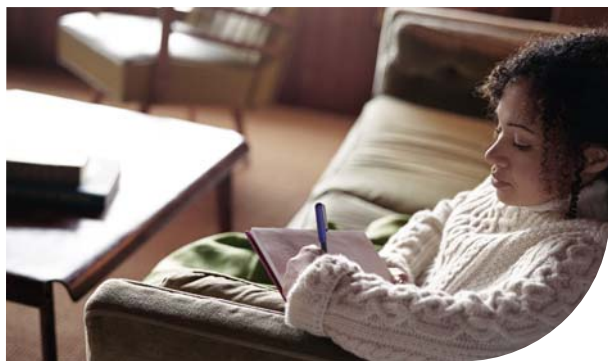




Canadian Cancer Society  
Société canadienne du cancer

# Living with Cancer

*A guide for people with cancer  
and their caregivers*



Let's Make Cancer History

1 888 939-3333 | [www.cancer.ca](http://www.cancer.ca)



## TABLE OF CONTENTS

<b>3</b>	<b>Introduction</b>
3	Definitions for some terms used in this booklet
4	How to use this booklet
<b>7</b>	<b>Reacting to the Diagnosis</b>
7	First reactions
7	Why has this happened?
8	Will there be pain?
9	Thoughts about dying
9	Hope
<b>11</b>	<b>Telling People about the Diagnosis</b>
11	Telling family members and friends
12	Telling children
15	Telling co-workers and employers
16	Responding to reactions
<b>19</b>	<b>Understanding and Sharing Your Feelings about Cancer</b>
19	Fear and uncertainty
21	Denial
22	Anger
23	Guilt
24	Stress and anxiety
25	Loneliness
26	Sadness and depression
29	Sharing your feelings about cancer
<b>35</b>	<b>Relieving Tension</b>
35	Venting your emotions
35	Laughter
36	Creative activities
36	Deep relaxation methods
37	Exercise
38	Complementary therapies

<b>41</b>	<b>Coping within the Family</b>
41	Finding balance if you're a caregiver
44	Cancer is a family affair
45	Younger children
47	Teenagers
48	Adult children
49	Parents
51	Partners or spouses
53	New romantic partners
<b>57</b>	<b>Dealing with Change</b>
57	Changes to self-image
62	Changing family roles
63	Changing where you live
63	Changing work or employment roles
65	Changes to finances
<b>67</b>	<b>Getting Help from Others</b>
67	Many different kinds of help
67	Difficulties in asking for or accepting help
68	Sources of help
<b>77</b>	<b>Where to Look for Cancer Information</b>
77	Your healthcare team
79	Resource centres and libraries
80	The Internet
81	The Canadian Cancer Society
<b>83</b>	<b>Thinking about the Future</b>
83	The end of treatment
86	Putting your affairs in order
88	The new "normal"
<b>91</b>	<b>Other Resources about Living with Cancer</b>
91	The Canadian Cancer Society
92	Suggested websites

# Introduction

Everyone's cancer experience is different. But whether you're newly diagnosed, in active treatment, or are caring for someone with cancer, you will probably need to deal with many practical issues, make tough decisions, and cope with a range of emotions. The information in this booklet can help you along the way.

## Definitions for some terms used in this booklet

**A person with cancer** refers to the person diagnosed with cancer.

**Caregivers** provide physical and emotional care to people with cancer. In many cases, caregivers are family members, often partners, parents or children, or close friends.

**People living with cancer** describes all the people whose lives are directly affected by a cancer diagnosis: the person with cancer, caregivers, and the people who live with them or are a close part of their lives.

**Partner** refers to a spouse, girlfriend or boyfriend. You may be married to your partner, live common-law or live separately. You may be in a heterosexual or same-sex relationship.

**Family** can be defined in whatever way that is most meaningful to you. It may be you and your partner, with or without children. You might be a step-parent, single parent or foster parent. Your family may include grandparents, siblings, close friends and neighbours, or other adults and children.

**Your healthcare team** includes the doctors, nurses, and other healthcare professionals such as pharmacists, dietitians and counsellors who provide care for you throughout your cancer experience.

## How to use this booklet

This booklet was written for people with cancer and their caregivers. It describes issues that are important to many people living with cancer. Because each person has a unique response to cancer, some topics may have more meaning for you, or seem more useful than others. You may want to read some sections right away, and come back to others later or not at all. If certain topics upset you, you may want to read about them when you are alone or with someone you trust.

Some information in this booklet is meant for people with cancer, while other information is for caregivers – and some information is for both. For example, people with cancer and those caring for them can worry about many of the same things. Both may worry about cancer disrupting family life. Cancer can bring up strong emotions, like anger and fear, for both people with cancer and their caregivers.

People with cancer and their caregivers can also have different concerns. For example, people with cancer may struggle with changes to how they look, while caregivers may worry about whether they are being supportive enough.

People with cancer and their caregivers may find that it helps to understand a bit more about how the other person might be looking at things. If that's the case for you, you may want to read the whole booklet and not just the parts that are aimed at you.

## **This booklet covers many topics:**

In **Reacting to the Diagnosis**, we look at some of the reactions and questions you may have when you first find out that you, or someone you love, has cancer.

In **Telling People about the Diagnosis**, we give you some practical tips for telling family members and friends, children, parents, co-workers and employers about the cancer diagnosis.

In **Understanding and Sharing Your Feelings about Cancer**, we look at some of the feelings that you might have when living with cancer, and provide tips on sharing these feelings.

In **Relieving Tension**, we suggest how you might relieve tension, including venting your emotions, relaxing, exercising and more.

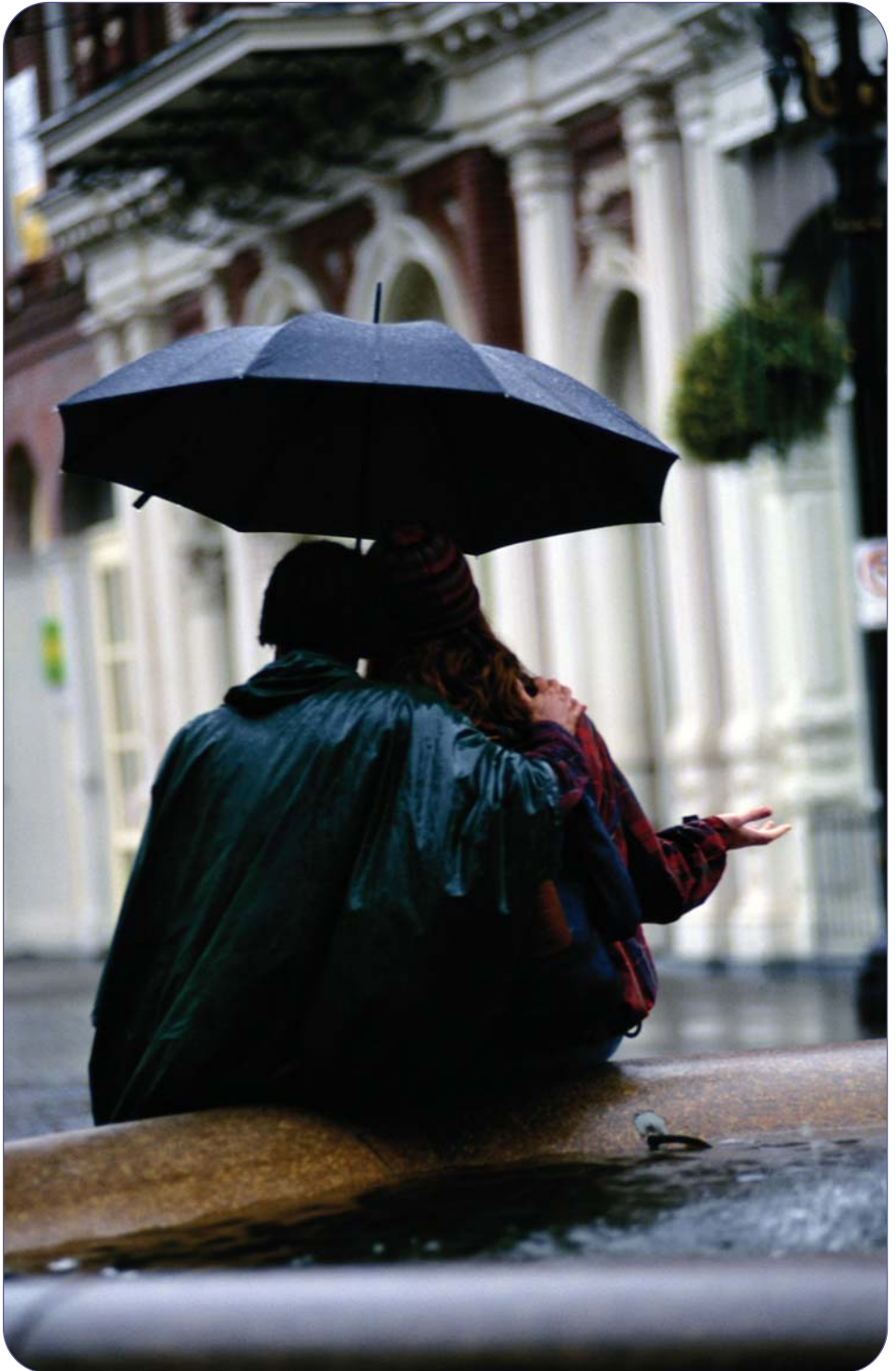
In **Coping within the Family**, we look at the challenges of keeping up with family roles. We highlight how different family members and people close to you may be affected.

In **Dealing with Change**, we describe some of the changes that may happen in your life, including changes to family roles, self-image, where you live, work or employment roles and finances.

In **Getting Help from Others**, we talk about the different kinds of help that you might need, such as help preparing meals or finding someone just to listen, and suggest where you might turn to for various types of practical and emotional support.

In **Where to Look for Cancer Information**, we guide you to some of your best sources of information, such as your healthcare team, libraries and resource centres, the Internet and the Canadian Cancer Society.

In **Thinking about the Future**, we discuss how you might feel about the end of treatment, how you can put your affairs in order, and moving forward into your new “normal”.



# Reacting to the Diagnosis

This chapter looks at some of the reactions and questions that you may have when you first find out that you, or someone you love, has cancer. Topics include:

- First reactions
  - Why has this happened?
  - Will there be pain?
  - Thoughts about dying
  - Hope
- 

## First reactions

A cancer diagnosis, whether yours or a loved one's, can be shocking and deeply distressing. You may feel overwhelmed, devastated, numb, frightened, angry or a sense of disbelief. Your reactions can be very strong, conflicting or disturbing. They may come and go quickly, and they may change often.

The diagnosis can raise many fears: of death, of physical change, unpleasant treatment or feeling sick, of being out of control, about how the family will react and cope, of how to handle day-to-day tasks, work or finances.

Some people feel all alone, even if friends and family are with them. Others report a sense of watching things happen to someone else, from the outside. Some people find it difficult to understand what the doctor is telling them, and need to be told the same information many times.

All of these responses are normal. It is also normal for similar feelings and fears to come up a number of times throughout the cancer experience.

## Why has this happened?

Many people with cancer and their loved ones search for a reason behind the illness. People often feel that they could somehow change the situation, if only they knew why it happened.

Cancer is a complex disease, and it is often impossible to know why things happen the way they do. This uncertainty can be hard to accept at first, and you may struggle with it throughout your cancer experience. It might help to remember that solving this mystery will not change the course of the illness. Trying to find the reasons behind the cancer may interfere with your ability to cope. Worrying about *why* can use up valuable energy that could be used to help you and your family deal with the disease instead.

Some people may feel guilty and blame themselves. They may feel that something they did in the past led to getting cancer. If you're struggling with feelings like this, it's important to recognize that no one deserves to get cancer. It may help to remember that you can't change the past – try to focus on the present and how to best deal with the situation ahead. If you are having a hard time moving past such feelings, it may help to talk to a counsellor or someone on your healthcare team.

## Will there be pain?

Almost everyone worries that cancer or cancer treatment will be painful. While some people do experience pain, some have pain only once in a while and some people don't have any pain at all.

There are many ways to control and prevent pain, and living with cancer does not have to mean living with pain. If you are worried about pain, or if you are in pain, it's important to tell someone on your healthcare team. Your healthcare team is there to help you. You don't have to face pain alone.

Emotions such as anxiety and sadness can sometimes make you more sensitive to pain or make pain harder to bear. Learning to cope with these emotions may help reduce pain and improve your mood. And finding ways to manage pain may make it easier to cope with difficult emotions.

## Thoughts about dying

Finding out that you or someone you love has cancer often leads to thoughts of death. This is a normal reaction. These kinds of thoughts can be overwhelming, especially at first.

When first diagnosed, many people with cancer and their families focus on the possibility of *dying of* cancer. Over time, as the reality of day-to-day life with the disease settles in, many people can begin to focus instead on *living with* cancer. That can mean finding the strength and resources to cope with the challenges of the disease, adjusting to so much uncertainty, and finding new ways to appreciate the pleasures and joys of life. This change of focus can take time.

## Hope

Once the initial shock of diagnosis has lessened, people often feel a sense of hope. Hope allows people to cope with the difficulties of the present and to imagine a positive future. Hope is very personal - you might find it easy to be hopeful or you might find it hard to bring hope to what is such a difficult experience.

Although hope is very important to people with cancer and their loved ones, it's important to keep a balance between realistic and false hope. Cancer is a serious disease, and a realistic picture of the future will help you or a loved one make decisions relating to treatment and care.

People find hope in different ways. You may find hope by enjoying nature or spending time with your family. Your faith may give you hope, or you may be inspired by stories about people who have overcome cancer, or who lead active, fulfilled lives during and after treatment. Many people find hope in the fact that cancer research has made so much progress in recent years, or in the possibility of living with certain cancers as lifelong diseases, like some forms of diabetes or heart disease.

For some people, a cancer diagnosis brings renewed clarity and purpose to life, and this can bring hope. Others find hope in starting new projects or making plans for the future - such as a trip to a new or favourite vacation spot, or planning next summer's garden.



## Telling People about the Diagnosis

One of the hardest parts of receiving a cancer diagnosis is having to tell other people. You're not alone if you just don't know how to begin. This chapter provides tips and suggestions for:

- Telling family members and friends
- Telling children
- Telling co-workers and employers
- Responding to reactions

---

### Telling family members and friends

Here are some tips on how to tell family and friends about a cancer diagnosis:

- Make it easy to have a private, quiet conversation. Turn off the TV, close the door, and try to make sure you won't be interrupted by other people or the telephone. It might be helpful to have someone who already knows about the diagnosis with you.
- Ease into the conversation by saying something like: "I think it would be good to tell you what's going on. Is that okay?" or "I have something serious to talk to you about." If the person knows a bit about the situation, you might start with, "I think you probably know some of this already, so why don't you tell me what you know so far. I can take it from there."
- Give information in small chunks, a few sentences at a time. Check regularly to make sure the person understands. You can ask: "Is this making sense?" or "Do you see what I mean?"
- Don't worry about silences. You may find that holding hands or sitting together quietly says more than any words. If silence makes you uncomfortable, you might want to ask a simple question, such as: "What are you thinking about?"
- Be as honest as possible about the situation and your feelings. You don't need to act upbeat and positive if that's not how you're feeling.

## Telling children

It might seem impossible to know how and what to tell your children about a cancer diagnosis in the family. Even so, it's important to be honest with children, because:

- They will know something is wrong anyway.
- They can imagine the worst if they're not told otherwise.
- Children can feel betrayed or stop trusting you if they hear the news from someone else.
- Children can feel isolated if they're not told about important family events.
- If you pretend to them that everything is fine, children may feel that they have to keep their worries to themselves, and they may not be able to tell you how they're feeling.
- It takes a lot of valuable energy to keep such a big secret.

### *Tips on telling children about cancer*

Here are some tips on *how* to tell children about a cancer diagnosis:

- Choose a time to talk when you're feeling calm.
- Try to have another adult present. That way, children will know that there are other adults they can talk to, and who will support them. In a two-parent home, try to talk to your kids together. If you're a single parent, you could ask a close relative or friend to be there. A doctor, nurse or social worker might also be able to help with difficult discussions.
- Be prepared to repeat the information, perhaps many times. Keep checking that children understand what you're saying. You may need to take cues from their questions, eye contact or body language.
- Be clear and direct. Don't create a feeling that cancer should be a secret by whispering or using terms such as "the big C".
- Don't be afraid to tell your children about your feelings if you want to. It may help them be able to express theirs.

Here are some tips on *what* to tell children:

- Provide some basic information, such as the name of the cancer, the body part it affects, the treatment and its possible side effects. It will help to use words and terms children can understand. For example, say “doctor” instead of “oncologist” or “medicine” instead of “chemotherapy”.
- Reassure children that they can’t catch cancer from you. It may also help to reassure them that it would be very unlikely for their other parent to get sick as well.
- Tell children that nothing they did caused the cancer. Children may worry that the cancer is their fault and they must have done something wrong for this to happen.
- Tell children how their lives might change. Children thrive on routines. Since cancer treatment can disrupt those routines, it’s important to prepare them for possible changes to school, lessons, meals, chores and so on.
- Give children time and other chances to ask questions and express their feelings. If they ask questions that you can’t answer, let them know that you will find out the answers for them. Don’t be afraid to say “I don’t know.”
- Tell your children how much you love them.

In addition to telling your children, try to tell other adults in your children’s lives (teachers, neighbours, coaches, relatives) about what’s going on. These other adults may be able to take your children to their activities, as well as listen to their feelings and concerns. Members of your healthcare team may also help by talking to your children and answering their questions.

### **How much detail do children need?**

You will be the best judge of how much your child will understand about the situation, but in general children need to know at least enough to be prepared for changes to their routine and day-to-day life. Reassure them that you’ll keep them up to date on what’s happening.

## ***What if your child asks if you're going to die?***

Just as it's frightening for you to think about death, it's scary for children to ask this question. Many may think about it but not ask.

You may want to prepare an answer to this question in case your child asks. Your response will depend on many things: the type of cancer and how easy it is to treat, the stage of the cancer, and what the doctor has told you.

It's important to let your children know that you're willing to tell them the truth, and that you will keep talking to them as you get more information. You could say:

- "I don't know what will happen in the future, so let's think about what's going on right now. I promise I'll tell you when I find out new information. I want you to ask me any questions you have and I'll do my best to answer them."
- "The doctors have told me that my chances of getting better are very good. I believe them and I want you to believe them too. I'll tell you if that changes."
- "Sometimes people do die from cancer. I'm not expecting that to happen because the doctors have told me they have very good treatments these days."
- "There's no way to know right now what's going to happen. I'll know more after the first treatments are finished."
- "They don't know a lot about the kind of cancer I have, so it's hard to know how I'll do. I'm going to try my best to get better, and my doctors are doing their best, too."
- "My cancer is hard to treat, but I'm going to do everything I can do to get better. I don't know right now if I will, but I will be honest about what's going on. If you are worried, I want you to tell me so that we can talk about it."

## **Telling co-workers and employers**

Whether you are the person with cancer or the caregiver, telling people at work about the cancer diagnosis is a very personal decision. It might be difficult to keep cancer a secret in the workplace, especially if you are gone for long periods or if your appearance changes. Your decision to tell your co-workers will depend on many things:

- Your relationships with them. Which co-workers do you trust and consider friends? How important is your privacy?
- Your company's corporate culture. Are you more like family or is it a strictly business work environment?
- Previous experience with illness in the workplace. Has someone else in the office been ill? How did people react?

### ***Who to tell at work***

If cancer and treatment will interfere with your ability to do your job, then you will probably have to tell your boss and possibly some people who work closely with you. They'll need to know if you need to take time off, if your productivity will be affected or if you need to change how you do your work. If you're the boss, you may need to explain the situation to at least some, if not all, employees - especially if the day-to-day running of the company will be affected.

If you don't know where to begin, or if you're concerned about how your employer will react, try starting with your human resources department or personnel manager. You can use their experience and support to guide you through the telling process.

### ***When to tell people at work***

It can be a good idea to wait until you know about treatment schedules before telling co-workers. That way, you can let people at work know if and when you'll be away, and for how long. Keep in mind that the more advance notice you can give people, the more they can plan to cover for your absence. Making plans for any absences you might have shows your employer and co-workers that you are committed to your job and your company.

## **What to tell people at work**

Many people are nervous about sharing the news of a cancer diagnosis at work. It's hard to predict how people will react. Some of your co-workers may know very little about cancer, or they may have strong opinions on it. They may think that it is contagious, or believe that it will automatically make you less productive, competent or reliable.

Try to be prepared for a variety of reactions, and plan your response. To start, you might want to tell people at work:

- your diagnosis and the plan for your treatment
- how much you expect to be away, if at all
- how you plan to handle your work during this time

If you have close relationships with co-workers, you may find it comforting to share some of your feelings, worries and concerns. Let them know that sometimes your mood or your ability to work will be affected, and that you may need their help. You can also prepare them for the fact that your appearance might change.

Don't be afraid to ask for the kind of support you need. For example, you may not want to talk about having cancer while at work. You can always ask a trusted colleague to let others know that you'd prefer to focus on the tasks of the day rather than on cancer.

## **Responding to reactions**

People will probably react to hearing the news in different ways.

Some people will know exactly what to say and do and will be easy to talk to. They will know how to support you over the course of the illness and treatment.

Others may not react in ways that you understand. Some people may think of cancer as an automatic death sentence, based on their understanding of the disease or previous experience with the disease. Learning about current treatments and approaches may lessen their fears and give them more hope.

People close to you may think they're protecting you by not talking openly or honestly about cancer, even when you want or need to talk about it. Sometimes, people can take a long time to come to terms with cancer, or want to rush you through the process of understanding and dealing with it. Some people just won't know how to respond. You might find it helpful to speak directly and honestly to them about how you're feeling and what you need.

Some people might withdraw from you. Their absence doesn't necessarily mean they don't care, but they may not feel able to deal with the situation. They may be scared to see you looking sick or in pain, or fear that seeing you will be upsetting or force them to think about the possibility of getting cancer themselves. They may be threatened by illness, or worry that they'll say the wrong thing or not be able to help. Whatever their reasons, this kind of behaviour can hurt.

If you feel up to it, you can try phoning an absent friend or relative, or sending an e-mail or letter. You can let people know what's happening and that you'd like to see them. You can ask them to do practical favours for you, like cooking a meal or returning videos. This makes people feel useful. Next time they might feel able to call you or just drop in. People sometimes need to be told how they can help.

In some cases, you may have to accept that someone might not be able to deal with cancer. While this can be upsetting, it's important to recognize that you haven't done anything wrong, and that they are staying away because they aren't able to accept or deal with your difficult circumstances.



# Understanding and Sharing Your Feelings about Cancer

Living with cancer can mean living with a range of emotions. Learning about the emotional effects of cancer can help you cope with the disease, and understand and support your loved ones through difficult times. This chapter looks at some feelings that can be the emotional effects of cancer, such as:

- Fear and uncertainty
- Denial
- Anger
- Guilt
- Stress and anxiety
- Loneliness
- Sadness and depression

Sharing your feelings about cancer is a very important way to cope with them. Topics in this section include:

- Why it's hard to talk about feelings
- Why it's important to talk
- Signs that someone is ready to talk
- Guidelines for talking about emotions
- If you don't want to talk

---

The wide range of emotions outlined below are a normal part of a cancer experience, so you're not alone if you feel any or all of them at some time or another. It's also normal to sometimes feel numb, as if you can't feel anything at all. Everyone's experience is different.

## **Fear and uncertainty**

It's human nature to fear the unknown. When cancer is diagnosed, life seems less secure and predictable. You may feel as if your life is out of control and that you don't know what the future holds. The time between diagnosis and the start of treatment can be particularly difficult.

The following things may scare you or make you feel very uncertain:

- You may wonder if you will die, or lose someone you love.
- You may worry that you or your loved one will feel sick or be in pain.
- Treatments and visits to the doctor take over your daily routine.
- People use medical words and terms that you don't understand.
- You may feel like you can't do things you enjoy, or that you have to put plans on hold.
- You may feel helpless.
- The healthcare professionals treating you or your loved one are strangers.

All this uncertainty can make you anxious, irritable, angry or frightened.

If you're feeling out of control, these tips may help:

- Learn as much as you can about cancer and its treatment. For some people, seeking information and using that information to make decisions helps them feel a bit more in control.
- Ask questions. Tell your healthcare team if you don't understand what they are saying, or when you want more information.
- Look beyond the cancer. Many people with cancer feel better when they stay busy. You may still go to work, even if you need to adjust your schedule. Hobbies such as music, crafts or reading can also help.
- Try to focus on what you *can* do, rather than feeling helpless. Remind yourself that you *are* coping, however bad you feel.
- Remember that the extreme uncertainty that comes with a new cancer diagnosis often fades as you and your family come to understand more about the disease, treatment and how you will cope.

If you find that fear or uncertainty is interfering with daily activities, counselling and support programs can help. Let your doctor or another member of your healthcare team know if you, or someone in your family, would like to talk to a counsellor or someone who has been through a similar cancer experience.

## Denial

Some people with cancer and their caregivers refuse to believe or accept the cancer diagnosis. This feeling is known as denial. It's important to be aware that true denial is very rare. People cope with cancer in their own way, and the term shouldn't be used to label someone who is coping with a diagnosis in a different way, perhaps by choosing to not talk about it a lot, or by remaining optimistic when the outlook is in fact not very good.

In some ways, a brief period of denial can be helpful because it gives a person time to adjust to the diagnosis and feel less overwhelmed by the news. But it can be a problem if it lasts too long (several weeks or months) and prevents someone from getting treatment or making important decisions.

If you feel that your loved one is in denial about the cancer diagnosis, allow some time for the news to sink in. Most people have accepted the diagnosis by the time treatment begins. If a refusal to accept the cancer diagnosis interferes with making treatment decisions, you can try to persuade the person to talk to a counsellor.

Denial can also cause tension in relationships if one person is in denial while the other person has accepted the diagnosis, and is ready to get on with planning treatment and making decisions. Talking to a counsellor together can help.

## Anger

You may feel angry at different points throughout your cancer experience. Anger is a normal response to what feels like a very unfair situation. You may be angry at:

- the cancer
- your healthcare team
- friends and family who are in good health
- your body
- yourself
- your God or gods

Sometimes, people get angry rather than express emotions that are more difficult for them to show – like fear, panic, sadness or frustration. Sometimes, people will get angry with other people, such as their healthcare team, or family and friends, when what they are really angry about is the cancer or the situation. Many of us have been raised with the idea that it's not acceptable to be angry, and so we may stifle anger instead of accepting it as a normal response to cancer.

If you feel angry, you don't have to pretend that everything is okay. Talk to your family and friends about your anger. Explain that you may seem angry or moody at times, and that really you're angry at the cancer and the situation, not at them. Most of the time, talking will help you feel a lot better.

If you feel that someone is taking out their anger on you, it can help to remember that they are probably angry at the disease and the situation. Still, no one should have to put up with extreme displays of temper or mood swings, or violence. If you are worried about someone else's anger, you can try to talk to them about it, take a break from each other or ask a trusted friend or family member, or a counsellor, for help.

## Guilt

Sometimes people with cancer feel guilty. They may:

- wonder if they could have noticed symptoms earlier and done something to prevent the cancer or make it less serious
- feel that they caused the cancer, because of lifestyle, attitude or work environment
- worry that other family members will also get cancer
- feel badly for upsetting loved ones, or feel guilty because they think they're being an emotional or financial burden
- envy other people's good health and be ashamed of this feeling

Caregivers, family members or friends may feel guilty for some of these same reasons or because they:

- are healthy while someone they love is ill
- can't help as much as they want to, or feel that they aren't doing a good job of helping
- feel stressed and impatient
- cannot make the person with cancer feel better
- may feel that they've caused the cancer

If you feel guilty, try to remember that cancer is not your fault and that no one deserves to be ill. Caregivers, family members and friends can remind themselves that there's no such thing as supporting someone else perfectly.

Counselling and support programs can help with feelings of guilt. Let your doctor or another member of your healthcare team know if you, or someone in your family, would like to talk to a counsellor or someone who has been through a similar cancer experience.

## Stress and anxiety

The challenges and changes that cancer brings to life can make people with cancer and their caregivers feel stressed and anxious. Stress and anxiety often have physical symptoms, such as:

- rapid heartbeat
- trouble swallowing
- pressure or tightness in the throat or chest
- chest pain, muscle pain or headaches
- rapid, shallow breathing (which can cause dizziness), or feeling like you can't catch your breath
- dry mouth
- sweating
- trembling or shaking
- upset stomach, nausea or diarrhea
- trouble sleeping, or getting too much sleep

You may find these ideas useful in managing stress and anxiety:

- Try to figure out what makes you feel anxious. Sometimes talking to someone who has had a cancer experience similar to yours can help you cope with anxiety.
- Decide how much you'd like to know about your situation. Some people become anxious because they have too little information, while others feel better not knowing everything.
- Keep a journal or diary during treatment. Writing down your thoughts and feelings can help relieve anxiety. A journal is also a good place to write positive feelings that you can return to when you're feeling low.
- Learn and practise some type of meditation or relaxation exercises. Regular physical exercise can also be very helpful.
- Cut down on caffeine (coffee, tea, cola drinks). Switch to decaffeinated drinks.

The chapter  
*Relieving Tension*  
starting at page 35 also  
has suggestions on dealing  
with stress.

Sometimes, the symptoms of stress and anxiety can be very severe. If you feel stressed or anxious most of the time, talk to your healthcare team. They may be able to help by teaching you some self-help methods, recommending a class to help you manage stress, referring you to a counsellor or support program, or prescribing an anti-anxiety medication.

## **Loneliness**

People with cancer may feel lonely or isolated from others. Sometimes, friends have a hard time dealing with cancer and may not visit or even telephone. You may feel too sick to take part in the activities you used to enjoy. And sometimes, even when you are with people you care about, you may feel that no one understands what you are going through.

Caregivers can also feel lonely. You may feel as though you've lost your best friend in the person with cancer, or that you have no one to talk to about what you're going through. You may feel overwhelmed with your new responsibilities and as though you don't have time to see friends or participate in the activities you enjoy. You may feel guilty about going out and having fun if the person with cancer can't do similar things. You may also feel overlooked by healthcare professionals, family and friends, who tend to focus most of their attention on the person with cancer.

You may feel less lonely if you can talk to other people who have cancer or are caring for people with cancer. Many people feel better when they join a support group or connect in other ways to people who are facing, or who have faced, the same challenges.

## Sadness and depression

Many people feel sad after a cancer diagnosis or while being treated for cancer. If you are unhappy at certain points or even throughout your treatment, this is a normal response to a stressful and upsetting situation. You may feel grief at the loss of your good health or your ability to enjoy your life as you would wish to.

Sometimes, people with cancer or their caregivers find that the low mood never lifts or that it gets worse over time. Depression is much more than simple unhappiness. Clinical depression, sometimes called major depression, is a mood disorder that is a significant mental health problem. It is not a sign of personal failure or an inability to cope.

Many people will experience depression at some point in their lives. It is an illness that can affect anyone at any age. If depression does occur, it can usually be treated successfully. The first step is recognizing it and then getting appropriate help as soon as possible.

The main symptom of depression is a sad, despairing mood that:

- is present most days and lasts most of the day
- lasts for more than two weeks
- impairs performance at work, at school or in social relationships

Other symptoms of depression may include:

- changes in appetite and weight
- sleep problems
- loss of interest in work, hobbies, people or sex
- withdrawal from family members and friends
- feeling useless, hopeless, excessively guilty, pessimistic or low self-esteem
- agitation or feeling slowed down
- irritability
- fatigue
- trouble concentrating, remembering and making decisions

- crying easily, or feeling like crying but not being able to
- thoughts of suicide (which should always be taken seriously)
- a loss of touch with reality, hearing voices (*hallucinations*) or having strange ideas (*delusions*)

## **Getting help**

The following strategies may help you cope with sadness or depression:

- Talk to family members or friends about how you feel. It may also help to talk to someone who has had a cancer experience similar to yours.
- Seek out positive people and events to keep your spirits up. People who have pets, especially cats or dogs, say contact with these animals can be soothing.
- Look to your spiritual faith for comfort to keep you going in difficult times.
- Eat well and be as physically active as you can. Exercise releases endorphins, natural mood-boosters.
- Try strategies for relieving tension, like yoga, meditation and exercise.
- Talk to your healthcare team or your family doctor, who can refer you to a mental health professional who specializes in treating depression.
- Ask your doctor about medicine to treat depression.

## ***Living with someone who is depressed***

It can be difficult to live with or help someone who is depressed. It may feel as though you're living with a stranger. A depressed person may not have the energy to do even simple activities or household chores. These changes are usually temporary, and nothing you have done, or failed to do, has caused the depression. When the depression improves, the person's usual personality generally returns.

While you can't solve someone else's problems or make their depression go away, you can support someone who is depressed by:

- listening and being patient
- reminding them that the depression will not last forever
- encouraging them to talk about their feelings
- encouraging them to try some strategies for coping or relieving tension
- offering to go with them to the doctor or mental health professional
- taking care of yourself so that you can cope better with the stress of living with someone who is depressed

### ***What to watch for***

Depression can become very serious. For example, someone who is depressed might refuse to eat or take medication, or have thoughts of hurting themselves. Try to persuade the person to talk to a doctor. If the depressed person resists, then you can talk to a doctor about getting help.

## Sharing your feelings about cancer

### *Why it's hard to talk about feelings*

Some of us aren't used to talking about personal, private feelings. This can make it difficult to talk about feelings about cancer – even if we want to. It can be hard to talk about emotions for many reasons.

You may:

- worry that you'll lose control and start to cry
- not know what to say and feel awkward
- have been raised with the belief that talking about your worries, sadness, anger, grief or fear is not appropriate or a sign of weakness
- think that having or talking about sad or negative feelings may make the cancer worse or treatment less effective
- not want people to worry about you, or not want to upset other people

### *Why it's important to talk*

Even though it can be hard, it's a good idea to talk about how you feel and share your emotions, instead of keeping them inside. Talking about how you feel can:

- make you feel better and more in control
- help you understand your feelings and make them seem less strange or overwhelming
- make you feel less alone
- strengthen the bonds between you and other people
- help you figure out what you really think
- help relieve stress
- make other conversations easier
- help your children learn how to express their feelings

## **Be honest about how you feel**

If you're trying to protect your loved ones by hiding worries and difficult emotions behind smiles, don't. When you have cancer, or are living with cancer, you have many reasons to be upset. You don't need to pretend to be cheerful when you're not. Spending lots of energy hiding your feelings doesn't leave a lot of energy for dealing with cancer in your day-to-day life.

Try to be honest and talk about all your feelings, not just the cheerful ones. Family and friends may tell you to "be positive" but this doesn't have to mean feeling or acting happy and cheerful all of the time. It can mean many things, such as:

- having hope
- taking care of your physical and mental health
- trying to focus on the good things in life instead of the bad
- being motivated to do things that make you feel good, like exercising, visiting with friends, eating well, volunteering or participating in hobbies

Try to think of being positive as facing up to the cancer, confronting it and dealing with it. If you can acknowledge and accept **all** your feelings, you might find it easier to deal with the harder ones. This may make you feel better – and more positive.

## ***Signs that someone is ready to talk***

Some people need time before they can talk about their feelings. If you're not ready to talk, say so. When you're ready, you may need to make sure that your listener is also ready. Sometimes, instead of saying so directly, people send a signal when they want to talk. They might:

- bring up the subject of cancer
- talk about things that have to do with cancer, such as a newspaper story about a new cancer treatment that they just read
- spend more time with you
- act nervous or make jokes that aren't very funny

You can help people feel more comfortable by asking them what they think or how they feel. Sometimes people can't put their feelings into words. Sometimes, they just want to hug each other, hold hands, sit quietly or cry together.

### ***Suggestions for talking about emotions***

- Let the person who's ready to talk, talk. When they want to talk, listen. Make sure you listen to how they talk, not just what they say. Try to hear what they mean but may not be able to say.
- Try to accept strong emotions and let people feel the way they do. For example, if the person you're talking to says, "I'm really worried," try saying: "That must be very difficult," rather than "Oh, don't worry, everything will be fine."
- Remember that emotions are not right or wrong. You are allowed to feel any way you like. Emotions aren't problems - but covering up strong emotions can make problems more difficult to solve.
- Respect the fact that some people don't want to talk about the illness. Others may want to talk about it one day but not the next.
- Try to *describe* your feelings instead of acting on them. If you say, "I'm feeling really angry today," this can start a conversation. But if you only show your anger by being rude, it can stop the conversation - and make everyone feel worse.
- Admit it if you don't know how you feel, don't know how you are going to cope or don't know what will happen. It's okay not to know.
- Try to help someone open up more by asking "*What* are you feeling?" rather than "*How* are you feeling?"
- Don't be afraid to say how you feel. You could say: "I think we're both finding this awful," or "I know you're worried about what could happen and so am I."
- Try to keep your eyes on the person you are talking to. If you keep looking around, they might wonder if you're being honest and open or even interested in listening at all.

- Avoid putting pressure on people. If you say: “You’re so brave,” or “You’re so strong,” it can put a lot of pressure on them to be strong when they may not feel up to it.
- Tell a joke and laugh – it can help to relieve tension and keep your mind off things.
- Don’t feel that you are not allowed to talk about any regrets you have. Everybody has some regrets in their life.
- Don’t feel that you have to say something all the time. Try not to get tense during silences or to fill silence with words. Silence can help people pull their thoughts together.

### ***If you don’t want to talk***

Some people just don’t want to talk about their feelings about cancer. For them, the best way to cope may just be to get on with things. If you feel this way, it’s fine to ask others to respect your wishes. You could say that you find that the best way for you to deal with your situation is to just get on with life. If you want to discuss it, you will bring it up.

You may decide that you don’t want to share your feelings with every person who asks. With casual friends or co-workers, it may be easier just to say a few words without going into detail. When they ask how you are, you can give a brief but honest answer like, “I had a bad day yesterday but today is better. Thanks for asking.”

If you find it difficult to talk about your feelings with people close to you, you may find it helpful to talk about your feelings with people who are not family or friends. You might want to find a support program for people with cancer or caregivers, or talk to a counsellor.

### **Sharing without talking**

If you find it hard to talk, think about other ways to share your feelings. For instance, you may find it helpful to write them down and then share them. Letters and e-mails can be good ways to share feelings without talking.

Even journals can be shared. Leave a notepad in a private place that both of you select. When you need to, write in the journal and return it to the private place. Your loved one can do the same. Both of you will be able to know how the other is feeling without having to speak aloud.

Your journal can also be online. Online journals or *blogs* are web pages that serve as a journal that anyone can read. You don't have to have a technical background to update the blog, although you do need to know a bit about computers in order to use the software. You can invite readers to post comments on your content.

### **Want to talk to someone?**

The Canadian Cancer Society can help you find the support you need close to home. Contact us to find out about professional counselling in your community or to find out what programs and services are available.

If you would like to talk to someone who can understand what you're going through, we can help you connect with a trained volunteer who has had a similar cancer experience. Depending on what's available in your area, you may meet with your volunteer in person or over the phone.

To find out more:

- Call us at **1 888 939-3333**.
- Visit the support / services section of our website at **[www.cancer.ca](http://www.cancer.ca)**.
- Contact your local Canadian Cancer Society office.





# Relieving Tension

Everyone has their own way to relieve tension. As you learn to cope with cancer, you may have to experiment to find the best way to make yourself feel better, and get a sense of control over the emotions that sometimes come with cancer. You might want to try:

- Venting your emotions
- Laughter
- Creative activities
- Deep relaxation methods
- Exercise
- Complementary therapies

---

## Venting your emotions

Sometimes, the stress of living with cancer can be overwhelming. You may feel as though you need to get rid of some of your tension or emotions quickly, before you explode. If you feel this way, you could try:

- letting yourself have a good cry
- hitting or throwing a pillow
- putting on some loud music and screaming
- writing down your fears and worries

Venting your emotions in any of these ways won't hurt anyone, and it may make you feel much better.

## Laughter

Although cancer isn't a funny subject, some people do find that laughter helps them deal with the disease. Using laughter to relieve tension doesn't mean you aren't taking the disease seriously.

It's okay to laugh at the funny side of life. When you laugh, your brain releases chemicals that relax your muscles and make you feel good. You may be surprised at the positive effects of watching a funny movie or TV show, enjoying the amusing things children or pets do, or laughing at a witty remark from a friend.

## Creative activities

Many people find that creative activities help them safely release their feelings. You don't have to be formally trained and you don't have to have special, expensive equipment. And, it certainly doesn't matter if you've never done these things before. Try something - and if you feel better, try it again. Experiment with:

- drawing or painting
- writing poetry or stories
- singing or making music
- dancing

## Deep relaxation methods

Learning to relax your body and your mind, even for short periods each day, can help you feel better, calmer and more in control. Relaxation can also help you cope with difficult emotions, pain and other symptoms. Books, tapes, DVDs and classes can teach you different self-help relaxation methods. You can also try the method below:

### *Deep relaxation*

This self-help method can help you fall asleep, give you more energy and reduce anxiety. Some of the techniques require deep breathing. If you have any breathing problems, talk to your healthcare team before you begin.

Most deep relaxation techniques can be done sitting up or lying down. Some people like to listen to music through earphones or a headset.

To begin:

- Choose a quiet place and make sure you are comfortable.
- Wear comfortable, loose-fitting clothing to help your circulation.
- Stare at an object or close your eyes and think of a peaceful scene.
- Concentrate on your breathing for a minute or two.

Once you're settled, two ways of reaching deep relaxation are *tension-relaxation* and *rhythmic breathing*:

## Tension-relaxation

Do this for a few minutes several times a day if you can. Try it when you are feeling tense or anxious.

- Take a slow, deep breath.
- As you breathe in, tense a particular muscle or group of muscles. For example, squeeze your eyes shut, frown, clench your teeth, make a fist or stiffen your arms or legs.
- Hold your breath and keep your muscles tense for a second or two.
- Then let go. Breathe out and let your body go limp while you feel the tension drain away.
- You can start with one group of muscles and move up or down the entire body. For example, you can start with your feet and legs. Then tighten and relax the stomach and back muscles, and finish by relaxing the arm, neck and face muscles.

## Rhythmic breathing

You can do this exercise for just a few seconds or for as long as 10 minutes.

- Take slow, deep breaths, keeping a slow rhythm.
- Keep saying to yourself, “**In**, one, two; **out**, one, two.”
- Each time you breathe out, feel yourself relax and go limp.
- To end your rhythmic breathing, count silently and slowly from one to three.

## Exercise

Many people with cancer and caregivers find they feel better, have more energy and are less stressed when they take part in physical activities such as swimming, walking, stretching or biking.

If you have cancer and have always been active, try to continue exercising – providing you feel up to it and your healthcare team says it’s okay. If you don’t usually exercise and want to start now, talk to your healthcare team about the activity you want to try first.

Many people living with cancer find that yoga or Tai Chi are gentle but effective forms of exercise that help relieve tension.

## **Yoga**

Yoga combines exercise for the body with breathing exercises and focus for the mind. There are many different types of yoga. Some are slower and more meditative while others are more athletic and faster-paced. Most types of yoga can be modified for people at all levels, ages or stages of health, and it can be done anywhere. You can take classes at gyms, community centres or local yoga studios, or practise at home.

## **Tai Chi**

Tai Chi is the ancient Chinese art of “moving meditation”, like slow dancing or swimming in air. When you practise Tai Chi, you move slowly and rhythmically through a set of continuous movements. Tai Chi can bring a sense of physical control to the body and stillness and balance to the mind. Many gyms, community centres and Tai Chi centres offer classes. Once you know Tai Chi, you can also do it at home.

## **Complementary therapies**

Complementary therapies are used *together with* conventional treatments. They may help people cope with the disease, its treatment or side effects, rather than treat the disease itself. Many people say that they have been helped by these therapies, but research is needed to understand if they are safe and effective.

Your doctor or a member of your healthcare team may be able to recommend therapies available at your treatment centre or hospital, or through your doctor’s office. If you are considering a complementary therapy:

- Let your healthcare team know about the therapy to make sure it does not interfere with the cancer treatment or the medication you are already taking.
- Consider the safety and effectiveness of the therapy. Ask if the provider of the therapy is a member of a recognized association.

- Tell your therapist you have cancer and the type of treatment you're having.
- Be wary of therapists who claim they can cure cancer. No reputable therapist will make this claim.

Many different activities, including exercise, creative activities and self-help relaxation methods, can be considered complementary therapies when they are used together with conventional cancer treatment. Other complementary therapies that focus on relaxation include guided imagery, meditation and massage.

### **A caution on using alcohol or other drugs to relieve tension**

Some people relieve tension by using alcohol or other drugs (illicit, prescription, over-the-counter or herbal). This behaviour can be risky,<sup>1</sup> particularly during a cancer experience. While the occasional drink may help you relax or stimulate your appetite, there are many reasons to be cautious, including:

- Combining alcohol or other drugs with cancer treatments can be harmful, and there are other possible negative effects on your health.
- Using alcohol or other drugs as a way of coping may prevent you from learning other healthy ways to cope during difficult times.
- Using alcohol or other drugs to cope may damage relationships with family and friends – relationships that are particularly important at this time.

If you choose to drink alcohol or use other drugs, talk to your doctor.

---

<sup>1</sup>While there is no precise "safe" level of drinking, the Low-Risk Drinking Guidelines from the Centre for Addiction and Mental Health (a Pan American Health Organization / World Health Organization Collaborating Centre) suggests spacing drinks an hour apart, and drinking no more than 2 standard drinks on any one day. These guidelines suggest that men should have no more than 14 standard drinks a week, and women no more than 9. It is important to note that the guidelines do not apply to everyone and may be more strict for some people. Talk to your doctor about what the guidelines mean in your situation. For more information, visit [www.camh.net](http://www.camh.net) and look for "Low-Risk Drinking Guidelines".



## Coping within the Family

This chapter looks at some of the issues that can come up for families living with cancer. It provides suggestions for coping and looks at the challenges of keeping up with family roles. Topics include:

- Finding balance if you're a caregiver
- Cancer is a family affair

This chapter also discusses how different family members and people close to you may be affected, including:

- Younger children
- Teenagers
- Adult children
- Parents
- Partners or spouses
- New romantic partners

---

### Finding balance if you're a caregiver

As a caregiver, you have new, important responsibilities. Caring for someone with cancer can be hard work, especially if it's combined with caring for the rest of the family. As well as caring physically and emotionally for the person with cancer, you may also be dealing with the added responsibilities of running a home, caring for children, dealing with finances, acting as a source of information for family and friends, and maintaining your own career.

Taking on these responsibilities, and being able to help support the person with cancer and your family, can be very rewarding. Making a positive difference, or meeting challenges, can be comforting during this stressful time. Many caregivers feel a closer emotional bond with the person who has cancer, as well as with family members and friends.

But being a caregiver can also be very difficult. You're likely dealing with the many emotions that can surface when a loved one is ill. Sometimes, being a caregiver can feel like being on an emotional roller coaster, with extreme highs and lows. You may worry about your loved

one, and you may feel frustrated if you can't just make everything better. It may be the first time that you have faced a problem you cannot solve.

You may experience many distressing emotions – like anger, fear, sadness, anxiety or guilt. At the same time, you may not feel as though you're allowed to have these emotions, that you must always “be strong” for the person with cancer. You may find it difficult to take the time to look after yourself.

### ***Taking care of yourself as a caregiver***

To care for someone with cancer and cope with so many responsibilities, you first need to take good care of yourself. You may worry that looking after your own needs seems selfish, but it's not. It may help to remember that caring for yourself is just one part of caring for someone with cancer. Keeping your strength and spirits up will help you cope with the challenges of being a caregiver.

Here are some ways that you can take care of yourself:

- Learn more about cancer and its emotional effects.
- Talk about what's happening. Sharing feelings and frustrations with trusted friends and family members can help reduce stress. You can also talk to a counsellor, or other people who have been through similar experiences. You might want to find out about support programs designed for caregivers.
- Don't feel as though you have to do everything. Even at the best of times, no one can be the perfect caregiver, parent, partner, wage earner, housekeeper and more. Trying to take on all these roles at once will likely make you feel more stressed. Let yourself ask for help, and say yes to offers of help.
- Be easy on yourself. Try not to feel guilty when you feel tired, frustrated or overwhelmed. These are normal responses to a stressful situation.

- Make simple, quick-to-prepare meals and accept help with cooking or housework when it is offered.
- Take a break. Go for a walk, have a massage, see a movie or meet up with a friend, play with your children or grandchildren – whatever activities you enjoy doing. If you're worried about leaving the person with cancer for a short time, you can ask someone you trust to come by while you're away, and leave a contact number so you can be reached if you're needed. Spending some time away to unwind can make it easier to return to your role as a caregiver.
- Pamper yourself in little ways. A favourite magazine or TV show, a hot bath, an early night with a good book – these are all examples of little treats to keep yourself going.
- Protect your physical and emotional health. Being a caregiver is a demanding job and its stresses can take their toll on your health. See your doctor if you have any health concerns. Make sure you get enough sleep, exercise regularly and eat well. It's okay to think about your own needs, and admit that you need help or are having trouble coping.
- Let your healthcare team know if you want to find out about *respite care*. With respite care, a trained person usually comes into the home to take care of the person with cancer while the caregiver goes out for a while. It gives you a break from being a caregiver so that you can rest, have fun, and take care of other duties.

## Cancer is a family affair

For people with cancer and their caregivers, family can be both a source of great comfort and strength, and also a source of stress or anxiety. The way your family handles the cancer diagnosis and treatment may depend a lot on how you've faced hard times together in the past.

Regular family meetings (perhaps once a week) are a good way for families to keep up with what's going on with everyone. They can be a special time set aside for everyone to talk about anything that is bothering them, to prepare for the coming week, to plan and to just spend time with each other. At family meetings, you can:

- Talk about the schedule of the week ahead. The person with cancer might have treatment, while children and other family members might have lessons or other activities. It can be useful to use a big calendar, posted on the fridge or somewhere very obvious, to keep track of everyone's activities.
- Arrange time to be together as a family.
- Prepare the family if you're expecting a difficult week.
- Make lists of jobs that need to be done and figure out who can do them.
- Let family members know if anything about the person with cancer's condition or treatment has changed, or find out if children have any questions or need more information.
- Talk about how the experience of living with cancer affects everyone in the family.
- Talk about anything that affects family life, not just cancer.

If family members who want to be kept up to date don't live in the same house or even the same area, they can still be included in meetings by phone, online chats, or they can be updated by e-mail after the meeting.

## ***Friends can be your family***

Many people have a circle of friends that they consider family and are closer to this group than to their relatives. If there are special people in your life that you want included as family, be sure to let your healthcare team know this.

Close friends often want to help and can provide a sounding board that is different from that of family members. They may be able to give a different perspective on family relationships and provide a break from day-to-day aspects of family life.

## **Younger children**

Younger children can be a source of great joy and comfort for people living with cancer. Having your children around may help you feel better. Children's hugs, kisses and love can be very comforting. Talking to your children and doing things with them can help improve your mood and take your mind off cancer.

Younger children, however, may have difficulties adjusting to cancer in the family. It can be especially hard if their routines are interrupted or if the person with cancer looks and acts differently or is in the hospital. You may feel guilty if you constantly ask your children to be quiet, help around the house or stay with friends after school. Your children may act out in different ways to get your attention: they may misbehave, act younger than they are, become clingy or insecure and refuse to leave your side.

Here are some ideas for helping younger children cope with your own or a family member's cancer treatment:

- Consider having someone else (such as a favourite friend or relative) look after your children when you're not feeling well or are busy caregiving. People are often happy to pick up children after school, drive them to lessons or appointments or arrange sleepover or play dates so that you can have a break and concentrate on feeling better.

- Be easy on yourself if you can't do all the things you usually do with or for your children. This doesn't mean that you've failed them in any way - it means that you need to balance your family responsibilities with saving your energy to cope as best you can with treatment, recovery or caregiving.
- Try to find ways to let children participate in your day-to-day routines, or give them small jobs that make them feel helpful: they can bring in the mail or draw pictures to put up in your room. Being able to help makes them feel special and good about themselves.
- Do what you can to make sure that children's routines - school, after-school activities, bedtime and other rituals - stay as stable as possible. Young children thrive on routines. Warn children in advance if a routine may change and let them help plan changes whenever possible. For example, you can say, "I have treatment tomorrow, so let's figure out who can pick you up from gymnastics. Would you like to ask Aunt Louise or Amy's mother?"
- Let children know in advance if a family member will be in hospital or will need to rest at home, and if you or your partner may not be able to do everything that has always been done with your children, like walk the dog or come to all of a child's hockey games.
- Think of your children's teachers, principals or guidance counsellors as partners in helping your children cope with cancer. Tell them about the situation and talk to them about any changes in your children's behaviour.
- Think about taking your children with you to the hospital so they can see what happens during treatment. This makes treatment less mystifying and scary. Let the hospital staff know that you plan to bring your children - it can help to have a healthcare professional around to talk to them if necessary.
- Keep things as simple as possible for your children. Divorced or separated parents may want to find strategies to ease tension in their relationship (if necessary) during treatment and recovery.

## Teenagers

Teenagers are at a stage in their lives when they are trying to break away and be independent from their family. When someone in the family has cancer, breaking away can be hard for teens to do. They may react in very different ways: getting angry, acting out, getting into trouble, withdrawing from you, taking on (but possibly resenting) more responsibility, or offering help and assurances of love. Like everyone else, teenagers may be worried that treatments won't work. Like younger children, they can also feel abandoned as the family focuses on the sick member.

Here are some ideas for helping teenagers deal with your own or a family member's cancer treatment:

- Encourage teens to keep doing the things they like to do. Like younger children, teenagers need to keep as much of their normal routine as possible. If keeping up routines is difficult, you could ask neighbours, friends or relatives for help. Another adult could regularly take your teen to sports practice or help out with homework.
- Try to make sure your teenager gets a break from the situation at home, perhaps by spending time with friends or having a regular night out for movies or pizza.
- Try to get your teens to talk about their feelings. Answer their questions as honestly as you can. Ask for their opinions and, if possible, let them help you make decisions.
- Ask teens how their friends have reacted to the news of cancer in the family. You can offer suggestions for how to deal with awkward situations.
- Encourage your teenage children to talk about their fears and feelings with people they trust and feel close to. Friends can be a great source of support, especially those who have also dealt with serious illness. Other family members, teachers, coaches and spiritual care providers can also help. Find out if there's a support program in your community for teens whose parents or relatives have cancer.

- Try to be patient if you can't understand or predict your teen's behaviour or emotions. Teens may not have the words or the ability to express emotions like anger, guilt or grief - and may resort to moodiness or outbursts instead.

## Adult children

Like teenagers, adult children of people with cancer are often in between two worlds: they are still your children, but they may also be parents and have the responsibilities of adulthood. Cancer may reverse your roles: your adult children, who are used to you taking care of them, may now take care of you. They may feel torn about how to fulfill all the obligations in their lives.

People with cancer and caregivers may find that their relationships with their adult children change with the diagnosis of cancer. For example, you may:

- Ask your adult children to take on new duties, such as making healthcare decisions, paying bills or taking care of the house.
- Ask your adult children to explain some of the information you've received from your doctor or to go with you to doctor's visits.
- Rely on your adult children for emotional support. For instance, you may ask them to act as go-betweens with friends or other family members.
- Become closer to your adult children and find that your family is brought closer together by the diagnosis of cancer.
- Want your adult children to spend a lot of time with you. This can be hard, especially if they have jobs or young families of their own.
- Find it hard to receive - rather than give - comfort and support from your children.
- Feel awkward when your adult children help with your physical care, such as feeding or bathing.

Even though they're grown up, your children may be scared of cancer and the possibility of losing a parent. They may feel guilty if they haven't been close to you, or if they cannot spend a lot of time with you because they live far away or have other duties. Some of these feelings may make it harder to talk or relate to your adult children.

Here are some tips on talking to them:

- Include your adult children when talking about your treatment and let them know your thoughts and wishes regarding your treatment and care. It is important to talk about cancer with your adult children, even if they get upset or worry.
- Make the most of the time you have with your adult children. Talk about how much you mean to each other. Express all your feelings – not just love but also anxiety, sadness and anger. Don't worry about saying the wrong thing. It's better to share your feelings rather than hide them.
- Let your adult children know they can talk to a doctor about their risk of developing cancer, and consider asking your doctor or healthcare team about risk factors for your children. Your children may be worried about whether your diagnosis of cancer affects their own risk of getting cancer.

## Parents

It is one of life's most painful experiences to be the parent of a sick child – even if that child is an adult. Although you may have been fairly independent from your parents, the changes in your life throughout your cancer experience may mean that you will turn to your parents more often than you used to.

If your parents are in good health, and they live close by or are able to spend extended periods of time with you and your family, they might be a source of great support for you. They can help you around the house, run errands, look after your children, or go to appointments with you. Your biggest challenge may be working with your parents to make them understand how they can be helpful without making you feel helpless or like a child again.

If your parents' health is poor and you've been caring for them, you may need extra help with this job while you're in treatment or caring for someone with cancer. There are no easy answers for sorting out what is best for your entire family in this situation. While you may feel sad or even guilty that you can't look after your parents as you have in the past or as you would wish to, it's important to focus on your own health issues.

Here are some ideas for helping you and your parents cope throughout your cancer experience:

- Make the most of the time you have with your parents. Talk about how much you mean to each other. Express all your feelings - not just love but also anxiety, sadness and anger. Don't worry about saying the wrong thing. It's better to share your feelings rather than hide them. If you or your parents are having trouble communicating, a counsellor may help.
- Try to keep your parents informed about your situation. They are likely feeling extremely helpless, or possibly left-out, and being informed may help them cope.
- Give positive feedback to your parents if they try to help. Be as specific as you can about what is most helpful. Most parents want to help, but aren't sure how.
- Respect the right of your parents to agree or disagree with decisions you are making at this time, but make it clear that they are your decisions to make.
- Turn to other family members and friends for help with looking after your parents (if necessary). Help through community agencies may also be available.
- Talk to your healthcare team or another healthcare professional if you're really struggling with feelings of guilt.

## Partners or spouses

Cancer is a very stressful event that can strengthen a relationship or strain it – or both. You and your partner may cope differently with cancer. For example:

- One of you may feel more hopeful, while the other is more pessimistic.
- One of you may want to find out all you can about the cancer, while the other feels better not knowing as much.
- One of you may want to opt for more aggressive treatment than the other does.
- One of you may be more comfortable talking about feelings and emotions, or asking for help, than the other.

If both partners can recognize their strengths and weaknesses, then your differences can be an advantage. For example, the person who likes to do research can take on that responsibility and feel useful, while the person who is better at talking about feelings and emotions can make sure that you both talk about what you need and feel.

Even the best relationships will be challenged by cancer. Here are some things to keep in mind as you and your partner face the disease together:

- As you cope with cancer, think about how you and your partner have coped with difficult times in the past. What strategies worked for you then? What would you do differently? It can help to write down a list of things that you both do to make the relationship strong.
- If you're feeling stressed, it may help to give yourselves short breaks from each other. You may be so worried about your partner that you forget to look after yourself. The partner with cancer may need time to be alone and not feel like “the patient” while caregivers need to rest and find ways to care for themselves.
- Sometimes talking to someone else – perhaps a friend or relative, or someone completely outside your situation, like a counsellor – can help. If this feels like a sensible idea, talk about it with your partner.

- Think about what you most need from the other person when times are tough. Then, ask for it.
- Try to keep communication open and honest. Avoid assuming, attempting to mind-read or expecting your partner to know just what you need.
- Be sensitive to signs of a bad day or a bad mood. Test the waters before launching into complex or emotional discussions.
- Give yourselves some “cancer-free” space – space where cancer is not the topic of conversation. Talk about and do other things together.
- It’s important for both partners to be involved in making treatment decisions. You can meet with the healthcare team together and learn about cancer and treatment options.
- Even though it isn’t easy, both of you should think about the future and make plans for it. Planning for your care in advance – and writing it down – lets you decide for yourself how you want to be cared for in different situations and who will act on your behalf, if necessary. Meeting with a lawyer or financial planner, or both, will help you plan for the future.

## **Sex and intimacy**

Cancer and its treatment can have an impact on your sex life:

- Being tired may result in your not wanting to have sex, while stress or worry can reduce sexual desire.
- Surgery can make certain positions painful, while chemotherapy or radiation may leave you feeling ill or tired and not in the mood for sex. Some cancer treatments and antidepressants can reduce your desire for sex or affect your sexual function (for example, the ability to become aroused).
- You may be worried or self-conscious about changes in your appearance such as weight gain or loss, the loss of your hair, scars or the loss of a body part.
- You may be worried that your partner won’t be attracted to you anymore.

A physical relationship is very important for some people and they are sad when it stops or changes. If cancer and treatment are affecting your sex life, talking about it with your partner may help ease your fears. Or, if you're not interested in sex at the moment, you can explain that it's because of fatigue or stress, not because you don't love or respect your partner. Knowing how the other person feels may help you both feel more secure.

If talking to each other about sex is difficult, a counsellor may be able to help you talk more openly. You can also let a member of your healthcare team know if you are having problems. There may be medicines that can help, or other ways you and your partner can give each other pleasure. Some people also find it helpful to talk with others about how to stay close while dealing with cancer.

You and your partner may find that sex and intimacy change during treatment. Hugging, touching, holding and cuddling may become more important than sexual intercourse and other forms of sexual activity. There are many ways to express sexuality and to satisfy your need for physical closeness. Together, you and your partner can decide what gives you both pleasure and comfort.

## **New romantic partners**

If you are single, you may feel differently about dating or starting new relationships. For some people, their outlook on dating changes for the better. For example, you may feel that going through cancer treatment has made you stronger and wiser, or has allowed you to know yourself and your priorities better, and that you now have more to offer in a relationship.

For others, dating becomes harder. There may be many reasons for this:

- You may worry about how your date will react, and whether having cancer will make it more difficult to find people to date.
- If your appearance has changed because of cancer and treatment, you may feel uncomfortable, unhappy or embarrassed about these changes, and find it difficult to feel attractive or sexual.

- If cancer has affected your fertility, you may worry about how a potential partner will feel about this.
- You may feel that you have changed a lot since you were diagnosed, and you aren't sure how to express your new self to others.
- You may feel uncertain about the future and not be sure how a new relationship will fit in to your life.
- You may worry that the cancer will return and how a new partner will react - will this person be able and willing to support you through another cancer experience?

If you'd like to date but are finding it difficult, it can help to:

- Keep in mind that dating and new relationships often make people insecure - whether or not they've had cancer.
- Get involved in activities where you can meet new people. You could join a club, volunteer, or take a class.
- Try to meet new people and make new friends, without worrying too much about dating at first. That way, you can get comfortable in new social situations, with less pressure.
- Try not to let cancer be an excuse for not dating or trying to meet people.
- Consider talking about your difficulties with a counsellor or look for a support program where you can talk about dating with other cancer survivors.
- Remember that not every date has to be a success. If someone doesn't want to see you again, you have not failed. After all, not all dates worked out before you had cancer.

## ***When to tell someone new about your cancer experience***

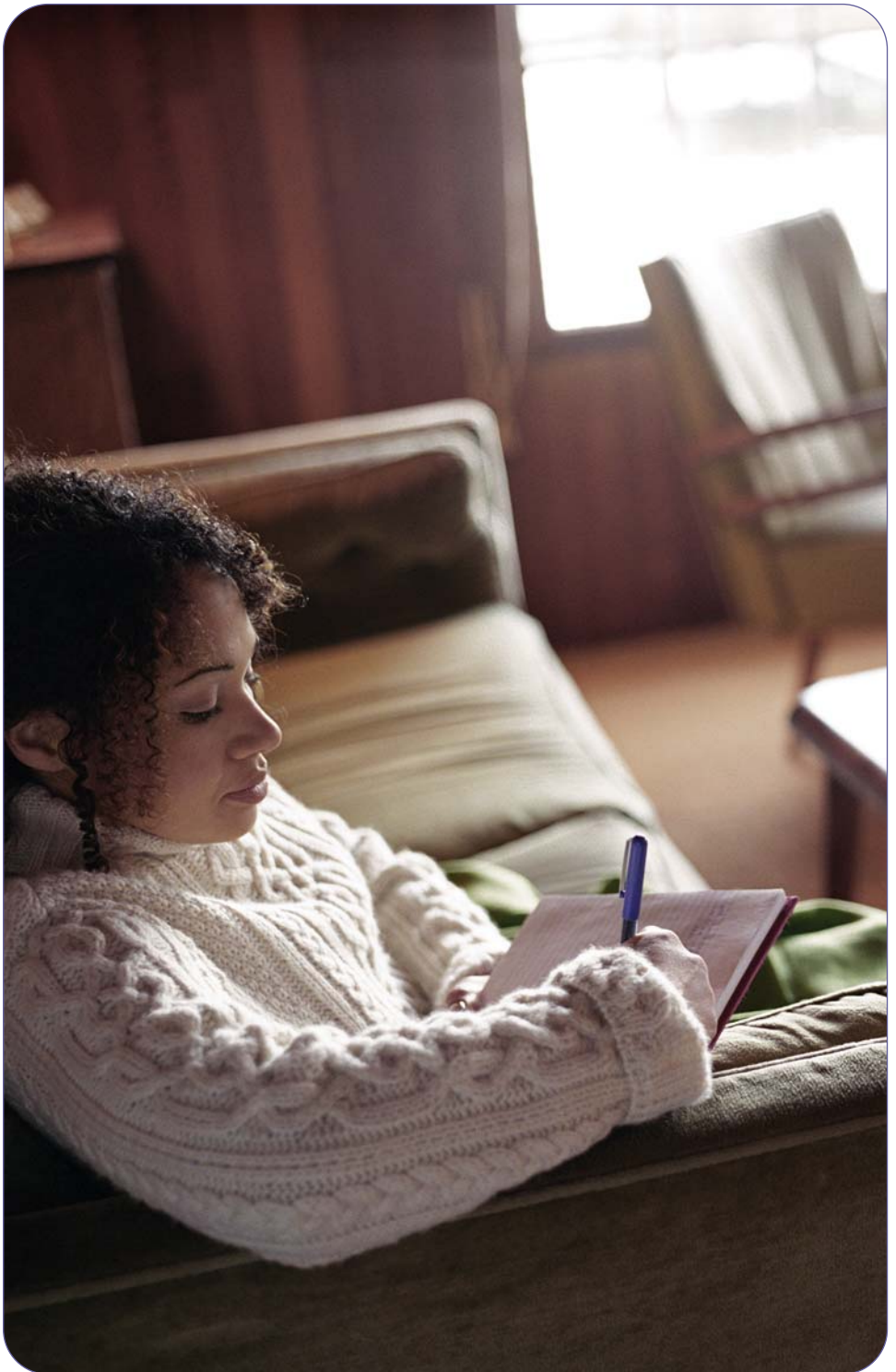
Deciding when and how to tell someone new about your cancer experience can be very stressful. You may choose to:

- Tell someone right away to get it out in the open and to see how the person reacts.
- Wait a while to get to know and trust someone a bit better before revealing this personal information.
- Take each situation as it comes and do what feels right for you.

You will be the best judge of when to tell someone new about your cancer experience. If you feel that it doesn't affect your new relationship, you may decide not to talk about it. In making this decision, though, remember that many people find honesty to be a very important part of a relationship, especially a relationship that becomes long-term.

If there is physical evidence of your cancer experience, it may be better to tell someone you're dating about your cancer experience before the relationship becomes intimate or sexual. Waiting to tell until the moment of sexual intimacy may add a lot of tension to what could already be an intense or emotional situation.

Pick a good time to talk about cancer with the person you're dating, when you can both focus on each other and not be distracted. You can rehearse what you'll say, and think about how you could respond to your date's reaction.



## Dealing with Change

Cancer can change your life and the lives of people around you. This chapter describes some of the changes that may happen, including:

- Changes to self-image
- Changing family roles
- Changing where you live
- Changing work or employment roles
- Changes to finances

No one can predict exactly how cancer will affect day-to-day life. While you can't control the future, you can think about the possibility of change and how you might like to handle certain situations if they come up.

---

### **Changes to self-image**

Having cancer can change the way people relate to their bodies and how people think of themselves in the world. Cancer can cause both physical and mental changes, and these changes can have a big impact on self-image. If you have cancer, or if you are caring for someone with cancer, you may experience some of the following changes:

- changes in energy levels
- mental changes
- changes to appearance
- changes to fertility
- changes to independence

While living with these changes may not be easy, it may help to remember that many of them are temporary.

### ***Changes in energy levels***

People with cancer can tire very easily, and may feel weak at times. They may have good days with lots of energy and bad days when their energy is very low.

If you are very tired and weak, you may have to make some changes. For example, you may not be able to drive or play sports. You may have to cut back your work hours, or take extended time away from work. You may have to rest more often, walk more slowly, or use a cane, walker or wheelchair. It can take time to adjust to these changes.

When you have less energy, you can:

- Let people know that you have both good and bad days. Try to do something special on days when you feel better. Let yourself rest on the days you are tired. Don't be afraid to tell others when you are tired, even if you need to change plans.
- Save your energy for the things you really want to do. You can reorganize your daily activities to make sure that you plan enjoyable things for when you're most likely to have energy. You can also set aside a time to rest every day.
- Try to stay active, even for short periods. Moderate exercise can boost your energy levels and your mood.

Caregivers can also experience fatigue, often from the stresses and extra responsibilities that come with caring for a person with cancer. Sometimes caregivers provide care during the night and so their sleep is interrupted. If you're caring for someone with cancer, try to make sure that you get enough rest, and ask for and accept help. Try not to feel that you must do absolutely everything for the person you're caring for. While people with cancer may tire easily, in many cases they will have many of the same capabilities as before. If they are physically capable and willing, most people with cancer can continue to take part in their usual activities.

## ***Mental changes***

Cancer and its treatment can sometimes affect a person's memory or ability to concentrate. You may forget a friend's name or where you left your glasses. It could be hard to do a simple math problem in your head. You could be easily distracted, or find it hard to concentrate on more than one thing at a time – like following a recipe while someone is talking to you. These changes are possibly a side effect of chemotherapy, or a result of stress, fatigue, anxiety or depression.

If you're having trouble concentrating or remembering things, you can:

- Plan activities where you need to concentrate for the times of the day when you are most rested.
- Keep track of things by making lists of things to do, appointments to keep, medicines to take, and so on.
- Ask a family member or friend to help you to remember by listening, taking notes and asking questions at appointments.

## ***Changes to appearance***

Cancer can change the way you look, temporarily or permanently. Some people gain or lose weight. Cancer treatments sometimes make your hair fall out and surgery can leave scars.

All these changes can affect self-image. At times, you may feel unattractive and negative about your body. You may worry about rejection or not want to be intimate with your partner. These feelings can be difficult to cope with. It can help to remember that some of the changes are only temporary, and you will probably begin to look and feel more like your old self when treatment is over. Staying active, visiting with friends and doing activities you enjoy can also help you feel better about your body image.

You do have some options when it comes to dealing with changes to your appearance.

If you lose your hair because of chemotherapy, you may want to wear a wig. If you want to match your usual colour and style, it's best to get the wig before you start treatment. Try to find a wig that fits well and doesn't scratch, since your scalp may be tender and sore. You may be able to deduct the cost of a wig from your income taxes or your health insurance may cover it. You can also try wearing a hat, scarf or turban.

If surgery to remove cancer has changed the way you look, you may want to talk to your doctors about plastic (reconstructive) surgery. For example, you may choose to have surgery to reconstruct your breast or improve the look of a surgical scar. Some people feel that reconstructive surgery helps them feel better about themselves.

### **If your partner has cancer**

It's natural for you to notice and worry about changes to your partner's appearance. You may feel less physical desire for your partner during cancer treatment. This may be because of changes in appearance, but it can also be because of fatigue, stress or other causes. During difficult times, do your best to maintain the bonds of closeness and caring between you and your partner.

It's worth reminding your partner that your love and attraction for them go beyond outward appearance to all sorts of inner qualities, like personality, intelligence, sense of humour or thoughtfulness. These don't change when the body looks different.

If you feel that your partner is hesitant to be intimate, reach out gently. Ask for a hug or hold your partner close. More than words, actions like these show your love.

## ***Changes to fertility***

Fertility is your ability to have children. Fertility can be affected by cancer and its treatment. If you think or know that you'd like to have children in the future, it's important to ask your doctor about how cancer and treatment can affect your fertility. You might want to look into having your sperm or eggs preserved for future use.

It's important to use birth control while you are being treated for cancer. Drugs used to treat cancer can damage sperm, which may lead to birth defects, and some cancer treatments can cause problems for a developing fetus. Ask your doctor about birth control if you think you or your partner could become pregnant.

Changes to your fertility can affect how you feel about yourself as a man or a woman. If you're struggling with your feelings about this at any stage in your cancer experience, including after treatment is finished, talking to a counsellor may help.

## ***Changes to independence***

Having cancer may make it harder for you to do some of the things you once did on your own or for yourself. You may need to ask for and accept help with errands because you can't get around as easily as you once did, or you may need help with cooking or yardwork, even though you have always looked after these tasks yourself. It can be hard to give up some of your independence.

You may have to learn to balance getting help with doing things for yourself. Try to accept help with some tasks, so that you don't feel too tired or overwhelmed. Be realistic about what you can manage, and seek help from your partner, family or friends before it all becomes too much for you to cope with.

## Help with personal or intimate tasks

At times, some people with cancer may need help with personal tasks, like eating, dressing, taking a bath or shower, or using the toilet. This can be a challenge, both for people with cancer and their caregivers. Some people with cancer are most comfortable when their partner can help them with these tasks. Others would rather accept help from a professional, someone they don't know as well. The same holds true for caregivers. Some will be comfortable and others will prefer to have some professional help to assist them.

Talk to each other about what you both are comfortable with, and ask your healthcare team for help in making these decisions. Sometimes, caregivers can feel more relaxed about helping with certain activities, for example, giving a sponge bath, once they have been shown how.

If you need day-to-day care, you can keep some of your independence by explaining how and when you would like things done, and by whom. If you can tell your caregivers what you need, and how they can best help you, you will both benefit. They can feel more confident in helping you, and you can feel that your life is still your own.

## Changing family roles

Looking after a family can be hard work - even when everyone in your family is well. Trying to care for a family while you cope with cancer may sometimes seem impossible.

People with cancer and caregivers may need to give up or reduce some or all of their family roles and responsibilities - as wage earner, homemaker, child caregiver, volunteer or caregiver for an aging parent - for a period of time to concentrate on treatment and recovery. At the same time, other family members may be asked to take on new roles and responsibilities. For example, a child may be asked to do more chores, or a partner may need to help pay bills, shop or do yardwork. Family members sometimes have trouble adjusting to these new roles.

The chapter  
*Coping Within the Family*  
starting at page 41 gives  
suggestions for helping your  
family through this transition.

## Changing where you live

To get the care they need, people with cancer sometimes need to make changes to where they live. The change could be permanent, or just for while you have treatment. You might need to think about changing your living arrangements if:

- You live far away from where you will be treated.
- You live alone or your caregiver doesn't live with you or near you.
- You no longer feel comfortable or safe in your home.

If you think you need to change your living arrangements, temporarily or permanently, it can help to talk about your options with family and friends. They may have ideas or suggestions that can help you decide where to live. You can also talk to your healthcare team or a social worker, who may be able to help you find temporary lodging during treatment.

Moving can be difficult. If you need to move, or if you must travel far from home for treatment, it can help to take a few little things from home with you, like family photographs or your favourite pillow or quilt. This way, there will be something familiar even in a strange place.

## Changing work or employment roles

### *Taking time away from work*

If you have cancer, it's very possible that your way of working will change. If you work outside the home, you may have to take time off or adjust your work schedule to allow for treatment and to rest and recover. If your work is running your household and taking care of your children, you may also need to change the way you do these jobs, perhaps by getting someone to help you.

For some people, taking time away from work may feel like a relief. But it can also be stressful, particularly if you have to live on less money.

Many people enjoy their jobs and it can be difficult to give them up. Giving up work for a period of time makes some people feel as though they are giving in to the cancer. If you feel this way, try to think of the

time away from work as an opportunity to concentrate on your health – and the sooner you do that, the sooner you may be back at work.

Caregivers may also need to take time off work to go to medical appointments or care for the person with cancer.

If you need to take time off work for treatment or recovery, or to care for someone with cancer, talk to your employer, human resources manager, personnel officer, union or employee association about what you are entitled to. Even if you don't need to use sick days or take a leave of absence, you may find it helpful to simply know what your options are.

If you can't or don't want to take time away from work, talk to your friends and family. If they can help out with day-to-day tasks, it may allow you to continue working.

### ***Returning to work***

Many people with cancer and caregivers welcome the time when they can return to work. They are happy to have their routines back and the company and support of their co-workers. But even if you're looking forward to it, it's normal to be nervous about returning to work.

You are the best judge of when you are well enough to go back to your job. When you're ready, talk to your doctor and your employer. If you can, give yourself time to make the transition back. You could start off working part-time hours and gradually move up to full-time. If you have a very demanding job, you may need to change the way you work or consider working part-time.

Some people with cancer can face problems when they try to go back to work or get a new job after treatment. Some employers may not want to hire someone who has had cancer. It is against the law to discriminate against someone who has cancer or any physical disability.

### **Discrimination is against the law**

If you feel that you have been discriminated against, you can contact the Canadian Human Rights Commission in your province or territory by calling 1 888 214-1090 or visiting their website at [www.chrc-ccdp.ca](http://www.chrc-ccdp.ca).

## Changes to finances

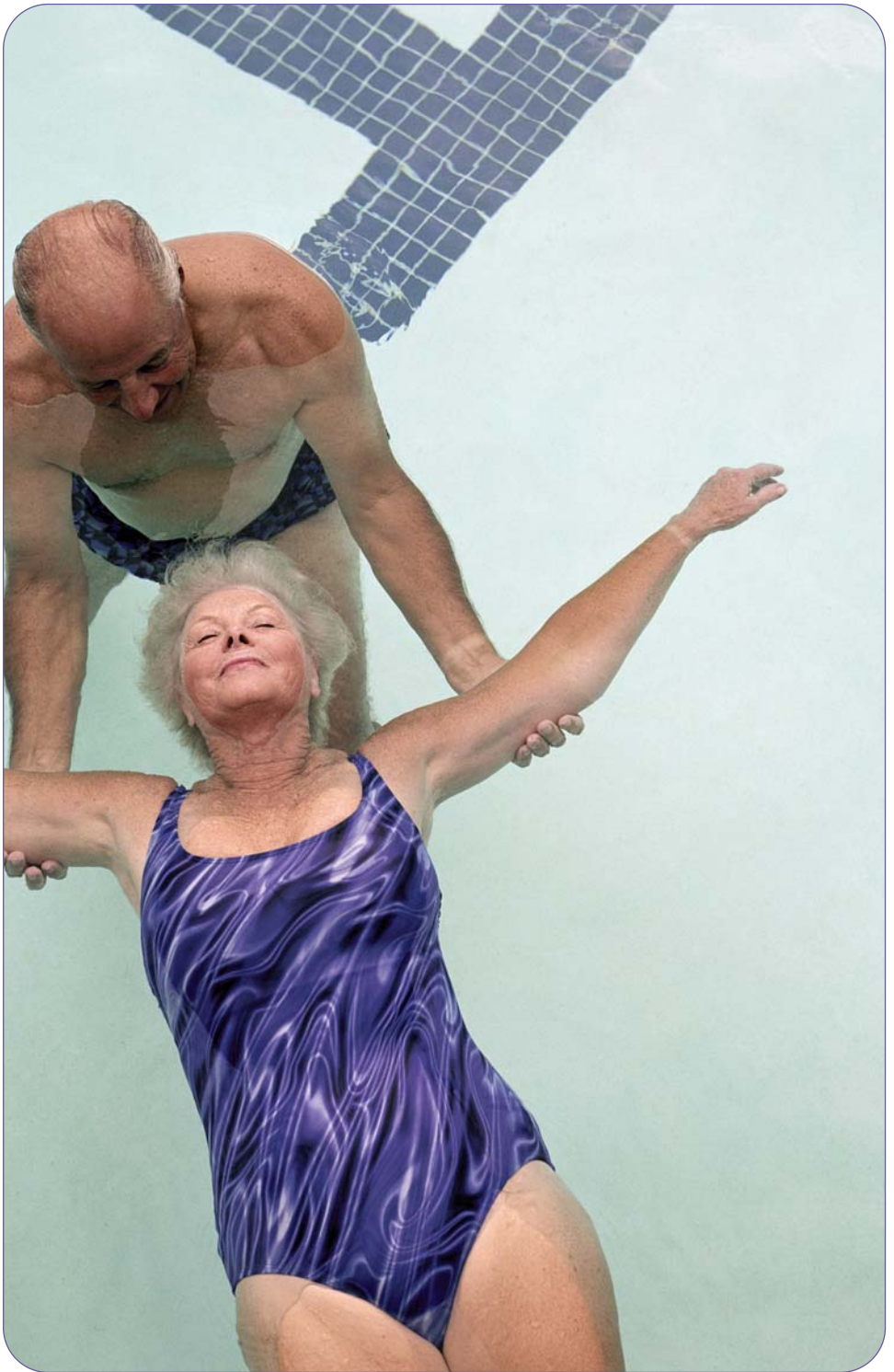
Cancer can affect your finances. You may have to spend more money on things like child care, help around the house, or drugs or therapies that aren't covered by your provincial or private health insurance plans. You may need unpaid time away from work, which can affect your income.

If you are concerned about money, a good first step is to understand more about health insurance. If you have private disability insurance or insurance through your employer, get familiar with the terms and conditions of your coverage. Find out what your insurance will pay for and what you will need to pay for. Ask about the terms and conditions of coverage - and how to access your coverage. For example, many policies have a waiting period before disability coverage starts.

If your income is affected, think about talking to the following professionals:

- Account managers at your bank, personal financial planners or advisors can help you budget your money, and help you decide whether you should access equity in your home, RRSPs or other investments.
- Social workers can help you find out more about financial assistance programs in your province or government benefits that you are entitled to. (Most hospitals and treatment centres have a social worker on staff.)

Don't forget about friends and relatives. You may know a bookkeeper, credit officer or accountant who would be happy to help you sort out some money matters.



## Getting Help from Others

While you may find it difficult to ask for and accept help, having help often makes it easier to cope with cancer. Topics in this chapter include:

- Many different kinds of help
- Difficulties in asking for or accepting help
- Sources of help
  - Your healthcare team
  - Family and friends
  - Other people with similar experiences
  - Mental health or psychosocial oncology professionals
  - Social workers
  - Spiritual care providers
  - Patient advocates, discharge planners and volunteers in the treatment centre

---

### Many different kinds of help

There are many different kinds of help and we all have different needs for help. Throughout your cancer journey, you might need help with getting to treatment, doing housework or yardwork, cooking meals and so on. Some people – often family and friends – are very good at this sort of practical help.

Another important kind of help is the kind that comes with listening, offering support or counselling. Some of your family and friends may support you by doing this, or you may also find it helpful to turn to other sources such as healthcare professionals or other people living with cancer.

### Difficulties in asking for or accepting help

Many people find it hard to ask for help. They may be used to being independent and managing everything on their own and see needing help as a sign of weakness. Some people are uncomfortable talking about their needs or asking people to do things for them. They may feel like they are being selfish or burdening other people.

If you're finding it hard to ask for or accept help, you can:

- Remember that many people *want* to help. People often don't know what to do when someone is ill, and helping out is one way for them to feel useful.
- Think about asking for help as a strategy to get through a difficult time.
- Think about what you would want to do when a friend or relative is ill.

You may be surprised at how many people are willing to support you, and how generous people can be with their time and energy.

## Sources of help

There are many different sources of help available to people with cancer and their caregivers.

### *Your healthcare team*

Your healthcare team is there to help you. In addition to planning your treatment and monitoring your physical progress, they can help you with other aspects of living with cancer. If you need practical assistance or emotional support, they may be able to suggest services in your community or refer you to cancer centre staff or mental health professionals.

### *Family and friends*

Your family and friends can be very supportive. Some will know exactly what to do and say without being asked. Others might not be sure how to help. It may be hard for you, but if you can let people know how to help, they are often happy to pitch in and can make your life much easier. When someone says, "Let me know if there is anything I can do," you can tell them if you need help with an errand or a ride to the doctor's office.

## What family and friends can do to help

- Keep other people informed by making phone calls or sending out regular e-mail updates.
- Water your plants, take in your mail or take care of your pets while you're at the hospital or recovering from treatment.
- Go grocery shopping or prepare meals that can be frozen and reheated.
- Clean the house, mow the lawn or shovel the snow.
- Check out or return library books.
- Rent or return videos and DVDs.
- Tape favourite television shows for you to watch later.
- Drive you to and from appointments.
- Drive children to school, lessons or appointments.
- Make school lunches for the children.
- Babysit on treatment days or days when you're very tired.

You might want to have somebody coordinate the jobs that need to be done and can set up a schedule of people to do them.

Sometimes, you may want or need someone from outside your circle of family or friends to help with certain tasks. For help with physical care (such as bathing or dressing) or skilled care (such as giving special feedings or medications), you may find the help you need through your local public health department.

## ***Other people with similar experiences***

Although your friends and family might be very supportive, it can also be comforting to spend time with people who are going through, or who have gone through, the same things as you are. You can often talk to these people about things you can't discuss with anyone else.

Someone who has had cancer can:

- understand how you feel
- talk to you about what to expect
- tell you how they coped with cancer
- help you learn ways to enjoy each day
- give you hope for the future

You may already know someone you can talk to, or you may meet them through friends, family or co-workers.

Some people meet other people with similar experiences through organized programs offered through the hospital or treatment centre, your doctor's office or not-for-profit organizations. These types of programs come in different formats to suit your needs:

- one-to-one support offered by telephone
- one-to-one support offered in person
- group-based support
- online support via the Internet

### **Everyone's medical situation is different**

No matter what type of support you choose, don't forget that everyone's medical situation is different. Talk to your healthcare team about information that is shared in your support program and whether it applies to you.

## Different types of support groups

Not everyone finds it easy to talk in a group setting, or wants to talk about their feelings with strangers. If you're not sure whether a support group is right for you, it's probably worth at least checking out what the group is like and then deciding whether to attend regularly. If you have a choice of groups, visit a few to see which suits you best.

There are many different types of support groups:

- Some groups are open to everyone. Others are for certain people, like women with breast cancer, men with prostate cancer, teenagers or caregivers.
- Some groups talk about all aspects of cancer. Others focus only on specific topics, such as treatment choices or self-esteem.
- Therapy groups (often led by mental health professionals) can help you learn particular coping skills, such as managing fears and uncertainty or dealing with communication problems.
- Sometimes, people with cancer meet in one support group and their loved ones meet in another. This way, people can talk freely without worrying about hurting someone's feelings. In other groups, patients and families meet together. These groups can be a good way for each to learn what the other is going through.
- Some support groups take place online - through chat rooms, listservs or moderated discussion groups. People in these groups can talk to each other by e-mail. People often like online support groups because they can take part in them any time of the day or night. They're also good for people who can't travel to meetings.

## Connecting with someone who has had a similar cancer experience

The Canadian Cancer Society can help you connect with a trained volunteer who has been through a similar cancer experience. Our telephone support program is available no matter where you live in Canada, and we also offer in-person and group support in many locations. All of our services are free and confidential.

We can also refer you to programs and services offered by other organizations in your community.

To find out more about what is available in your area, you can:

- Call our *Cancer Information Service* at **1 888 939-3333**.
- Visit the support / services section of our website at [www.cancer.ca](http://www.cancer.ca) to search an online directory of cancer-related programs and services.



## *Mental health or psychosocial oncology professionals*

Some people living with cancer find it helpful to talk to a mental health professional. Many different professionals, including psychologists, psychiatrists, advanced practice nurses and social workers, can provide counselling. Chaplains or spiritual care providers at treatment centres can also provide counselling. In many centres they are called *psychosocial oncology counsellors* and are part of the supportive care or psychosocial oncology departments. These professionals are trained to listen and to help you deal with your situation. They can:

- help you find and understand information about your cancer and make decisions
- help you cope with emotions such as fear, anger, guilt, depression and anxiety
- help you with identity, self-esteem and body image issues

- help you individually, as a couple or as a family, to address communication issues, family issues and relationship problems (including problems with sexuality and intimacy)
- help you find meaning and purpose in life

In most cases these professionals will see you or your family members for cancer-related concerns at any point along your cancer experience, including after treatment. Don't worry if you are not clear about how counselling might help or even exactly what it is you want help with – the counsellor will help you sort that out. Counselling usually involves telling the counsellor where you are in your cancer experience and how it is affecting you, sorting out with the counsellor what issues or concerns you want help with, and coming up with a plan of action to deal with those concerns. Many issues can be addressed in just a few sessions, or maybe even just one.

### ***Social workers***

In addition to providing support through counselling, social workers can help you meet your practical needs throughout your cancer experience, such as:

- talking about cancer with employers
- filling out forms, applications and paperwork
- dealing with money matters
- learning about health insurance
- finding rides to the hospital, clinic or doctor's office
- setting up home visits from nurses

If a social worker isn't currently part of your healthcare team, you can ask to speak to one.

## ***Spiritual care providers***

Spirituality and religion have different meanings for many people, even though the terms are often used in place of each other. Religion can be defined as a specific set of beliefs and practices, usually with an organized group. Spirituality can be defined as an individual's sense of peace, purpose, connection to others, and beliefs about the meaning of life. Spirituality can be expressed through an organized religion, or in other ways.

Cancer can affect people's spirituality, sometimes weakening it and sometimes deepening it. For others, spirituality plays a less important role, or none at all. The way cancer affects spirituality is different for everyone.

Cancer may challenge long-held beliefs. Sometimes, people living with cancer feel that their faith has let them down. For example, you may struggle to understand why you have cancer or question your relationship with your God or gods. This unresolved spiritual conflict and doubt is sometimes called spiritual distress.

For others, a cancer experience can encourage new and stronger beliefs. Many people living with cancer find that their spirituality is a source of comfort and support. Cancer may bring a new or deeper meaning to their faith. They find they can cope better with cancer's difficulties when they pray, read spiritual books, meditate or talk with members of their spiritual community.

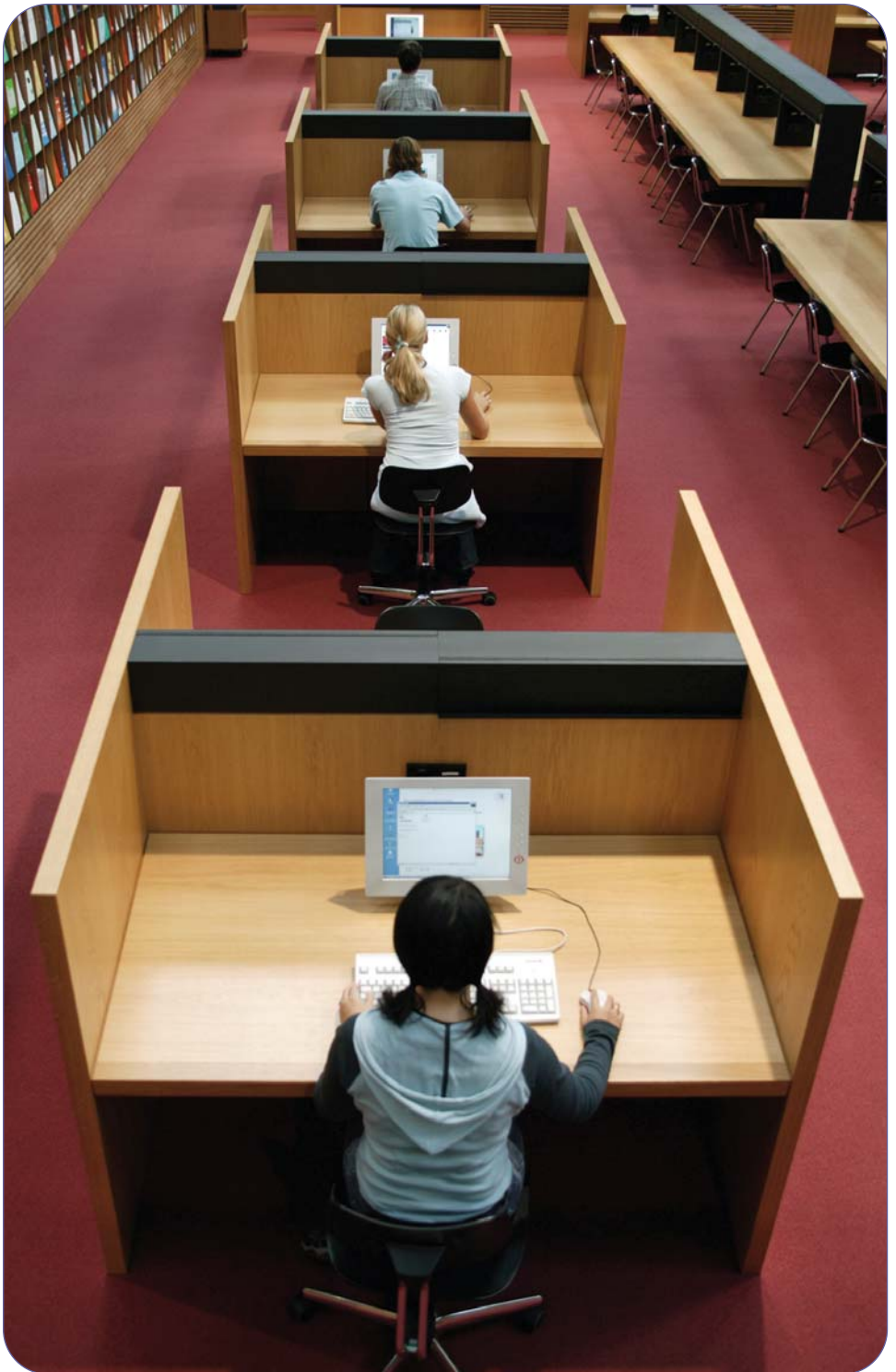
If you'd like to talk to someone about spiritual issues, don't worry if you haven't attended religious services regularly or aren't sure what you believe. Spiritual care providers are used to dealing with uncertainty. Their job is to help you sort through your ideas, doubts and beliefs, and find peace of mind.

If you don't have a spiritual care provider to talk to, ask a member of your healthcare team if there is a chaplaincy service available to you. Hospitals and treatment centres often have chaplains on staff to help you and your family with spiritual concerns. While they come from specific faith traditions, they are trained to provide support to people with traditions different from their own.

## ***Patient advocates, discharge planners and volunteers in the treatment centre***

Many treatment centres and hospitals have people on staff to help make your cancer experience a little easier.

- **Patient advocates** can help when you have a problem or concern that you don't feel you can discuss with your doctor, nurse or social worker.
- **Discharge planners** work with you and your family as you get ready to leave the hospital. They can help with tasks like setting up follow-up appointments and making sure you have the things you need at home.
- **Volunteers** often visit with patients in the hospital and offer comfort and support. They may bring books, puzzles, or other things to do. Many volunteers have had cancer.



## Where to Look for Cancer Information

There's a lot of information out there on cancer. Sometimes, the amount of information can be overwhelming, and you may not know where to begin. This chapter looks at some of the different sources of information on cancer and its treatment including:

- Your healthcare team
- Resource centres and libraries
- The Internet
- The Canadian Cancer Society

### **How much information do you need?**

Everyone's need for information is different, but many people feel better when they can learn and understand more about cancer and its treatment. Often, knowing what to expect can help put things in perspective and help you make decisions.

Some people with cancer prefer not to know as much about their disease. They would rather not ask about it or research it, and are comfortable simply following the directions of their healthcare team. If you feel this way, it can help to say so to the people around you. It may be difficult for your family and friends to understand and accept, but it's up to you to decide how much information you need.

### **Your healthcare team**

Your healthcare team will probably be your first source of information. They are there to answer your questions and will continue to provide information over the course of your treatment. Your healthcare team may not be able to answer all your questions in full or right away, but you have the right to ask whatever you want to know. You can also ask them for printed materials (such as booklets or fact sheets) about cancer and treatments.

It's not easy to understand everything your healthcare team tells you, especially if you're scared or confused. Try these tips to make sure you get the information you need from your healthcare team:

- Write down your questions ahead of time and bring them with you to your appointments. Sometimes you can even send your questions in advance, so that your doctor can get information ready for you. If you have a lot of questions, you and your doctor may want to plan extra time to talk about them.
- Ask questions and share your concerns. Don't worry if your questions seem silly - your questions are important and deserve an answer. It's okay to ask your doctor to use simpler words and explain terms that are new to you. To make sure you understand, use your own words to repeat back what you heard the doctor say.
- Don't worry if you forget to ask something. Write it down and ask it the next time.
- Take someone with you to appointments. This person (often your caregiver) can help by listening, taking notes, asking questions and talking about the appointment with you later.
- Make notes of your conversations with your doctor. Many people have trouble remembering conversations with their doctors. You might also want to ask if you can call your doctor between appointments if you have other questions.

### **Questions to ask your healthcare team**

What type of cancer do I have and how far has it progressed?

How does this type of cancer usually respond to treatment?

What are my treatment choices?

When will treatment start and end, and how often will I have it?

What are the possible side effects of this type of cancer or its treatment?

How can I manage side effects?

Should I make changes to my day-to-day life?

Everyone's cancer and treatment plans are different, so if you get information from other sources, it is important to ask your healthcare team about how that information applies to your situation.

## Resource centres and libraries

Many hospitals and treatment centres have resource centres run by patient or health educators. They can help you understand cancer by explaining difficult concepts and finding information that fits your needs. You can ask whether there is one on staff at your hospital or treatment centre.

Resource centres contain books, videos, computers and other tools to help you and your family. These tools can help you understand the type of cancer you have, your treatment choices and side effects, and give tips for living with and beyond cancer. Resource centres may also have cancer education programs for people living with cancer.

A library is a good place to find information on cancer. In addition to books, encyclopedias, magazines and journals, many libraries also have audio books, videos and DVDs that you can borrow. If what you need isn't available at your local library, many libraries can request it from another library. You can ask a librarian to help you.

If you do not have access to a computer or the Internet at home, many public libraries have computers you can use.

## The Internet

Finding information about cancer on the Internet can be a quick, efficient way to learn about cancer and related topics.

The Internet offers millions of pages of information about cancer, but it isn't perfect. There are no regulations as to what can be posted on a site, and it's hard to know whether that information is accurate, complete or relevant to your situation. To help make sure that the information you get from the Internet is trustworthy, look for:

- Websites developed by organizations such as the government, hospitals and healthcare centres, academic and research facilities, or other credible not-for-profit organizations.
- Information that is up to date. Check the date when the information was posted or updated, and the dates of any studies or reports.
- Information that is easy to read and explained clearly. The site should guide you easily through the information, give you the option to send in questions, and provide links to related sites that may be helpful.
- Information that is relevant to cancer care in Canada.

Watch out for sites that claim to have the cure for cancer, especially if the cure is for sale. A credible site will not make this claim.

## The Canadian Cancer Society

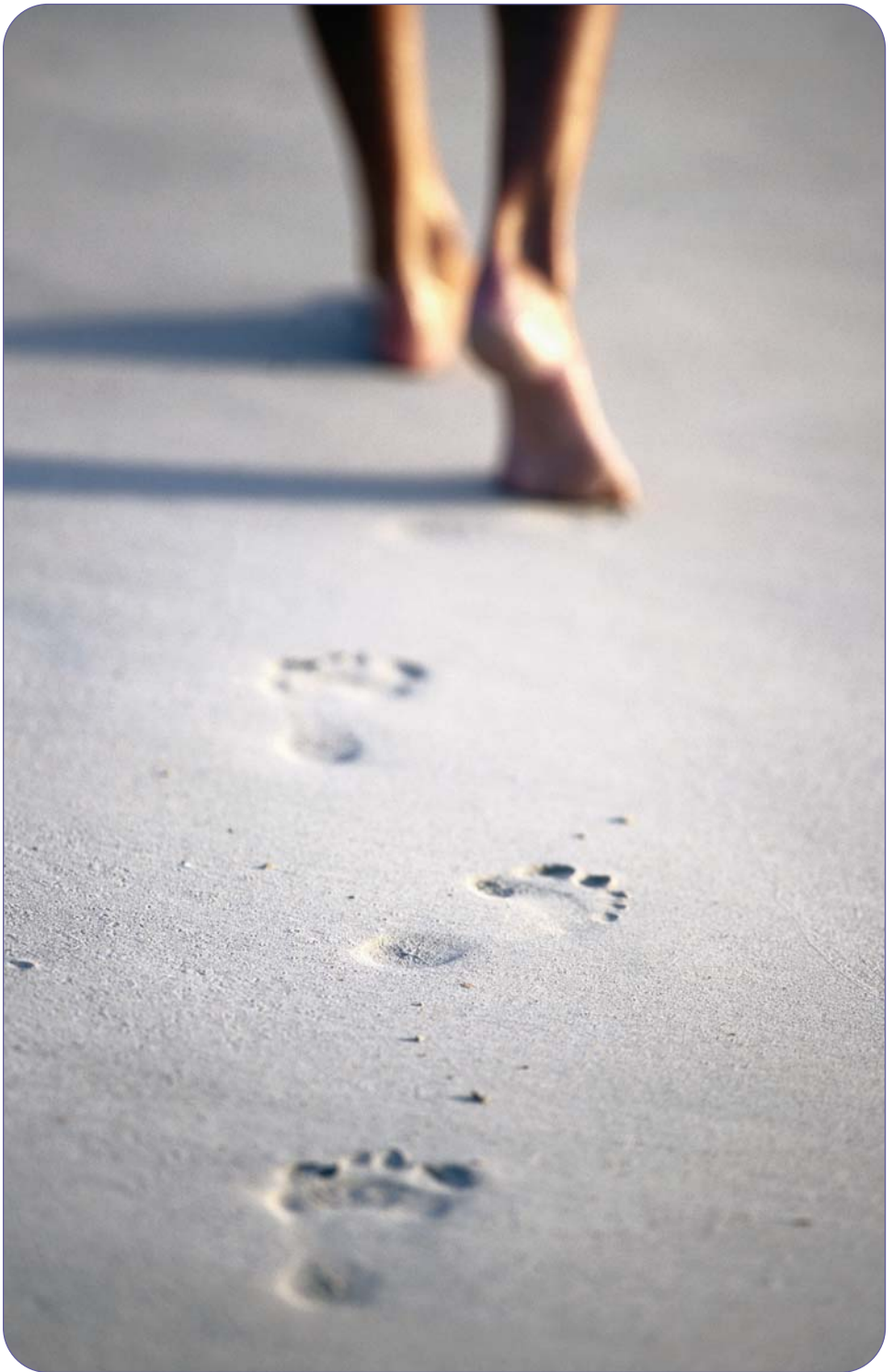
The Canadian Cancer Society meets your information needs by providing credible and up-to-date information about cancer by phone, online and in print. We provide information about all types of cancer, treatment, managing pain, managing side effects, dietary needs throughout your cancer experience, and many other topics.

At our toll-free *Cancer Information Service*, trained information specialists take the time to talk about your questions and concerns, using clear and understandable language. The information they provide is tailored to your needs and can help you cope with cancer or make decisions about treatment. They can also find services available in your community, such as emotional or practical support.

### When you want to know more about cancer

Call a Canadian Cancer Society information specialist toll-free at **1 888 939-3333**, e-mail us at **[info@cis.cancer.ca](mailto:info@cis.cancer.ca)** or visit our website at **[www.cancer.ca](http://www.cancer.ca)**.





## Thinking about the Future

Throughout your cancer experience, you may find yourself thinking more and more about what life holds for you after treatment is completed. This chapter focuses on thinking about your future. Topics include:

- The end of treatment
- Putting your affairs in order
- The new "normal"

---

### The end of treatment

When treatment ends, you may feel very positive – glad that treatment is over, excited about your future, and ready to move forward. Everyone around you probably expects you to be pleased. But you may not feel this way. Some people have mixed feelings about treatment ending – and you might be surprised to find that you are still emotional about the experience. If your emotions keep changing, you're not alone. Many people find the time after treatment to be a period of transition and adjustment, and more of a challenge than they expected.

The support of others who have gone through similar cancer experiences can be very helpful at this time. Your healthcare team is also there to help you.

As you go through and finish treatment, it can help to think about what you want to do when you feel well again. Some people find it fun to do something to celebrate the end of treatment, like take a vacation or learn a new skill, such as gourmet cooking or ballroom dancing. Other people don't mark the end of treatment in any way, preferring to get back to their usual routines as best they can. It's important to do whatever feels right to you.

Some people find it helpful to set goals, as this gives them something to think about and work towards. If your goal is to travel at the end of treatment, you might want to spend your treatment time researching the places you want to visit or learning a new language. You may even

find yourself thinking about a career change or going back to school. Goals can also be related to your health. At the end of treatment, some people make the effort to exercise regularly, develop healthy eating habits or quit smoking.

### ***What if cancer comes back?***

It's normal to wonder if cancer will return, and to think about how you will react and cope if it does. Worrying that the cancer will come back is one of the most common fears people have after cancer treatment. For many, living with the possibility of cancer coming back is very challenging. As time goes by, many people find that their fear of cancer coming back becomes less, and they find themselves thinking about cancer less often. Certain events, however, may bring the worries back. These include:

- follow-up medical visits
- critical dates, such as the date of diagnosis or surgery
- illness of a family member
- symptoms similar to the ones that led to a cancer diagnosis
- the death of someone who had cancer
- personal reminders, such as going to a restaurant that you used to frequent during treatment

If you find that you're worried and anxious all the time, or if your anxiety is interfering with your daily activities, you may want to talk about your feelings with a counsellor or another member of your healthcare team. It's important to get your worries under control so that you can focus on living, take good care of your health and make the most of each day.

## ***Making decisions about end-of-life care***

Sometimes, people diagnosed with cancer don't get better. Throughout your cancer experience, you have made many decisions about your treatment and care. You can also make decisions about care when dying.

*Palliative care* is a special kind of healthcare for people who are living with a life-threatening illness that is usually at an advanced stage. The goal of palliative care is comfort and dignity for the person who is ill, as well as the best quality of life for both the person and the person's family. Palliative care may be the main focus of care when a cure for the disease is no longer possible, but because an important part of palliative care is to relieve pain and other symptoms, it may also be helpful at earlier stages in the illness.

Palliative care can happen at home, or in a hospital or hospice. A hospice is a special healthcare facility that looks after people who need care, often at the end of life.

Some people with cancer may want to talk about end-of-life care arrangements even if they feel well and may be treated successfully. Others want to have a discussion about it only if they know they will need it. Either way, this topic can be a very difficult one to talk about. Palliative care specialists can often help make these discussions a bit easier.

You can talk to your doctor, members of your healthcare team or a social worker about palliative care.

## Putting your affairs in order

A cancer experience often motivates people to put their affairs in order. It's a good idea for *all* adults – whether or not they have cancer – to do things like:

- Have an up-to-date will.
- Appoint guardians for minor children.
- Decide how you'd like to be cared for if you become seriously ill and can't make decisions for yourself.
- Give someone you trust power of attorney in case you can't make decisions for yourself.
- Decide how you would like your life to be acknowledged after your death.

Sorting out these important matters – and writing decisions down – does not mean that you will die of cancer and it does not mean that you're giving up. Putting your affairs in order makes sense for everyone, sick or well. Resolving these matters allows you to live each day to the fullest and think about the future.

Some people use a cancer diagnosis as a chance to tie up other loose ends, both practical and emotional. For example, you might:

- Make a list of important documents and details (your will, the deed to your house, bank accounts and insurance policy numbers) and where they are.
- Make a list of people who should be told if you die, including friends and family, your lawyer, the executor of your will and your employer.
- Get rid of clutter, clean out the basement or the attic, donate things to charity.
- Organize your photos and put them into albums or make a scrapbook.
- Write down your family history.
- Contact old friends or mend old quarrels.

- Write down instructions for the everyday tasks you've always done, like where you get the car serviced, or how to turn on the heating or use the washing machine.
- Write letters to people who are dear to you.
- Visit old or new places.

Some of these tasks can be healing or satisfying as they give you a chance to reflect on happy and sad times. Some, all or none of them may appeal to you. The important thing is to do what feels right for you, when it feels right.

### **Why it's important to have a will**

When you have a will, you can make sure that your property or possessions go to the people or charities of your choice. If you don't have a will, your property and finances are settled according to federal and provincial laws, and your possessions may not be divided up as you might have chosen. As well, without a will, it can often take much longer to sort out your affairs after you die, and it may put a financial strain on your estate. Having a will makes it easier on your loved ones.

It may feel painful or strange to think about making your will. Once it's done, however, you may also feel relieved to have taken care of an important task. You may feel pleased that you are helping to safeguard your family's future, or satisfied that your gift to your favourite charity will help others. Once you have a will, you can always update or change it by talking to your lawyer.

Making a will doesn't have to be difficult or expensive. A lawyer experienced in wills can make sure that your will is drawn up properly and that your wishes will be carried out exactly as you want. (A lawyer can also help you plan for your care in advance through a power of attorney and other directives.)

If you don't have a lawyer, you can ask friends or relatives to recommend one to you, look in the phone book, or contact your province's or territory's law society or bar association.

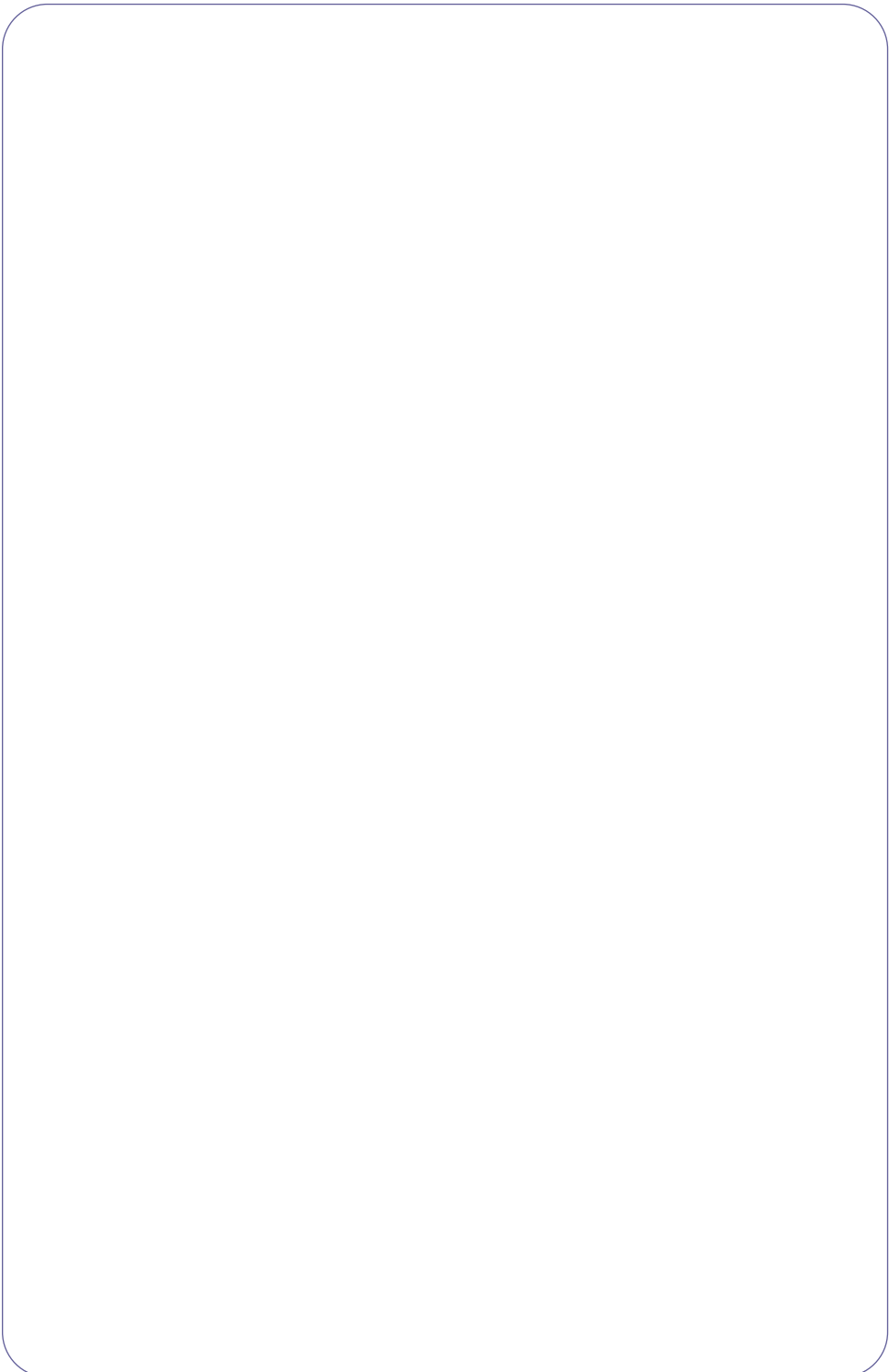
## The new "normal"

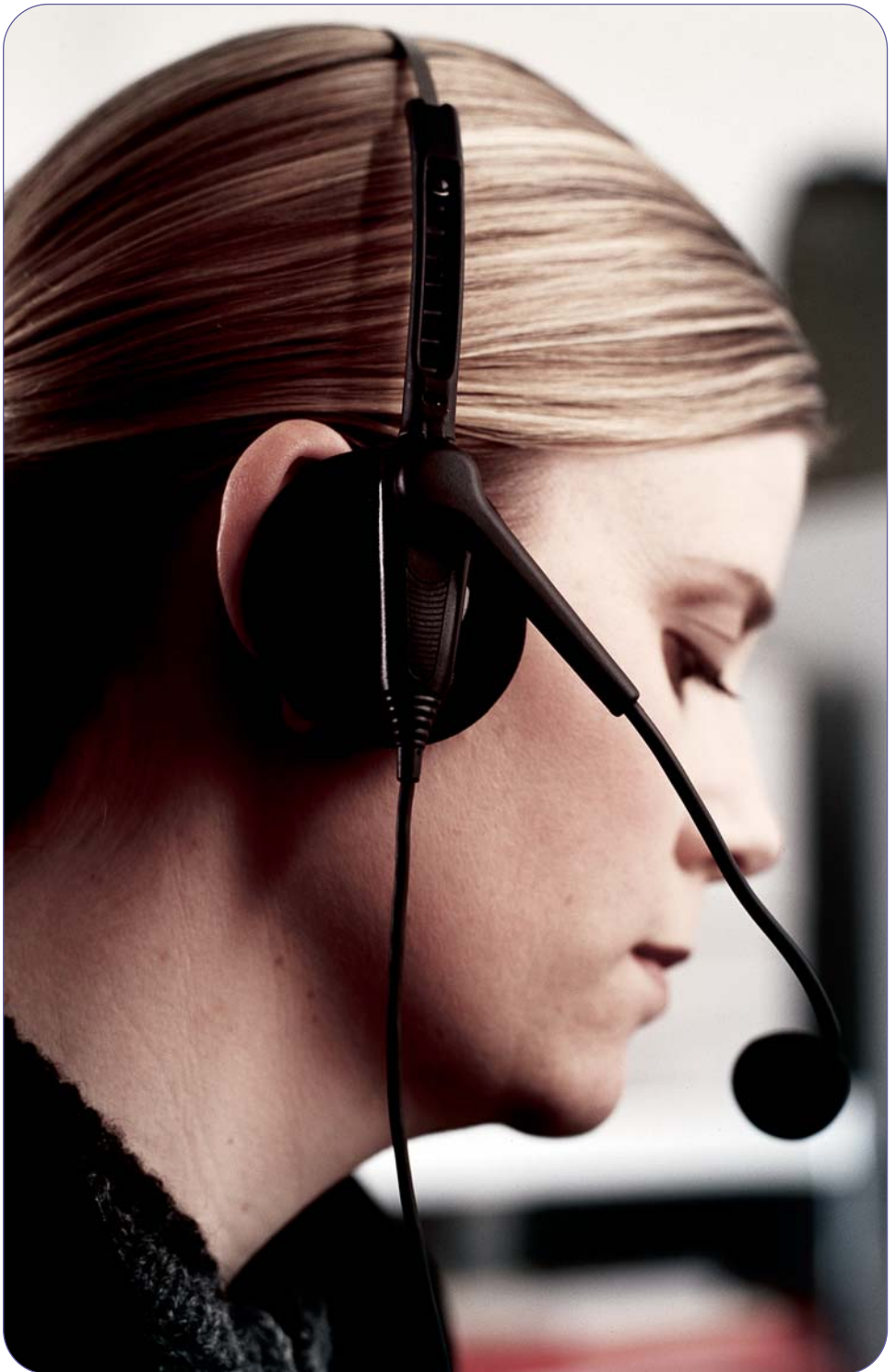
What is “normal” after cancer treatment? Just as everyone’s cancer experience is unique, adjusting to life after treatment will be unique as well.

For some people, depending on whether they feel their cancer experience has changed them, normal may mean going back to exactly how their life used to be. The best thing about treatment ending will be getting back to their previous routines and ways of doing things.

For others, life has definitely changed. There may be new physical or practical issues that are a permanent part of life – perhaps new health regimens or financial realities to deal with on an ongoing basis. Values and priorities may have changed – material things may be less important than spending more time with loved ones, doing volunteer work, or enjoying hobbies or sports. If you feel that your cancer experience has changed you, it’s not so much a matter of getting back to what used to be normal as it is figuring out what will now be normal for you and your family.

You may find that you’re somewhere in between – in some areas of life your new “normal” is very different from your old, and in other areas, things go back to exactly as they used to be. One way isn’t better than the other – the most important thing is figuring out what works for you.





## Other Resources about Living with Cancer

### The Canadian Cancer Society

#### *Helping you understand cancer*

Trained information specialists at our *Cancer Information Service* take the time to answer your questions over the telephone and search for the information you need about:

- accommodation during treatment
- counselling
- home, respite or palliative care
- emotional support
- transportation to treatment
- treatment and side effects
- nutrition
- many other cancer-related issues

#### *Talking with someone who has been there*

If you have been touched by cancer and would like to talk to someone who has had a similar cancer experience, we can help you connect with a trained volunteer – in person, over the phone or in a group setting.

#### **To contact the Canadian Cancer Society:**

- Call us toll-free at **1 888 939-3333** (Monday to Friday, 9 a.m. to 6 p.m.).
- E-mail us at **info@cis.cancer.ca**.
- Visit our website at **www.cancer.ca**.
- Contact your local Canadian Cancer Society office.

Our services are free and confidential.



## **Suggested websites**

**Canadian Association of Psychosocial Oncology**  
**[www.capo.ca](http://www.capo.ca)**

Look for: The Emotional Facts of Life with Cancer

**Canadian Hospice Palliative Care Association**  
**[www.chpca.net](http://www.chpca.net)**

**Canadian Virtual Hospice**  
**[www.virtualhospice.ca](http://www.virtualhospice.ca)**

**National Cancer Institute**  
**[www.nci.nih.gov/cancerinfo/takingtime](http://www.nci.nih.gov/cancerinfo/takingtime)**

**American Cancer Society**  
**[www.cancer.org](http://www.cancer.org)**

Look for: Supporting patients

**Cancerbackup**  
**[www.cancerbackup.org.uk/Resourcessupport](http://www.cancerbackup.org.uk/Resourcessupport)**

Look for: Relationships and communication

## Canadian Cancer Society Division Offices

### British Columbia and Yukon

565 West 10<sup>th</sup> Avenue  
Vancouver, BC V5Z 4J4  
(604) 872-4400  
1 800 663-2524  
inquiries@bc.cancer.ca

### Alberta/N.W.T.

200, 325 Manning Rd NE  
Calgary, AB T2E 2P5  
(403) 205-3966  
info@cancer.ab.ca

### Saskatchewan

1910 McIntyre Street  
Regina, SK S4P 2R3  
(306) 790-5822  
ccssk@sk.cancer.ca

### Manitoba

193 Sherbrook Street  
Winnipeg, MB R3C 2B7  
(204) 774-7483  
info@mb.cancer.ca

### Ontario

1639 Yonge Street  
Toronto, ON M4T 2W6  
(416) 488-5400

### Quebec

5151, boul l'Assomption  
Montreal, QC H1T 4A9  
(514) 255-5151  
webmestre@quebec.cancer.ca

### New Brunswick

PO Box 2089  
133 Prince William Street  
Saint John, NB E2L 3T5  
(506) 634-6272  
ccsnb@nb.cancer.ca

### Nova Scotia

5826 South Street, Suite 1  
Halifax, NS B3H 1S6  
(902) 423-6183  
ccs.ns@ns.cancer.ca

### Prince Edward Island

1 Rochford Street, Suite 1  
Charlottetown, PE C1A 9L2  
(902) 566-4007  
info@pei.cancer.ca

### Newfoundland and Labrador

PO Box 8921  
Viking Building  
St. John's, NL A1B 3R9  
(709) 753-6520  
ccs@nl.cancer.ca

## What we do

Thanks to the work of our volunteers and staff, and the generosity of our donors, the Canadian Cancer Society is leading the way in the fight against cancer. The Canadian Cancer Society:

- funds excellent research for all types of cancer
- advocates for healthy public policy
- promotes healthy lifestyles to help reduce cancer risk
- provides information about cancer
- supports people living with cancer

Contact us for up-to-date information about cancer, our services, or to make a donation.



Canadian Cancer Society  
Société canadienne du cancer

Let's Make Cancer History  
1 888 939-3333 | [www.cancer.ca](http://www.cancer.ca)

This is general information developed by the Canadian Cancer Society.  
It is not intended to replace the advice of a qualified healthcare provider.

The material in this publication may be copied or reproduced without permission; however, the following citation must be used: *Living with Cancer: A guide for people with cancer and their caregivers*. Canadian Cancer Society 2005.