You and your family will need information about your illness, the course it is likely to run, the treatments that may help you remain comfortable and the support that is available to you. The hospice palliative care team is there to help you.

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Ask questions. Having knowledge about your care will give you a sense of security and peace of mind. You may need to ask these questions several times because your situation may change or because you need to hear it several times so you can understand it.

It is natural for you and your loved ones to wonder what the future holds and how much time you have left together. Doctors do not know with any certainty how long a seriously ill person has to live. Palliative Physicians may be able to give you a general idea in terms of years, months or weeks at best. Try to live each day to the best of your ability, making the most of the time you have left together.

How well you talk to your hospice palliative care team and understand each other is important to ensuring comfort, peace, quality care and happiness. You and your loved ones will need to talk through, with various team members, the many decisions that need to be made.

Making clear or correct decisions concerning end-of-life care is difficult. Some people pursue every life-extending treatment possible, no matter what the side effects or risks. Others value quality of life above all, and therefore choose different options.

There is no one right answer for everyone. Your hospice palliative care team is experienced in helping people and families make decisions about end-of-life care. They are there to guide you and help you make the decisions that are right for you.

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