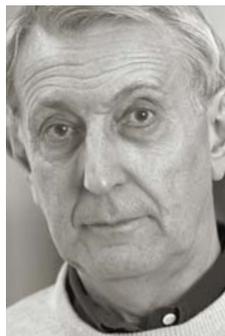


Living Lessons®

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

*A Guide for
Caregivers*



Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

The GlaxoSmithKline Foundation

This handbook was created to help caregivers for people facing the end of life, to give you the tools you need to help your loved one live as well as possible to the end of life. To begin with, you should know that you are not alone. We are here to help. We speak as caregivers who have experienced the death of a loved one, and as members of hospice palliative care teams across the country. Our stories and wisdom draw on the experience and the insights of the many who have taken this journey before you. Our knowledge will help you understand what lies ahead. We know how to provide support and quality of life in the last stages of life, and we can help you help the person you love.

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It is a matter of living. You make up your mind that there is going to be quality of life for someone you love. It is a source of great comfort to me that I was able to provide it to my husband Barry until the very end. I didn't approach it well at first. It was a very dramatic time for me when he told me he was dying. A nightmare. We struggled every day. Yet I gained strength and courage from him. As hard as it was, I wouldn't do anything differently if I had it to do over again. I made it so comfortable for him, and I remember the last day of his life as beautiful. It was like the beginning of life, his breath like the pushes that gave birth to our children. I was able to whisper to him that it was time to go, that we loved him. Caring for him at the end of his life was the most rewarding experience of my life. I feel a better person, and stronger for having done it.

Karen Fralick

Introduction

- How Your Relationship Might Be Affected
- How You Can Help
- What Does It Mean To Live In Hope?
- Things to consider for Dying at Home
- Physical needs

We know that there are few more difficult—or more human—experiences than caring for someone you love in the end stage of life. We all face the end of life in ways that are as unique as the life each of us leads. What we have in common, however, is that most of us share the hope that when death comes to us or to someone close to us, it will be peaceful and free of pain. We hope to face death feeling comfortable and well cared for.

Both you and the person you are caring for will face many choices on this journey. We have prepared this end-of-life caregiver guide to help you with some of the questions, concerns and common situations you may encounter, using the principles of hospice palliative care as an underpinning. Our ultimate goal is to enhance quality of life for you and the one you are caring for.

The *Living Lessons*® Guide for Caregivers will introduce you to ways you can manage your situation, whether you are caring for a dying child, parent, spouse or good friend. It gives guidance on how to provide comfort and care for your loved one, how to manage pain and symptoms, how to communicate effectively with all members of the family and care team, and how to get practical and emotional support throughout your journey from available circles of support.

The fears and questions that thousands of Canadians have about the end-of-life journey have been addressed across the country by hospice palliative care. Hospice palliative care—care for people facing life-threatening illness—meets the physical, emotional and spiritual needs of the patient and his loved ones. It is individualized care that emphasizes living fully until the end of life, with dignity and in comfort, surrounded by a circle of support. It can be provided to adults or to children, in any setting—at home, in a nursing home, in a specialized hospice or in a hospital. Hospice palliative care can help make a very difficult life passage both manageable and meaningful.

As you go down this difficult path, you are in the company of over three million Canadians caring for loved ones who have a long-term health problem. Ready to support you is a network of organizations, grounded in the life-affirming principles of hospice palliative care.

We have organized this guide according to the key relationships that may provide essential support and improve quality of life for you and your loved one through this daunting journey. We focus on your relationship with the patient, your relationship to your own role as a caregiver and your relationship with the support networks that you may draw on: the health-care system, the community, the care team, and family and friends. You may want to read the guide from beginning to end, or to refer to sections that answer questions you have at various points in your journey. A note of explanation about the terminology we have used in writing this guide: generally, we talk about the person facing end-of-life not as a patient but as a loved one, and this term can encompass a whole range of relationships: a spouse, a same-sex partner, a parent, a child, a friend. As well, we alternate the use of the personal pronouns “him” or “her” from paragraph to paragraph to avoid repetition, but they are used interchangeably throughout.

Our personal experience in hospice palliative care, earned at the bedside of thousands of Canadians over the past 25 years, has taught us some important lessons:

- *We have learned that dying is an essential human stage of living and that when physical and emotional needs are met, the journey toward death, though always difficult, can be a rich experience that gives meaning to life.*

Hospice palliative care meets the practical and emotional needs of a loved one and his family. It emphasizes living fully until the end of life in comfort and with dignity.

- *We have learned that, by managing the pain and symptoms of those facing death, more energy can be dedicated to embracing the life of the mind, heart and spirit so essential to quality of life.*
- *We have learned that providing practical, emotional and spiritual support to the caregiver through all stages of illness and bereavement can allow caregivers and loved ones to experience special moments of growth, communication and intense connection with each other.*
- *We have learned that everyone faces death in his or her own way and that the power of having control and exercising choice is an important component of maintaining dignity in the final stages of life.*
- *We have learned that caregivers and patients alike must be well-informed, active participants in the care team and be prepared to be advocates for the quality of end-of-life care everyone deserves.*

The Living Lessons® Guide for Caregivers is part of a national initiative to increase awareness of hospice palliative care needs and services in Canada. Living Lessons® is an ongoing project of the Canadian Hospice Palliative Care Association (CHPCA) and hospice palliative care organizations across Canada, and is part of the GlaxoSmithKline Foundation's commitment to promoting quality of life during the end stage of life in Canada. The Living Lessons® campaign was launched in 1998 with the dual goals of initiating public dialogue and promoting understanding, support and better access to quality care in the last stages of life. To date, Living Lessons® has established a CHPCA staff help line (1-877-203-INFO) and a website (www.living-lessons.org) and has developed publications aimed at increasing awareness of end-of-life issues for policymakers and doctors.

Thank You

We thank the following people, who are among the many within the hospice palliative care community who have contributed their insight, experience and invaluable feedback to this guide:

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Find out everything you can. The more you know, the more empowered you feel. Use that knowledge to make a game plan so that you can care better for the person you love, so that you can focus on the living you're doing. Brendan died when he was three years and nine months old. The summer before he died we made the decision to care for him at home. He was very sick. It was agonizing. Yet we could care for him at home, and we could be a family. Even throughout that agonizing time there were phenomenal moments. At the end of the summer Brendan was well enough for the four of us to take a walk to the corner to buy a toy for the kitten that he and his sister had begged for. That was it, our summer outing. It was a gorgeous sunny day, and we were so happy, walking home with this squeaky octopus, being together. Ten years later, I still look back on that day, on what a treasure it was.

Joanie Turner

Caring for Your Loved One

- What You and Your Loved One May Be Experiencing
- Early Questions and Choices
- Supporting Your Loved One
- Your Loved One's Needs:
Day-to-Day Care, Emotional and Spiritual Needs
- Living Well
- Communicating with Your Loved One

We know that the support of family and friends is the single most important element in coping with disease in end-of-life care. As a caregiver, you play an extremely significant role in ensuring quality of life—both physical and emotional well-being—at the end of your loved one’s life. In this section we will look at several aspects of your relationship to a person facing the end of her life, including the choices and questions you face, how she may react, how your relationship might change, her emotional and physical needs, issues of communication and how you might help.

What You and Your Loved One May Be Experiencing

You need to know a few things about how your loved one may be responding to the diagnosis of a life-threatening illness. Such a diagnosis usually unleashes a range of powerful emotions. There are no right or wrong feelings or emotions. Fear of the unknown is one of

the most difficult things to come to terms with. The person you are caring for may feel a sense of loss, grief, shock, anger, panic, hopelessness and emotional turmoil. Denial is also a very powerful response—many people just don’t want to deal with their approaching death.

Some people respond by gathering information to regain a sense of order, control and comprehensibility in their lives. The

need for control is a natural response in the face of fear. Initially, your role may be to help the dying person maintain his sense of control, and this may evolve into helping him accept his increasing lack of control as the end of life approaches.

As a caregiver, you can play an extremely significant role in ensuring the physical and emotional well-being of your loved one at this time of her life.

Early Questions and Choices

You and your loved one 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 will probably find yourselves asking questions like these:

- *How long will we have?*
- *What pain and symptoms will he experience and how can they be managed?*
- *Who will help all of us cope, and how will our family live with the loss?*
- *How can I care for my loved one and keep him comfortable?*
- *What decisions can we make together that will allow the last stage of life to be lived as well as possible?*
- *What options are available, whether at home, in hospices or hospitals?*
- *Will it be possible to stay at home at the end?*

Supporting Your Loved One

One of the first things to do when someone close to you receives a diagnosis of a life-threatening disease or terminal illness is to ask what she needs and wants. Together you can establish a plan that meets both your needs and capacities. This may not be an easy conversation, but it is the first step in a dialogue that will pose many questions and address many issues (see the section titled “Communicating with Your Loved One”).

- *Do your best to be a good listener.*
- *Give careful thought to your role in helping your loved one live with quality until the end.*
- *Be truthful, even if one of you isn't doing well.*
- *Be prepared for your loved one to express strong emotion, even anger that he may unwittingly direct at you.*

- *Try to enjoy the good days. Make the most of your time, reflecting on your life together and trying to resolve any unfinished business, if necessary with the help of another person with whom you both feel comfortable.*
- *Help the dying person do what he needs to do to accept death—put his affairs in order, capture oral or family histories, write letters, put together family scrapbooks and photo albums to help give perspective to what is meaningful and enduring in his life.*

Your Loved One's Needs

Understanding the unique needs of a dying person will help you accept what is happening and assist her through her end-of-life journey with the maximum possible quality of life. Everyone's experience will be different and based on the individual's particular physical and emotional needs.

Day-to-Day Care

You will probably need to acquire a whole new set of nursing and practical skills. Most caregivers find that the more practical information they obtain, the better. You may need to learn about and deal with many aspects of physical care, especially if you have decided to care for your loved one at home. You will need to know how best to feed your loved one, how to keep him clean and comfortable, and how to manage his medication. You may need to learn how to move a person safely and how to manage his pain and symptoms.

Understanding the unique needs of your loved one will help you to accept what is happening and to assist her through her end-of-life journey.

Caregiving can be the ultimate test of resourcefulness. You may find yourself spending a great deal of time solving problems to make life easier and more “normal.” For instance, using a hiking stick with a wrist strap may be a good solution for a person with balance problems who can't

Living Well

*The focus of hospice palliative care
is on living as well as possible until the end.*

This can mean:

*Living free of pain or having “manageable” pain
(many people find strength in their suffering and don’t want
to be so sedated that they can’t communicate)*

Maintaining one’s dignity

Having one’s decisions and choices respected

Being treated with openness and honesty

Having the companionship of family and friends

*Being cared for with love and respect and
without feeling that one is a burden*

*Living and dying in one’s choice of comforting surroundings
among familiar and comforting things*

Not dying alone

grip a cane. Wearing tear-away pants, which allow a practised caregiver to deal with a leg bag easily and unobtrusively, may mean that a person using a catheter can continue to go to the theatre or a restaurant.

Don't be afraid to ask questions as you try to puzzle through the challenges presented as an illness progresses. Occupational therapists, home-care nurses, hospice palliative care volunteers and other caregivers are all good sources for brainstorming and practical tips. Bookstores, the library and the Internet will also be useful. Using a search engine such as Google (www.google.com) to obtain information on “bedsores,” for instance, will result in a list of web-sites and articles on the subject.

The Palliative Care Association of Alberta and the Military and Hospitaller Order of St. Lazarus of Jerusalem have produced an excellent handbook—*A Caregiver's Guide: A Handbook about End of Life Care*—focusing on the physical aspects of care. It is available free online at www.albertapalliative.net, or you can call 780-447-3980 for a hard copy (free for family caregivers in Alberta, \$25 for those elsewhere).

Emotional and Spiritual Needs

Keep in mind that all of these feelings and responses are normal and that there is no easy way to move through them, although there may be ways that you can help your loved one deal with her emotional, spiritual and physical needs and move toward an acceptance that will help her live fully in the time she has left.

Maintaining Hope

Maintaining hope is often an important goal for people approaching the end of their life. Hope can mean different things at different stages of life and dying. At the time of diagnosis, it may mean finding a cure. It may evolve into a hope of

*Ask what your loved
one's needs and wants
are, this way you
both can establish a
plan together that
meets each of your
needs and capacities.*

living as normally as possible. Hope may also involve a sense of reconciliation with life and death—in other words, preparation for death at an emotional and practical level. Good relationships can provide a sense of meaning in the life of a seriously ill person, and this meaning can create a sense of motivation for them.

Anticipatory Grief

Many people at the end stage of life experience anticipatory grief—a sense of mourning their own deaths that may be accompanied by depression and sadness. This stage of grief can also be a time of searching and growth, and of establishing those connections that give the final separation meaning. The most difficult “work” of the dying may be in receiving and understanding the truth and in reviewing the meaning of their life. It may also include confronting and understanding suffering, coping with losses, accepting love and completing the process of dying with a sense of dignity.

Existential and Spiritual Needs

The person faced with a life-threatening illness may also have existential and spiritual needs and concerns. These will vary widely, but they often include a fear of death and dying, a fear of leaving nothing of himself behind and deep questions about the meaning and purpose of his life. He may also experience a need for reconciliation with loved ones or a spiritual community, and a need to draw strength from faith or rituals (or conversely, a sense of betrayal and the abandonment of faith). Some turn to work and hobbies and distraction; others find comfort in the presence of family and close friends.

Your Relationship

Your relationship to the dying person might transform in the

final stage of life. Roles may change, as when a mother and caregiver of four children becomes the one who is cared for. If you are losing your spouse, it may affect your family dynamics, your financial stability, your work or your day-to-day life and habits. You may find that you don't "recognize" your loved one, as changes brought about by his disease can result not only in physical decline, but also in personality changes. It is a time that may deepen your relationship and draw you closer together than ever before as you both focus on the things that really matter to you in your lives. However, the converse can also happen—sometimes the burden of end of life puts huge strains on relationships, and this is also normal.

Additional Psychological and Emotional Needs

Caring for your loved one's psychological needs may involve consultation with a psychiatrist, a clinical psychologist or a social worker. Serious depression may be a part of many end-stage illnesses (it

is in as many as 40 percent of cases). Depression can be triggered by disease or be a side effect of commonly prescribed drugs. Signs of depression—chronic sadness, lack of energy, disruption of sleeping and eating patterns, frequent crying, withdrawal, suicidal thoughts—should be discussed with health-care professionals so that the depression can be treated.

Receiving the proper professional care for the overwhelming emotional and psychological effects of an end-stage illness is often immensely beneficial for the emotional well-being of the dying person. Occasionally, unresolved emotional issues can be the basis for intractable physical pain, so it's important to treat

Listening is more important than giving advice, offering false hope or speaking in clichés. Just being there is meaningful.

the soul pain (sometimes called “psychic pain”) and the physical pain holistically.

Communicating with Your Loved One

Most of us find it very difficult to know what to say when someone we care for is dying. Start by putting yourself in the dying person’s situation or imagining yourself in a time of crisis: think about the way you felt, what you wanted and the responses you appreciated most.

Often, listening is more important than giving advice, offering false hope or speaking in clichés. Just being there—with the gifts of your presence and care—is significant. Try to give as much control as you can to your loved one, as an increasing dependence on others can be a major source of his suffering.

We recognize that a dying person may need to communicate some things. She may want to resolve long-standing conflicts and satisfy final wishes. Take your cues from her needs and wants, and try to be a good listener. Help her contact and communicate with family and friends if doing so helps her deal with her sense of isolation.

When families and caregivers can negotiate with each other and be aware of the complex nature of the changes going on in all their lives, adjustments can be easier. Open discussion—not just between you and your loved one, but also among all family members—is very important.

Depending on the type of illness and its effect on your loved one’s physical and mental capabilities, you may have to adjust the way you communicate. Conversations may fluctuate, especially if he is experiencing periods of confusion or delirium. You may feel that he’s not the same person you knew, and for a good reason: disease can change people’s thinking patterns and their ability to communicate.

Remember that communicating can be done in many ways: talking and listening may evolve into non-verbal communication, espe-

cially if end-stage disease has caused significant degeneration. Even comatose people respond to touch and voice, so don't stop communicating with your loved one. Touch becomes increasingly important. You may need to look for subtle messages—changes in breathing pattern, tiny facial reactions, changes in body rigidity—that may indicate that your loved one is sending and receiving messages.



I am looking at long-term care for my husband. It took me a long time—and getting sick myself—to figure this out, but I finally came to see Michael and me as an equation. In many ways, I am the most important element in that equation. If I am not healthy and happy, everything stops working. I learned to ask for help. I learned to take the time to have breakfast with friends, to have a facial or a body massage, to get my hair done, to walk around the block. I figured out what I needed to do to get a good night's rest. I learned how to ask for help—not just sympathy, but real help—from friends and family. True friends will help, but they can't read your mind; you have to be direct and tell them exactly what you need.

Martha Gombita

Caring for Yourself

- The Big Picture
- Your Role as Caregiver
- Getting the Help You Need
- What You Can Expect
- Aspects of Grieving
- Mourning and Bereavement
- Caregiver Compassion Fatigue
- Coping Tools
- General Coping Tips

The Big Picture

You are one of about a quarter of the adult Canadian population that provides some form of home care (which may include hospice palliative care) to a person who has a long-term illness or disability¹. Nearly three-quarters of caregivers are women, and many caregivers are caring for children, as well as an aging parent.

Your Role as Caregiver

You face a journey that may well be one of the most demanding and challenging experiences of your life. We know that we are all going to die, but somehow that knowledge doesn't mean much until you live the end stage of life, day-to-day, with someone you love. The knowledge that all of us die makes each individual death no less painful or difficult.

Your choice to become a primary caregiver means that you face a time of many questions and few easy answers. It means escalating demands on your time and energies. It means a toll on your physical, emotional and possibly financial well-being.

You may need to consider a number of things before taking on the commitment of primary caregiver:

- *How will I juggle my work, my children and the day-to-day care of someone I love so much?*
- *Can I take a leave of absence from work?*
- *Is it a role I am suited to?*
- *Will I have the physical and emotional strength or the practical support that I will need?*
- *Is it desirable or physically possible for me to care for a dying person in my home?*

The caregiver role in hospice palliative care involves many things. As a caregiver, you are a central part of a team that may

¹ 2001 edition of *Health Care in Canada*, an annual report by the Canadian Institute of Health Information.

General Coping Tips

Accept that you may need help from others.

*Talk regularly with family,
friends or mental health professionals.*

*Find a local or online support group and share
your feelings so that they don't escalate into problems.*

*Set realistic expectations. Know your limits,
and learn to say no to taking on more than you can handle.*

Eat well, exercise regularly and get enough sleep.

*Let go of unrealistic expectations and demands.
Don't be a martyr.*

Hang on to your sense of humour.

include health-care professionals (doctors, palliative care experts, nurses, pain management specialists, hospice staff), community organizations and support networks (volunteers from hospices and palliative care organizations, hospitals) and family and friends. You will find yourself providing physical and emotional support to your loved one. You will be her advocate, information gatherer and confidante.

Getting the Help You Need

You are not alone on this journey, and it is important for you to know how to obtain the help you need from the support networks, systems and people who can smooth this difficult road. Asking for help is not a

sign of weakness or an admission of failure. We have been on this journey, and we are ready and eager to help you. Many of the people involved in hospice palliative care, especially the volunteers in the hospice palliative care community, are among the most compassionate and understanding people you will ever meet. Many of us are here because we've been through the experience ourselves and believe we have wisdom and energy to offer to others who are going through what we have seen many times. Respite care (see page 40) is often available and can give you the time

you may need to go grocery shopping, take a break or do the things you need to do to regain your balance.

You're not alone. Asking for help is not a sign of weakness or an admission of failure. Making use of available support networks, systems and people can make a difficult road easier.

What You Can Expect

The experience of caring for someone approaching death can affect every aspect of your life. It is a time of strong emotions (sadness, hopelessness, fear, anxiety) that will fluctuate from day to day. This is normal. It is natural to grieve the death of a loved one before and after their passing. Knowing that your loved one is approaching death can trigger a number of responses.

Aspects of Grieving

One of the most profound and normal reactions you and your loved one may experience is anticipatory grief, or the grief you feel in anticipation of death. Ultimately, anticipatory grief is a way of allowing us to prepare emotionally for the inevitable. When you are grieving, you may be incapable of eating, have trouble sleeping, suffer from depression and experience blurred vision, forgetfulness or panic attacks. You may be more acutely aware of your own mortality. You may also feel helplessness, guilt and anger at everyone, including the person who is dying. Crying is but one visible form of grieving. There is no right and wrong when it comes to your feelings. Anticipatory grief gives the family more time to slowly get used to the reality of the loss. You may feel the need for a sense of resolution or completion in your relationship with the dying person. You may need to say “I love you,” “I forgive you,” “forgive me,” “thank you” and “good-bye.”

You may also experience guilt or shame for “wishing it were over” or seeing your loved one as already “gone” intellectually. It is important to recognize these feelings as normal.

Many caregivers experience a worsening of their own physical and mental health. You may also suffer depression and profound

emotional turmoil. Nearly half of all caregivers experience some form of depression. Don't be afraid to seek help: take care of your own physical needs, and seek professional help if you need it.

Mourning and Bereavement

Mourning refers to the social and cultural rituals surrounding a person's death that are part of the grieving process (funerals services and grieving rituals vary considerably in the main faiths practised in Canada, including the Protestant, Hindu, Buddhist, Sikh, Roman Catholic, Jewish, Muslim and Baha'i religions, as well as in the less defined belief systems of atheists and humanists.) Bereavement is the state of suffering a loss. During the time of mourning and bereavement, there are usually four "tasks" of grieving: accepting the reality of the loss, experiencing emotional pain and suffering, adjusting to living without the loved one and letting go. Bereavement support for the caregiver is an integral part of the hospice palliative care philosophy. Such support is often available in the community and through funeral homes.

You may find that the grief you are experiencing is so difficult and traumatic that you are having trouble carrying on. As a caregiver, you may find the months following a loved one's death to be particularly difficult, as the people who formed your support network return to their lives and you struggle to find a new "normal." There is no easy answer as to how long bereavement will last. The symptoms of bereavement may abate over time, but there may be triggers and significant occasions, such as holidays and celebrations, that throw you back into a very deep sense of grieving. You may struggle with practical issues as you return to work or redefine your habits and routines. You will likely make slow emotional adjustments that allow you to get on with your life as you come to terms with the changes.

Caregiver Compassion Fatigue

Compassion fatigue results from a feeling of deep sympathy and sorrow for another who is stricken by suffering and misfortune.

Compassion fatigue can be accompanied by a sense of helplessness in the face of a strong desire to alleviate the sufferer's pain or remove its cause.

Symptoms of compassion fatigue may include weariness and exhaustion; inability to eat or sleep; inability to concentrate or think clearly; increased dependence on tobacco, alcohol or drugs; and weight loss or gain.

Coping Tools

Taking care of yourself will increase your ability to provide care for the dying person and handle the heightened physical and emotional demands that caregiving places on you. Everyone has a “toolbox” of coping mechanisms that gets him or her through difficult times. It is worth taking stock of your own toolbox and making sure you take the time to use the tools that can help you.

Spiritual coping tools:

When you are caring for the dying, it is often a time to come to terms with your beliefs about death and dying. Where do you get your strength? From your family? Your faith? Nature? What does the experience of losing someone you are close to mean to you as a person? Do you need to do more of the things that give you strength?

Physical coping tools:

Don't neglect the physical things you do to blow off steam or relieve tension—going for an early morning walk, swimming, gardening—the things you do to keep balanced. Maybe housework is the last thing you want to do, so delegate that to someone who has offered his help. Try to eat well—make double portions when you cook, or assign the preparation of certain meals to people who have offered help. Look after your own health: see your doctor if you need to or, if you are feeling overwhelmed, take advantage of 24-hour telecare lines that provide health advice and are available in some provinces. Carefully assess your physical needs now: how are you coping and what do you need to tend to?

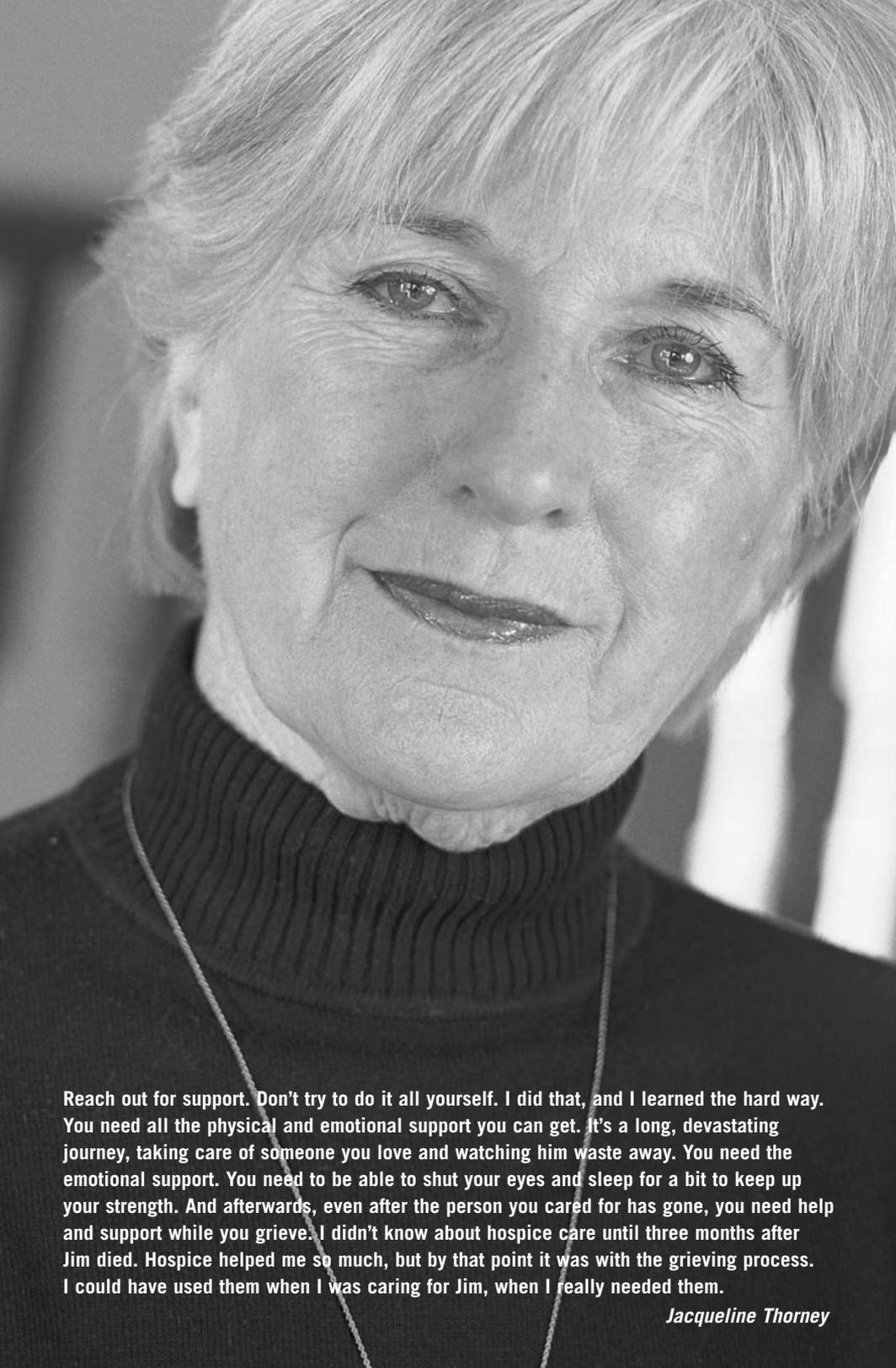
Emotional coping tools:

Look back to your history for ways you have coped emotionally. Do you talk it out, write about it in a journal or get help from a therapist or social worker? Is there enough time for talking to the dying person?

Sometimes it helps to make time for reflection, for being sad and crying, and also for feeling happy about something and for laughing. Give yourself permission to feel the way you're feeling—the more we bury these feelings, the more difficult they are to deal with. Some people find organized caregiver support groups valuable. Many people find it helpful to hear how others have met similar challenges and to share stories. Ask members of the health-care team or contact a local hospital, provincial hospice organization or local hospice to locate the best support groups for you.

Social coping tools:

How are you coping socially? What is your financial situation, and what can you do about it? Look into things such as third-party insurance, Veteran Affairs, local or provincial insurance plans and work insurance plans, or ask your home-care nurse if any resources are available that you haven't considered. Consider the social side of your life: how much energy do you have to expend on it? Is it supportive, or would it be better for you to narrow down your social contacts to conserve time and energy?



Reach out for support. Don't try to do it all yourself. I did that, and I learned the hard way. You need all the physical and emotional support you can get. It's a long, devastating journey, taking care of someone you love and watching him waste away. You need the emotional support. You need to be able to shut your eyes and sleep for a bit to keep up your strength. And afterwards, even after the person you cared for has gone, you need help and support while you grieve. I didn't know about hospice care until three months after Jim died. Hospice helped me so much, but by that point it was with the grieving process. I could have used them when I was caring for Jim, when I really needed them.

Jacqueline Thorney

Establishing Your Support Networks

- Navigating the End-of-Life Journey
- What Is Hospice Palliative Care?
- End-of-Life Options:
*Hospice Care in the Home, Residential Hospice Palliative Care,
Bereavement Support Programs*
- Who Pays for Hospice Palliative Care?
- Residential Hospice Palliative Care Options
- In-Home Care Options

Navigating the End-of-Life Journey

Help is available to you from the health-care system, and understanding how to get that help is invaluable. Your ability to navigate the various hospice palliative care support networks in is an important component in ensuring good end-of-life care. Evaluate very early in the end-of-life journey the resources that are available in your community to help you, even if you don't need them immediately.

In Canada, the supply of hospice palliative care services generally is exceeded by the demand for them, so figuring out what is available early on can increase the probability that the person you are caring for will receive the type of care you collectively desire when it is most needed. Identify someone—for instance, a home-care support person—who can help you develop this crucial circle of support.

We understand that navigating your way through the complex health-care services related to end-of-life care can be a daunting and difficult task. In large part, this is the result of shortcomings in the way our health-care system delivers hospice palliative care. Hospice palliative care standards vary widely across the country, and rural residents have considerably less access to hospice palliative care than people who live in cities. End-of-life care is by no means seamlessly integrated into the Canadian health-care system. Few provinces have designated hospice palliative care as a core service with a specific budget, and such care relies largely on charitable donations. Most of the costs and other burdens of home care end up being assumed by the family. As one hospice worker noted, we take good care of those coming into the world, and, as yet, have more difficulty with those going out.

Slowly, changes are occurring that address some of the needs of family caregivers. The Government of Canada and provincial and ter-

ritorial governments are beginning to collaborate on ways to improve access to health care and on better integration of home care and community care within the health-care system. As Canadians, we are increasingly recognizing that an integrated approach to end-of-life support is crucial and goes beyond the physical to encompass psychological, social, emotional and spiritual needs. However, of the 220,000 people who die every year in Canada, three-quarters of them die in hospitals and long-term care facilities, and only an estimated 5 percent of dying Canadians receive the integrated interdisciplinary palliative care that is so beneficial to them.

Our health-care system is not always perfect. You may find that disappointment and frustration with the delivery of—and occasionally with the inconvenience of—care, services and diagnostics will add to the emotional stress of your caregiving experience. Don't allow yourself to be overwhelmed; some aspects of caregiving may call for patience and understanding on your part. Keep in mind that a huge amount of work invariably goes into setting up the best possible end-of-life care and directly reflects your ability to advocate on behalf of your loved one. If aspects of the health-care system are not working for you, you may want to provide constructive feedback advocating for improved hospice palliative care services to those directly concerned or to your provincial and federal politicians, who may be able to influence policy on end-of-life care.

Figuring out early what services are available increases your chances of receiving the type of care you and your loved one want when you need it.

What Is Hospice Palliative Care?

In Canada, hospice palliative care is now much more broadly defined to describe the full spectrum of end-of-life care, whether it is offered

in the community, in hospitals, in your home or in a nursing home. Hospice palliative care is a special kind of health care for individuals and families who are living with a life-threatening illness that is usually at an advanced stage. The goal of hospice palliative care is to provide comfort and dignity for the person living with the illness, as well as the best quality of life for both this person and her family (“family” is broadly defined to include whomever the patient says it does:

relatives, partners and friends). Physical comfort, pain relief, symptom management and the the ill person’s spiritual, social, psychological and financial needs all become the focus of hospice palliative care, as does ongoing bereavement care for the family.

Hospice palliative care is usually employed when a cure for the illness is no longer possible (although hospice palliative care services are also helpful at earlier stages in the illness, when palliative care may be combined with treatments, such as chemotherapy, aimed at reducing or curing the illness).

Many people who receive hospice palliative care have cancer, but it also helps people living with other diseases, such as end-stage heart, respiratory and kidney disease, Alzheimer’s, AIDS, ALS and multiple sclerosis, among others.

End-of-Life Options

You should be aware of the variety of hospice palliative care alternatives and the fact that such care is available at home, in hospitals, in long-term care facilities and in freestanding hospices. The options may vary depending on where you live. Not all people in the final stages of life receive hospice palliative care; some die in acute-

Hospice palliative care can take place at home, in hospitals, in long-term care facilities, and in free-standing hospices. Your options may vary depending on where you live.

care hospital wards without the benefit of specialized expertise in pain and symptom management. For this reason, it is very important for you to find out all you can about the hospice palliative care available in your community that can better equip you to provide good end-of-life care for your loved one.

You should consider several things when you're deciding whether to choose home-based hospice palliative care. First, evaluate whether it is important to you, your family and your loved one to care for him at home. Then, assess whether the physical layout and facilities of your home are suitable to the type of care you would need to provide. Finally, ascertain whether a palliative care team—a doctor willing to visit the house, nurses and hospice volunteers—is available.

Hospice Care in the Home

Most Canadians want to be able to die in familiar, comfortable surroundings. Most also feel they would need outside help to be able to care for a terminally ill family member. Being at home may help people remain involved with their families and live as normally as possible. Some people feel that when they are at home they have more freedom to make choices about their care.

Hospice palliative care is generally provided in people's homes through home-care programs, sometimes known as community care access centres. These programs offer professional nursing care and a variety of home support services. In some provinces, home-care programs manage the delivery of home-care services, as well as the coordination of referrals to an alternative care setting when it becomes necessary. Other services may be available in some communities to help people remain at home, including volunteer services, day programs in a variety of places in the community (including hospices) and, in some areas, pain and symptom management teams and 24-hour response teams that respond to urgent needs on a short-term basis.

Residential Hospice Palliative Care

In Canada, three types of settings provide residential, or 24-hour, care: residential hospices, hospice palliative care units in hospitals and long-term care facilities.

Bereavement Support Programs

Bereavement support programs span the full spectrum of care and can bridge any or all of the previously described areas as an integral part of the hospice palliative care philosophy. Bereavement support can start before death, especially in working through the dying process with children. As a person nears death, bereavement support begins in earnest for her caregivers. Many people find that it is helpful to have bereavement support for 12 or 13 months after the death of a loved one. Specialized bereavement support groups are available, including grief groups for children, men and bereaved families. Family service agencies, as well as funeral homes, are other sources of support.

Who Pays for Hospice Palliative Care?

Hospice palliative care is paid for in different ways across the country. Who pays often depends on where care is being provided (at home or in the hospital) and on whether it is a core service funded by the local government. It is important to find out as soon as possible who pays for what and what additional financial assistance may be available in your particular case and region.

Community hospice palliative care programs provide services free of charge to clients and their families, and these community organizations are normally supported by a variety of individual and community donations.

Palliative care at home may be paid for by the provincial health plan as part of a home-care program. These plans do not always

Residential Hospice Palliative Care Options

Hospitals

Some hospitals have special hospice palliative care units. Others set aside a certain number of beds in different units in the hospital for people needing palliative care. Hospitals may also have a palliative care team made up of health professionals who are specialists in palliative care. They help the staff provide palliative care on the unit where the dying person is staying.

Long-term or Continuing Care Facilities

Hospice palliative care services may also be offered in long-term care facilities, such as nursing homes or continuing care facilities. Residents who need more specialized palliative care services must sometimes enter a hospital. Currently, long-term care facilities are less likely than hospitals to have specialized hospice palliative care units.

Residential Hospices

Although they are still relatively scarce, “free-standing,” community residential hospices—separate settings where hospice palliative care is provided in a home-like environment—are increasing in number. These hospices are often disease specific, although sometimes they accommodate people with any life-threatening disease. The average stay in a community residential hospice is about two weeks. Some people do not want the memory of a loved one’s death having occurred in their home or, for various reasons, are unable to provide care at home. Patients in residential hospices have the benefit of a home-like atmosphere, and their family members may relinquish their roles as primary caregivers and concentrate on being loved ones. Residential hospices can also be a resource for people who don’t have other support at the end of their lives.

include the cost of drugs and equipment used at home. Some plans allow only a certain number of paid hours of professional and home support services. Before the allotted hours are used up, you will need to look for other ways to pay.

People may use private insurance or their own money to pay for palliative care services at home. Some may receive assistance from social agencies, service clubs, local cancer societies and other similar organizations.

Hospice palliative care provided in a hospital is usually paid for by provincial health plans. These plans generally cover most care including drugs, medical supplies and equipment while the person is in the hospital. In long-term care facilities, residents are usually required to pay for some of their care. Costs vary, depending on the facility.

Bereavement support is usually free. Often it is provided as part of hospice palliative care services offered in hospitals or by non-profit or volunteer organizations in the community.

In-Home Care Options

Home-Care Programs

Home care programs, or community care access centres, can provide nursing and home support services in the dying person's home.

In-Home Nursing and Respite Care

Community-based services and program services in the home can provide occasional respite for the caregiver, wherever the patient is—at home, in the hospital or in a long-term care facility. Many organizations provide in-home nursing. One of the oldest national organizations is the Victorian Order of Nurses of Canada (VON Canada), which has over 8,000 health-care providers and 15,000 people who deliver home nursing, health promotion and support to Canadians across the country.

Volunteer Services

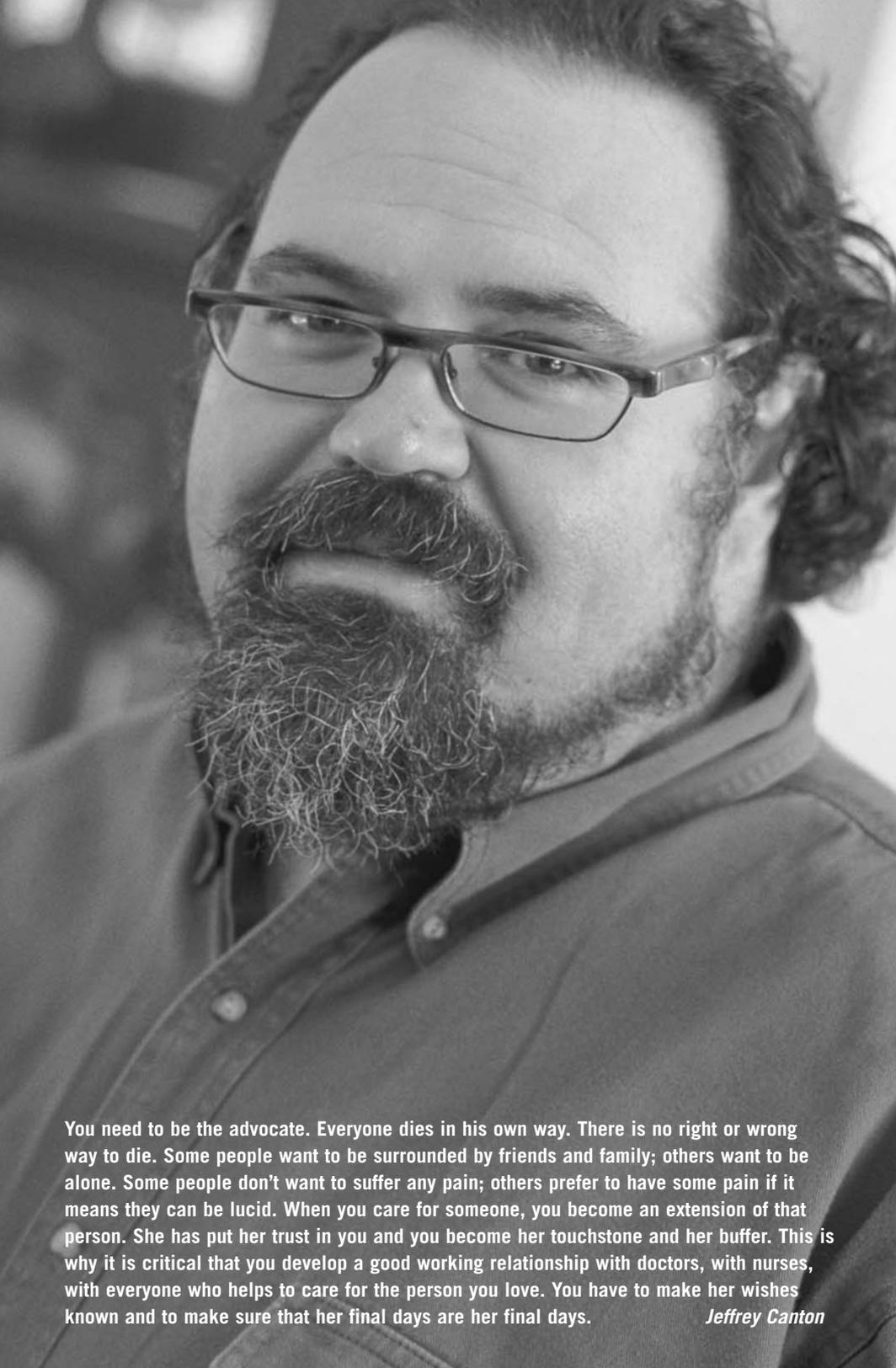
Community volunteers can often enhance the quality of care provided by the team. Especially in rural areas, community volunteer services can play an important role and provide emotional support up to and after death. Volunteers are a source of information and practical help for both the patient and his caregivers. National qualifications are currently being standardized, and volunteers can offer support to caregivers in some or all of these areas—bereavement, emotional issues, information, nutrition, physical care, social and spiritual issues, mobility and rest,—and to provide them with respite. Some volunteer organizations may be able to provide some or all of the following: equipment, a transportation service to drive people to appointments, meal delivery, respite care and so on. Ask members of your hospice palliative care team what support is available in your community.

Day Programs

Day hospice programs are offered in a variety of places in the community. In our experience, these programs are wonderful for people whose disease is not too far advanced. Day programs are social, caring environments, often run by a hospice palliative care program for all or part of the day. They offer various kinds of support, including meals, complementary therapies, activities and outings.

Pain and Symptom Management Teams and Emergency Response Teams

In some places, you may be able to obtain services such as pain and symptom management, as well as the services of emergency response teams—including a hospice palliative care nurse or doctor—that respond to urgent needs on a short-term basis. These services are usually coordinated regionally or, if your loved one is at home, through community care access centres.



You need to be the advocate. Everyone dies in his own way. There is no right or wrong way to die. Some people want to be surrounded by friends and family; others want to be alone. Some people don't want to suffer any pain; others prefer to have some pain if it means they can be lucid. When you care for someone, you become an extension of that person. She has put her trust in you and you become her touchstone and her buffer. This is why it is critical that you develop a good working relationship with doctors, with nurses, with everyone who helps to care for the person you love. You have to make her wishes known and to make sure that her final days are her final days.

Jeffrey Canton

Your Relationship with the Health-Care Team

- The Health-Care Team
- Communicating with the Health-Care Team
- Pain Management and the Health-Care Team
- Tips for Caregivers

The Health-Care Team

Establishing good channels of communication with the doctor and the entire health-care team is vital to achieving physical and emotional comfort for your loved one. The team can be quite large and may include a hospice palliative care doctor, hospice case managers or hospice case coordinators, a home-care nurse, occupational therapists, physiotherapists, social workers, respiratory therapists and volunteers, personal care workers or home support aides who provide respite care, your pharmacist, a dietician and complementary therapists. Having a good relationship with the primary or family doctor—one of the most important people on the team—is essential.

Communicating with the Health-Care Team

A core principle of hospice palliative care is that the patient is ultimately responsible for decisions about her own care. As her primary caregiver, however, you may find yourself actively involved on her behalf with other members of her health-care team. You and your loved one must be able to communicate well with the various members of the health-care team. Ideally, caregivers and doctors work in partnership. How well team members talk together and understand each other can influence your loved one's happiness and comfort.

You and your loved one 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 medical care is difficult. Some people choose to pursue every life-extending treatment possibility, no matter what the side effects or risks. Others value quality of life above all, and this principle governs their care decisions.

Pain Management and the Health-Care Team

One of the conversations you may need to have with your doctor concerns the management of pain. We have come a long way in dealing with the pain that is inevitable in many end-stage diseases. Most pain and symptoms can be controlled. People do not become addicted to pain medications that are used correctly, although doses may have to be increased over time if pain worsens and the patient's body develops a tolerance.

Pain management techniques are constantly evolving. If you feel that your health-care team's approach to pain management is not working, you may want to suggest that your doctor consult a pain management specialist or contact an organization such as Pallium (www.pallium.ca), which is dedicated to the education and professional development in palliative care of Canadian health-care professionals and citizen-consumers. Alternatively, you can call the Living Lessons® Help Line to find out if alternative sources of pain management are available in your community. As the primary caregiver, you must have an informed discussion of pain management issues with your doctor.

Communicating well with the health-care team is essential. How well members talk together and understand each other can influence your loved one's happiness and comfort.

Tips for Caregivers

The tips listed below may help you achieve open, honest communication between you, your loved one and your doctor.

- *You are your loved one's primary advocate on the health-care team.*
- *If you have decided to provide care in the home, find a doctor who will visit you there.*
- *Schedule a triple appointment instead of a single one: the average doctor's appointment is seven minutes, which may not be enough time to ask and get answers to all your questions.*
- *When making a doctor's appointment, explain why you need to see the doctor and what you hope to get from the appointment.*
- *Make a list of questions you want to ask and identify their priority. Give a copy of this list to the doctor.*
- *Your list might include questions such as these: What can we expect from this treatment or procedure? What is its goal? For instance, if palliative chemotherapy is offered, is the goal comfort or a decrease in pain? What kind of crises can we expect, and what might go wrong?*
- *Many of your questions will stem from fear of the unknown, and many will have no answers. No one can predict how long someone will live; it is more realistic to talk about probabilities rather than ask for precise answers.*
- *Arrange for friends or volunteers to attend a doctor's appointment with the patient if you or other family members can't. Ask them to prepare questions.*
- *As primary caregiver, you should act as a second pair of ears during appointments. Take notes so that you can refer to them later.*
- *Keep a logbook or journal of all care and treatment. Include in it details of the administration of drugs, appointments, names and numbers of the health-care team and so on.*
- *Remember that, as caregiver, you may notice changes and symptoms that other members of the health-care team do not. Communicate these to other members of the team.*
- *After appointments, ask for a report or a diagnostic summary if you feel it would be helpful.*

- *Talk to your doctor before you use alternative or complementary therapies, which may interact with prescriptions. Although some alternative therapies may be a way of providing hope and a sense of regained control, scrutinize them as carefully as you would any treatment. Ask how they will improve quality of life, whether they will interfere with other treatment and what you can expect from them. Seek out authoritative research to substantiate claims made about these treatments. Many complementary therapists are registered, including those practising touch therapy, herbal therapies, chiropractic medicine and so on.*



I worried—throughout the nine months and five days of Devon's life—about how I was going to live when she was gone. How could I possibly go on with my life without her? I lived my grief in anticipation. I realize now that you can never know and you can never be prepared. I have the rest of my life to know what it is to be without her. If I had it to do again, I would spend my energy treasuring every moment.

Yet even now, as I look back, the normal life we worked hard to create gives me great peace. We didn't draw the curtains and stay inside. We lived the lifetime that Devon had. We still had parties, went on grand adventures, flew on airplanes, swam in the lake. We had one Easter and one Christmas. We made memories. It gives me comfort to look back and see that those were good things, things that were done right. *Stephanie Guthrie*

Community Circles of Support

- Community
- Family Communications
- Enlisting Help from Family and Friends
- Talking about Dying
- Communicating with Children about Death

Community, friends and family are all important components of the informal support network that will help you and your loved one. Experience has taught us that it is best to be active in coordinating this help. Think about who is available to help and how they are best suited to do so. Be clear with them about what they can do and how they can best do it. Your network might include family, friends, neighbours, members of the social organizations or faith community to which you belong, ministers, priests or other spiritual advisors.

Community

Your community can play an important role in your circles of support, especially in rural areas and tightly knit immigrant or ethnic communities. Places of support within the community might include everything from neighbourhood centres, schools, faith communities, women's groups, family resource centres, public health services, prenatal care groups and regional and provincial branches of Family Services. For example, hospice palliative groups increasingly are offering bereavement support in schools.

Family Communications

Family relations can be very difficult where the death of a family member is concerned. The more openly you can talk among yourselves, the better. Family discussions are an integral part of care decisions.

Direct clear communication is crucial. Families can be tempted to protect the dying person from the truth. In our experience, it is most helpful to give information honestly and to deal with the issues directly as they come up.

A family conference is one good way to bring the family together with the patient to discuss important issues about the care plan,

such as where care should be delivered and by whom, the time or desirability for do not resuscitate orders or any other issues of common concern.

Emotions can run very high in families at the best of times, but especially at the end of the life of a loved one. It might be useful to begin family meetings by having family members describe how they are changing and evolving because of the impending death of their loved one. Sometimes it is best to appoint one family member to represent the family in discussions with the health-care team so that information-sharing and decision-making are as efficient as possible. Other family members can be assigned other important tasks, such as researching services.

Establishing your own informal support network can be a huge help to you and your loved one. It can include family, friends, neighbours, or members of the social organizations or faith community to which you belong.

Enlisting Help from Friends and Family

Experience tells us that it is important that you be crystal-clear with family and friends in telling them how they can best support you. Do you need meals cooked? Do you need someone to take on the job of phoning or e-mailing friends and extended family with news of how your loved one is? Do you want people to drop by unannounced, or is it best that they plan their visits?

Don't be afraid to ask for help. Most people want to help, but remember that they may be as inexperienced as you are in a support role and will be most comfortable with clear parameters based on what the dying person needs and can accept. Perhaps you might make a

list of what you need done and post it so that visitors and family can sign up for a task and you will know who is doing what and when. Just remember, it's sometimes hard for people to accept being cared for, especially if they value their independence and autonomy.

Talking about Dying

You may find that friends and family are uncomfortable talking about dying. Like the proverbial elephant in the room, death is the subject that everyone knows is there but is uncomfortable addressing. The mechanisms of denial can be very powerful, and often we lack the language or the comfort to talk about dying.

Dying people still have much to contribute to their families, and part of keeping hope alive for them is helping them to understand that.

It may help to ask questions like these: Do you feel this is the last stage of your life? What does quality of life mean at this stage? Now that you are at this stage of life, what things do you need to do? A useful exercise is to ask family members to think about the aspects of their relationship with the dying person that they might need to finish, and try to help them find the words to do so.

Recognize that throughout all the stages of life people need to do certain things. Dying people still have much to contribute to their families, and part of keeping hope alive for them is helping them to understand that. A man might have a nugget of fatherly advice for his daughters. A woman might say the unsaid to her sister.

Communicating with Children about Death

In our experience, the grieving process of children is often eased when we are open and honest with them about death. The following are a few tips on communicating with children about death:

Children need to learn to cope with loss. If we don't discuss death with them, they get the message that the subject is off-limits.

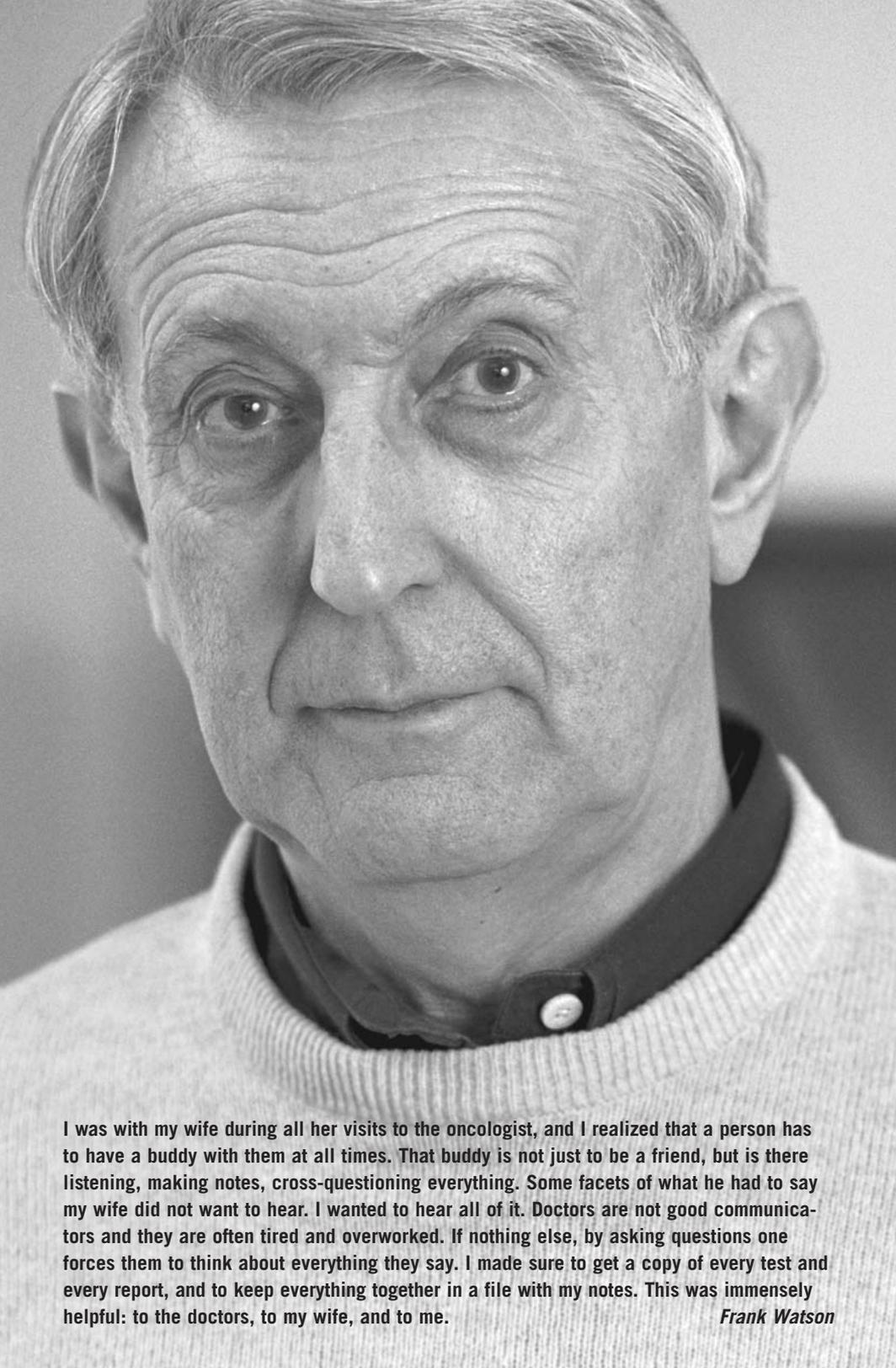
Children need explanations, but these should be simple, direct and truthful. Use as much detail as the child is able to understand. Answer children's questions honestly and directly.

Children need to be reassured about their own security; they often worry that they will also die or that their surviving parent will go away. Give children lots of reassurance.

When discussing death with children, use words such as "cancer", "died" and "death". Words like "passed away", "he is sleeping" or "we lost him" can confuse children and lead to misunderstandings.

*Use a story (*The Fall of Freddie the Leaf: A Story for All Ages* by Leo F. Buscaglia and *The Velveteen Rabbit* by Margery Williams Bianco are two good examples) to help children talk about living and dying.*

When a death occurs, grieving children are helped if they are included in the planning of memorial ceremonies and can participate in them. These events help children (and adults) remember loved ones. Children should not be forced to be involved in these ceremonies, but they should be encouraged to take part in those portions of the events with which they feel comfortable.



I was with my wife during all her visits to the oncologist, and I realized that a person has to have a buddy with them at all times. That buddy is not just to be a friend, but is there listening, making notes, cross-questioning everything. Some facets of what he had to say my wife did not want to hear. I wanted to hear all of it. Doctors are not good communicators and they are often tired and overworked. If nothing else, by asking questions one forces them to think about everything they say. I made sure to get a copy of every test and every report, and to keep everything together in a file with my notes. This was immensely helpful: to the doctors, to my wife, and to me.

Frank Watson

Practical Issues and Information

- Practical Issues during the Illness:
*Inventory of Assets and Important Documents, Wills,
Financial Provisions and Bank Accounts, Insurance and Benefits,
Powers of Attorney, Funeral Arrangements, Living Wills and
Do Not Resuscitate Orders*
- Practical Issues after Death
- Information and Resources

Practical support in sorting out your loved one's wishes can be an important way for you to reduce fear and anxiety about dying. Often end of life involves the desire to plan in advance—what we call putting one's affairs in order. Practical issues may include writing a personal directive (for nonfinancial matters, including medical care), writing an enduring power of attorney (for financial matters) and making a will (to plan for the disbursement of financial and personal assets after death), as well as ascertaining the patient's wishes for funeral and memorial services.

Family members often feel confused, exhausted and numb when a loved one dies, and practical business affairs that keep them occupied for the first few weeks may be a welcome distraction. However, pre-planning can decrease family tension and lighten the load during the illness and immediately following death.

Practical Issues During the Illness

Inventory of Assets and Important Documents

Make a list of assets—insurance policies, stocks and bonds and assets in bank accounts and safety deposit boxes—and where they are. You may also want to make a list of where to locate important documents, such as powers of attorney and the dying person's will, social insurance number and birth certificate.

Wills

Make arrangements to prepare a will if this has not been done. Make any necessary changes to a pre-existing will, for instance, in the choice of executor or in specific financial provisions for the guardianship of children.

Financial Provisions and Bank Accounts

Because the bank accounts of a person are frozen after his or her

death, before the death set up (or add to) a savings account in the surviving spouse's name. The funds in that account can be used to provide for the family immediately after the death of the loved one. Joint accounts are not usually frozen.

Insurance and Benefits

Make sure that life insurance beneficiary clauses are up to date. If necessary, contact the employee benefits department of the dying person's work place to ensure that desired beneficiaries are named.

Powers of Attorney

Sometimes the dying person may want to give someone else the authority to make decisions if she is no longer able to do so. A power of attorney is a document that appoints a person to act financially on behalf of someone who is either physically or mentally incapacitated. A Continuing Power of Attorney for Property and a Power of Attorney for Personal Care allows a dying person to give these powers to a family member, relative, friend or professional.

Funeral Arrangements

Consider making advance arrangements for the funeral, including details of memorial services. Your loved one may want a particular poem or psalm to be read or a favourite piece of music to be played. A funeral director can handle the purchase of a cemetery plot and bill you later (in cases in which death is imminent) for its cost and other charges.

The practical sorting out of your loved one's wishes can be an important way for you to reduce fear and anxiety about dying, and can decrease family tensions and lighten the load during and following death.

Living Wills and Do Not Resuscitate Orders

You may wish to help your loved one make clear his wishes about medical care in a document known as a living will, sometimes also known as a personal or advance directive. You can help put these wishes in writing so that, in the event that he is unable to tell you what he wants at any given time, you, other family members and health-care providers will know what his wishes are. Because the laws concerning living wills vary from province to province, seek advice about them within your community. The provinces of Alberta, Manitoba, Newfoundland, Nova Scotia, Ontario, Quebec and Saskatchewan have legalized the making of living wills. British Columbia and Prince Edward Island have also passed laws about living wills, but they are not yet in force.

Living wills go by various names and have different powers, depending on where you live. The directives may cover decisions about health care (including extreme measures to maintain life or refusal of life-sustaining treatment, sometimes called a do not resuscitate order, or DNR), as well as about accommodations (where your loved one will live) and nonfinancial legal matters. For more detailed information or to be sure that the living will is valid, consult a lawyer.

Practical Issues after Death

Meeting with Lawyers and Executors

Arrange to see your loved one's lawyer and executor or co-executor within two or three days of the funeral. Speed is important in case the lawyer has to probate the will.

Arranging for Benefits

Copies of the birth certificate, marriage certificate and death certificate will be required in order to receive benefits from insurance,

CPP and other sources. Benefits may be available through Veterans Affairs. The funeral director can provide appropriate claim forms.

Life Insurance Forms and Banking

Phone life insurance companies to request claim forms. Notify, where applicable, the insurer carrying the deceased's homeowner's health and auto insurance policies, his employee benefits department and banks (thus freezing accounts). Notify credit card companies and destroy or surrender the credit cards.

Information and Resources

A great deal of detailed information on hospice palliative care is available in print form and on the Internet. You can start by calling the Living Lessons® Help Line at 1-877-203-INFO or by contacting your provincial hospice association. If you require more detailed information, much is available under specific topics, such as bereavement, caregiver information, pain management, living wills and so on. You may also find useful information related to specific diseases, such as cancer, ALS or AIDS.

National Resources

Living Lessons® Help Line

1-877-203-INFO

www.living-lessons.org

Pallium

www.pallium.ca

This organization is mostly relevant to Alberta, Saskatchewan, Manitoba and Northwest Territories but is also valuable for people in other areas.

Victorian Order of Nurses

613-233-5694

www.von.ca

Canadian Hospice Palliative Care Association (CHPCA)

1-800-668-2785

www.chpca.net

Caregiver Network (Canadian)

www.caregiver.on.ca

Family Services Canada

See “Social Services” (provincial) in the Blue Pages or call 1-800-622-6232 for the number of your provincial center and for more information on Government of Canada programs and services related to caregivers.

Health Canada

www.hc-sc.gc.ca

Health Canada provides resources through the Division of Aging and Seniors (613-952-7606) and the National Advisory Council on Aging (613-957-1968). For information on additional services and programs call Government of Canada 1-800-622-6232.

Provincial Associations

BC Hospice Palliative Care Association

1-877-422-4722

www.hospicebc.org

Palliative Care Association of Alberta

780-447-3980

www.albertapalliative.net

Saskatchewan Palliative Care Association

306-382-2550

Hospice & Palliative Care Manitoba

204-889-8525 or 1-800-539-0295

www.crm.mb.ca/health/mbhospic.html

Hospice Association of Ontario

1-800-349-3111

www.hospice.on.ca

***Hospice Association of Ontario's
LifeLine***

416-979-9779

www.hospicelifeline.com

Ontario Palliative Care Association

905-954-0938 or 1-888-379-6666

Association québécoise des soins palliatifs

514-890-8189

www.aqsp.org

Nova Scotia Hospice Palliative Care Association

902-752-7600

New Brunswick Palliative Care Association

506-623-3405

***Hospice Palliative Care Association
of Prince Edward Island***

902-368-4498

Newfoundland & Labrador Palliative Care Association

709-777-5742

Financial Aid

Several sources of financial aid may be available as you care for a terminally ill loved one. Ask a member of your health-care team about provincial and regional sources not listed here.

Canada Pension Plan

Guaranteed Income Supplement

Old Age Security

1-800-622-6232

Social Assistance

1-800-277-9914 (English) 9915 (French)

www.canada.gc.ca

Employment Insurance Benefits

1-800-622-6232

Department of Veterans Affairs

www.vac-acc.gc.ca

Canadian Cancer Society

1-888-939-3333

*You are not alone, you are in the
company of over three million
Canadians caring for loved ones who
have long-term health problems.
Ready to support you is a network
of organizations, grounded in the
life-affirming principles of
hospice palliative care.*



You need to accept your feelings. It took me a long time to understand, but all of those feelings are okay, and you are going to feel them all: happy, sad, angry, strong, weak. Resentment. Fear. Regret. A negative feeling doesn't mean you aren't a good caregiver. It means you're human. You're not guilty of anything. You're doing the best you can.

Amina Rasool



dignity

choice

compassion

human comfort

meaning

support

community

life

1-877-203-INFO
www.living-lessons.org

Living Lessons® is an ongoing project of the Canadian Hospice Palliative Care Association (CHPCA) and hospice palliative care organizations across Canada, and is part of the GlaxoSmithKline Foundation's commitment to promoting quality of life during the end stage of life in Canada. The Living Lessons® campaign is focused on initiating public dialogue and promoting understanding, support and better access to quality care in the last stages of life.