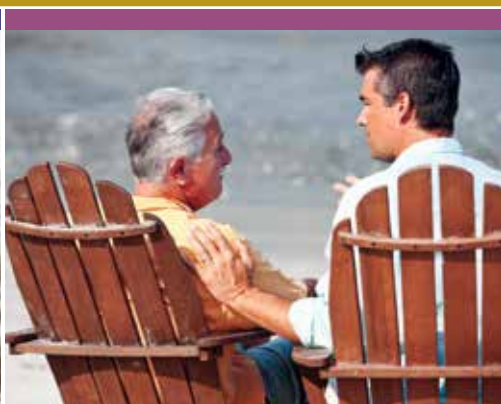




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Advanced Cancer



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While many of the stories in this booklet are from people we talked to, some of the other quotations are from research or published material or that informed the published conclusions. These sources are listed below:

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Introduction

This booklet is for people who have advanced cancer and their caregivers. A caregiver is someone who provides physical care and emotional support. They are often family members, partners, parents or children. They can also be close friends, neighbours, co-workers or community group members.

Different doctors use different words to describe where you are in your cancer journey. You may have heard words such as advanced, end-stage, secondary, metastatic or progressive cancer. We use *advanced cancer* to describe cancer that is unlikely to be cured. When a cure is unlikely, the focus of care shifts in physical, emotional and practical ways.

In this booklet we offer information and support to help you care for yourself and for each other. We talk about physical, emotional, social and spiritual needs. Sometimes these will be the same for both the person with advanced cancer and for caregivers. But sometimes they will not.

As you work through this challenging time together, try to remember:

- One of the best things you can do is talk about how you feel and the problems you have. Then get the support you need.
- The goal of treatment may change, but people with advanced cancer deserve good medical attention and support from their healthcare team.
- You can still make many choices to help you live the way you wish to every day.

How to use this booklet

Reading about the topics in this booklet may not be easy. Read the pages that are useful to you now and read the others when you feel ready. The information is divided into 3 sections:

- **Section 1** is for both the person with advanced cancer and the caregiver.
- **Section 2** is written for the person with cancer and deals with concerns different from those of caregivers.
- **Section 3**, for caregivers, offers advice and looks at issues from their point of view.

Throughout the booklet, you will hear from Canadians who've been where you are now. Their stories may not be the same as yours, but their words are offered here to help you understand that you're not alone. With help and with the right support, this can be a time of purpose and meaning.

“

*Everyone has a limit on their life,
but mine is very visible now.*

Section 1

For the person with advanced
cancer and their caregivers



Reacting to the diagnosis



“ Yeah, well, my life came to a screeching halt when this started.

While advanced cancer can be a shared journey for someone with cancer and their caregivers, everyone reacts to it and copes in their own way. Many people go through a range of feelings and react in different ways from day to day. It's important to know that you don't have to pretend everything is OK or try to hide how you feel.

Common reactions

Shock is a common first reaction. You may feel so confused that you don't know what to think or feel. You may forget where you are, feel like time has stopped or be unable to complete simple tasks. **Disbelief** is also common at first. You may find it hard to believe that this is happening or it might feel like a dream. As time passes, these often give way to other emotions.

“ You just go completely numb at first and you can't think. And everything just sort of starts spinning around you. Because life is still going on, but you're in this little whirlpool. You're in such a panic inside – it really takes a lot of effort to concentrate and think carefully about what it is you're hearing.

You may feel **anger** – at yourself, your family and other people around you, doctors, the world, your god or fate. Anger can come from the loss of control over your life and can cause you to lay **blame** for what is happening to you. It's important to find a way to manage these emotions if they begin to affect close relationships.

“ My husband became very angry, and there was a kind of a rage in his eyes too. Not so much against me but against his illness and what this illness did to him. And then of course his anger turned against me too. Against everybody really. That was really, really difficult.

As you think about the future, you may experience **anxiety**, **fear** and **uncertainty**. Anxiety is a general feeling of worry and unease. Fear is about something specific, such as the fear of dying.

You may feel **sad** and **grieve** the losses caused by the illness (for example, physical ability, a job or a trip) or feel anticipatory grief, which means you begin to mourn death, and what might be missed, before it happens. You may find that you **avoid** or **withdraw** from friends, family and regular activities. Feelings of sadness and grief can affect energy levels, appetite and sleep.

“ I have tears. And I don't try to hide them. There's no sense in hiding them because it just makes you sick inside. So if I have to let the tears go, they go. And I just let it happen.

Denial is the mind's way of coping with painful facts. You might reject the diagnosis or what the doctors are telling you about the illness. These feelings can come and go and can affect both the person with cancer and their family and friends.

“ He only heard what he wanted to hear. I don't think he ever heard that he was dying. I think he only heard that he wasn't going to live forever.

As you come to accept that you or your loved one is not going to get better, you may find that you **bargain** for recovery or more time. You might make a mental deal with yourself to be a better person or do more good works, with the hope that good health will return.

After a diagnosis, people with cancer often begin to review their life or consider why they became ill. This can lead to feelings of **guilt** and **regret** over things you feel you should or should not have done. The illness may even seem to be a form of punishment. Caregivers can also feel guilt and regret over many of the same things.

Marla's story: Dealing with denial

Marla was 27 years old when her father, Heath, was diagnosed with advanced pancreatic cancer. Marla and her younger brother became his primary caregivers. And they soon discovered how powerful a response denial can be. Their father refused to believe his cancer was incurable, despite what the doctors said.

"He'd say, 'I don't believe you, I know I can fight this,'" Marla recalls. "He was very strong-willed. Anything the oncologist would say, he wasn't hearing it."

The denial continued for more than 3 years. But as his health began to suffer, there were moments of recognition. "Sometimes he'd break down and cry because it would kind of hit him. And then he'd build it back up and say, 'No, this is what's going to happen and I'm going to make it happen my way.'"

Marla went to doctors' appointments with her father so that she could hear what he would not hear. She read the information pamphlets her father left unread. And when the moment seemed right, she tried to gently talk about it. "I'd say, 'But when the doctor says this, what does that mean to you, Dad?' And I'd repeat back some of the words of the doctor. But I wouldn't push it all the time. I'd let him have his way too."

Marla's father never completely let go of his denial. But in the final weeks of his life, he did discuss what Marla calls the business side of death. "He put me in charge of knowing what he wanted for his funeral arrangements, making sure I knew where things were in the safe box and all that kind of stuff."

Coping with difficult feelings

There are many ways to cope with difficult feelings. How you cope will depend, in part, on your personality and how you've dealt with challenges in the past.

“ This is just another challenge in my life. I may not get through this one, but at least that's my approach – to meet it head on.

Joanne learned to cope with difficult emotions as she cared for her husband, Guy. He lived at home with her for more than 4 years after his diagnosis of advanced brain cancer. She describes those years as an “emotional rollercoaster” – with highs as well as lows. “You have a good day and then you have a bad day, and you just kind of manage it as it comes along. And then it's over and then maybe the next day is better.”

> TIPS

- Talk to someone you trust. Family and friends may help you cope. Some people find it easier to talk to a counsellor or social worker. Or you may find it helpful to speak to a mental health professional, such as a psychologist or psychiatrist, who can help with things like making sense of your feelings, setting priorities and talking to friends and family members.

“ It’s important to make sure you have somebody that you can confide in or talk to. And if you don’t have that person, find out who could do it.

- Stay active in whatever way you can.

“ I go for a walk to the library ... that kind of active.

- Make healthy food choices and try to get enough sleep.
- Avoid using alcohol or other drugs as a way to cope.
- Spend time outdoors and enjoy a change of scenery.

“ To be able to go out, to enjoy the trees and the flowers, and to hear the birds singing – that’s quality of life.

- Express yourself creatively – try writing, painting, photography or any other hobby.

“ I try to make every day as interesting as I possibly can. I write, teach and fool around with my hobbies, such as composing music.

- Distract yourself with something you enjoy.

“ A bath at night, even just reading ... music also worked.

- Find humour where you can.

“ If you can’t laugh about yourself, then you can’t really have a lot of fun in your life.

Moving forward

Some people find it helpful to think of this as a period of time when you hope for the best but plan for the worst. Planning for the worst might mean writing a will, deciding on a substitute decision-maker or sharing your thoughts on a funeral or memorial service. At first, this may make you feel like you're giving up – but you're not. You're taking control and focusing on what's most important to you.

“ I am having trouble putting it all together. I know I must accept it but I cannot accept it all at once.

Some people never accept the situation completely. This is OK. It's their life to live as they want, right to the end. It isn't easy, but do your best to respect your differences and keep moving forward. Most people eventually understand what will happen, but they also hope that treatment will control the cancer and allow for good quality of life for whatever time is left.

Paul's wife, Carolyn, was diagnosed with inoperable lung cancer at age 58. Instead of the lengthy shared retirement they'd been working toward, they were now told that Carolyn had perhaps a year to live. “We had a lot of questions,” Paul remembers. “There was some anger ... Why is this happening to me?” But after talking together and with their 4 grown children, they began to plan for what came next. “Once we knew that it was terminal, we tried to plan what we would do. We both accepted it, and we knew that we had to make the best use of the time we had left.”

Family meetings with the healthcare team

Some people find it helpful to plan a meeting with their family and their doctor or other members of the healthcare team. Sitting down together in the same place at the same time gives everyone a chance to share information, ask questions, learn what each other's goals are and make a plan for treatment and care.

As acceptance grows, some people find that, in addition to the difficult emotions, there are positive feelings as well. They learn to appreciate life in a new way.

“ The small things in life – that maybe we take for granted – become very beautiful and give me lots of strength.

Over time, you may also begin to find hope. Many people are surprised to find that the role of hope in their cancer journey changes rather than ends. Hope for a cure may change to hope for peace and contentment, a moment of joy or simply a good day. Hope allows you to see that meaningful activities and achievements are still possible. It can carry you through hard times and help you keep a sense of dignity.

“ I don't think about how I'm going to win this. I just think about what I'm going to do today and what I'm going to do tomorrow.

Helping younger children (1 to 6 years)

Children are sensitive to stress and how loved ones behave, even when they are very young. When a parent or family member is sick, children have to cope with a lot of changes. It's important to be aware of how they're feeling and know how they might respond.

Young children cannot express themselves with words as well as older children can, but listening and watching them can help you understand their thoughts and feelings. Young children will often express themselves through self-talk, play, songs and drawings.

Some of the ways that younger children show how they are feeling include crying or whining, bedwetting, thumb-sucking, wanting to be held or being clingy, having stomach aches or headaches, keeping themselves apart from others, having trouble eating or sleeping, having tantrums or acting out.

Be patient and try not to overreact. Children have special needs, and they need to know that they will always be loved and cared for.

> TIPS

- Keep to normal routines for meals and bedtime. Regular activities like games or sports and seeing friends can help children cope. Ask for help from an adult the child likes and knows well.
- Schedule some time for the whole family and some time alone with each child. Even a few minutes a day, without interruptions, can help. You could take a short walk, read a story together or let children show you something they've done or are excited about.
- Organize special activities or outings for children to look forward to. You can ask for help from an adult the child likes and knows well.
- Praise children for good behaviour.
- Reassure, comfort and hold them.

Helping older children (7 to 11 years)

Older children may also react to stress and changes around them by getting upset. At this age, children are becoming aware of possible dangers to them, their friends and their loved ones.

Along with showing some of the same behaviours of young children, older children may also argue more than usual with siblings or say they are afraid of being injured or separated from loved ones.

> TIPS

- Take their fears seriously. Respect their feelings by comforting and reassuring them.
- Give children a chance to talk about how they feel.
- Explain the situation as well as you can, even if it means admitting you don't know the answer to something.
- Let your kids know that you have the same feelings they do sometimes. If you can show your sadness and cope with it, this will let kids know that it's OK for them to feel upset as well.

Helping teens

It's tempting to think of teens as smaller versions of adults – but they are not. Teens are still learning responsibility and are going through the process of becoming independent from family. They are old enough to be aware of what's going on, but at the same time they are still very vulnerable. Some may offer to help in times of stress, while others will seem to ignore what's happening.

> TIPS

- Recognize that how you handle a situation will affect how your teen handles it. But know that teens express their feelings differently, both in direct and indirect ways.
- Know that conflicting feelings are normal. Being a teenager is stressful, and teenagers often feel things intensely. How they behave isn't always related to cancer.

- Give teens time and space to process their feelings, while letting them know that you're there for them when needed. Teens may ignore you even as they want your support. They may behave badly but deny they are upset.
- Make sure they have time for regular activities and seeing friends. Normal routines are important, especially for teens who are still going through normal teenage issues.
- Understand that gaining independence from family is a healthy part of being a teenager. If your teen resists being pulled back closer to family because of a cancer diagnosis, it doesn't mean they don't love the person with cancer. It means they're acting as many teenagers would.
- Make sure they have healthy supports around them. Teens need to talk about their feelings, but they might be uncomfortable talking to parents. Friends or other adults (a grandparent, family friend, teacher or coach) may be able to provide support.

When to seek help for your children and teens

Children and teens are strong, and during this time they can cope well if they have enough support. This can be challenging when you're also grieving yourself. If you're not sure what to say or how to say it, or are worried about your ability to provide support, a spiritual advisor, teacher or guidance counsellor may be able to help.

If you're worried about changes in your child's mood, you may want to get help from a psychologist, social worker, family doctor or psychiatrist. These healthcare professionals can also be consulted if your child or teen:

- has increased problems with learning or paying attention
- is often angry or defiant
- no longer seems interested in social activities
- has problems sleeping or eating
- complains a lot about how they feel physically (for example, stomach aches or headaches)
- starts taking more risks than usual or getting in trouble with the law
- is taking drugs or drinking alcohol
- talks about death a lot

Talking about death

“ We didn’t really talk about it. I never asked my husband, ‘How do you feel about if you’re going to die?’ He did say to me one day, ‘I just don’t want to lose all of this.’ And I just hugged him and that was about it.

For most people, talking about death is very hard. You might worry that it will hurt friends and family or make them upset. You may fear, even though there is no reason to, that talking about it will make it come faster. You might find that the subject, once raised, is rejected with words like “everything will be fine” or “it’ll all work out.” How your family has handled death in the past and differences in traditions or customs can also affect how you speak about it.

But what is clear is that we all die, some day. Not talking about it will not make it go away, and talking about it can have many benefits:

- Talking can help relieve fear and anxiety.
- Not talking about a fear can make it worse.
- Talking can help heal a relationship.
- Speaking clearly about what you want or don’t want as death approaches can make your healthcare and personal wishes clear to everyone. This reduces confusion and improves the quality of your care.

In her years working as a nurse, Cecile saw many families struggle to speak freely about death. When her husband, Stan, was diagnosed with advanced lymphoma, she made a point of encouraging him to talk – when he was ready. “I think it was the best thing I said to him. I said, ‘We’ve always had good communication. I want us to go through this together. But I want to respect when you are ready to talk.’”

Stan struggled with acceptance and denial. When he avoided talking about it, he became tense and angry. “The tension would build up, and then we would sit down and have a really good talk. We would hold each other and cry together. Those are my best memories of that time. And afterwards my husband would say, ‘I feel better, it was good to talk about it.’”

> **TIPS**

Sometimes people are willing to talk about death but don't know how to start. These tips can help:

- Take some time to plan what you want to say before you start talking.
- Find a quiet time and place without distractions.
- Ask if it's OK to talk.
- Sit close enough to touch one another if the time feels right.
- Try to maintain eye contact as you speak or listen.
- Let the other person know that they can end the conversation at any time.
- Speak clearly, honestly and directly.
- Encourage your loved one to speak by nodding your head or offering an encouraging word.
- Accept that even if you're ready to talk, the other person may not be. Be patient and try again later.

Some people find it easier to talk to someone outside the family. You can ask for help from a spiritual advisor or a mental health professional such as a psychologist or social worker who may already be a member of the healthcare team. They can meet with you on your own or with your loved one so that you can share your thoughts and feelings.

Medical assistance in dying

Some people think of ending their life when they find out that their disease can't be cured. Perhaps symptoms like pain or depression become too much. Or there is a fear of becoming dependent, being a burden or causing too much work for others.

Don't be afraid to ask for help if you have thoughts of ending your life or if someone you know has them. Symptoms like pain and depression can usually be well managed. Talk to a doctor, or you may need to ask to be referred to a palliative care specialist. Talking to a trusted friend or family member can also provide much needed emotional support.

In Canada, you can ask for medical assistance in dying. You must meet certain conditions in order to be eligible for this assistance, and only certain people, such as physicians, are allowed to provide or help provide medical assistance to someone who wishes to die. People who help someone to die must follow rules set out in federal, provincial and territorial law.

For the most up-to-date information on this topic, visit cancer.ca.

Talking about death with children and teens

Children of all ages and teens need to know that they didn't cause the cancer or death by anything they said or did. They also need to know they can't make it go away.

You may want to protect your kids from sadness or pain by not telling them the truth. But avoiding the truth can lead to trust issues later on and can leave them unprepared to cope with the future. And saying nothing leaves children to imagine the worst. Being honest helps them know what to expect, which can give them a sense of security.

Younger children may have a sense that something bad is happening but have little understanding of what death means or that it's permanent. They may confuse death with sleeping, which can make them worry about their own sleep.

Older children may understand that dying is forever but may be more focused on right now rather than thinking about the future.

Teens understand death but need to know that grief is not permanent. They need to know that it takes time to get over the loss and that getting over it doesn't mean forgetting about the person who died. It means finding healthy ways to cope with the pain as it gets better.

> TIPS

- Give information in small amounts in a level of detail that fits your child's age and stage of development. Let them know if the person with cancer will be in the hospital or at home in bed sometimes.
- Encourage your children and teens to ask questions at any time. A child may ask the same question many times, looking for reassurance. Will the person with cancer die? Did I cause the cancer? Can I catch it? Will you catch it? Who will look after me?
- Answer questions as honestly and plainly as you can. If you don't know the answer, say you'll try to find out and then keep your promise. Try to avoid using phrases like "passed on" or "gone to rest" when you mean "death" or "dying." Adults may find them comforting, but they can confuse children.
- Watch how your children and teens are behaving. Ask questions about what they are thinking and feeling. You can also ask them what they know about cancer and then clear up any misunderstandings.
- Describe your own feelings and emotions. This shows that it's OK to talk about them. It also gives you a chance to help kids and teens find healthy ways to express and cope with the feelings they have.
- Recognize that when a close family member dies, the way the family used to function often changes entirely. Do your best to make sure everyone has the time and support they need to heal in healthy ways.

Many families are unsure about children, especially young children, seeing a loved one who is dying of cancer. This is a decision that each family must make, taking into account the age of the child or teen and their relationship with the loved one (whether a parent, grandparent, sibling and so on). You can help before the visit by describing what the room looks like, what they might see there and if the person with cancer will look different. Talk to them afterwards about how they felt.

When death is expected to be soon, try to give older children and teens a last chance to see their loved one, especially if it's a parent. This provides an opportunity to say goodbye and also to begin to process what may be a range of feelings (sadness, grief and anger, along with good memories).

Kim's story: Coping as a teenager

Kim had just turned 17 when her mother, Pearl, 39, was diagnosed with advanced colorectal cancer. Pearl was a busy stay-at-home mom who helped out on the family farm and ran a home sewing business on the side.

Over the next year, Kim and her younger sister did more on the farm and around the house. Kim sometimes drove Pearl to the hospital for chemotherapy sessions. "It was a good bonding time for her and me. That really was a time when we did become closer and started talking more."

Like any teen, Kim was busy with her own life and her own emotions. She was in grade 12, looking forward to graduation and ready for more independence. "I was really trying to express my own freedom and find out who I was as a person. I felt – and I still feel incredibly guilty about this – very selfish. I would question why I couldn't go out or do certain things because I had to be at home. It was a big struggle."

Pearl helped by keeping life as normal as possible. She encouraged Kim and her sister to keep up with all of their normal activities. But as Pearl's health got worse, she spent more and more time in the hospital. She managed to sew Kim's graduation dress and go to the graduation party. "That was a really big thing," Kim says. "She was really sick. I remember a few people saying, 'You can tell she's fighting – she wants to be there.'"

"You have such conflicting emotions. You want her not to suffer anymore. But at the same time you have this hope that she'll pull out of it and be OK. Eventually my dad had to step in and say, 'No, you have to understand, she's fighting as hard as she can to be here for as long as she can but there's nothing else they can do.'"

Kim and her sister chose to be at their mother's side when she died. Many years later, it's still a painful memory. Now married with a daughter of her own, she sees how the caregiving experience changed the course of her life. Kim says, "I think it makes you realize that life is very short and you have to make the most of it."

Choosing care and treatment



“ When we first came to the hospital, it was so frightening. You walk through the doors and think, Oh, what’s going to happen to us? What’s waiting for us here? But it’s been a very positive experience.

Treatment doesn’t end when cancer is advanced – but it does change. Making choices about care and treatment involves both the person with cancer and caregivers. Some people choose to explore every option that might help them live even a month longer, perhaps taking part in a treatment clinical trial for a small number of people. Others are more concerned with quality of life for whatever time is left. Some people want to do a lot of research, while others do not.

“ One of the ways of keeping my sanity was to get on the Internet and start researching and start reading. And start looking for what there was and what was available. And what I was about to be subjected to ... knowledge is something I need. Because then I know what to expect.

If you go online for information, make sure that you look at websites for cancer care in Canada. Be sure to talk to your healthcare team before making decisions about treatment – online information may not be accurate, complete or relevant to your situation.

Working as a team

Working together can make important decisions easier. Sometimes, the person with cancer feels like they’re being pulled in different directions, trying to decide between others’ wishes and their own. Take some time, talk to the healthcare team and try to agree on the best and most realistic decision for all. Even when goals or choices differ, do your best to discuss them with honesty and respect.

Caregivers can play an important role as advocates – getting information, asking questions and working with the healthcare team to ensure the best possible care. When John was diagnosed with advanced prostate cancer, his wife took on many of these responsibilities.

“ I made all the notes. He made notes too. I know it sometimes bothered him if the doctors would talk to me instead of him. He'd get really mad. He'd say, 'I'm the patient here, talk to me!' But there were times when he would get confused and he didn't really know how confused he was.

An advanced cancer diagnosis often leads to changes in the healthcare team. For example, a pain specialist might join the team and you may not see the same doctors that you used to see. The people helping you will depend on your needs and where you live. Members of the team who may now work with you include:

- medical doctors (for example, family doctors, oncologists, pain specialists, palliative care specialists, psychiatrists)
- nurses (for example, advanced practice nurses or clinical nurse specialists)
- social workers
- psychologists
- physiotherapists
- occupational therapists
- dietitians
- pharmacists
- spiritual care workers
- home health aides

It's normal to miss the support of healthcare professionals who helped you earlier in the cancer journey – you may have known them for a long time and become very comfortable with them. But your new team has special skills and training to help you now.

“ I have enormous confidence in my nurses. I think they've seen every situation imaginable. I feel really ... so secure with them because I feel they really want to help me. We work hand in hand.

“ The social worker was very helpful. She was very supportive. And she told me how to go about different things. I found that really helpful because I didn't have the foggiest idea.

Who decides?

Decisions about treatment need to be made by the person with cancer, with information provided by their healthcare team. Many people, especially caregivers and family, will offer suggestions, advice and support, but the decision is not theirs to make. The person with cancer has the right to accept or refuse treatment at any time and the right to change their mind later on.

You may decide that you no longer wish to have treatments that are intended to help you live as long as possible. You may have many reasons to make this decision. Give yourself time to think carefully about your options. Talk with family, doctors and members of your healthcare team.

Families sometimes find it hard to accept decisions about treatment. But it's important for everyone to understand that the choice is with the person who has cancer.

Communicating effectively with your healthcare team

One of the best ways to make sure you have good care is to communicate effectively with your healthcare team. Try to be honest, open and direct. Both the person with cancer and caregivers can talk to the team about how things are going and keep the team informed about goals for treatment, how much information you want to receive and the end of life when it comes.

Tell the healthcare team about any cultural or spiritual concerns or practices that are important to you. If it's easier for you to communicate in another language, including sign language, ask for an interpreter.

Doctors and other members of the healthcare team need to communicate effectively with you too. It's part of their job to provide you with the information you need to make decisions about care. This includes explaining treatment choices, and their benefits and risks, in a way you can understand. They should answer all of your questions or arrange a follow-up appointment to do so. You should be informed and consulted at every stage of care and treatment. You may want things explained several times or you may find it helpful to record the conversation. This can be a good time to talk about advance care planning - making decisions about your care if you become unable to do so.



If I don't feel I got the answer, I will ask the question again and again and again.

It takes time to develop a good relationship with your healthcare team. If you find it hard to talk to your doctor, tell them and perhaps together you can find ways to communicate. And if the relationship still isn't working, you may be able to find a new doctor.

June has experience on both sides of the healthcare system, as a long-time nurse and as a caregiver to her father after his diagnosis of advanced oral cancer. She believes it's important to trust your doctor. "If you're going to be in something for a long time, there has to be a good relationship there."

When June and her father were unhappy with the care provided by his specialist, she found another one. "We just made that happen. I think lots of people would have just put up with it because they were so afraid that they weren't going to get in to see another specialist. But I thought it was a risk worth taking."

June also emphasizes the importance of speaking up for yourself. "People are afraid to ask questions. They trust that they're being told what they need to be told," she says. "You need to ask questions at every level. You need to be your own advocate. And if you can't be your own advocate, find someone who can help you with that."

“ I was very satisfied with the care that I had, but I wouldn't have been satisfied if I hadn't done my homework and if my wife and I hadn't decided that we would really advocate like we did for ourselves.

> TIPS

- Prepare a list of questions in advance. Ask how much time you will have to discuss these questions and ask the most important ones first. Take notes or ask if you can record the discussion so that you can review the answers later.

“ We always made lists of questions before we came. And we also thought about the alternatives. We literally had 3 sets of questions when we'd come in.

- Go to appointments together. Caregivers need information and support too.

“ Any time any type of decision had to be made about my husband’s medical treatment, I was there.

- Keep a binder or diary (paper or electronic) with contact information for members of the healthcare team, a list of medicines and side effects, information about community and medical services and an appointment calendar. Bring this with you to appointments.

“ I kept a diary. I thought, This is going to be a long journey and I’m going to have to keep track of things.

- Be prepared to wait.

“ I do crossword puzzles and bring something light to read. I bring my supply because otherwise I’m going to sit there and get angry, and I don’t want to do that.

- Find out what to do in an emergency – who to call and where to go.

Asking difficult questions

“How much time do I have left?” “How soon will my loved one die?”

Not everyone asks these questions, but most people think about them. They are difficult to ask and impossible to answer in an exact way. Doctors can give only their best estimate, or guess. Some people will live much longer and others for a shorter time than expected.

Understanding palliative care

Many people have doubts or fears about palliative care because they don't understand what it is and then fear what they think it means. People often think of palliative care as care that is limited to the last few days or weeks of life – but this is only a small but important part of it.

Palliative care is a type of care that provides physical, emotional, social and spiritual support for people with cancer and their families. Palliative care can help by relieving symptoms, focusing on quality of life and providing support for you and your family at any stage of the cancer journey.

This care can be provided in pain or palliative care clinics, palliative care units in hospitals, hospices, long-term care facilities or your home.

A **palliative care clinic** is a clinic where people can receive pain and symptom management as well as emotional and practical support. It's set up for outpatients, which means you don't sleep or stay there.

A **palliative care unit** is where people can receive specialized palliative care in a hospital setting. It's for inpatients, which means you stay and sleep there. These units have specific admission criteria, and there are often waiting lists. It's a good idea to fill out an application early, with the help of a healthcare professional. Most palliative care units provide care in the last months or weeks of life, but some acute palliative care units are set up for short stays to manage symptoms.

A **hospice** facility or program offers supportive care for people at the end of life as well as their families. Hospice volunteers can provide support in the home, and residential hospices are places where people with cancer can be cared for at the end of life in

a homelike setting. It's a good idea to plan early for where you would like to be at the end of life, as there are waiting lists. You might have a Plan A, which may be at home, and a Plan B, which may be in a hospice or in a hospital's palliative care unit.

Palliative care specialists include doctors, nurses, psychologists, social workers and other team members who have special training and can assess each person's needs. The healthcare team may recommend palliative treatments such as radiation, chemotherapy, surgery or medicines for pain, nausea, shortness of breath or other symptoms. These treatments are not intended to cure the cancer but to relieve symptoms and improve quality of life.

“ We had a good talk with the specialist, and he said, ‘We will do chemo but it will be palliative and we’ll do it as long as it helps. This is just to improve and prolong your life.’ We had the best doctor – he was so good and so patient. He explained it so well.

Getting palliative care services when you need them

Palliative care services vary by community. Many programs have waiting lists and you may have to pay for some services. It can be helpful to get to know the palliative care team sooner rather than later. Talk to your doctor, social worker or another member of the healthcare team. Or contact our Cancer Information Service to find out more about hospice care and services in your area. Call toll-free 1-888-939-3333 or email info@cis.cancer.ca.

Palliative care at home

Some people choose to stay at home for as long as possible. They want the privacy and comforts of home. Both the person with cancer and caregivers need to understand what staying at home will involve. Your healthcare team can explain what this choice means in terms of care and responsibilities.

Palliative care services can be offered in the home as support for the person with cancer and their caregiver. You may be able to arrange for home visits by nurses, doctors, social workers, home health aides, occupational therapists and volunteers.

You may need to make changes so that your home is comfortable and safe. This can be as simple as removing a rug that someone might trip over or as major as adding wheelchair ramps or renting a hospital-style bed. Speak with a social worker or other member of the healthcare team if you need help rearranging your home.

Joanne kept her full-time job while her husband stayed at home. Home care support was necessary. “Every afternoon someone would come in – a hospice volunteer, my sister-in-law, some other friends. At first he didn’t want the hospice volunteer because he ‘didn’t need a babysitter,’ but eventually they became really good friends.”

Even with the right supports, there may come a time when it is no longer possible to care for someone at home. Caregivers can reach the point of exhaustion. They might be coping with health problems of their own. Sometimes the person with advanced cancer has medical needs that cannot be fully met at home. It’s important for both of you to recognize that this is not a failure. Try to talk about your doubts and concerns, and focus on what will improve quality of life for everyone involved.

Paul and Carolyn's story: Choosing care

When Carolyn was diagnosed with advanced lung cancer, she and her husband, Paul, agreed that she would stay at home for as long as possible.

Over time, they made changes to the home, adding a hospital bed to the master bedroom, a bench for the bath and an extension for the toilet so that Paul could lift and lower her more easily. Home care nurses visited regularly to help bathe Carolyn and give Paul a break from caregiving.

For Paul, the biggest challenge was his bad back. He had trouble lifting Carolyn out of bed. At the suggestion of their oncologists, Carolyn and Paul looked into a small hospice nearby. They liked its homelike feel – the beautiful gardens, the large living room, a kitchen and sunroom for everyone to share and 6 private bedrooms.

“Every one of the bedrooms had a view outside. There was a birdfeeder on every window and a huge covered patio in the back,” Paul remembers. “All the meals were cooked there. It really had all the comforts of home. And you were allowed to bring anything from home that would make you feel more comfortable.”

Carolyn had an interview and went on a waiting list before a space became available. When the phone call came, they were both ready for it. “Carolyn was happy about it because we had lots of information. And she knew that I was struggling to keep her at home.”

During her 6 weeks in the hospice, a team of specially trained nurses, social workers and volunteers attended to her every need. “They looked after her so well, and they provided all the care that I wasn’t able to give her,” says Paul.

Paul and Carolyn were comfortable with their decision – they felt that they’d made the right choice. Carolyn could die with dignity here. Looking back now, Paul has one piece of advice for families: “Get the whole family involved, so that when it does happen, they know that you’re not giving up on the person. You’re trying to make their last days, weeks or months as comfortable as they can be because obviously the most important person is the one who’s dying.”

Other choices

Complementary therapies

Some people find that complementary therapies help them cope during this time. Complementary therapies don't treat the cancer itself. They are used *together with* conventional cancer treatments (such as chemotherapy and radiation therapy) and aim to improve overall well-being. For example, research shows that music therapy can improve mood, lower pain and enhance the quality of life for people in palliative care.

Complementary therapies may be offered as part of hospice or hospital care. Before using any complementary therapy, talk to your doctor or another member of your healthcare team about the possible risks and benefits.

Clinical trials

There are different kinds of clinical trials, which are research studies that involve people. Supportive and palliative care clinical trials focus on managing symptoms related to cancer and its treatment and conditions that may occur after treatment or at the end of life.

Every clinical trial has its own rules about who can take part. If you qualify, talk to your doctor so you can make the best choice for you. While a clinical trial may be a good choice for some people, it may not be the best choice for others.

Taking part in a clinical trial is voluntary. If you join a clinical trial, you have the right to leave it at any time without affecting your care.

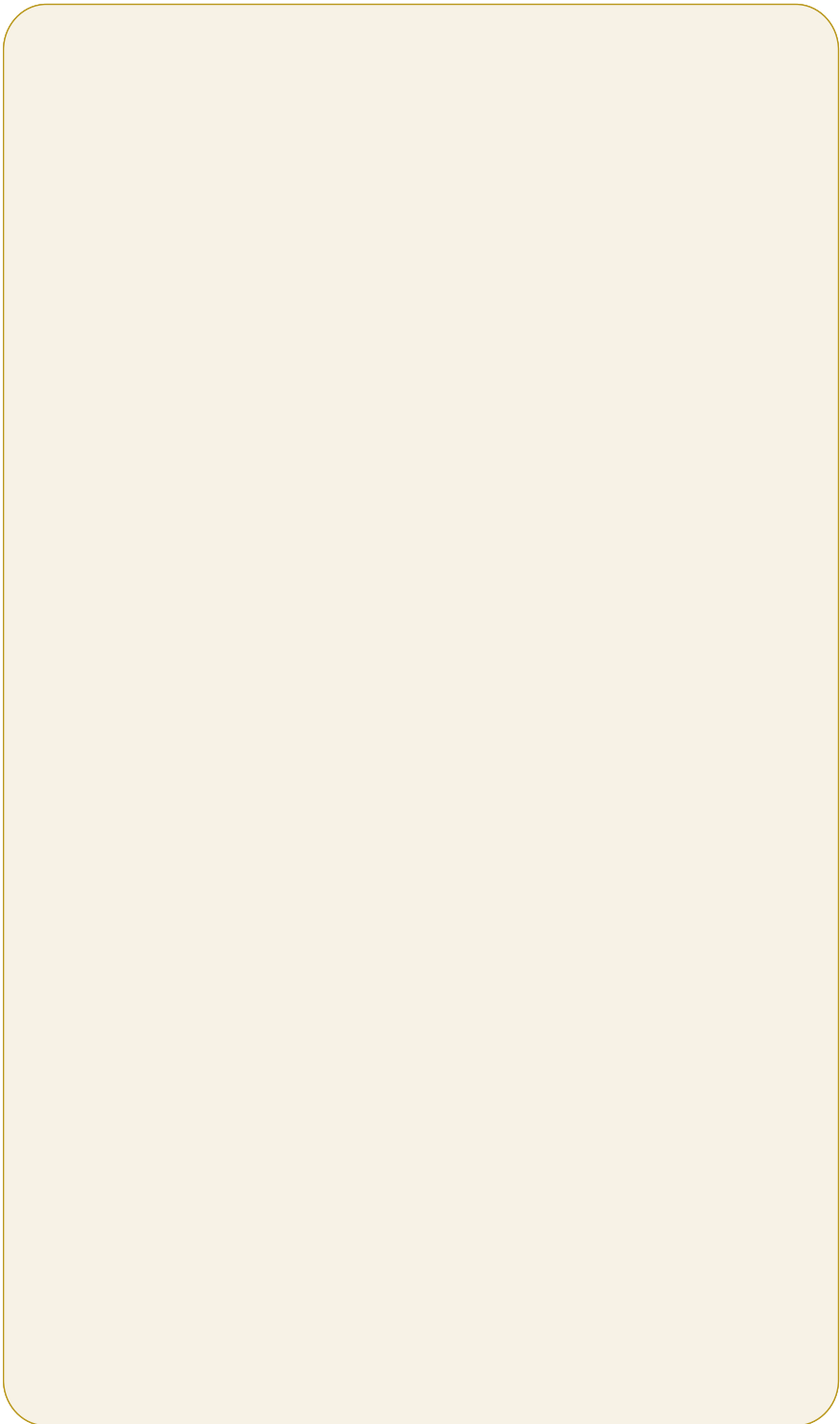
Want more information?

Our brochure *Clinical Trials* has detailed information on this topic.

Alternative therapies

Alternative therapies are scientifically unproven therapies that are used *instead of* conventional treatments. Refusing to have conventional treatment and using an alternative therapy instead is a personal decision. Make sure that your decision is a well-informed one. Some people spend a lot of time, money and energy trying these types of unproven therapies.

If you decide to postpone or refuse conventional treatment to try an alternative treatment, keep in contact with your oncologist. Your oncologist may not agree with your decision, but it's important for someone to keep track of how you're doing. You may decide to use conventional treatment later.



Common symptoms and how to manage them



“ When you’re feeling sick, when you’re tired and you’re nauseated, boy it’s hard to think there’s anything good going on. Yeah, eventually it passes.

Cancer and the treatments for it affect everyone differently. Some people have no symptoms for a long time. Some people have a few symptoms and others have many.

Ignoring symptoms can make them worse and affect your quality of life. There are ways to manage symptoms at every stage of your cancer journey, so tell the healthcare team about yours as soon as you notice them. You may need to ask to be referred to a palliative care team.

Pain

Pain is the symptom many people fear the most after a diagnosis of advanced cancer. Talking about pain and talking about it early can lead to treatments that manage it better. If you are living with pain, you know that it’s very tiring. Good pain control can improve your physical, mental and emotional well-being by helping with sleep, appetite and mood.

“ My quality of life? Number one is to keep the pain under control. After a while it wears you down. It fatigues you, wears down your will to find pleasure in things. And that’s what the nurses have really helped with. They played around with the medication.

Everyone feels pain differently. Admitting that you have pain is not a sign of weakness, and it doesn’t mean that the cancer is getting worse. Let your doctor or another member of your healthcare team know as soon as you begin to feel pain. Pain is easier to manage if it’s controlled right from the start. Doctors can prescribe many types of pain-relieving medicines. These may be given as pills, liquids, suppositories, patches or injections. It can take time to find the right drug or combination of drugs and dosages.

What your healthcare team needs to know about your pain

To help you get relief, your healthcare team needs to know:

- where it hurts
- how long it lasts and how often it occurs
- how severe the pain is (on a scale of 0 to 10 with zero as no pain and 10 as the worst pain possible)
- what the pain feels like (for example, burning or aching)
- if anything in particular causes pain or makes it better (for example, a movement or activity)
- how the pain is affecting your life (appetite, sleep and so on)
- what medicines you have tried, what dose and if they helped or not

> **TIPS** when taking pain medicines

- Take medicines as prescribed and at regular times during the day.
- Don't skip a dose because the pain seems better. The pain may be better because the medicine is working. Not taking a dose can allow the pain to return and make it harder to control.
- Ask your doctor whether you are likely to have breakthrough pain. Breakthrough pain is pain that occurs between regular doses of medicine. Your doctor may prescribe extra doses of medicine to take as needed.
- Tell your healthcare team if you have side effects from pain medicines. Many side effects, such as nausea and sleepiness, often go away after a few days. Some side effects do not:
 - › Constipation is a common side effect that does not go away on its own. If you're constipated from pain medicines, you need other medicines to control it. Medicines for constipation need to be taken every day, not only when you think you need them.
 - › Hallucinations (seeing things that aren't there) or bad dreams are also side effects that a doctor needs to know about. If the pain medicine is causing them, it can be changed.
- Tell your doctor if the medicine stops working. There is no typical dose – only a dose that works. It is common to need medicines changed or increased over time.

People sometimes fear they will become addicted to pain medicine. Or they're afraid that increasing the dose will speed up death. Caregivers can also have the same worry. These fears can stop people from taking pain medicine. But addiction to pain medicine is rare if the medicine is being given to control pain, the correct dose is taken and the doctor is monitoring the situation.

“ She was in very little pain. It was well controlled so she was not suffering. Carolyn was on a pain pump, and if it got bad, she could push a button and it would give her a boost. But it was computerized so you could not overdose or take your own life. So the pain was always well controlled.

Complementary therapies such as acupuncture, relaxation techniques, massage or meditation may also help with managing pain.

Anxiety

It's normal to feel anxious when you have cancer or are caring for someone with cancer. It's a stressful time and there are many things that can make you feel very worried – as if you can't cope. For example, pain that isn't being managed can make you anxious. Feeling abandoned and alone or worrying about the future can also make people anxious.

Many people find it hard to cope with strong feelings of anxiety. It may be that you can't concentrate, are irritable and easily distracted, sleep badly and get tired easily. These feelings may come and go or they may be there all the time. Some people notice physical changes such as being out of breath, dizzy or sweaty or having chest pain.

If worry and fear are constant and overwhelming, it's important to get help. Talk to a member of your healthcare team about a referral to a psychologist or psychiatrist if the feelings become worse or last a long time and are starting to take over your thoughts and negatively affect your daily life.

Breathlessness

Shortness of breath can be caused by cancer, by conditions related to cancer or by other illnesses. Having difficulty breathing or feeling unable to catch your breath can be frightening. It is important to contact the healthcare team if breathing becomes very difficult or if there is chest pain or fever. There are medicines that can help.

> TIPS

- Rest or sleep in an upright position.
- Open a window.
- Turn on a fan, humidifier or vaporizer.
- Loosen or remove tight clothing and bedding.
- Try deep breathing exercises or listen to calm music to lower anxiety.

“ The shortness of breath has been the worst side effect that I’ve had. I didn’t like losing my hair but once I lost it in about a week, well, you live with that. But shortness of breath interferes with my life. If I have it, I have to stop what I’m doing.

Confusion

Cancer and its treatments can affect memory, awareness, reasoning and concentration. People might not be able to answer a simple question or may need to be gently reminded of where they are or who you are. This can come and go during a day, and it can also upset sleep patterns. In some cases, the person may feel threatened or become aggressive. It can be distressing for the person with cancer, who may feel that they are losing control over their lives or at risk of losing their dignity. It can also upset family members who may feel like they've lost their loved one before the person has died.

The healthcare team can work to find the cause and may change medicines or their dose.

> TIPS

- Try to remain calm. Speak slowly and calmly.
- Don't disagree with what the person says. Arguing can make them feel threatened. Let them know that you can see how upset they are, and promise to try to help.
- Help the person see and hear as well as they can by keeping hearing aids and glasses (if used) close by.
- Have other people nearby to help if needed.
- Limit the number of people that the confused person has contact with, especially if visitors make them anxious or make them behave aggressively.



His cognitive abilities were affected and he had some confusion. He couldn't dial a phone number. Then he would get mad if I tried to do it for him. 'I'm not an invalid! I can do it myself!' ... That was difficult. My husband was a very competent man who had been vice-president of his company. He always took care of every situation.

Constipation

Constipation can be caused by cancer and its treatment and some medicines. It can also happen because of change in your activity levels, your eating habits or how much fluid you're drinking.

If you're constipated, talk to your healthcare team. They may recommend a stool softener, laxative or enema.

> TIPS

- Drink plenty of liquids throughout the day.
- Be more physically active if and when you can. Even a walk around the house can help.
- Ask your dietitian or doctor whether eating more fibre would help. (It may not, depending on what is causing the constipation.) Examples of some high-fibre foods are bran, whole grain breads and cereals, brown rice, vegetables and fruit.
- Take medicines for constipation as prescribed. Don't skip a dose because you feel better because this may make the constipation worse the following day.

Depression

Depression is a term that describes a depressed mood (such as feeling sad, hopeless, tearful or discouraged) or the loss of pleasure in nearly all activities. All of these feelings can come and go after an advanced cancer diagnosis – for both the person with cancer and their caregiver. But these feelings could be a sign of clinical depression if they:

- become worse or last a long time
- go along with other symptoms such as feelings of worthlessness or guilt, changes in appetite, weight or sleep, difficulty thinking or regular thoughts of death or suicide
- start to take over your thoughts and negatively affect your daily life

Depression can and should be treated. It is not a sign of weakness. A person who is clinically depressed can't "snap out of it" or "cheer up" through will power alone. Only a medical doctor, psychologist or psychiatrist can diagnose depression. If you are clinically depressed, you may need treatment such as medicine or therapy. Talk to a member of your healthcare team if you think you or someone you're caring for may be clinically depressed.

“ I went through a little stretch where I was feeling depressed. I actually came and spoke with one of the doctors, and we figured it was the steroid combination that I was on. I saw something on the street or something and I'd start to feel weepy, and I thought, This is really strange. But we figured out it was the steroids.

Fatigue

Fatigue is a feeling of extreme tiredness or exhaustion. It is different from sleepiness. It can affect mental function, appetite and mood and can lead to a loss of interest in usual activities. Fatigue can be caused or made worse by some medicines or by stress and changes in diet or sleep patterns. The healthcare team may recommend changes in medicines or diet.

> TIPS

- Figure out what time of day energy levels are highest and schedule activities for these times.
- Rest or take short naps between activities.
- Stay as active as possible. Gentle exercise can give you more energy.
- Ask to speak with an occupational therapist. They may suggest using a walker, a wheelchair or other equipment.

“ The worst is the fatigue. I try to stay as active and as normal as I can, working through those things. But physically, that tiredness is the most aggravating.

Loss of appetite and losing weight

Changes in eating and appetite are common as cancer progresses. Some medicines can decrease appetite, or it may feel like eating has become a chore. At times like this, it can be hard to meet your nutrition needs. This can cause weight loss. Talk to a dietitian or another member of your healthcare team about changing the way you eat or using commercial nutritional supplements to keep you as healthy as possible.

> TIPS

- Try to eat small amounts of high-calorie foods, especially favourite foods, throughout the day. Snacking is a good way to get the calories and nutrients your body needs. They can also boost your energy between meals.
- Drink fluids (like soup or juice) when solid food isn't appealing.
- Use smaller plates to make portions seem more manageable.
- Do not pressure a person to eat more if they feel unable to.

Eating the way you used to may not be possible at this time. Even if others think you should have food, let your body decide. The goal should not be gaining weight - it's more important to be comfortable.

“ He actually couldn't eat very much. We found chicken noodle soup and things like that worked for some nourishment.

Nausea and vomiting

Nausea and vomiting can be caused by the cancer itself, pain medicine or constipation, or because digestion slows down. Feeling tired or anxious can make nausea worse. The healthcare team may suggest changes to your diet or prescribe anti-nausea medicines. Be sure to tell them if you are vomiting often or can't keep down medicines, food or fluids.

> TIPS

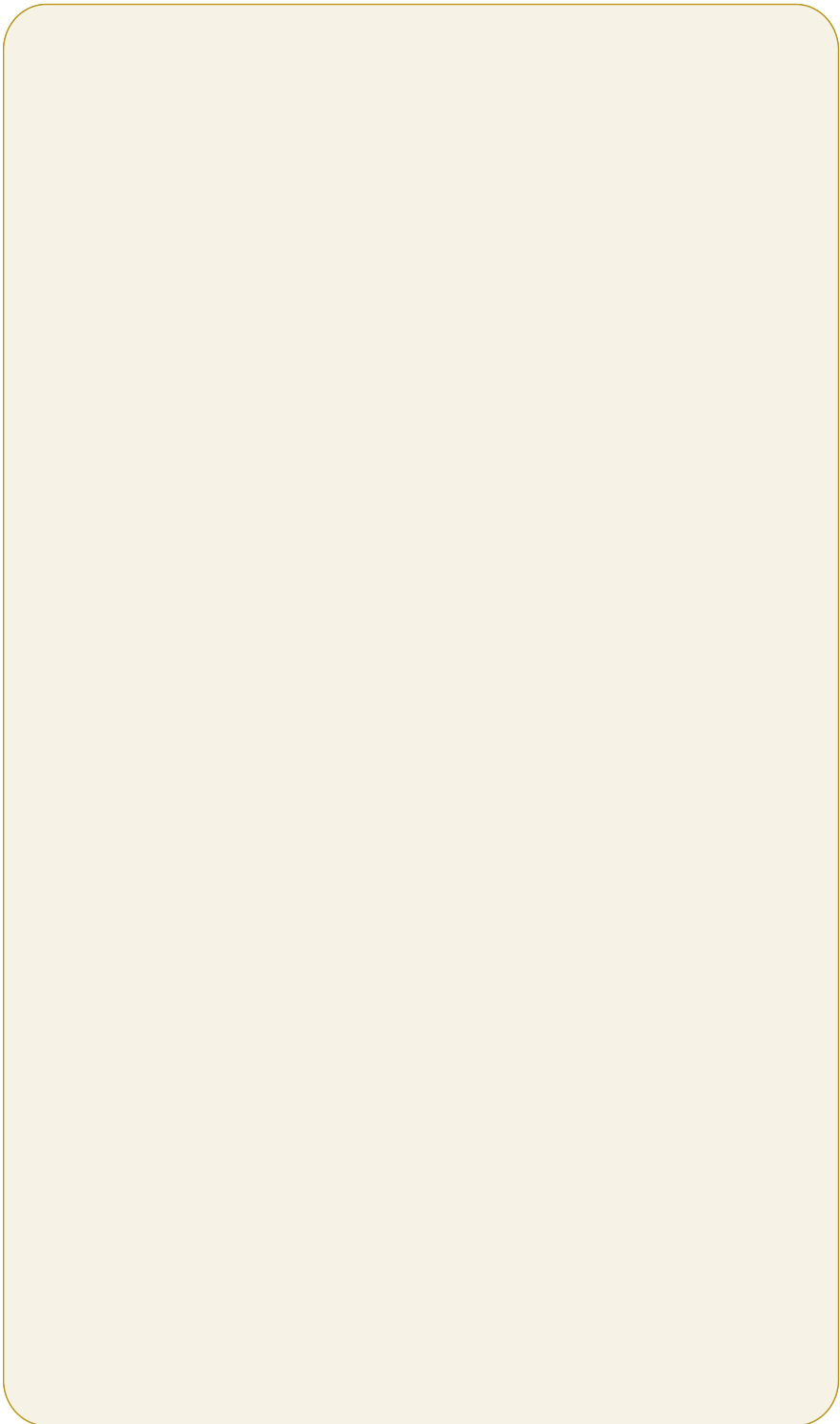
- Try eating small, light meals of bland (easy to digest) foods throughout the day.
- Eat slowly.
- Avoid spicy, sweet, fatty or acidic foods and foods with strong smells.
- Sip water and other liquids throughout the day. Cool or lukewarm liquids may be easier to drink than hot or cold ones.
- Rinse your mouth often with water or club soda to remove unpleasant tastes. And keep your mouth clean by brushing your teeth at least twice a day.
- Try deep breathing and relaxation exercises, or try a distracting activity like listening to music or watching television.

Sleep problems

Physical discomfort, medicines, stress, emotional upset or fear of not waking up can change your normal sleep patterns. Lack of sleep and feeling tired can make weakness and other symptoms worse. Talk to your doctor or another member of your healthcare team. They can work to find the cause and change treatments as needed. Medicines may be prescribed if sleep problems continue.

> TIPS

- Try to keep to a normal sleep routine. Short naps may help as long as they are before 3 or 4 p.m. Any time later may interfere with sleep at night.
- Be active during the day if possible.
- Try relaxation and breathing exercises, meditation or soothing music at bedtime.
- Try to limit alcohol, caffeine (found in coffee, chocolate, non-herbal teas), smoking and anything that tends to keep you awake as evening approaches.
- Avoid computer screens for a few hours before bedtime. The light can trick your brain into thinking it's daytime.
- Drink warm milk before bed.
- Create a comfortable sleep environment as much as possible. At night, to allow your body to follow its natural rhythm, try to go to bed when you feel drowsy, rather than staying up until a set time.



Practical concerns



Work and finances

Work and financial issues can cause problems for many people coping with cancer. Some people try to keep working and still fit in medical appointments, hospital admissions, sick days or caregiving. Others stop working or reduce the hours they work. You may be surprised by how you feel about these changes.

Some people are relieved to get away from the stresses of work if they can. But the loss of income can be very stressful as well. There can be extra expenses for medicines, treatment, medical supplies or home care that are not covered by provincial or private health insurance plans. Caregivers may feel guilty for worrying about money or missing work while a loved one is so sick.

Stopping work or even thinking about no longer working can make you feel sad or as if you're missing out on something. Work and income are often connected with self-esteem or identity. Sometimes work can help reduce stress and offer a change of pace.

“ My job was sort of a relief. It gave me something else to think about.

“ I miss not going to work. I miss my job. I got some fulfillment from it of course but just because it's normal. You see people, you interact with them.

If you're having a hard time at work, talk to your employer. You may be able to take sick leave, compassionate leave or leave without pay to cover days off. Flexible work hours, working from home or other changes to your work schedule may relieve some stress but allow you to keep working and earning.

Talk to a social worker if your income has been affected by cancer. They can help you find out about government benefits and financial assistance programs that you may qualify for.

Government services

For information on federal government services and how to apply for them, call 1-800-0-Canada (1-800-622-6232) or visit canada.ca. If you're a caregiver, you may be eligible for Employment Insurance (EI) Caregiving Benefits and Leave.

Advance care planning

All adults should think about, plan for and tell their loved ones about the type of healthcare they would like to have in their future. This process is called advance care planning.

It's normal to want to avoid subjects like how you feel about breathing machines or feeding tubes, but it can help everyone if you talk about these tough subjects early on. It can help the person with cancer to know that their wishes are understood. And it can relieve some of the stress and uncertainty for caregivers and family. You may find it easier to talk about if you tell yourself that you can still have hope even when you plan for your advance care.

It's important to talk about:

- the use of breathing machines or ventilators
- the use of CPR (cardiopulmonary resuscitation) if breathing or heartbeat stops
- artificial feeding such as tube feeding
- continuing or not continuing with medical treatments

Talk to your doctor about whether they would recommend these treatments. They are unlikely to improve survival and can cause a lot of discomfort, so they are often not recommended for someone with advanced cancer. It is always your right to refuse treatment and to make this wish known.

“It was really hard to say, ‘OK Dad, if your heart stops beating, what are your wishes?’” says June. “But you have to talk.” In her working life as a nurse, June has seen many families struggle to discuss these difficult issues. “But you can deal with them on a positive note. And that’s kind of what Dad did. He never said, ‘I don’t want.’ He said, ‘I *do* want, this is what I want.’ It was more of a positive thing than a negative thing.”

Many hospitals have a policy of asking people if they want CPR to try to revive them if their heart or breathing stops. If not, the person can agree to a DNR (do not resuscitate) order or No CPR order, which is written in their medical chart by their doctor. It may be called different things in different hospitals, so it’s best to ask.

Write it down

Decisions that you make about your care should be written down, and the originals need to be kept somewhere safe. You can also give copies of any legal documents related to medical care to your doctor or other members of the healthcare team. Many people worry that once things are written down, they can’t change their minds. But even once things are written down, advance care planning can still be talked about and you can make changes to the plan.

Along with making sure that your loved ones and the healthcare team understand your wishes, it’s a good idea to choose someone to be your substitute decision-maker. This person needs to be someone you trust and someone who understands your values. Your substitute decision-maker needs to understand what you want because doctors and nurses will ask this person to make decisions about your healthcare if you can’t. This person can also be known as your power of attorney, which means they have legal authority to act for you on your behalf. (You can also choose a power of attorney to make financial decisions for you.)

Organizing important papers

- Make a list of where your family can find important papers, or gather them together yourself if you can.
- Give copies of the documents to family members or healthcare professionals. Keep original documents for legal purposes.
- Keep your originals in a fireproof box, a safety deposit box or with your lawyer. Make sure someone knows where they are and how to get them.
- If you keep your important papers in a safety deposit box, make sure that a family member or friend has access to the box.

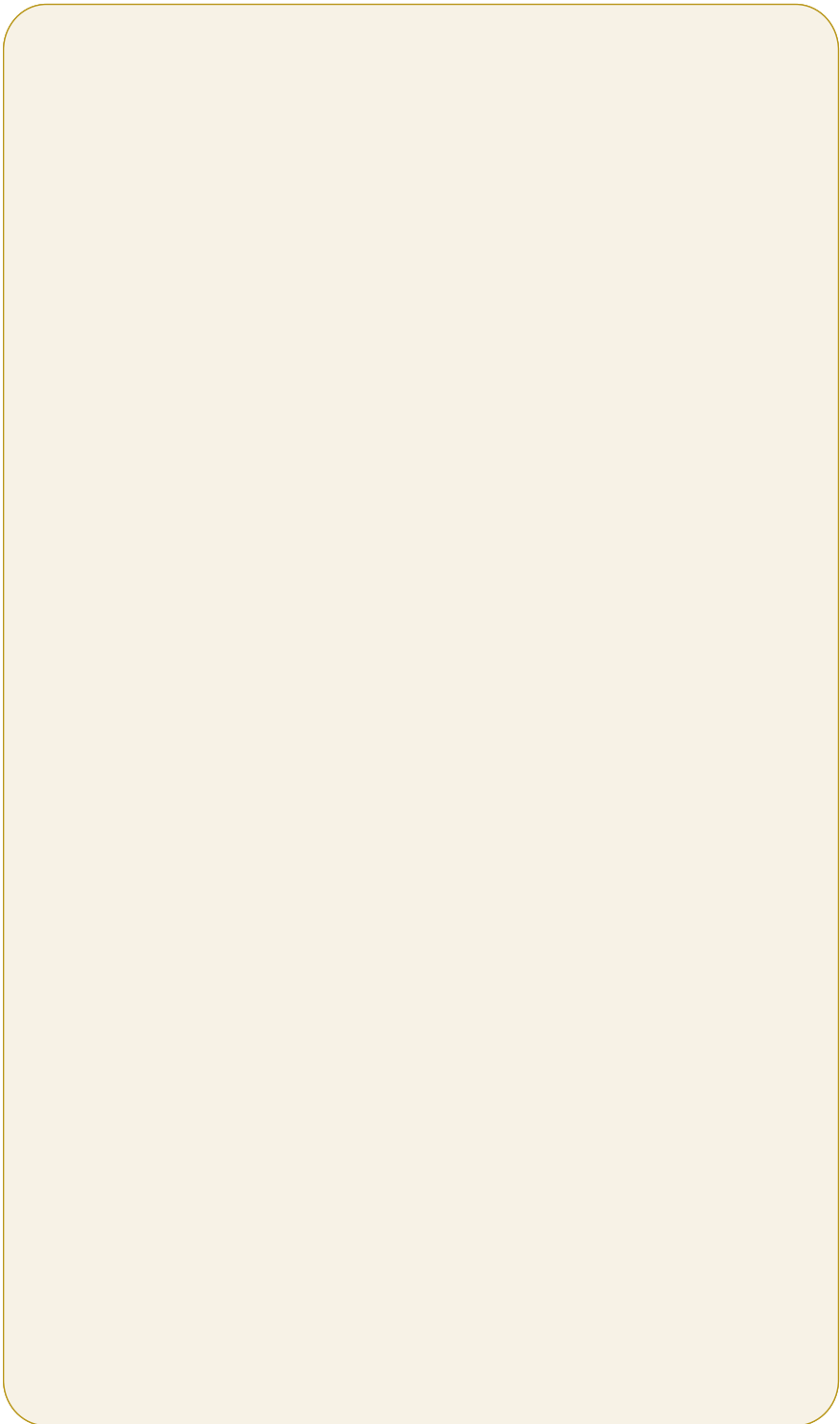
Wills

You may want to change an existing will or create a new one. A will gives legal instructions about how people want their money, property and other assets to be handled when they die. It can also include information about who might look after a person's children (under age 18) after death. You may also want to include who you want to look after your pets. When writing a will, get advice from a lawyer to make sure that the document is legal.

Funeral planning

Some people want to plan their own funeral, memorial service or other special tribute or event. Others may not. If you're ready, this is something you can do together. Talk to a funeral director, spiritual advisor or social worker. If you have specific religious or cultural customs, be sure to make these known. Planning ahead means others won't be left to make decisions for you.

“ My husband asked 3 of his friends to speak at his funeral. He would tell me what he wanted and I would write it down. Had he not told me his wishes, I probably would not have had his funeral in his hometown where he wanted it. I didn't know he wanted to be buried there.



“ Everyone says, ‘Oh, how can you do this?’
I think most people can do it, it’s just they’re
not faced with it. And when you are faced
with it, it depends on how you choose to cope.

Section 2

For the person with advanced cancer



This section recognizes that sometimes the person with advanced cancer has needs, feelings and concerns that are different from those of caregivers, family and friends. “My family obviously is affected by all this too,” says Natasha, a 61-year-old wife and mother diagnosed with advanced kidney cancer. “But I don’t know that they understand what I’m feeling.”

“ *The whole world turned upside down for me. Not for anybody else but for me!*

You may feel a sense of loss when you look in the mirror. Your family and friends see your body changing too, but only you experience these changes from the inside out.

“ *I've lost a lot of weight. I don't look like myself any more, though I know I am me inside.*

You may worry about how hard your illness is on friends and family – no matter how often they tell you that they want to help.

“ *It disturbs me tremendously. I need to be washed, taken care of, fed. I was proud. It's not easy.*

Staying connected





The only way I could get through this is with friends – meeting new people, being open to that.

Some people with advanced cancer want very few people around them and others want a lot. Friends and family can be the most reliable, caring supports available. There are many benefits to having support – it can help you cope, gives you better quality of life and makes it less likely you'll have mental health issues such as depression or anxiety.

But staying connected can take some effort. Even close friends and family members will have feelings and coping styles that differ from yours at different times. They will have days when they are feeling down, just as you do.

Trying to explain your changing mood, energy levels and symptoms or side effects can be tiring. “I know how I'm feeling, and I know days I feel good,” says Shannon, who has advanced endometrial cancer. “I know that, but they don't. That's the difference.”

When Gerri's breast cancer returned, she decided not to tell anyone. It just didn't seem worth the effort. “Sometimes you get some uneducated comments that are just more than you can deal with.” But over time, Gerri changed her mind. “I'm not a good liar,” she says. “So I told them. And I am now so surprised at the level of support I've gotten. If I wouldn't have told them, I would be missing all this support.”

Like Gerri, most people find that staying connected is worth the effort. Here are some of the relationship challenges that you may experience and some suggestions for coping with them.

Talking with people close to you

Talking can help – people often feel better when they express what’s inside and say what’s most important to them. Talking can also reduce your stress and make you feel closer and more connected to others. This is especially important when coping with serious illness. People sometimes feel the need to share powerful memories and emotions.

So if talking is good for us, why is it sometimes hard to do? Perhaps you’re not used to speaking freely. Sometimes physical discomfort gets in the way. Sometimes the things you need to say are painful.

“ It’s awful because you’re sick and you have this whole other element of having to relate to people that, unless you’re in my shoes, it’s very hard to understand.

Your family and friends may feel uncomfortable about having such personal conversations too. Because they love you, it can be painful for them to talk about your illness. They may be uncomfortable with the idea of illness or death, or it may raise fears of their own death. Or perhaps they just don’t know what you need to hear from them.

For all these reasons, you may not be able to find the words just when you need them most. Often, the hardest part is getting started. Once a conversation has begun, words can flow a lot more smoothly.

“ People are uncomfortable. You know, when you have a heart problem you can tell the world. Everybody wants to talk about it. But some of my friends, they don’t know what to say.

> TIPS

- Tell people how they can offer comfort. Let them know that sometimes all they need to do is listen.
- Let people know that you will listen too. Tell them they can feel free to ask questions and share their own feelings.
- Encourage people to be themselves and remind them you are the same person you have always been.
- Keep trying if there are things you need to say. It can take time to find the right words.
- Try a hug or squeeze of the hand if you can't find words.
- Respect someone's wishes if they choose not to talk about serious issues. For many people it is helpful, but it's OK if someone chooses not to.
- Write a letter if you find it too hard to talk about important issues.

Changing family relationships

“ My family probably is the most important part of my life. Talking to them. Seeing them. If I can't get to see them, then at least talking to them on the phone, online or whatever I can find them on. Because they're the thing that gives me strength to keep going.

For many people, family is the most important and most reliable source of strength.

A diagnosis of advanced cancer will likely change family life. With more time spent on medical appointments, treatments and managing symptoms, there can be little time left to focus on relationships. Long-held family roles often change, especially if your illness limits your physical abilities. It takes time to get used to these changes.

“ Yeah, there were my children looking after me. And it was so completely different. I've always looked after them.

Over time, relationships can become stronger and more meaningful as people develop a new understanding of one another. This is especially true in relationships that were strong before the start of an illness. But some relationships suffer, especially ones that already had problems. Conflict and tension can arise even when we don't intend them to.

“ I'm Mum. And I'm supposed to carry on the way it was before. And they are very aware that I can't. But they are still expecting me to be there and do the same things I always did.

Remember that everyone has their own set of expectations, worries, fears and ways of coping. You may understand medical information differently. You may feel frustrated when you're feeling up and others are feeling down (or vice versa). Differing spiritual or religious beliefs can cause disagreements. And family and friends sometimes act in surprising ways. For example, they may:

- withdraw
- deny your diagnosis or the possibility of death even if you have accepted it
- continue to look for or suggest new treatments
- avoid talking about your illness
- seem unsympathetic, even rude
- become overly protective or try to do everything for you

These reactions are not your fault - they reflect what's inside each person. It can help to simply acknowledge one another's feelings. Sometimes, a little time apart can also help reduce the tension.

If you want help repairing or maintaining an important relationship, contact a counsellor, psychologist, spiritual advisor or other professional who can work with you on your own or together.

Intimacy

Sex and physical intimacy can also change when your caregiver is your partner. This may be a result of some of the relationship changes you're going through. Or you may be uncomfortable with changes in your physical appearance or ability. Perhaps you're in too much discomfort to think about sex or worry that you cannot enjoy the experience.

For some couples, this isn't an issue. For others, it can be a serious problem. And it can affect the rest of your relationship if one or both of you feel hurt, rejected or guilty.

Try to talk about these issues. Together, you may find new ways to be intimate and show your love. Ask your partner about kissing, touching or holding. Even quiet time alone together, holding hands or cuddling, can be healing for both of you.

Want more information?

Our booklet *Sex, Intimacy and Cancer* has detailed information on this topic.

Friends and co-workers

“ We live off friends, true friends. It’s a phone call – ‘How you doing?’ Then off the subject and on to normal life.

In times of serious illness, people may surprise you. Some friends and co-workers are really there for you while others stay away. And support doesn’t always come from where you most expect it. “The people that you thought were your best friends are not always there when you need them,” says Natasha. “But people that you never really saw as your best friends are the people who come forward and support you. So you’re disappointed by some, and yet others just step in.”

Some people may leave it up to you to make contact. They may not know what to say or if you want to hear from them. Others may offer unwanted help or ask too many questions. Sometimes, visits and phone calls can feel like too much.

“ I have cut off a lot of people. I felt really bad, but I got tired of them wanting to know what was happening.

> TIPS

- Tell people as much or as little as you want about your health.
- Remind people that they don’t have to talk only about cancer. They can talk about their own lives or shared interests.
- Keep people informed by asking a friend or family member to record voicemail updates, send group emails or post updates on social media.
- Ask someone you trust to answer the phone and your emails or put a sign on the door if you want time alone or don’t want to see someone in particular.

Building a support system

“ I am blessed in that I have an entourage. I have the dream team taking care of me and I have met some patients who seem to be on their own, and I feel for them and I worry for them. And I don't know where they get their strength.

Building a support system is important to your well-being. Your own personal support system can include family, friends, co-workers, neighbours, volunteer agencies or community groups.

Some people have trouble asking for help or accepting it when it's offered. You might think that you're making work for others. But many people see the opportunity to help as a gift, something that benefits both giver and receiver. It's often easiest if you simply tell others how they can help. Here are some things you can ask people to do for you:

- Act as a “point person.” Someone can ask for and organize help on your behalf. This person might create charts or lists giving people tasks for specific dates.
- Give practical help. People can cook a meal, take the children for an afternoon, walk the dog, shop for groceries, clean the yard, drive you to medical appointments and so on.
- Keep you company. Some people can help just by being there, sitting with you, listening when you need to talk or sharing what's going on in their lives.
- Provide a welcome distraction. People can plan an outing, enjoy movies, TV shows or music with you, give you books or magazines, or tell a joke. Children are often excellent diversions.
- Research and advocate. Someone can gather health information, find community services or advocate with healthcare professionals on your behalf.

“ I think my dad's friends actually organized themselves as a crew, and they had a schedule of who would come in when, to make sure there was someone there every couple of days.

Support groups

These involve regular meetings with people with cancer – in person, over the telephone or online. You may be able to find others who share your specific diagnosis. Together, you can talk about feelings and experiences, offer comfort, share suggestions for coping and exchange useful information. Support groups are one way to know that you are not alone.

“ I found a website and a discussion forum, so you can ask questions and other people across Canada will try to answer them for you. It just makes you feel that there are others out there who will support you.

Counselling

Some people find it easier to talk to a professional, such as a psychologist, psychiatrist, social worker or spiritual care worker, rather than someone they know personally. Professionals are trained to listen, offer support and help you work through difficult emotions. Some specialize in cancer care or end-of-life issues.

“ When you hear ‘end stage,’ it’s so devastating and you don’t know if anybody could understand. But if you can have the support, you can get over that.

Talking to someone who’s been there

If you would like to talk to someone who’s had a similar cancer experience, you can connect by phone with a trained volunteer who will listen, provide hope and suggest ideas for coping – all from the shared perspective of someone who’s been there.

Register for this free program at match.cancer.ca or call us at 1-888-939-3333.

Want to connect with someone online?

If you’d like to join our online community, visit CancerConnection.ca. You can read news, join discussion groups that may interest you, get support and help others at the same time. You’ll find caring, supportive people there.

Looking for meaning





I have an illness but I also have time to look at my life, so it makes a very big difference.

People with advanced cancer often want to think about their lives – their past, present and future – as never before. Working through “the big questions” – Why am I here? What is my purpose? What matters to me most? – can bring deep contentment, peace, even joy. It can lead to a new appreciation for relationships and life itself.

“Facing your own mortality just changes a person’s complete outlook on life,” says Ethan, who has advanced breast cancer. Since his diagnosis, he’s begun to appreciate his life in a new way – the small things like a sunny day or a trip to Quebec City with his wife. “You value it more. I value my family, my faith and my friends.”

Looking for meaning is a deeply personal process. For some people, it means quiet, solitary reflection, while others look to a spiritual leader for guidance.

Finding strength through spirituality

Living with cancer can be a time of spiritual discovery. Spirituality is a person’s sense of peace, purpose and connection to others as well as their beliefs about the meaning of life.

For some people, spirituality involves organized religion. Since his diagnosis, Ethan has started attending daily religious services.



I thought, That’s something I want to do. I don’t necessarily agree with all the teachings, but I like the spirituality of it.

In hospital, you can ask for a visit from a spiritual care worker who is trained to offer spiritual care and support according to each person’s individual beliefs. If you’re questioning your faith, you can speak with a spiritual advisor for guidance. Their role is not to judge but to help you find peace and comfort.

For other people, spirituality is something separate from organized religion. They may find it in nature, in the goodness of others or the connections between us all. They may meditate or follow rituals from different cultures.

“ The person that came to see me turned out to be a meditation and yoga therapist. I was able to find that comforting space that I could tap into when I needed it and to go about getting spiritual strength. And that was really a gift I didn't expect.

However you define it, spirituality can be a part of your search for meaning. “I just think it's a place within,” says Shannon. “I think it's a feeling more than anything else. Just peace. Can't ask for much else.”

Creating special bonds and finding peace in relationships

Anna's relationship with her sister had been unsatisfying for many years. “She was never capable of expressing her love and consideration nor of receiving it.” After her diagnosis of advanced cancer, Anna created an audiotape for all of her siblings. She talked about the positive aspects of her relationships and said what she had to say before she died.

“It was my sister who responded the best,” Anna says. “Now she calls me every Monday morning. And each time before we hang up, she says, ‘I love you, you know.’ She *never* said that in her life, never.”

As Anna's experience suggests, you may want to find peace in important relationships. This can mean making contact with someone after years apart or clearing up past disagreements, misunderstandings and hurt feelings. It can also mean forgiving yourself and others for past mistakes.

It can take a lot of courage and honest self-reflection to start these conversations. Some disagreements may be too deep to resolve. But often the results are worth the effort, as they were for Anna and her sister.

If you want to resolve misunderstandings or re-establish contact with someone, you might start with a note, message or phone call explaining that you are ill and would like the person to contact you. You can also get help from a counsellor, spiritual care worker or other mediator if needed.

Life reviews



I've been through lots in my life. I've been exposed to all kinds of things, so I've had a very exciting life ... I have those things to think about.

A life review means thinking back on your life and perhaps talking about it with another person. It can be an important part of bringing your life to a meaningful close and remembering the many ways in which your life has had value and meaning.

Through a life review, you can explore every part of your life so far - your childhood, your loves, your family, career, health and sexuality. You can think back to the important moments and people in your life and how, together, all of these make you who you are today.

Gerri, for example, took time to reflect on her childhood - her mother died of colon cancer when she was 9 years old. She now sees that growing up without a mother shaped her personality more than any other life event. It also shaped her attitudes about her own diagnosis of advanced cancer. "I became a fighter. You have to be strong because there's nobody there that's going to pick you up because that's what moms do. I guess it makes you realize that whatever comes your way, somehow you'll deal with it."

Life reviews can be hard work. They take honest and deep reflection on who you are and how you came to be that person. Confusing and difficult feelings of grief, guilt, regret and shame can be mixed with pride, gratitude and joy. Often, a life review can help you make sense of your thoughts and emotions.

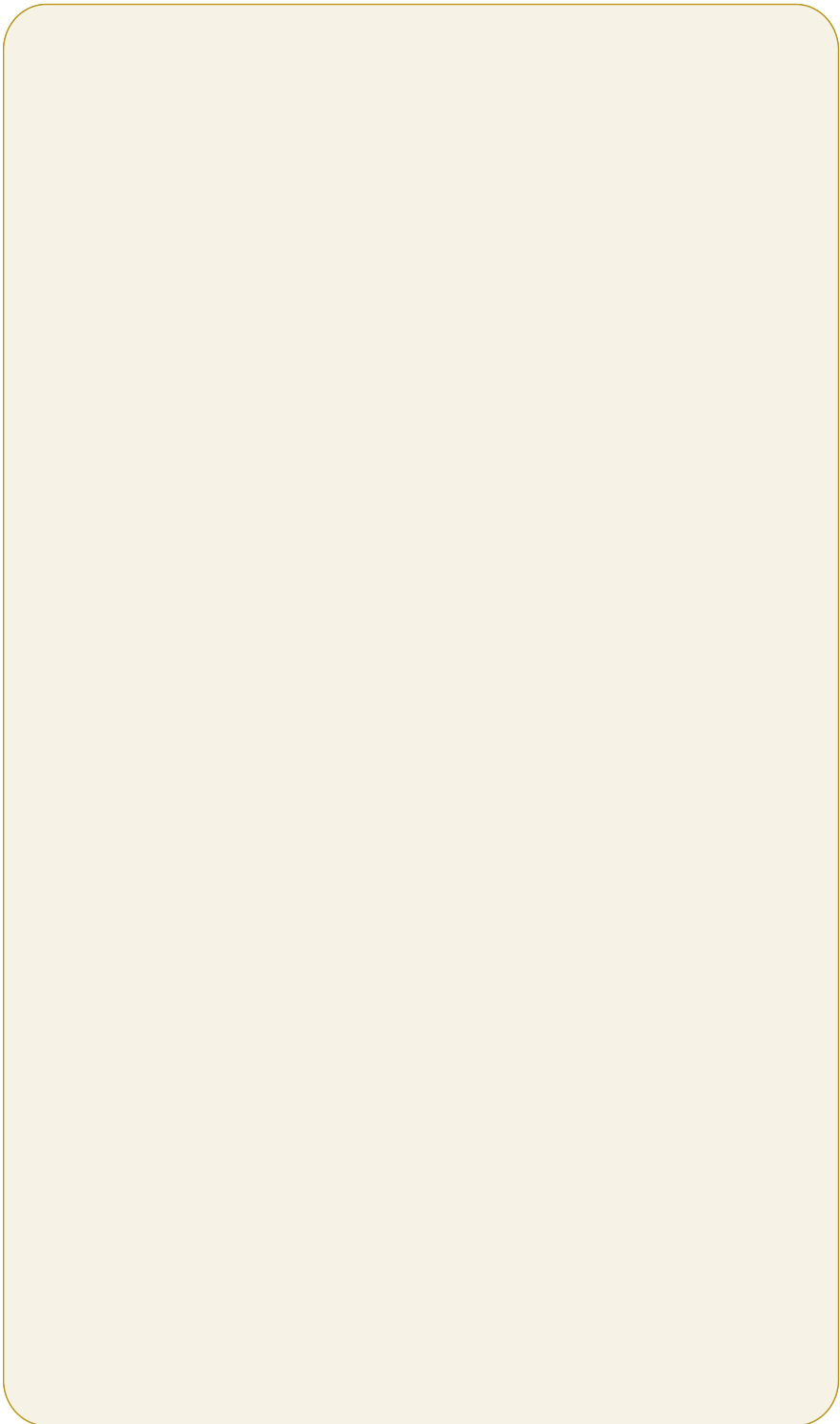
A life review can also be a lasting gift for family and friends if you share what you've discovered about yourself. You can do a life review with help from a therapist or working in a group. Or you can do it yourself by writing stories, making a video or audiotape or writing down thoughts in a notebook. You could create a memory box to hold mementoes such as photos or objects that were special or unique to you. Memory boxes can help children remember you and take your memory forward.



I had a beautiful life. It is a new adventure for me and for my children, my wife. We have been able to talk about it easily, with enthusiasm and even with pleasure. They are well prepared ... they have memories.

Celebrating your life

If you prefer not to do a life review, you can find other ways to celebrate your life and appreciate your accomplishments, either alone or with family and friends. You can talk about your memories, look through photo albums or old letters, create a family tree or history or express yourself creatively with poems, music, artwork or scrapbooks. You might also want to visit a special place from your past.



Saying goodbye





I don't feel too sad. I obviously feel that I've got more to contribute, but on the other hand, I feel that I haven't wasted my life, that I've tried to live my life the fullest that I possibly can.

One way to prepare for death is by thinking about how you want to say goodbye to family and friends. You might want to see or speak with old friends, write letters or have private conversations telling people how important they've been in your life. You might also offer a gift or something you have made. If you have children, you might leave special gifts or letters for milestone events such as certain birthdays, graduations or marriages.

Despite its sadness, saying goodbye is also a way of staying positive. It's something you can control and feel good about by creating special memories for the people around you.

Special ways to say goodbye

In Section 1, several caregivers shared their stories. Here, some of them describe the special ways their loved ones chose to say goodbye:

"When my wife died, she had lost control of being able to write. So one day when I was out - I only found this out the day after the funeral - she dictated a letter to my daughter who then transcribed it and gave it to me the day after the funeral." - Paul

"My husband made an audiotape for us. He recorded on a tape every day. He talked about his favourite things - the things he liked to do at the lake and how much he loved each one of us and how we should look after each other." - Connie

"My mother wrote both my sister and I a little journal and we didn't get that until after. That was something I think she really wanted to do for us that had its own special message to both of us. It talked a little bit about what happened when we were both born, which is completely invaluable now, especially being a parent myself. It still, to this day, is a huge comfort for me." - Kim

Facing the end of life

“ At one point death’s not bad. It’s a release.
It’s an end.

Dying is a part of life and it can have value and meaning.

Professionals who work with dying people talk about the idea of a “good death.” It means different things to different people. Many people think a good death has no suffering or fear.

But a good death can mean more than physical comfort. It can mean choosing where you want to die – at home, in a hospital or in a hospice – when possible. You may want your physical surroundings to look and sound a certain way (for example, with music, pictures or flowers) and want certain spiritual rituals or practices to take place.

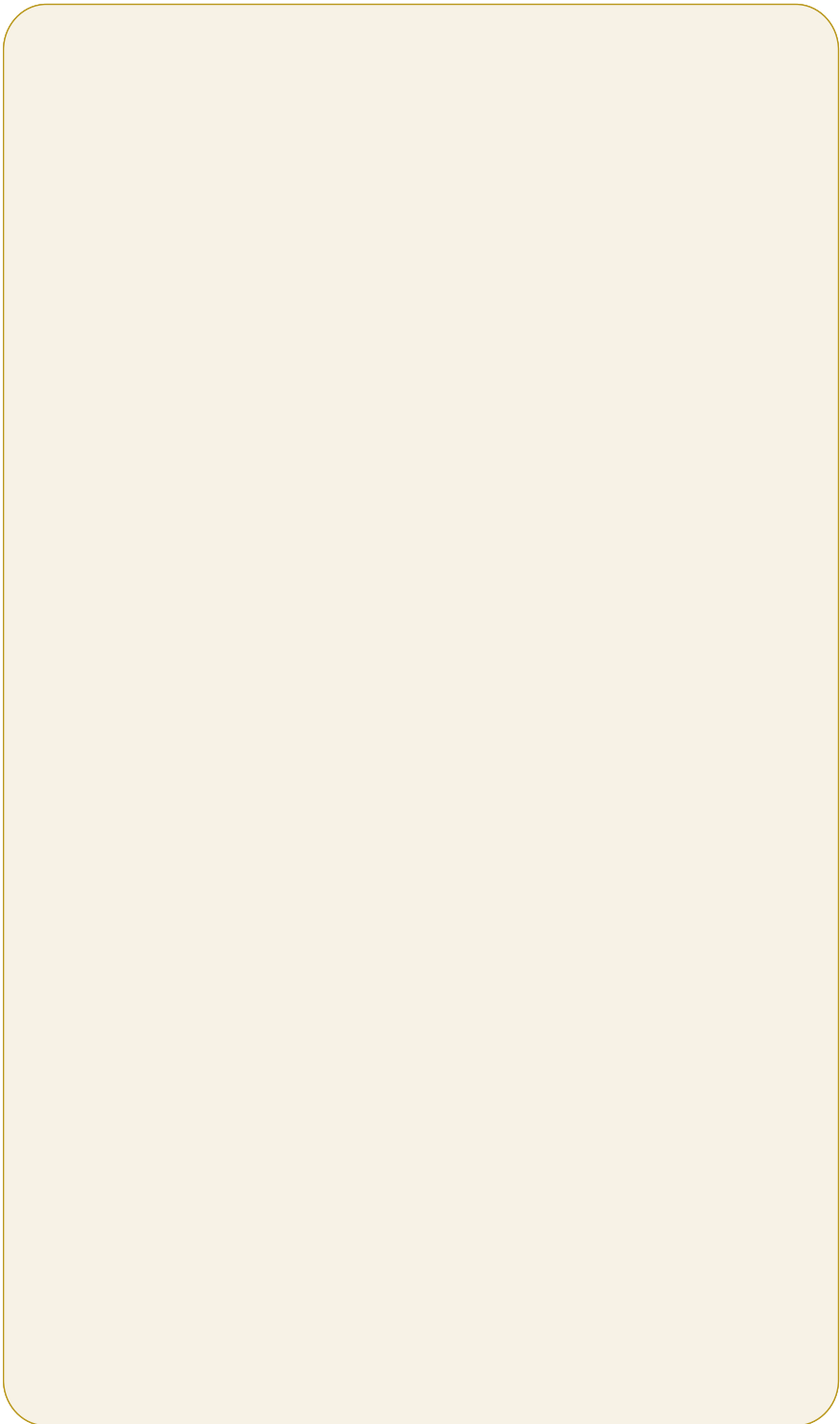
Often, a good death means keeping your sense of self. It’s sometimes called “dying with dignity.” Keeping a sense of dignity near the end of life reduces anxiety and suffering and increases a sense of peace and meaning.

Here are a few thoughts people have shared about what a good death means to them:

“ I want to die as myself, not somebody that I’d like to be.

“ As far as I’m concerned, it’s the most important part of life. So it should be gentle, it should be kind, it should be funny, it should be caring.

“ I want to go in calm. I know I cannot predict what will happen. But I believe it will be gentle.



“

At the end of the day, you're human, not a superhero. As a caregiver, it's not just about sitting beside the patient, holding their hand ... there is so much more involved.

Section 3

For caregivers



Caring for someone with cancer will likely be one of the hardest things you ever do. It can also be one of the most meaningful. That's why this section is written for you, the caregiver. It recognizes that you have needs, feelings and concerns different from those of the person you're caring for. You will hear from many people who share their honest reflections, thoughts, experiences and suggestions.

“

It's such a paradox because on the one hand, I recognize what a privilege it was for me to spend 10 months with her in an environment where we appreciated every day. On the flip side, it's a job I didn't really want. It's not like you graduate out of it with a promotion, you know?

When Steve's partner was diagnosed with advanced cancer, he knew right away that he would take care of him. "There was just no way that I would allow him to face this alone. I wanted and did everything I could to be there for him."

Most caregivers can agree that the experience changed their lives. But caregiving is not an easy job. Many people, like Steve, want to provide care, but others take it on because they feel they have to. Caregiving can go on for a long time – many months or years. And it's probably something you didn't expect or plan ahead for.

“

At the beginning, you think your life's going to be miserable and horrible from that point on. But we have a really good life with each other and looking after him is part of that.

Caring for yourself



Lily admits that she's been spoiling her husband Ethan since his diagnosis of advanced breast cancer. "He wants lasagna, we have lasagna for dinner," she says with a laugh. "Some of my friends have pointed out to me that I need to make sure I'm looking after me too. Maybe I'm not being as careful with myself as I am with him."

Lily's experience is very common. Caregivers are often so focused on the person they're caring for that they forget to care for themselves. They may feel that they must ignore their own feelings or needs because their loved one is ill. As daily routines change, they often start to feel a loss of control over their lives. They may stop seeing friends, lose sleep, miss meals and feel guilty about doing anything fun.

But it's important to pay attention to your own health and well-being while you care for someone else. If you find it hard to do this, remind yourself that doing so will also be good for those around you. The person you're caring for can be relieved to know that you are also caring for yourself. And if you don't, you may "burn out" and be too tired to help anyone. Allow yourself to have your own feelings and reactions about things – and say yes to offers of help.

It's normal to feel like you've had enough and can't continue. As June, a nurse and caregiver to both parents, says:

“ You just get to the point of, I can't deal with this one more day. You don't want to be like that because you know that they aren't going to be around for a long time. So then you run into the guilt – it sort of overlaps. It's just about looking after yourself and knowing your own limits because if you're not looking after yourself, you'll be in no shape to look after anyone else.

Respite care

Respite care means the person you're caring for stays in a hospice, palliative care unit or other facility for a few days or weeks, so that you can have a short break and regain some strength. You can also arrange for someone to come into the home to give you a break.

If there is respite care in your community, someone on your healthcare team can help set up a respite admission or increased home care. If there isn't, you may be able to arrange something informally with a trusted friend.

"I increased the respite hours. It's really difficult because at the back of your mind you're always thinking that the one you're caring for should come first. But unless you start taking care of yourself, you won't be able to take care of your family member."

Knowing your strengths and limits

“ It all happened so fast that I didn't really have time to think about myself. I didn't do anything for myself. But if I had to do it over again, I would.

Looking back, some people say that they wish they had been able to do more. Or they say they tried to do too much. They wish they had accepted more help sooner. They only realized after it was over how hard caregiving was both physically and emotionally.

“I guess I waited too long to get help,” says Cecile, who was her husband's main caregiver for more than a year after he was diagnosed with advanced lymphoma. “I should have started earlier because I got so exhausted.”

A retired nurse, Cecile had always been healthy and energetic. But as a caregiver she found her health began to suffer. “I could not sleep for the first time in my life. I was losing weight. You sit down for a meal and have to get up 10 times while you're trying to eat. The weight of my husband's dependency on me was very heavy, yet I felt I was expected to be strong and I was expected to handle it.”

Many caregivers are coping with other responsibilities – work, children, finances. They put themselves last on the list of things to take care of. Then they don't get the support they need. Often they hide their difficulties from others and pretend that they can deal with everything. Or they're afraid that if they say they need help, others will think they're complaining.

“ I was having to get care for my child to go look after my father to relieve my mother ... you know, on and on. But I'm the one that's strong, I'm the one that doesn't show emotion up front. I'm the one that coordinates and organizes and all that. And then I crash.

Not taking care of yourself can affect your health. Research shows that caregivers are more likely to have sleep problems, depression, anxiety and other physical problems that can affect their long-term health.

“ Sometimes it doesn't matter how hard you try. We all think we can do it, and we all think that we are strong. But sometimes, you break down.

For all of these reasons, be honest with yourself about what you can and cannot do. Think about what is most important, and put aside what is not.

> TIPS

- Look after your health. Make time to eat healthy meals, get some sleep and keep up with your own medical appointments.
- Make time just for you. Take breaks from caregiving by exercising, going for a walk, taking a bath, talking to a friend – or doing any of the things that have always given you pleasure.
- Make time for other family members, especially children. Enjoy time together and keep family routines whenever possible.

- Try to live in the moment and take things one day at a time rather than thinking about what's ahead.
- Think about what makes you happy, energized or relaxed. Schedule these activities to help yourself and your loved one.

“ I always made sure that I had time for myself. I would go for a walk, spend a little time with the family, be on the telephone with friends and sisters, read, write and yes, I am very much aware that I needed that and I made sure that I got it.

Marla's story: Caregiver burnout

“Taking care of myself? I think it was the number one thing I should have done.”

When Marla's father became ill with advanced pancreatic cancer, she and her brother became his primary caregivers. She's the first to admit that she pushed herself too hard. For many months, while her father was able to live alone at home, Marla's daily routine was picking up groceries, cooking and delivering meals. Later, when her father was in hospital, Marla would visit every day. She was 27 and had just started a full-time job.

“I don't think I realized what a toll it was taking at all. It just became part of the routine.”

“My brother was good at keeping the balance in his life whereas I wasn't. Physical activity was totally out. I gained quite a bit of weight. I wasn't taking any time for myself. My mother would try and tell me, 'Why don't you stay home today?' and I just couldn't. I had this driving need to be there to help him.”

Marla also forgot about her social life, rarely seeing friends. When she wasn't with her father, she was thinking about him. “If I left work at 4 p.m., I'd be with my dad until 8 or 9 at night when he'd go to bed. And then I'd be almost too exhausted. It was all based on his schedule.”

Marla has no regrets – and many fond memories – about the time she spent caring for her father. But she does have some hard-earned advice for other caregivers:

“Try to recognize your limits. You need to schedule time for yourself. Find out what resources are out there in the community that can help you cope ... And find someone to talk to when you need to talk.”

Getting support

Getting the right support is an important part of caring for yourself and your family member. Asking for and accepting help is not a sign of weakness. Research shows that the caregivers who cope well are the ones who ask for advice and find help early on, before becoming overburdened.

The challenges of denial

If the person you're caring for is in denial about their diagnosis, your job as caregiver has its own challenges. You may find it harder to manage their medical care or you may feel more guilty and less in control than other caregivers. It's very important that you get the support you need throughout this time. You may need to speak to the doctor on your own, either to find out more about medical issues or to ask for support. Doing this doesn't mean you're betraying your loved one.

Your own support system might include family and friends, neighbours, co-workers, volunteer agencies and community groups. You may think that you're asking too much of others, but many people do want to help. The important thing is to find out who can help you and when.

Building support networks

Building a support network can take some research and effort on your part. If you need help with this, consider asking someone to act as a "point person" to find and organize help for you. They can even create lists or charts giving people tasks for specific dates.

Friends and family can be the most important and reliable supports around. They can help by just being there, making you feel less alone. Sometimes friends and family members don't offer help because they aren't sure what you need. It's OK to tell them how they can help. For example, they can:

- Give practical help by cooking a meal, walking the dog, taking the children for an afternoon, shopping for groceries and so on.
- Help with caregiving. When you need a break, they can take the person you're caring for to medical appointments, pick up medicines or stay with them for a few hours, or even overnight, so you can get some sleep.
- Provide emotional support by listening, offering a hug, encouraging you to express your feelings, or if a face-to-face visit isn't possible, an email or phone call can help just as much.
- Provide a distraction by taking you out for an afternoon, making you laugh and telling you stories about their own lives.
- Do research on your behalf by gathering information and finding community resources to help you.

“ I was very lucky. I got casseroles and gift baskets and lots of help. I'm so grateful for that because from talking to other people, I know that's not always the case.

Caregivers often say that they are surprised by who helps and who doesn't. Some people are really there for you, and others - even people close to you - stay away.

“ I found that people tended to stay away. I guess they don't know what to say or what to do. You need them so much when you have a horrible thing happening in your life. But some people hear terminal cancer and they can't deal with it.

Cecile's story: Accepting help

Cecile was her husband's primary caregiver after his diagnosis of advanced lymphoma. They had recently moved to a new city and had no close family nearby. "My husband was very dependent on me," she says. "I was the only person he trusted, and he wanted me to be with him 24/7."

Like many caregivers, she found that some friends were not there for her when she needed them most. "I felt very lonely. I felt most people were not supportive. People don't know what to say, but they don't even need to say anything. They just need to listen."

On the other hand, some people she hardly knew became wonderful sources of support. She met a woman in the community who offered to come by and play Scrabble. "She would come at least once a week. That was my only entertainment. We would sit outside in the summer while my husband was resting in bed, and if he needed something, he could call. That was so important to me."

Cecile had to learn to accept help. She and her husband had always been very independent – they were usually the ones helping others. A turning point came when a friend arrived for an out-of-town visit. "He said, 'What needs to be fixed around the house?' I was going to say nothing. But I said, 'OK, Dave, I'll make you a list.' And I made the list and he just kept going. He was happy to help."

Cecile encourages caregivers to accept help freely and even ask for it as needed. "Because people have a good heart. They want to help, but they don't always know how to approach you."

Support groups are another source of help. Groups of caregivers can meet in person, over the telephone or online. Together, you can talk about feelings and experiences, share suggestions for coping, offer comfort and exchange useful information. Support groups are one way to know that you are not alone.

For Connie, whose husband was diagnosed with advanced pancreatic cancer, an online chat room was a great source of support. Through it, she connected with many caregivers.

“ It was just a message board, and you could go on there and leave a message about what was happening in your life and then people would reply. It was all caregivers, and they would reply with what worked for them. That was very supportive. I’m still connected to those people to this day.

Counselling is another option that helps many caregivers cope. Psychologists, social workers, psychiatrists and spiritual care workers are trained to listen, offer support and help you work through difficult feelings. Some specialize in cancer care or end-of-life issues.

If you need help finding a support group or professional counselling, ask your doctor, social worker or another member of the healthcare team.

Talking to someone who's been there

If you would like to talk to someone who's had a similar cancer experience, you can connect by phone with a trained volunteer who will listen, provide hope and suggest ideas for coping – all from the shared perspective of someone who's been there.

Register for this free program at match.cancer.ca or call us at 1-888-939-3333.

Want to connect with someone online?

If you'd like to join our online community, visit CancerConnection.ca. You can read news, join discussion groups that may interest you, get support and help others at the same time. You'll find caring, supportive people there.

Visitors: Keeping a balance

It's nice to know that people care. But sometimes the number of visits and phone calls can become too much. There are times when you might want time to yourselves.

> TIPS

- Put a sign on the door when one of you needs a rest. Ask people to call before visiting, or reschedule if you need to.
- Put a time limit on visits – long visits can be tiring.
- Respond when the time is right for you. Let phone calls go to voicemail. Don't feel that you have to reply right away to emails or texts.
- Keep people informed without having to repeat yourself. You or someone you trust can put regular updates on your voicemail, in group emails or on social media channels.
- Ask a trusted friend or family member to answer the door or phone and return messages if there is someone that you would prefer not to speak to.

Working together as a family

“ We became closer as a family. You really have to pull together. We didn't do any big trips, we didn't do anything monumental, but I think we just became a lot closer.

Stressful times can bring out the best and worst in people. Research shows that strong relationships stay that way or become stronger, but relationships with problems often get worse as families cope with advanced cancer.

When families work well together, cancer care can go more smoothly and everyone can focus on appreciating each day. By surviving the hard times, you can make relationships stronger.

“ It definitely brought my brother and me closer. And my brother at the time was starting a serious relationship - right after my father passed away, he actually got engaged - and his fiancée was an amazing support too. She'd be around and help out, and we got close in a funny way.

But there are many reasons why this doesn't always happen. Having to deal with such a serious illness can make the other challenges of everyday life, such as marital disagreements or family communication issues, even harder. Family members may understand medical information differently. They may not approve of the decisions you and your loved one make about treatment and care - and may even try to push other options on you. Other family members may focus so much on the person with cancer that you, as the caregiver, feel left out. And you may find that visits from out-of-town relatives are more work than help.

Cecile found her husband's family unhelpful, even disruptive at times. “When my in-laws came to visit, they would say to me, ‘You're so strong, you take such good care of him,’ and the message I would get from that was, ‘You'd better stay strong, don't you fall apart because we won't know what to do.’ Sometimes I would've liked a shoulder to cry on.”

Family members, including Cecile's 2 stepdaughters, were experiencing denial. Instead of offering help, they acted as if nothing was wrong. "They were convinced their dad would live at least 10 more years. I had no support from them. They would not even come to see him."

In times of tension or conflict, it can help to remember that everyone is coping in their own way. Each person has their own set of fears, doubts and expectations. And these may be very different than yours.

“ When his family came, he would put on a show - ‘Oh yeah, I’m getting better and we’re going to go camping.’ And the next day he could not even see them, he was too tired. He had given all his energy to put on a show for them. He couldn’t be real with them.

Open, honest communication can help. Be direct about what you need. "If anything helped, it was saying what I really wanted as opposed to internalizing it," June says. "And saying it to the people that could make a difference. No point in telling my husband when I really have to talk to my mum."

If working together continues to be a struggle, you may want to try individual, couple or family therapy with a social worker or psychologist. This can help everyone deal with changing roles, responsibilities and ways of relating to each other.

Living well and finding meaning

Living well means more than looking after your health. It means understanding that there is still life to be lived. It can mean finding pleasure in small moments that may or may not be related to cancer. It means looking for peace and acceptance in times of uncertainty.

“ You have to cherish the time that you have together. Think of the things you want to do that would be most memorable, as hard as that is. It doesn't have to be a big trip or anything. It could even be just a conversation. But something that you'll look back on and remember.

Each person finds their own way to live well. Some take time to be in nature, to meditate or quietly reflect. Others make the most of life with special trips or adventures.

Joanne and her husband, Guy, took several trips together after his diagnosis of advanced brain cancer. It was something they both wanted to do. Guy's health was up and down. He had brain surgery, radiation and chemotherapy. They went where they could when they could.

“ For our 30th anniversary, we went to Niagara Falls because we could drive there in an hour and a half, and if he had to get back, we could.

Joanne says her husband's approach to life influenced her. He tried to make the most of each day. “I couldn't be sitting there feeling sorry for myself when he was the one going through it and doing it so well.”

Finding meaning

“ I've decided to start exploring meditation more and art and spirituality. To try and discover who I am because you really get lost.

Many caregivers look for meaning in their lives and in the caregiving experience. What purpose does it serve? What can they learn from this time? This is a deeply personal process.

You might want to think about what you can celebrate, what you can be thankful for or be proud of and what you've learned along the way. You can do this together or on your own by writing in a journal, looking through photo albums, making a scrapbook or memory box of special items, or making a video or audio recording.

Reflection and time to grieve often help people get to a place where they're able to see something positive. Caregivers often say it helped them to grow and learn and to appreciate life in a new way.

For some caregivers, the search for meaning is connected to spirituality. Spirituality is a person's sense of peace, purpose and connection to others, as well as their beliefs about the meaning of life.

For some people, spirituality means organized religion. Kim and her sister started attending religious services with their mother after her diagnosis of advanced cancer.

“ It was a really big thing for my mum, finding that peace with everything. I think it was that sense of belonging and community that she felt there. We wanted to be supportive of what Mum had chosen to do, so we did go too.

In hospital, you can ask for a visit from a spiritual care worker, who is trained to offer spiritual care and support according to each person's individual beliefs. If you are questioning your faith, you can speak with a spiritual advisor for help. Their role is not to judge but to help you find peace and comfort.

For some people, spirituality is something completely separate from organized religion. It may include meditation or rituals from different cultures or finding peace in nature.

Caring for the person with advanced cancer



There are many ways to show a person who has advanced cancer that you care. One of the most basic ways is simply to enjoy their company - holding hands, watching television together, listening to music, playing cards or reading aloud to them. But there is a lot more to caregiving than this.

Understanding changes to relationships

Your relationship will likely change with a cancer diagnosis. Long-held roles and patterns of relating to each other can change. Cecile still remembers her husband bringing a jar for her to open. “In previous years I would go to him when I couldn’t open a jar. That was difficult.”

Sometimes you might find that, as you work together, your understanding of one another grows. The small things that used to be a problem are no longer important. “I don’t think my husband and I argued for 2 years after the diagnosis,” says Joanne. “We would argue like any couple beforehand. When he was diagnosed with a brain tumour, nothing was important enough to argue about.”

It’s important to recognize that not all relationships grow stronger. Even with the best of intentions, relationships can suffer. Spending more time together than usual can create tension. “I hadn’t spent that much time with my father in quite a few years,” says Marla. “So it was a different dynamic having him be such a huge part of my life.”

Also, the focus of your time together can change. You may be so busy with medical appointments, treatments and managing symptoms that there’s very little time left to look after the relationship or enjoy being together.

Some time after June’s father was diagnosed with advanced oral cancer, her mother needed surgery for colorectal cancer. June was trying to support both parents. “I found it difficult to go and just

enjoy their company because there were always so many things, including medical things, going on,” she remembers. “That was really hard.”

Sometimes the person you’re caring for may be unkind to you because they’re upset or frustrated with their situation. “He sometimes was not very nice with me, which was totally unusual,” says Cecile. “I would tell him, ‘You know, this is very hard for me and I know things are difficult for you, but I’m also your wife and I love you and I find it hard to cope with that.’”

“You’ve got to take into account that sometimes they may say or do something without realizing that they’ve upset you,” says Paul, who cared for his wife Carolyn after she was diagnosed with advanced lung cancer. “That’s not Joe or Joan talking, that’s the cancer talking. So you’ve got to have an open mind knowing that this is a terrible thing and that there will be days when it’s not going to be very pleasant for you or your spouse or whoever it is.”

Your feelings will also affect your relationship. Resentment and anger are common among caregivers. As much as you care about someone, you can resent or feel bitter about how their illness has changed your own life. And then you may feel guilty about feeling that way.

“ Resentment was part of how I was feeling. She didn’t understand what I was going through. She wasn’t my mom anymore. She wasn’t the person that I’ve known all my life. She’s a sick, dying, weak, dependent person. And that’s not my mom.

You can also become overprotective and treat your loved one as if they are helpless. Let the person with cancer give back in their own way. Encourage them to take part in family routines and activities as they are able. Ask them to teach you how to do tasks that were once theirs. Let them know how they can help you too.

June's father was a carpenter. At the same time that his illness got worse, she and her family were building a house for themselves. "Dad felt so bad because he wasn't able to help with some of that stuff." June encouraged her father to work with what he could do. "And when he couldn't build houses any more, he built bird houses. It's just little things like that, just giving people a purpose."

Intimacy

Physical intimacy and sex can also change when the person you're caring for is your partner. This may result from some of the relationship changes discussed here. Or your partner may be uncomfortable with changes in their physical appearance or ability. You may also feel the same way. Perhaps your partner is in too much discomfort to think about sex – or you're so worried about hurting your partner that you can't enjoy the experience.

For some couples, this is a small matter. For others, it can be a serious problem. And it can affect the rest of your relationship if one or both of you feel hurt, rejected or guilty.

Try to talk about these issues. Together, you may find new ways to be intimate and show your love. Ask your partner about kissing, touching or holding. Even quiet time alone together, holding hands or cuddling, can be healing for both of you.

Want more information?

Our booklet *Sex, Intimacy and Cancer* has detailed information on this topic.

Talking and listening

Open communication is very important after a diagnosis of advanced cancer. Sharing thoughts, feelings, hopes, fears and concerns can be good for both of you. It can clear up misunderstandings and bring you closer together.

Most of us find it hard to talk about cancer and death. It may not be a subject you're used to discussing. And if communication between you and the person with cancer was poor before the diagnosis, you may continue to struggle to know what to say.

Sometimes people with advanced cancer have a strong need to clear up past disputes and make peace by forgiving or asking forgiveness. These can be painful subjects for you to discuss. Sometimes, all you can do is listen.

You may have things to say but feel unable to say them. Some caregivers feel nervous about saying the wrong thing. Or you might hold back because you don't want to burden them. But often the hardest part of a conversation is getting started. Once it's started, words can flow more smoothly.

If you continue to find it hard to talk, try to connect with other caregivers to see what worked for them. You can also ask for help from a psychologist, spiritual advisor, social worker, psychiatrist or other healthcare professional. It's important that you both get to say what you need to say.

> TIPS

- Try listening quietly and waiting for the other person to talk. Encourage them to talk by nodding your head or saying simple things that don't interrupt them like "I see" or "Tell me more." Let them finish their thoughts before you respond.
- Reassure the person that you'll be there for them and that their wishes will be followed.
- Confirm what's been said by repeating back important thoughts or phrases. This shows that you hear what's being said and helps to avoid misunderstanding.
- Ask if it's OK for you to share your own thoughts and feelings. Offer advice only if they ask for it.
- If the person doesn't feel like talking, respect their wishes, but let them know you'll be there when they're ready. You can also ask about talking at a later time.
- Don't change the subject or make jokes if you feel uncomfortable.
- Ask if they would prefer to talk to another friend or family member about how they're feeling.

The importance of touch

Sometimes when you can't find words, a squeeze of the hand or a gentle hug can say just as much. Touch is a powerful way to communicate. It can help with feelings of loneliness and isolation and can show how much you care.

“ The thing I really remember most is my mother's legs becoming quite swollen. We would sit down at night, and my sister and I would rub her legs to make her feel a little better and just kind of sit there and be with her.

Giving physical care

“ The healthcare system expects us to change Mom and do all of this personal care at home when in actual fact there're no resources to do it with. You want us to do the work of professionals at home when we don't have that as an occupation.

Caregivers may have to give more of the physical care once given by nurses and other healthcare workers. Some types of physical care you might need to learn are:

- Bathing – help getting in and out of the tub or shower, sponge baths in bed
- Lifting and moving – help getting into and out of a bed or chair, moving cushions and turning or rolling over in bed
- Toileting – help getting onto and off the toilet, helping with use of bedpans, incontinence pads and catheters
- Mouth care – help with brushing teeth, keeping lips moist, rinsing the mouth
- Hair, skin and nail care – washing and drying hair, moisturizing skin, trimming nails on hands and feet
- Giving medicines – including pills, liquids, ointments, sprays, suppositories or injections; keeping track of timing, dosages and storage of medicines

If this sounds like too much, you may be surprised at how much you can learn and how quickly. That was the case for Joanne, who cared for her husband at home for more than 4 years:

“ I was able to manage him pretty well because he mostly sat in a chair. And for a long time he had a catheter on so I would have to change that, get his pills ready, do all those sorts of things. And I don't know, you just do it. Even when I was working, I was still having to do a lot of things like that.

It's important to get help and training if you need it. Some caregiving manuals and websites offer detailed information about physical care. Hospitals may also have pamphlets, guides and other information available for you to take home. A home care nurse, physiotherapist or occupational therapist may be able to show you how to do certain tasks. They can also provide support over the phone.

“ The nurse phones and says, ‘Well, how are things?’ I think it does help because you are not alone. You feel like there is somebody there if you need them.

Don't be afraid to ask for help – it can make a big difference. Training will reduce your stress levels as well as the possibility of injury to both of you.

If physical care is becoming too much for you, consider using home care aides, nurses or personal care workers. Depending on your situation and where you live, you may have to pay for these services. Research shows that having enough practical help is an important factor in a caregiver's continued ability to cope with home care. In some cases, the person with cancer may also prefer to have someone else take over their personal care. Some people find that keeping the family member and caregiver roles separate can be better for their relationship.

“ It did come to some breaking points where my father really couldn't take care of himself when it came to bodily cleansing and stuff. It wasn't really an area he wanted us to be a part of, and we didn't want to either. We talked to home care, and they provided some more service, which was good.

If the person you're caring for doesn't want people coming into the home, try to explain why this help is important to you. With time, they may change their mind.

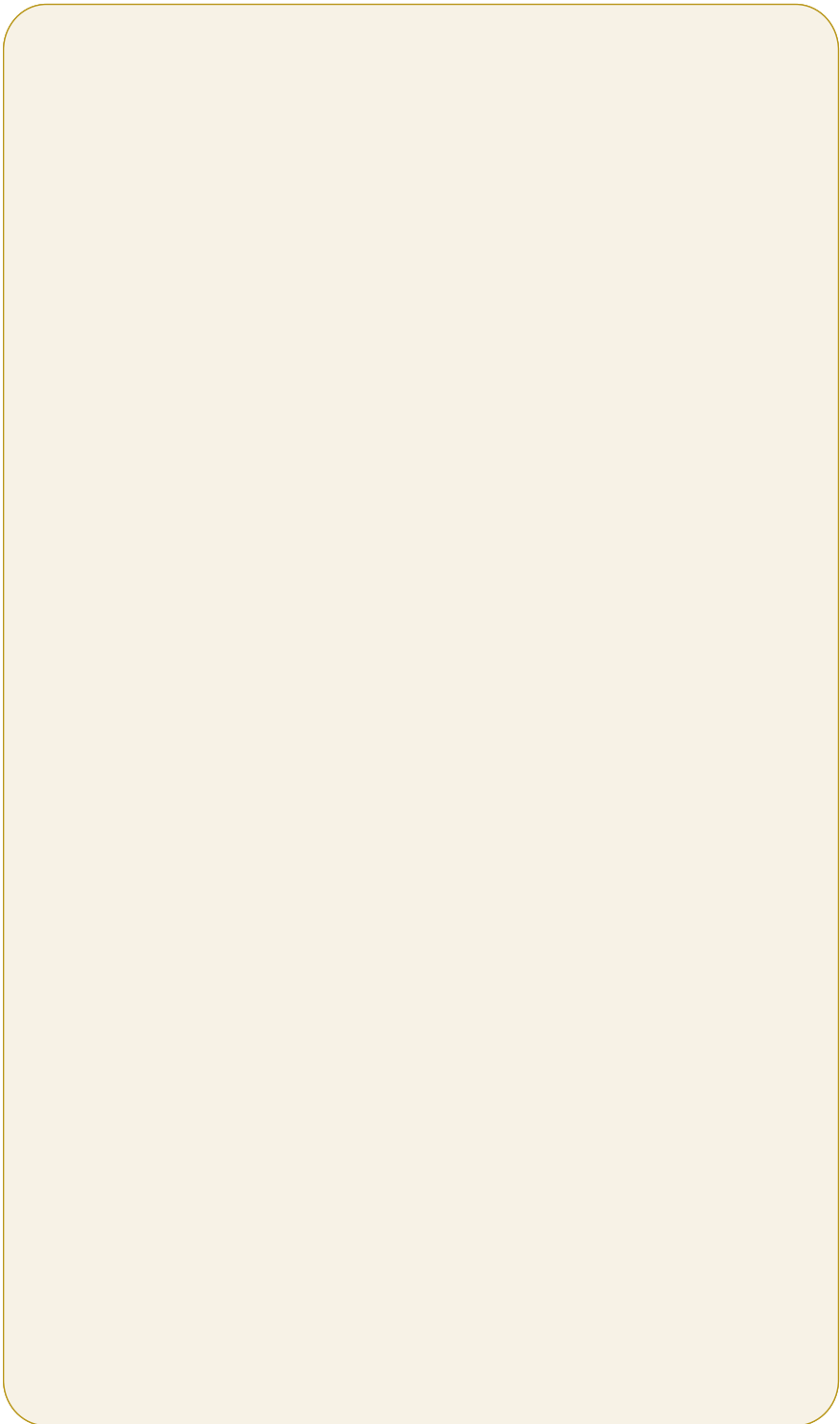
Long-distance caregiving



I found that the most difficult thing was being that far away and worrying, and not being able to give the right answers.

If you live in another city and cannot be close by most of the time, you won't be able to be the main caregiver for a loved one with cancer. But you can still offer support and help, even from a distance. You can:

- Offer emotional support and stay in contact with regular phone calls, emails or video calls.
- Send special objects from your shared past or create new ones.
- Contact the main caregivers regularly to get updates and find out about news and plans.
- Visit when you can, and ask family members to let you know when it's important to be there. This may be during changes in care or in the last few weeks of life.



At the end of life



We don't know exactly when or how a life will end or how we'll cope when it happens. Along with the uncertainty, everyone will have their own feelings to deal with.

After weeks or months or years of struggle, you may now find that all you need to do is sit quietly. Often, the person near to death will sleep a lot and eat little. Don't pressure them to stay awake or eat more. You can offer comfort with blankets and pillows, ice chips or soft lighting. Speak gently. Even if there is no response, they may still hear you and know that you're there.



The nurses explained to us that even if his eyes weren't open, touch and talk are very important. The awareness is still there.

When your loved one is awake, you might want to talk about the past and share memories. You can tell the person that they are loved and will not be forgotten. Some people sing or play music, say prayers or read aloud. Let healthcare professionals know about any religious or cultural rituals or traditions that are important to you. You might also ask for a visit from a spiritual care worker.

Signs that death is near

As a person gets closer to death, you can expect to see changes in how the body works:

- Drowsiness – the person may sleep more and become difficult to wake
- Loss of consciousness – the person may go in and out of consciousness or slowly lose consciousness and fall into a coma
- Confusion – the person may not recognize family or friends or know the time or date
- Involuntary jerking movements of the arms and legs – these may upset you, but they usually don't bother the person experiencing them
- Loss of appetite – the person has less need for food and fluids and may have difficulty swallowing
- Loss of bladder or bowel control – the person may urinate less, and urine may become darker
- Cool skin – the person's hands and feet may feel cool to the touch, and skin may look slightly blue or purple
- Difficulty breathing – breathing may slow down, become shallow or stop for several seconds at a time, or it may get louder, with gurgling or rattling sounds

Having one or more of these signs or symptoms does not necessarily mean that a person is close to death.

Some people stay alert right to the moment of death, but many do not. Often, death comes quietly. Here's how death happened for Joanne's husband, Guy:

“ The last day or so, he really didn't know too many people and he couldn't eat anymore and that sort of thing. He waited till I got up in the morning. We had a homemaker and she called me, and then I called the kids. And he kind of took his last breath just as we were all there. It was like he was waiting for us.

Immediately after death

There is no need to rush or hurry with arrangements after a person dies. For some time after death, caregivers and family members may want to sit with their loved one, talk to them one last time, say their goodbyes or pray. It's OK to touch and hug loved ones after they die. It's also OK to gently close the eyelids if they're still open and you'd feel better if they were shut. Some people find they want to tidy up around the room or around the bed, and this is fine, too.

Sometimes a person's culture will affect what happens after death and how the body is handled. Some cultures have beliefs about who can prepare the body and how soon the body should be buried or cremated. There may be other religious, spiritual or cultural rituals that need to be followed at this time.

Once you're ready, follow the guidelines provided by the healthcare team, such as contacting the person's doctor, appropriate authorities or the funeral home.

The next chapter



Grief

Grief is a normal response to loss. It is a necessary process that cannot be hurried. Each person takes their own time with it and grieves in their own way. How you grieve will depend on your relationship with the person who has died, your support system, cultural and religious beliefs and how you've coped with loss before.

Strong emotions – including shock, anger, fear, guilt, regret and sadness – are normal and may come at unexpected times. Physical symptoms are also common including fatigue, trembling or shaking, tightness in the chest and trouble sleeping or eating. Sometimes people stop socializing and feel that no one understands them. Some feel depressed or anxious.

You can get support from many places, including grief counselling and support groups. Here's how some of the people you've met in this booklet coped with grief:

“ After my husband died, I went to a grief support group and it was very good. There was a good library there so I borrowed books on grieving and mourning. I did a lot of journalling and that to me was very helpful – to write down my feelings. It was an outlet for me. ~ Cecile

“ I was determined to take the trip I had postponed when my father became ill – over 3 months in Europe, Asia and Australia. I did a lot of mending. I slept well for the first time. It was a time of recovery for me. It was a rebuilding of self. ~ Marla

“ My family stayed in touch with me every day and they still do. They call me just to see how I'm doing. And I get out every day. I go down to the lake, which is close by. I get on my bike and I can spend hours down there. I don't try to sit around and worry about what might have been. And the letter that my wife gave me kind of told me to do that. ~ Paul

“ I think because my husband was sick for so long, I had prepared myself for it in a way. I didn't have a lot of trouble. I didn't go to grief counselling or anything like that, but I had friends to talk to and I think I just have that kind of personality that I was OK. I was able to cope with it. I was just luckier than most. ~ Joanne

During the grieving process, try not to rush into major life changes such as changing jobs, selling a house or moving to a new city. If you can, take some time to get used to your new situation. Look after yourself before taking on too much.

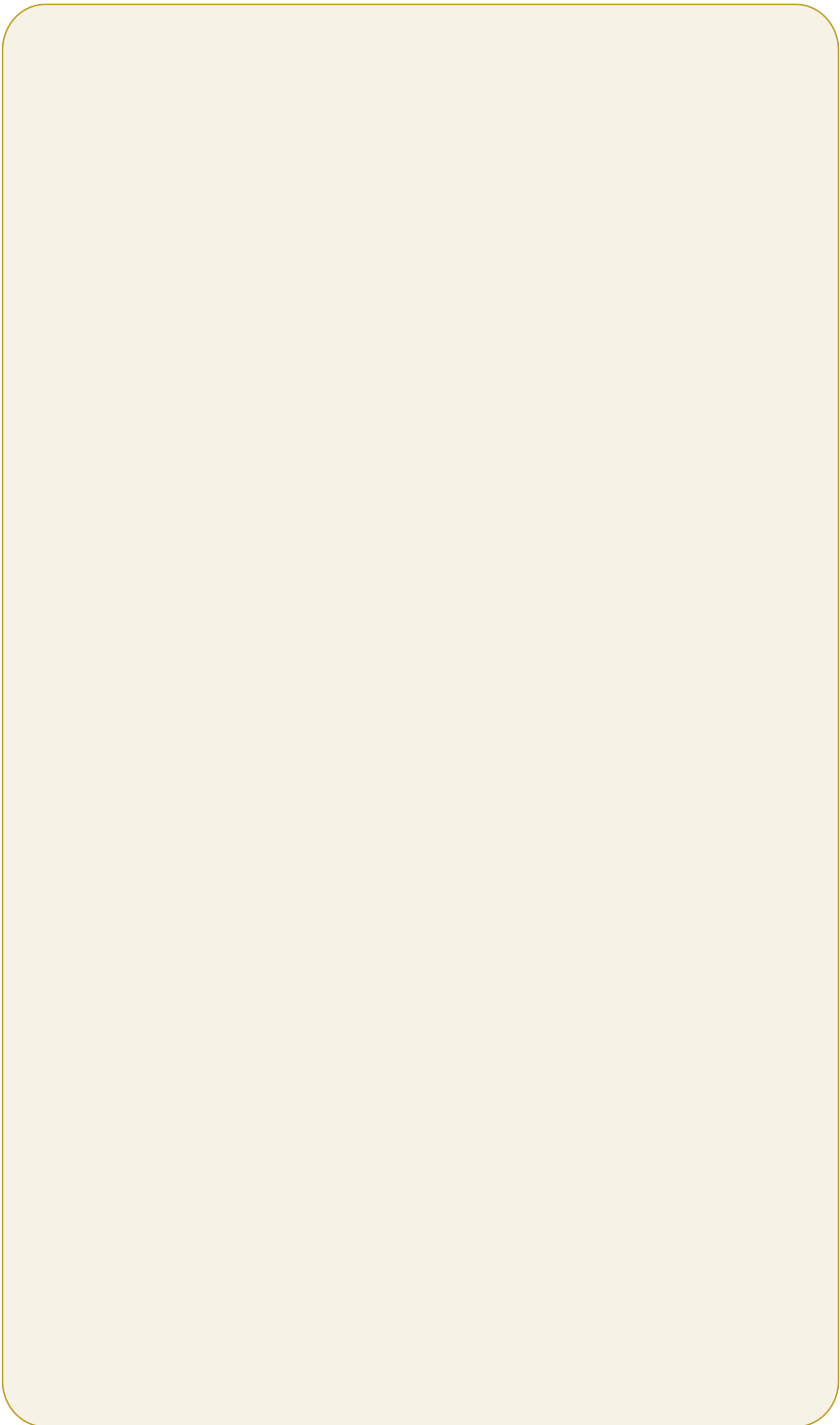
Life continues

It may feel like you will never recover. Feeling sad or a sense of loss whenever you think about your loved one may never go away, but most people find that it hurts less intensely as time goes on. Many caregivers say that as painful as it was, the experience changed their lives forever in many positive ways. They are proud of what they were able to do and how they were able to cope. They discovered new strength in themselves and a new way of looking at life and relationships.

“You probably couldn't have told me that when I was going through it,” says Kim. “Even a year or 2 later, I probably wouldn't have grasped the impact it had on who I am as a person.”

With time and patience, you may recognize yourself in Paul's words:

“ I think I appreciate life a little more. Before, from day to day you took a lot of things for granted. But now, after this has happened, you live for the day.



Resources



Canadian Cancer Society

We're here for you.

When you have questions about treatment, diagnosis, care or services, we will help you find answers.

Call our toll-free number 1 888 939-3333.



Ask a trained cancer information specialist your questions about cancer.

Call us or email info@cis.cancer.ca.



Connect with people online to join discussions, get support and help others.

Visit CancerConnection.ca.



Browse Canada's most trusted online source of information on all types of cancer.

Visit cancer.ca.

Our services are free and confidential. Many are available in other languages through interpreters.

Tell us what you think

Email cancerinfo@cancer.ca and tell us how we can make this publication better.

Suggested websites and books

Canadian Virtual Hospice

virtualhospice.ca

Support and personalized information about palliative and end-of-life care. You can ask a question about end-of-life issues directly – you'll receive a detailed, personal response from an expert. The discussion forums allow patients and caregivers to support each other online. Videos demonstrate many caregiving tasks, such as how to safely help someone move from a bed to a chair or how to change the sheets with the person still in the bed.

Canadian Hospice Palliative Care Association

chpca.net

Information, resources and a national directory of hospice palliative care services.

Legacies

legacies.ca

Provides free online resources about home and long-term care, palliative care, family and caregiver grief and spiritual care, as well as managing financial, legal and medical records and healthcare.

Speak Up!

advancecareplanning.ca

Offers information on what advance care planning is, making a plan and tips for sharing your plan with family members.

Service Canada

canada.ca/en/services/benefits/ei.html

Search for > Employment Insurance Caregiving Benefits and Leave

Government of Canada – Seniors Canada

seniors.gc.ca

Information on services, benefits and resources for senior citizens and caregivers.

A Caregiver's Guide: A Handbook about End of Life Care

by K. MacMillan, P. Jacquie and D. Hycha, 2004.

(Available free from your local hospice or provincial palliative care and hospice association.)



What we do

The Canadian Cancer Society fights cancer by:

- doing everything we can to prevent cancer
- funding research to outsmart cancer
- empowering, informing and supporting Canadians living with cancer
- advocating for public policies to improve the health of Canadians
- rallying Canadians to get involved in the fight against cancer

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



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