Canadian
Cancer
Society

Advanced Cancer

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Advanced Cancer

We provide a support system for people affected by cancer. Our services help answer your questions about cancer, manage life with cancer, find community and connection, and build wellness and resilience. Many of our programs are available in different languages.

From diagnosis to treatment to life after cancer, you can trust our publications for reliable information that's easy to understand.

We're here to support you.

The Canadian Cancer Society would like to thank the people with cancer and caregivers who gave their time and shared their personal experiences in workshops that helped us develop this booklet. We would also like to thank the experts who reviewed the booklet for their time, input and guidance.

We have short, easy-to-understand videos on common cancer topics. Visit **cancer.ca/cancerbasics.**

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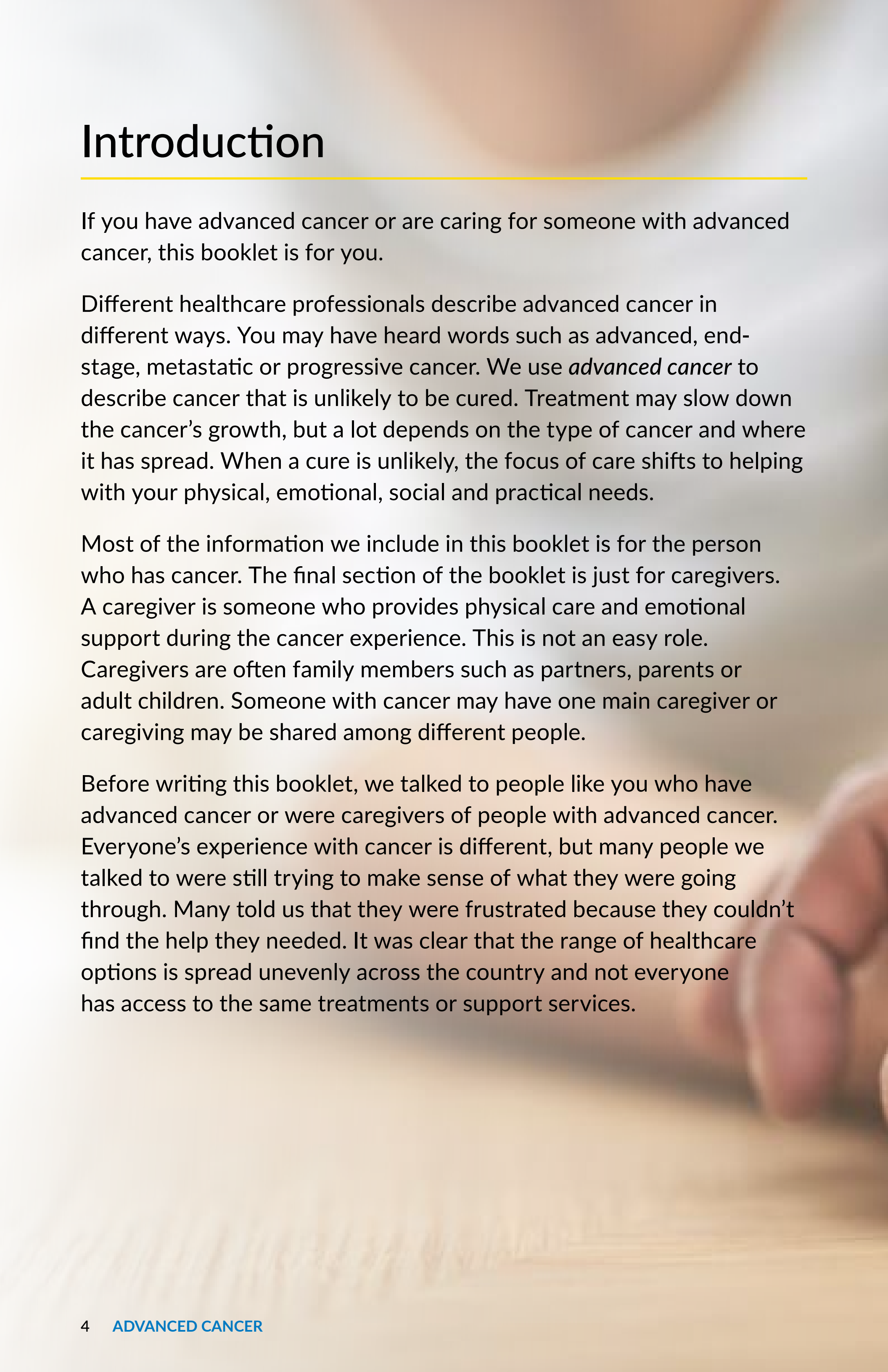


Introduction

If you have advanced cancer or are caring for someone with advanced cancer, this booklet is for you.

Different healthcare professionals describe advanced cancer in different ways. You may have heard words such as advanced, end-stage, metastatic or progressive cancer. We use *advanced cancer* to describe cancer that is unlikely to be cured. Treatment may slow down the cancer's growth, but a lot depends on the type of cancer and where it has spread. When a cure is unlikely, the focus of care shifts to helping with your physical, emotional, social and practical needs.

Most of the information we include in this booklet is for the person who has cancer. The final section of the booklet is just for caregivers. A caregiver is someone who provides physical care and emotional support during the cancer experience. This is not an easy role. Caregivers are often family members such as partners, parents or adult children. Someone with cancer may have one main caregiver or caregiving may be shared among different people.

Before writing this booklet, we talked to people like you who have advanced cancer or were caregivers of people with advanced cancer. Everyone's experience with cancer is different, but many people we talked to were still trying to make sense of what they were going through. Many told us that they were frustrated because they couldn't find the help they needed. It was clear that the range of healthcare options is spread unevenly across the country and not everyone has access to the same treatments or support services.

People who have advanced cancer and their caregivers deserve to be heard and to have good support, treatment and care when they need it. This booklet tries to provide information and support that will help you get the care that best meets your needs.

We encourage you to talk to your loved ones and your healthcare team about the topics in this booklet. Sharing what you learn can lead to better care and to new sources of support and understanding.

Looking after your overall well-being

In this section, you'll first learn about different emotions. Sometimes just being able to give something a name is helpful. We also suggest ways you can try to cope with your feelings. But if these ways don't work for you, it's important to seek help from a trained healthcare professional like a doctor, counsellor or therapist.

Everyone who is diagnosed with advanced cancer will react and cope in their own way. Many people go through a range of feelings – sometimes intense ones – and react in different ways from day to day. You're not alone if you're shocked or find it hard to believe that this is happening to you. For a time, you may even reject the diagnosis or what the doctors are telling you about the illness. You may want to blame others or feel angry at yourself, your family and friends, doctors, the world, your god or fate. If you begin looking at your life or wondering why you became ill, this can lead to feelings of guilt and regret.

How you and your loved ones respond and cope with your diagnosis may depend on how you faced other problems and crises in the past. You may find that your usual ways of coping also help now, or you may need to learn new coping skills or get help from healthcare professionals.

There are 3 very important things to know about looking after your overall well-being when you have advanced cancer:

- Having advanced cancer is not punishment for something you have done or not done.
- You don't have to hide how you feel or pretend that everything is OK.
- You do need to find ways to cope with many different emotions.

Stress and anxiety

Stress is a reaction to something that is dangerous or that is a challenge to us. It helps our bodies get ready to run away from danger or to fight it. Some stress is a good thing because it can help us get things done or solve problems. But too much stress can affect your mental and physical health.

Anxiety is a feeling of worry or unease and being afraid that something bad is going to happen. Feeling anxious when you have cancer is normal, but sometimes anxiety can get so bad that it overwhelms you. Anxiety may be diagnosed as a condition that needs – and can be helped by – treatment.

How you coped with feeling stressed or anxious in the past may or may not work now. But there are many things you can do to cope better. Lowering your stress levels and managing your anxiety can help your mood and give you emotional strength to get through the tough times. It is worth taking some time to figure out what works for you. Talk to your healthcare team. They may be able to help by teaching you ways to cope, suggesting a stress management class or referring you to a support program, counsellor or mental health professional.

Many people react in different ways from day to day.

Feeling out of control

There is so much about cancer that you can't control – the diagnosis, test results and some side effects are just the start. You may also feel that you have lost control of certain things in your life, like your finances or your relationships. Or you may feel like you have lost control over everything else in your life – including your emotions. This can be very hard to cope with, especially if you're used to being independent or being the one who takes care of everyone else.

When you feel this way, it's important to focus on what is within your power to change. Remind yourself that even when you can't control something, you can still decide how you'll respond to what is happening around you. Talking about these feelings with your healthcare team and with important people in your life can also help. They may be able to offer information or make changes that can help you feel in better control.

For some people, knowledge is power and learning more about cancer helps them feel more in control. Others do not feel this way. And that's OK – everyone's need for information is different.

Loneliness and isolation

Cancer can make you feel very alone. You may feel too sick to work or enjoy social activities. You may find that your desire for company changes. Some people want to spend time alone or only with certain people. But even if you're surrounded by loved ones, you may still feel lonely if it seems like they don't or can't understand what you're going through.

Sometimes family or friends may not visit or contact you as much as you'd like or as often as they did before. Most people are very uncomfortable with the idea of serious illness. They may worry they'll say the wrong thing or be afraid to see someone looking sick. They might worry about becoming emotional themselves. But even if these are their reasons, it can still hurt.

Your family and caregivers can also feel lonely or that they have no one to talk to about what they're going through. They may feel that they can't see friends or at times they may be overwhelmed by new responsibilities. Things have changed for them too, and it's important for them to have support.

If you or your caregivers feel alone or isolated, it can help to connect with people going through a similar experience by joining a support group or online community.

Support groups can connect you with people going through a similar experience.

Depression

Many people who have cancer feel sad, tearful, hopeless or discouraged at times. These feelings are normal. But sometimes they don't go away, last a long time, get worse or get in the way of day-to-day life. When this happens, these feelings could be a sign of depression. This is also called clinical depression. Other signs of depression are:

- changes in appetite, weight or sleep
- feeling worthless or guilty
- finding it hard to think clearly
- thinking regularly about death or suicide

It's easy to miss the signs of depression – but recognizing them is the first step to feeling better. Depression can and should be treated. It is not a sign of weakness. A person who is depressed can't "snap out of it" or "cheer up" through willpower alone. Most people with depression need support from a healthcare professional to help them get better.

Depression can be caused by cancer treatments or by the cancer itself. You may be at a higher risk for depression if you have advanced cancer, have had depression before or don't have a support network of family or friends.

Talk to someone on your healthcare team if you think you may have depression or are thinking about suicide. You may need to be referred to a mental health professional such as a social worker, psychologist or psychiatrist for therapy or medicine.

Grief

Grief is the sense of loss that you feel when you lose something that is important or valuable to you. It's often about a death, but it can also be about other things. People who live with cancer may grieve for many things, such as the loss of their sense of health and security, a lost body part, the inability to have a child, changes to future plans or money problems due to time away from work. You or your caregiver may also grieve a loss of identity. This can happen because advanced cancer changes so many things in your lives that it affects how you see yourselves and what makes you unique.

We all go through the process of grieving in our own way and in our own time, learning to cope with our loss as we go along. No one can tell you how you should grieve, when you should feel certain emotions or in what order.

Grief can make you withdraw from people. The way you grieve depends on:

- whether the loss was expected or unexpected
- how much you valued what you have lost
- your personality
- how you've coped with loss before
- the support systems in your life (family, friends, and spiritual, religious and social communities)

You may have some physical symptoms or reactions when grieving. You may:

- cry more easily and more often
- have trouble sleeping
- eat less or eat more
- feel anxious
- feel tired or weak
- have problems concentrating or remembering things

Anticipatory grief

Anticipatory grief is the mourning that happens when a death is expected. It may start when you're first diagnosed and will likely stay with you until the end. Anticipatory grief is not just about accepting that death is near. It's also about accepting that many things may be lost as your illness progresses.

While these emotions can be intense, they're a normal part of the process for you and the people who love you. Caregivers may feel guilty when they grieve and start to prepare for a death before it happens. When you all allow yourselves to feel and talk about anticipatory grief, it can deepen your appreciation for the people in your life and for the things that matter to you.

And while it's important to let yourself feel all the emotions of grief, try not to focus on it all the time. Remember to do something you enjoy and take care of yourself – watch a movie, read, take a hot bath or listen to music. If your feelings become overwhelming and you struggle to take a break from your grief, reach out to your healthcare team for support.

Try to take breaks from grief by doing things you enjoy.

Coping with your emotions

People cope with emotions in different ways. You may want to try some of these different coping strategies to see what works for you. These ideas can work for caregivers as well.

Recognize and be honest about your feelings. Try to name, describe or talk about them. It may be hard to tell your family and friends how you really feel because you want to protect them. But being honest can help improve communication and strengthen your relationships with the people you care about. Trying to hide your feelings all the time can drain your energy. It can also stop you from talking about fears and emotions that are real and that deserve to be addressed.

Talk to someone. Finding the courage to talk to just one person can be the first step to feeling better. It could be a friend, a family member or a mental health professional. It may also help to talk to someone who has had a similar cancer experience. Many people turn to online communities for support and information on coping. These communities include groups on social media platforms and online message boards for people with cancer. They provide a place to share your experiences and build relationships without leaving your home.

Tell your healthcare team how you're feeling. Let them know if you're having problems coping. They can suggest resources that can help you cope. Ask questions. Tell your healthcare team if you don't understand what they're saying or when you want more information.

Learn as much about cancer as makes you comfortable. Some people find that looking for information and using that information to make decisions helps them feel more in control. Ask your healthcare team for recommended resources. Other people prefer not to know too much. Tell your healthcare team how much you want to know.

Be as physically active as possible. Exercise helps improve your mood, your sleep and your appetite. Even a short walk can help.

Eat as well as you can. Eating a variety of foods and balanced meals can help you feel better and stay stronger. But it can be hard to eat well when you have advanced cancer. For help and support in meeting your nutritional needs and feeling your best, talk to a dietitian.

Keep your life as normal as possible while you can. Even though an advanced cancer diagnosis can upset many things in your life, try to carry on with your normal routine and habits as much as you can. If your energy is limited, spend it on what is most important to you.

Decide what's important to you. Stay involved in activities that you enjoy and that have meaning for you. You can manage your time by making a realistic list of things to do each day.

Try meditation, yoga or relaxation techniques. These practices can teach you ways to cope with stress, anxiety or anger, helping you feel calmer and better able to cope with what's happening in your life.

Avoid using alcohol or other drugs as a way to cope. They may seem to help in the moment, but they often mask current problems. They can also interfere with any treatments you're having or cause more severe side effects.

Spend time doing things that you enjoy. Many people feel better when they stay busy. Hobbies such as music, crafts or reading can help take your mind off cancer for a while. Spend time with people who make you laugh or do something that makes you feel good. Many people find that spending time with pets helps them feel calm and more positive.

Change your surroundings. Take a break or a walk and give yourself some quiet time. Connecting to nature can sometimes be helpful. Spend some time at a place that you find calming, like a beach or park.

Look to your spiritual beliefs or faith. You may find comfort in sharing your thoughts and feelings with someone in your spiritual or faith community.

Try writing or other ways to be creative. Writing down your thoughts and feelings, no matter what they are, can help you understand your emotions and cope with what you are experiencing. If writing isn't for you, try another creative outlet. Photography, drawing, painting and music are also great ways to express your emotions.

When nothing seems to help

Some people cope using the ideas above. If these ideas don't work for you, tell your healthcare team that you're still having problems coping with your emotions. They may refer you to a specialist such as a psychologist or psychiatrist. These healthcare professionals can treat depression or anxiety, which may include therapy, medicine or both.

HOW WE CAN HELP YOU COPE

The Canadian Cancer Society is here to help you cope with your emotions when you have advanced cancer.

- Call our Cancer Information Helpline at 1-888-939-3333 (TTY 1-866-786-3934) or visit cancer.ca. We provide reliable, up-to-date information about cancer.
- Join CancerConnection.ca. Our online community of people offers support and connection to other people going through similar experiences.
- Use our Community Services Locator at csl.cancer.ca to search a database of over 4,500 cancer-related services and resources nationwide, including support groups in your community and counsellors for emotional support. If you can't find what you need, contact us to help with your search.

Finding hope

Hope is very important to many people with cancer and their loved ones, but it's also important to keep a balance between realistic hope and wishful thinking. Having a realistic picture of the future helps you make better decisions about your treatment and any longer-term plans you have.

It might be hard to find any hope in what you're going through right now. And that's OK. You don't have to pretend to feel a certain way if you don't.

But if you can manage your emotions, you may also begin to find hope. Hope can help you find meaning in activities and see that achievements are still possible. Hope can carry you through hard times and help you keep a sense of dignity. Many people are surprised to find that the role of hope in a cancer experience changes rather than ends. Hope for a cure may change to hope for peace and contentment, the sharing of memories and stories, a moment of joy or simply a good day.

Making decisions about treatment and care

In this section, you'll learn about the sorts of decisions you can make for your care and about the important idea of quality of life.

Treatment for advanced cancer usually aims to control the cancer and help you live longer. It may also aim to relieve your symptoms and improve your quality of life. You still have choices you can make about your care and about how you live each day. Talk to your healthcare team about what your options are and how you can make the best decisions for you.

Making decisions about treatment and care when you have advanced cancer often comes with great sadness and other emotions. It often means facing very hard truths. But with the right support and approach, it's possible to find meaning in the decision-making process.

Who decides on care?

Decisions about care 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 isn't theirs to make. The person with cancer has the right to accept or refuse treatment at any time. They also have the right to change their mind later on.

Only you can decide what is right for you. You may decide that you no longer wish to have treatments that are intended to help you live as long as possible. What brings peace to one person may be different for another.

Families sometimes find it hard to accept decisions about treatment. Working together can make important decisions easier. Even when goals or choices differ, do your best to discuss them with honesty and respect. You may feel like you're being pulled in different directions as you try to decide between the wishes of others and your own. But it's important for everyone to understand that the choice is up to you, the person with cancer.

If there is a time when you cannot make a decision yourself or you cannot communicate that decision, your healthcare team will ask your substitute decision-maker. There is more information about this and other parts of advance care planning starting on page 36.

FINDING RELIABLE INFORMATION

Some people go searching for information to ask their healthcare team about, while others do not. You need to do whatever makes you comfortable.

There is a lot of information out there about cancer, especially online. Some of it is accurate and some of it isn't. But even if it's correct, it may not apply to your situation. Be sure to talk to your healthcare team about information that you find before using it to make decisions about your care.

The Canadian Cancer Society offers you information:

- in print
- online at cancer.ca
- by phone at 1-888-939-3333 (TTY 1-866-786-3934)

Our information is reviewed by Canadian experts and updated regularly. It's there to help you, but it's never meant to replace your relationship with your doctor or the other healthcare professionals on your team.

What is quality of life?

In the simplest of terms, quality of life is your ability to do and enjoy the things in your life that mean the most to you while feeling as well as possible. It means different things to different people. Quantity of life is the amount of time that you live.

Before cancer, you may not have thought a lot about your quality of life versus your quantity of life. You were just living. Now, as you and your loved ones face advanced cancer, quality of life may become a balancing act with quantity of life.

When you have advanced cancer, you need to think about what is important to you and what you want to do with whatever time you have left, whether it’s 6 months or 6 years. You may also discover what isn’t important to you or realize that there are things you don’t want to have in your life.

The amount of time they have is very important to some people with cancer. To be able to have this time, you may put up with treatment side effects that are very unpleasant or that last a long time. You may be willing to have as many treatments as possible, if they’re offered to you, or take part in a clinical trial that might give you more time.

Or you may find that your priority is to feel well enough to do what is most important to you for as long as you can. Some people do not want to continue treatments for a long time, especially when the side effects stop them from living their life how they want to. If you’ve already had several different treatments, you may feel that you’d rather have some time to enjoy your life without being in treatment.

What quality of life means to you may change over time. If it does, you may want to revisit or change some of your decisions.

Talk to your healthcare team about your quality of life. They can tell you how your treatment options and their side effects may affect your ability to enjoy the things in your life that mean the most to you. Your healthcare team can also find ways to help you cope with the quality-of-life issues that you’re most worried about.

Priorities and making decisions

When it comes to decisions about treatment and care, you may feel overwhelmed and not know where to start. Try first thinking about what is most important to you – your priorities – rather than any decision itself. Letting your priorities guide you may make decision-making easier. It may also help you feel more in control.

Your priorities can guide you, your caregivers and your healthcare team. While different people will have different priorities, these common ones might help you when thinking about your own.

- *Prolonging life* – You may continue with treatments your healthcare team offers or take part in a clinical trial testing a new treatment.
- *Avoiding suffering for yourself and your loved ones* – You may focus on managing your pain and having palliative care as soon as it's offered or seeking it out.
- *Strengthening relationships with family and friends* – You may spend more time with your loved ones and be mindful when choosing the people you see.
- *Being aware of what makes you happy* – You may look for what brings you joy, whether that is dancing every day, spending time in nature, writing, painting or being creative in other ways.
- *Not being a burden on others* – This may mean you focus on financial planning, your will and advance care planning, and explore options related to care such as hospices, home care and respite care.
- *Achieving a sense that your life is complete* – You may complete projects that share your legacy with your loved ones or fundraise or donate to causes that are meaningful to you.
- *Making peace with end of life* – You may work with people in your spiritual or faith community, meditate and connect with nature.

Palliative care

Many people have doubts or fears about palliative care because they don't understand what it is. You may think that palliative care is limited to the last few days or weeks of life. It is not. You can have palliative care at any age and for any type and stage of cancer.

Palliative care provides physical, emotional, social and spiritual support for people with cancer and their families. It focuses on quality of life and can help by:

- relieving symptoms
- managing pain
- providing support for you and your family

People who have palliative care are often more satisfied with their treatment. Having this type of care can lead to a better quality of life, no matter how much time you may have left. Remaining focused on living during the uncertainty of death can be a helpful way to find a greater sense of peace.

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 therapy, 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.

Consider getting to know the palliative care team sooner rather than later. Many programs have waiting lists, so it's best to apply early. Your instinct might be to avoid palliative care for as long as possible, but it works best when you start it as soon as you need it during the treatment process.

FINDING PALLIATIVE CARE SERVICES CLOSE TO HOME

Palliative care services vary from community to community. You may have to pay for some of them. Ask your doctor, social worker or another member of the healthcare team for information about what is available near you.

We can also help you find services. Our Community Services Locator lists over 4,500 cancer-related services and resources nationwide, including palliative care. Visit csl.cancer.ca. If you can't find what you need, contact our Cancer Information Helpline at 1-888-939-3333 (TTY 1-866-786-3934) or visit cancer.ca for help with your search.

Where palliative care is offered

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

A *palliative care clinic* is where people can have pain and symptom management. They can also get 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 have 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. 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 with life-limiting illnesses and their families. Hospice volunteers can provide support in the home. Residential hospices are places where people with cancer can be cared for at the end of life in a home-like setting.

Find out more about hospice care from:

- Canadian Virtual Hospice at virtualhospice.ca
- Canadian Hospice Palliative Care Association at chpca.ca

Having palliative care at home

Palliative care at home may be an option for you. 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.

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 caregiver need to understand what staying at home will involve. Your healthcare team can explain what this choice means in terms of care and responsibilities.

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 or finding specialized equipment.

What about complementary therapies?

A complementary therapy does not treat cancer, but it may help you cope physically and emotionally during this time. These therapies can help ease some side effects or help you cope with stress, anxiety and other emotional challenges you may face. For example, having acupuncture to help with nausea caused by chemotherapy is a complementary therapy. So is doing yoga to help you feel more relaxed and sleep better.

Some people feel that using a complementary therapy helps them gain a sense of control and feel more involved with their healthcare. Others feel that complementary therapies help improve their quality of life.

Complementary therapies may be offered as part of hospice or hospital care along with palliative treatments such as chemotherapy and radiation therapy. If they are not offered at your hospice or hospital, you can still find and work with complementary therapy practitioners in your community. But before using any complementary therapy, talk to your doctor or another member of your healthcare team about the possible risks and benefits.

To find out more about complementary therapies, visit cancer.ca.

Clinical trials

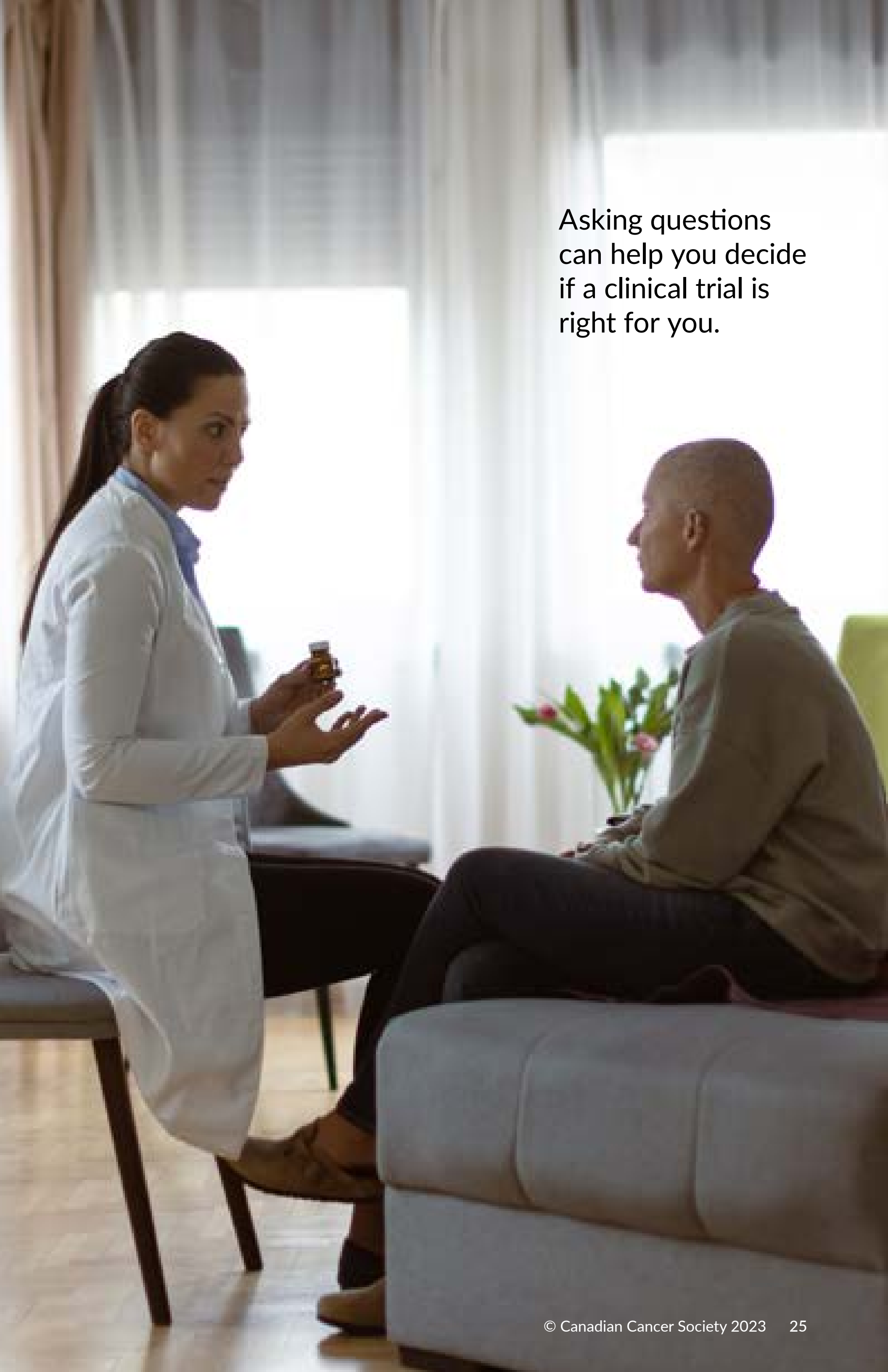
Clinical trials are research studies to find out if a new treatment is safe and effective. Supportive and palliative care clinical trials focus on managing symptoms related to cancer and its treatment. They also look at ways to manage the conditions that may happen after treatment or at the end of life. Other clinical trials focus on new drugs for treating cancer.

Every clinical trial has its own rules about who can take part. If you qualify, it's important to speak openly with 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 one, you have the right to leave it at any time without affecting your care.

In most cancer treatment trials in Canada, your provincial or territorial health insurance plan or the group sponsoring the study will cover the cost of care, medicine and testing. But it's a good idea to ask the clinical trial team about possible extra costs or expenses and if they are covered. These might include the cost of getting to the treatment centre or medicine to treat side effects of treatment such as antinausea drugs.

To find out more about clinical trials, talk to your healthcare team or visit cancer.ca.



Asking questions can help you decide if a clinical trial is right for you.

Medical assistance in dying

In Canada, you can ask for medical assistance in dying (MAID). You must meet certain conditions to be eligible for this assistance. All Canadians have the right to information, support and access relating to MAID. You may choose to find out about MAID, and then use it or not use it even if you're eligible.

Only certain people, such as doctors, are allowed to provide or help provide medical assistance to someone who wishes to die. People who help someone die must follow rules set out in federal and provincial or territorial law.

If you want to learn more about MAID, visit the Government of Canada at canada.ca/en/health-canada/services/medical-assistance-dying.

Working with your healthcare team

In this section, you'll learn about building a good relationship with the healthcare professionals on your team and how speaking up for yourself makes you an active member of the team. You'll also learn about who can help you find your way through the healthcare system, which can sometimes be very confusing.

It takes teamwork to manage your treatment and care. The team is you, your caregivers and the many healthcare professionals who are focused on your physical and emotional health. These professionals may include your family doctor, oncologists, surgeons, nurses, social workers, psychologists and many others. Building good relationships on the team takes time and effort from all sides.

If you were first diagnosed at an earlier stage of cancer, the people on your team may change to include more specialists in palliative care. You may miss the healthcare professionals who helped you earlier. You may have known them for a long time and become very comfortable with them. But your new team has skills and training to help you now. For example, a pain specialist might join the team or you may be referred to an occupational therapist and a home health aide. Some of this will also depend on where you live and what is available in your community.

Getting the most out of your care

Here are some tips to help you get the most out of the time that you spend with your healthcare team.

Keep track of your appointments and contacts. Make sure you go to your test or treatment appointments and show up on time. It may help to use an electronic calendar on your phone or computer, or you can use a printed one if you prefer pen and paper. Keep a list with the names and phone numbers of your healthcare team, cancer treatment centre, lab and pharmacy – and make sure that your caregivers know where you keep it.

Take someone with you. It can be hard to listen well and remember everything that your doctor tells you during a visit, especially if you're upset. A family member or friend can help you remember what the doctor said and can give you emotional support.

Make a list of questions and take it with you to appointments. It may take more than one visit to talk about all the questions and concerns that you have. If you don't get all your questions answered, you'll have other chances to ask them. Also, your doctor may not need to be the one who answers all your questions. Some questions can be answered by the nurse, the social worker or other members of the healthcare team.

Keep good records of what you and your healthcare team talk about. You might keep handwritten notes in a journal or type notes on your phone or another device, whichever is easier. You can also make note of anything that's important to share with your healthcare team at your next appointment. Include information about test results, medicines and side effects that you have or should watch for. If you want to record anything that the healthcare team tells you so that you can listen to it later, always check the rules with your healthcare team first.

Ask your healthcare team to explain anything that you don't understand. Unless you tell the healthcare team that you don't understand something, they'll assume that you do. So if you do not understand what is said, say so. Repeating what your healthcare team has told you in your own words is a good way to make sure you understand it correctly.

Try open-ended questions. If you're not sure you understand what your healthcare team is telling you, try asking open-ended questions such as:

- Tell me more about ...
- Why is that important?
- Why did you make that recommendation?
- What are the other options?
- How will I know ...?
- What is the purpose of ...?
- Can you explain that again using different words?

Take information that you find with you to discuss with your healthcare team. They can help you understand the information and tell you how it does or does not apply to your situation.

Know who to call and when. Ask your healthcare team who to call if you have questions or if something happens between visits. They can tell you what things you should phone about during office hours and what would need an emergency call outside of office hours.

Helping your healthcare team to get to know you

It's important that your healthcare team understands more about you as a person, outside of your treatments and appointments.

Talk to your healthcare team about your life outside of the cancer world. Tell them about your culture and your spiritual or religious beliefs and how they affect your attitudes, preferences and decisions around your care. Let them know what's important to you such as your work and home life, hobbies or interests. It's also helpful for your healthcare team to be aware of issues that are causing you stress or anxiety, which can include family problems or concerns about money.

Let your healthcare team know how you're feeling. Let them know about your hopes for treatment. Share your fears or concerns about treatment or side effects so they can help you. Something that seems minor could affect your treatment or something you think is serious might be very easy to deal with.

Tell them what, and how much, you want to know. It can help your healthcare team to know what types of information you want and if they're giving you too much or too little information. Ask them to recommend some reading material or places where you can look for more information.

Sometimes your loved ones want to know more than you do about your cancer and treatment. Let your healthcare team know how much can be discussed with them. It may be helpful to choose one family member or friend to talk to the healthcare team. That person can then share the information with other loved ones on your behalf.

Speaking up when you need to

Many of us think that Canada's healthcare system does a good job of meeting the needs of Canadians. Even so, sometimes you have to ask for what you need. Speaking up for what you think you need or asking someone else to speak up for you is often called advocating. Caregivers can play an important role as advocates. They can get information, ask questions and work with the healthcare team to help make sure you get the best possible care.

If you're not sure that you're getting the care that you need, you can and should say something. Being respectful, clear and honest with everyone on your healthcare team makes you an active partner in your care. Talk about your concerns. Tell your team about how things are going. They won't know if you don't tell them. If you're upset or frustrated about your care, try to let your healthcare team know without getting angry. People can become defensive if they feel unfairly criticized or misunderstood.

Your healthcare team needs to communicate effectively with you, too. It's part of their job to give you the information you need to make decisions about your care. This includes explaining the benefits and risks of treatment options in a way you can understand. They should answer all of your questions or schedule a follow-up appointment to do so. If the relationship with your team is not going well, a social worker, patient advocate or patient navigator may be able to help.

Some people decide to look for different healthcare professionals if they feel they are not getting the care that they need after speaking up. Being able to do this really depends on your personal situation, but everyone has that choice. You may want to consider your energy levels, what you can easily access where you live and the risks of the time spent waiting to see someone new.

Navigating your way through the healthcare system

Finding your way through our healthcare system is sometimes very hard. The system can be complex and confusing. Waitlists and the availability of healthcare professionals and treatments can vary, depending on where you live in Canada.

You can ask for help and information from anyone you're comfortable with on your healthcare team. If you have a family doctor, talking to them can be a good first step in understanding what's available to you and how you can access it. If you don't have a family doctor, your region might have a nurse practitioner who can help.

Some cancer centres and hospitals have patient navigators. A patient navigator acts as a link between you and the healthcare system. They may coordinate services and address a variety of physical, social, emotional and practical needs. A patient navigator is sometimes called a nurse navigator. If you're interested in using a patient navigator, ask your healthcare team if they can provide one.

Seek out a social worker

A social worker can help you make sense of the healthcare system and some services that exist outside of the system. Social workers can also act as advocates for you and your family.

Social workers can help you and your family cope with social and emotional concerns caused by cancer. This could include helping families look for extra support for money problems due to cancer. They can also provide counselling to help people cope with the emotional aspects of living with cancer.

In the palliative care and hospice settings, social workers guide you and your loved ones through parts of the end-of-life planning process and connect you with other support services such as advance care planning, financial planning and funeral planning.

If you'd like to talk to a social worker, ask your healthcare team for a referral or recommendation.

Practical concerns

In this section, you'll learn about issues around work and finances and where you can find more information. You'll also learn about the importance of advance care planning and having a will, along with what you can do if you'd like to participate in making your final arrangements.

There are many practical things to consider when you have advanced cancer or when you're a caregiver for someone with advanced cancer. Take control where you can. Not many of us enjoy spending time on things like filling out forms or having what can be tough conversations before doing the paperwork. But you may find that you have a sense of peace after these tasks are done. This can allow you to then focus on what you find more meaningful, like spending time with loved ones.

Work and finances

Many people with advanced cancer and their caregivers wonder what to do about work. It's also common for families to worry about money and how cancer affects their finances. Everyone has to figure out what is right and necessary for them.

Some people try to keep working around medical appointments, hospital admissions, sick days or caregiving. They may want to continue working because sometimes work can help reduce stress. Going to work and thinking about something besides cancer offers a change of pace or a sense of normality. Or they may try to work as much as they can because the loss of income can be very stressful. You may have extra expenses for medicines, treatment, medical supplies or home care that are not covered by private, provincial or territorial health insurance plans.

Others stop working or reduce the hours they work. Continuing to work may be too hard because of symptoms such as pain and fatigue. Some people are relieved to get away from the stresses of work if they can. But stopping work or even thinking about no longer working can

also make you feel sad or as if you're missing out on something. Work and income are often connected with self-esteem or identity.

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. But be realistic about what you can manage. Some workplaces also offer counselling services that may help you or your family.

If you have extended health benefits through your employer or if you pay for your own extended health benefits, get familiar with the terms and conditions of your coverage. Make sure you understand:

- what you will need to pay for and what your benefits will cover
- if your policy has a waiting period before disability coverage starts
- if your policy has a yearly or lifetime cap (the maximum amount they will pay out) on benefits

Talk to a social worker if your income has been affected by cancer. They can help you find out about federal and provincial or territorial government benefits and financial assistance programs for people with cancer and for caregivers.

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. Your decisions are called advance directives.

Part of the process is choosing someone who could make decisions for you, if necessary. This person is sometimes called your substitute decision-maker or your healthcare proxy. As long as you can speak for yourself, healthcare professionals will speak directly with you about what you want in terms of your care. But there may be a time when you can't speak for yourself. Having an advance care planning conversation with your substitute decision-maker will help them understand what you want for your care. They can then communicate your wishes to your healthcare team if needed.

It's important to talk about topics such as:

- where you prefer care to happen (for example, home, hospital, palliative care unit or hospice)
- the use of breathing machines or ventilators
- tube feeding
- continuing or not continuing with a medical treatment
- the use of CPR (cardiopulmonary resuscitation) if breathing or heartbeat stops

Talk to your healthcare team about whether they would recommend any of these treatments for you. They are often not recommended for someone with advanced cancer because they probably won't improve survival and can cause a lot of discomfort. It's always your right to refuse treatment and to make this wish known.

Many hospitals have a policy of asking people if they want CPR to try to revive them if their heart or breathing stops. If they don't want CPR, 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.

It’s also important to understand that there is paperwork that goes along with dying at home. Loved ones need to be able to show documents that say a death was expected. Without these documents, emergency services need to be called when someone dies at home. This paperwork is called different things depending on where you live. Your healthcare team can help make sure the right documents are in the home.

It’s normal to want to avoid subjects like this, but it can help everyone if you talk about these tough topics early on. It can help you to know that your wishes are understood. It can also relieve some of the stress and uncertainty for caregivers and family. These are not easy conversations to have, but they can help you find peace.

Find out more from Advance Care Planning in Canada at advancecareplanning.ca.

Wills

All adults should have a will and keep it up to date. It’s one of the best things you can do to protect yourself, your partner and your family. 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 (younger than 18 years of age) after death. You may also want to include who you want to look after your pets.

You may want to change an existing will or create a new one. When writing a will, get advice from a lawyer to make sure that the document is legal.

ORGANIZING IMPORTANT PAPERS

Besides a will, you probably have other important legal and financial documents such as marriage and birth certificates, insurance policies, bank statements, investment summaries and account passwords. Here are some tips on looking after this important information:

- Gather important papers together, if you can. Make a list of what they are and where your family can find them.
- 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 someone has access to the box.

Making final arrangements

All adults should think about preplanning or at least talking about their wishes for their final arrangements. Not everyone is comfortable doing this. But preplanning means that your family or close friends won't have to make these decisions when they're grieving and have little time to think them through. Knowing that your wishes will be carried out can also bring you a sense of peace. Deciding on your final arrangements can include decisions about:

- your wish to be buried or cremated
- if you'd like your ashes to be buried, scattered or kept by loved ones
- your wishes for a funeral, memorial service or something else, where it should be held and any special instructions for it

If you're ready, talk to a funeral director, social worker or a leader in your spiritual or faith community. Share your decisions and plans with family members and keep a copy of documents related to final arrangements with your other important papers. If you have final wishes related to any religious, spiritual or cultural practices around dying or after death, make sure caregivers and the healthcare team know about them.

How cancer can affect relationships

In this section, you'll learn about how cancer can affect your relationships with the people you're closest to – your partner, family and friends, as well as your younger children and teens (if you have them). You'll learn about how you can try to keep these relationships strong.

Advanced cancer brings many changes and overwhelming emotions to your life. The people closest to you are also feeling many of the same things. Facing this challenge can sometimes bring you together, while other times it can feel like it's pulling you apart.

Understanding that your relationships may change can help you find ways to keep them healthy, strong and supportive for everyone. If you're still raising children, understanding where they are in their development and how they are affected by advanced cancer in the family can help you and other family members help them.

Facing cancer with your partner

If you're in a relationship, you may find strength and comfort in knowing that you and your partner are facing the cancer together. But advanced cancer challenges even the best relationships.

While you may be the one diagnosed with cancer, your partner is living with cancer as well. Your partner may be as afraid, angry and shocked about what you're facing as you are. But each of you may cope with the situation very differently. And one of you may be more comfortable asking for help or talking about how you feel.

Here are some of the areas that may challenge you and your partner.

Your roles may change, shift or become reversed. If you have advanced cancer but up to now you have been the caregiver in your relationship, it can be very hard to accept that you now need to be cared for. Some people have trouble accepting that care gracefully. If you haven't been

the caregiver in your relationship, it can be hard to suddenly be placed in that position. To start adjusting to your new situation, try sharing your experiences without judgment and listening to each other's views. And be patient. Many people find it hard to get comfortable in a new role.

Your responsibilities may change. Cancer and its treatments can take a physical toll. You may not have the strength or energy to do chores or work around the house, which means your partner has more responsibilities at a time when they're already overwhelmed. This may make the caregiver feel frustrated and resentful, while you may feel guilty and sad. Do your best to talk openly about how things are going. Based on what your healthcare team has told you, you might try to plan ahead in terms of how to manage responsibilities. It's also important to be open to outside help from friends, family and healthcare workers.

Your physical needs will likely change over time. Some changes are more drastic than others. At some point you may need help dressing, bathing, eating or using the toilet. Changes like these can make you feel like a burden on others and can even affect your sense of identity. Asking for help can be hard. Be open and honest about what you need. Your partner might be reluctant to offer help at first because they don't want to offend you by assuming that you need it. Talking openly about what you need can help your partner care for you. If you and your partner are uncomfortable with managing some of your physical care, talk to your healthcare team about what options you may be able to find in your community.

Your emotional needs may change. We all need to feel loved. During a difficult experience like coping with advanced cancer, this need for connection may increase for both you and your partner. Try to be sensitive to these changes. Some people find that they need professional help to deal with the change in emotions. It's important to be able to openly express emotions in ways that avoid overwhelming the other person. Ask your family doctor or healthcare team for advice on finding a social worker, counsellor or therapist.

Sex and physical intimacy may be different. Sex and physical intimacy can change when your partner is also your caregiver. This may be a result of some of the relationship changes you're going through. Or you may be uncomfortable with changes in how you look or your ability to have sex. Perhaps you're in too much discomfort to think about sex or worry that you won't 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 feel close to your partner 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. If you find it hard to talk openly about sex, speak with a therapist, counsellor or your doctor about ways to reduce sexual side effects and maintain intimacy.

You may find it hard to accept the loss of your shared future. A cancer diagnosis can change the hopes and dreams that partners may share about retirement, travelling, raising a family together, finances or almost anything. It's understandable if you feel angry and sad when the brightness of the future suddenly dims. You can't change the future, but you can try to take control of the present. It can help to be open about how you feel, re-evaluate your priorities and focus on short-term goals such as ways to spend time together and to make it meaningful.

Getting support from friends and adult family members

In times of serious illness, support doesn't always come from where you expect it. Some people are really there for you while others stay away. Friends and family can be a great support to people with advanced cancer and their caregivers, but they often need guidance on the type of help and support that you need. If you're single, you may rely even more on friends and family members for support. Your needs and desires for support may change over time, so it's important to figure out how to communicate and keep relationships with family and friends strong.

These ideas can help.

Put someone in charge. Putting one person in charge of communication can save you time and energy because you don't have to repeat information and give updates to many people. This person can be your caregiver or a close friend who can work with your caregiver to send emails or post social media updates, make phone calls and assign tasks to other friends and family members who have offered their help.

Be prepared for relationships to change. A friend or family member may not know what to say or do when they learn that you have advanced cancer. They may feel sad or scared, or it may remind them of losing a loved one in the past. But you may also be surprised at the support you receive from others.

Start the conversation. If you want to talk about cancer, you may need to bring it up. If some of your friends and family members seem to avoid talking to you, they probably don't know what to say or they're worried that talking about cancer will upset you. If you like, tell friends and family that it's OK to talk about cancer. But be honest with them when you prefer to talk about other things.

Be direct about help from others. The people in your life will likely want to provide whatever help you need, but they may not know what that is. Be as direct as possible. Try creating a list of tasks that people can help with such as shopping for food, cooking or picking up medicines.

You might also have friends or family members who try to do too much. Being honest, whether you speak to them yourself or have someone else talk to them for you, can help to set boundaries so your needs can be met in the ways you want.

Stay as social as you can. Research shows that people diagnosed with cancer cope better when they have connections to other people. Your friends and family may not know how much you can or want to participate in the activities you were once a part of, so let them know. And when you're not feeling up to doing something – emotionally or physically – tell them. But you may find that even just sitting quietly with someone is helpful and can raise your spirits.

WE CAN HELP YOU FIND SUPPORT

Many people with advanced cancer and their caregivers find it helpful to talk to someone who is facing similar challenges. For caregivers, this can mean connecting with other caregivers both during and after their caregiving experience.

The Canadian Cancer Society can help. We can offer support, answer questions you might have and help you find other support services.

- Call our Cancer Information Helpline at 1-888-939-3333 (TTY 1-866-786-3934) or visit us at cancer.ca.
- Search our Community Services Locator at csl.cancer.ca. You'll find information about support groups and more in your community.
- Join our online community, CancerConnection.ca. It helps people with cancer, as well as loved ones and caregivers, connect with others who know what they are going through.

Parenting children and teens

Children of all ages will have to cope with changing family roles and with their own feelings about a parent being ill and dying. There are ways to help.

Helping younger children (1 to 6 years old)
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.

Try helping younger children in these ways:

- 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 old)

At this age, children start to understand that death is something that happens to all living things. This can make them anxious about their own health and safety and that of their loved ones.

Older children may also react to stress and changes around them by getting upset. 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.

Try helping older children in these ways:

- Take their fears seriously. Respect their feelings by comforting and reassuring them.
- Give them 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 them know that you have the same feelings they do sometimes. If you can show your sadness and cope with it, this lets them 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.

Try helping teens in these ways:

- 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 them time and space to process their feelings, while letting them know that you're there for them when needed. Teens may ignore you even when 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. If you're not sure what to say or how to say it, or are worried about your ability to provide support, a teacher, guidance counsellor or leader in your spiritual or faith community 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 gets in trouble with the law
- is taking drugs or drinking alcohol
- talks about death a lot

Facing the end of life

In this section, you'll learn that there are benefits to talking about death, even though it can be very hard. You'll also learn about how you can have these conversations with your loved ones and how you might approach the idea of dying at home.

Dying is a part of life and it can have value and meaning. It isn't a failure. Accepting that death comes to all of us – and even that yours may come sooner rather than later – doesn't mean that you have given up on living. In thinking and talking about death, we start to have conversations that help us understand what really matters to us when we're alive.

Professionals who work with people who are dying 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. It can mean choosing where you spend most of your time toward the end of your life and choosing – when possible – where you want to die. This might be at home, in a hospital or in a hospice. For some people who are eligible for medical assistance in dying (MAID), it can also mean choosing when they die. Some people want their surroundings to look and sound a certain way (for example, with music, flowers or pictures) or need spiritual rituals or cultural practices to take place.

A good death can mean more than physical comfort. It can mean dying knowing that you have lived life how you wished to and have accepted what you haven't been able to do. Often, a good death means keeping your sense of self. It's sometimes called "dying with dignity." Keeping a sense of dignity at the end of life reduces anxiety and suffering and increases a sense of peace and meaning.

Talking about death

For most people, talking about death is very hard. Having the courage to start the conversation can make a big difference. How your family has handled death in the past and differences in traditions or customs can also affect how you speak about it. You might worry that it will hurt or upset friends and family. You may fear, even though there is no reason to, that talking about death 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.”

But what is clear is that we all die, someday. Not talking about it won’t 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 improve the quality of your care.

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

- Take some time to plan what you want to say before you start talking.
- Find a quiet time and place.
- 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, such as a close friend or someone from their spiritual or faith community. You may want to ask for help from 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 ones.

Talking about death with children and teens

You and your caregivers may want to protect the children and teens in your life from sadness and pain by not telling them the truth about your diagnosis. But avoiding the truth will not help them in the present or in the future. Being honest now gives them a sense of security and trust because honesty helps them know what to expect. And research tells us that children are much better at facing losses in the future when adults communicate with children in an open and honest way about death.

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

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 also need to know that it takes time to get over losing someone 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.

Ask children questions about what they’re thinking and feeling.

Here are some ideas that can help you and your loved ones talk about death with children:

- Give information in small amounts in a level of detail that fits the child's age and stage of development. Let them know if you'll be in the hospital or at home in bed sometimes.
- Encourage them to ask questions at any time. A child may ask the same question many times, looking for reassurance. 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 "pass away" or "go to sleep" when you mean "death" or "dying." Adults may find these terms comforting, but they can confuse children and even make them afraid to go to sleep.
- Ask children questions about what they're 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 children 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 nearing the end of life. This is a decision that each family must make based on the age of the child or teen and their relationship with the loved one. It can help if children have an idea of what the room will look like, what they might see there and if you'll look different. Having an adult who is close to them talk to them afterward about how they felt is also helpful.

When death is expected to be soon, it can be helpful to let older children and teens spend some time with you. This provides an opportunity to say goodbye and to begin to process what may be a range of feelings (sadness, grief and anger), along with good memories.

Dying at home

Some people would prefer to spend as much time as possible at home rather than in the hospital or hospice. There is a sense of familiarity and comfort that comes from being at home. Once someone becomes very ill, a home death may not be easy to achieve. In some cases, treatments and procedures may be better performed in the hospital. You might not have the family or private caregiver support you need or the financial resources to cover the costs that dying at home can involve. But given enough support – especially nursing care – it's possible for some people to die at home or elsewhere in the community (such as in a long-term care home or a residential hospice) if they choose.

It's important to understand how each option might work for you and whether one is more aligned with your own situation and desires than another. Your family and healthcare team can help you decide which option is best for you. 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.

Looking for meaning

In this section, you'll learn about some of the different ways that people make sense of and see value in their lives or the memories that will live on after them.

People with advanced cancer often want to think more deeply about their lives – their past, present and future. Looking for meaning is a personal process. It's not always easy, and it can be very sad at times. But working through big questions – Why am I here? What is my purpose? What matters to me most? – can bring deep contentment and peace to you and your loved ones. It can lead to greater enjoyment in relationships and in life itself.

Finding strength through spirituality

Spirituality is a person's sense of peace, purpose and connection to others. It also includes their beliefs about the meaning of life. Whatever spirituality means for you, it can be a part of your search for meaning. There is no single or right way to connect with your spiritual side when you have advanced cancer, and it's also OK if you don't feel any spiritual connection.

For some people, spirituality involves organized religion and guidance from a spiritual advisor from their faith. They find their faith to be a source of comfort and strength. Organized religion often involves a community of people who share similar experiences and can provide support. This framework can allow you to address spiritual questions that come up during your cancer experience.

For other people, spirituality is something separate from organized religion. It means quiet, solitary reflection. You may find comfort in nature, in the goodness of others or in the connections between us all. Some people practise meditation or rituals from their culture or learn new rituals from another culture. Others find spiritual value in activities such as journalling, making or viewing art, yoga or music.

In many hospitals, you can ask for a visit from a spiritual care worker who is trained to offer support based on your individual beliefs. Their role is to offer guidance to help you find peace and comfort.

Finding peace in relationships

Some people with cancer want to heal relationships from their past. This can mean contacting someone after years apart or clearing up old 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. You can get help from a counsellor, spiritual care worker or other mediator, if needed.

Looking back on your life

Looking back on your life can be a part of how you find meaning in it. You may choose to work with a healthcare professional who is trained in helping people review their life experiences. There are different types of therapies, such as dignity therapy, life review therapy or reminiscence therapy. These therapies can help you explore every part of your life so far – childhood, family, love, sexuality, career and health. You can think back to the important moments and people in your life and how, together, they all make you who you are today.

If you choose to share what you've discovered about yourself, you and your therapist can create a video or document that can be a lasting gift for family and friends. 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 purpose. Your legacy matters.

Looking back at your life can be hard work. It takes 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. Your therapist is there to help you make sense of your thoughts and emotions.

Celebrating your life

Not everyone wants to look back on their life with a therapist. And that's OK. There are other ways to celebrate your life and appreciate your accomplishments, either on your own or with family and friends. You can talk about your memories and look through photo albums or old letters. You may choose to create a family tree or history or to express yourself creatively with poems, music, art or scrapbooks. Some people make their own audio or video recordings. You can make a memory box to hold mementoes such as photos or objects that are special or unique to you. All of these ways of celebrating your life can help people remember you and share their memories of you with others.

For caregivers

In this section, you'll learn that taking care of yourself as the caregiver is the best way to also care for the person with cancer. You'll also learn more about what might happen as death gets nearer, what grief can look like and what can help you adjust to life after caregiving.

A caregiver is someone who provides physical and emotional care to someone with cancer, but they aren't paid to do this work. Caregivers are usually the partner or spouse, parent, adult child or close friend of the person with cancer.

You may be the only caregiver for the person with cancer. Or you may be part of a group of people who share caregiving. Caregiving shared with other family members or close friends can help make it easier. Each person can focus on the responsibilities that they're most comfortable doing or that they have time to do. You may have a flexible schedule so you can drive the person with cancer to treatment and other appointments. Another family member may be trained to help with physical care and can take over bathing and other personal care. Others may find they can help by cleaning the house, doing laundry, going grocery shopping or cooking meals.

Being a caregiver for someone with advanced cancer will likely be one of the hardest things you ever do. It can be lonely and exhausting. It can also be a time of meaning and connection. Most caregivers agree that the experience changes their lives. When looking back on caregiving, caregivers have reported:

- feeling a closer bond with the person with cancer
- finding added meaning in life
- finding new strength
- developing a new appreciation for family and friendships

Most caregivers agree that the experience changes their lives.

Taking care of yourself

Caregiving can be a very intense and tiring job. While you're caregiving, you may be so busy that you forget to take care of yourself. But it's very important to do so. Caregivers who get the information, help and support they need to take care of their own needs can better take care of their loved one with cancer. And, for your own sake, you'll want to avoid what healthcare professionals call caregiver burnout or caregiver fatigue.

Stay healthy

To have the strength and energy to care for someone else, you need to be healthy yourself. Here are some things you can do to try to stay healthy.

Eat well. It's not easy, but try to eat a balanced diet that has a variety of foods each day to get the nutrients you need for good health. Just do your best – and accept help from others with meals.

Be active. You may feel exhausted, but a little bit of movement can go a long way to help you feel better. Go for a walk, swim or bike ride. Being active can help you cope with stress and improve your sleep – and it just generally makes you feel better.

Get enough rest. When you're well rested, it's easier to cope with the demands of caregiving. Try to get a complete night's rest when you can. If you need to, try to nap when the person you're taking care of is resting or sleeping.

Don't ignore your own health. Make sure you go for regular checkups with your doctor and dentist. Be sure to report any concerns you have about your health.

Find ways to cope with stress. There are many ways to cope with stress. Because everyone feels and handles stress differently, everyone will also have their own way of managing it. One person may like to play or listen to music, while another person may choose to spend time in nature. Some people learn to meditate and practise mindfulness, while others sweat it out at the gym or playing a sport. Keep trying until you find ways to cope with stress that work best for you. Talk to your healthcare team if you're having trouble handling stress on your own. They may suggest taking a class that teaches different ways to manage stress or refer you to a self-help group, support program or counsellor.

Share your feelings

It's normal to feel stressed, angry, afraid, helpless, frustrated, sad or guilty. It's also normal to feel like you must ignore your own feelings to stay strong for the person with cancer. Even though it can be hard, it's a good idea to talk about your feelings instead of keeping them inside. Hiding your feelings can use up energy that you need for caregiving.

Talk to someone, like a trusted friend, a family member, a counsellor or someone in your spiritual or faith community. A support group for caregivers is a good place to talk to others who have gone or are going through the same experience.

CONNECT WITH OUR ONLINE COMMUNITY

Finding others who know what you're going through can help you cope as a caregiver. This includes finding support in dealing with grief after your loved one dies.

Get started at CancerConnection.ca.

Ask for and accept help

You can't do everything. Be honest with yourself about what you can do. Decide what's most important to you, and don't worry about the other stuff.

Get help from family members, friends or people in the community when you need it. People are often happy to babysit, clean the house, look after pets, help with meals or stay with the person who is ill. Talk to the healthcare team about home care or other community services to help with house or yard work or with physical care. Don't hesitate to tell others exactly what sort of help you need from them.

Even with the right support, there may come a time when it's no longer possible to care for someone at home. Sometimes the person with advanced cancer has medical needs that cannot be fully met at home. This is not a failure on anyone's part. Try to talk about your doubts and concerns and focus on what will improve the quality of life for everyone.

Take a break

Taking time to rest and recharge is a key part of taking care of yourself. Go for a walk, have a massage, see a movie or meet up with a friend – whatever activities you enjoy doing. If you're worried about leaving your loved one alone, ask someone you trust to come by while you're away.

If you can't get out, take a break with a favourite magazine or TV show, a hot bath or an early night with a good book.

RESPITE CARE
If the person with cancer needs a lot of physical caregiving, talk to the healthcare team about respite care. It can give you a short-term break from your caregiving responsibilities, while making sure that your loved one is still getting care. Respite care can be provided in the home or sometimes is offered within residential hospices. You may ask for a regular afternoon or day of care or have it arranged for a longer period of time, if you need it. Your healthcare team or local hospice can help arrange care and explain any costs involved.

Nearing death and immediately after

Most of us don't know what to expect when someone is close to death. The unfamiliar is often very scary, so understanding what may happen can help ease your fears and anxiety.

In general, as a person gets closer to death, their body functions start to slow down. But it's important to understand that every situation is different. Having one or more of the signs below doesn't necessarily mean that the person is close to death.

Withdrawal – The person may be less interested in the world around them, activities they enjoyed and talking or being social.

Drowsiness – The person may sleep more and become difficult to wake. They may slowly lose consciousness in the days or hours before death.

Eating and drinking less – The person has less need for food and fluids and may find it hard to swallow.

Changes to 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.

Loss of bladder or bowel control – The person may not be able to control their bladder or bowels (when they pee or poop). The healthcare team may use a tube called a catheter to drain the urine (pee) into a bag.

There will be less urine and fewer bowel movements (poop) if the person isn't eating or drinking very much.

Changes to skin – The person's hands and feet may feel cool to the touch, and skin may look slightly blue or purple.

Delirium – The person may become restless, anxious or confused. For example, the person with cancer may not know loved ones, what day it is or where they are. They may even see or speak to things that others can't see.

After devoting your energy to caring for someone with cancer for weeks, months or even years, you may find that now all you need to do is sit quietly with your loved one. 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.

Sometimes people who are near death improve for a short period of time. They're more alert and can interact with those around them. As hard as it is, it's important to remember that these changes do not last and the person will get worse again. But this time could be used to share important feelings or thoughts with the dying person and make a deeper connection in the final days or hours before death.

After death

There is no need to rush or hurry with anything after a person dies. 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 someone after they die. It's also OK to try to gently close the eyelids if they're 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.

A person's culture will affect what happens after death and how the body is handled. Many 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. This can include contacting the person's doctor, the appropriate authorities or the funeral home.

Grieving

Grieving the death of the person you were caring for is a necessary process that cannot be hurried. Each person takes their own time with grief and grieves in their own way. How you grieve will depend on many things such as:

- your relationship with the person who has died
- the support system you have
- your cultural and religious beliefs
- 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 and can include 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 such as the palliative care team, grief counselling services and support groups.

Life after caregiving

Just as you needed to adjust to being a caregiver, at some point you'll need to adjust to not being a caregiver. Even if you were expecting it, caregiving ends suddenly when your loved one dies. This can leave you feeling lost and unsure, especially if you were a caregiver for a long time. You may also feel a great sense of relief now that the caregiving is done – but this relief may also make you feel guilty.

It can take time for life to get back to normal after caregiving has finished. For some people, it can be hard to move forward now that they're no longer caregivers. These ideas might be helpful.

Make yourself a priority for a while. You may not have been taking time to live a healthy life or do the things that you enjoy. Now that caregiving is done, it's time to put some time into your health and life.

Get ready to go back to work. If you've taken time away from work to care for your loved one, getting back into a routine at work can help you get used to life after caregiving.

Reconnect with people. Often the demands of being a caregiver mean that you lose touch with some family members and friends. It can take a bit of effort to get back on track. People may not contact you because they aren't sure if you're ready to see them again or they don't want to burden you. So if there is someone that you'd like to see, contact them and make plans.

Get out and do things. While you were being a caregiver, you may not have had a chance to go out to a movie, for a meal or to celebrate a friend's birthday. Now that your caregiver role is over, you can get out and enjoy some activities that you may not have had the time or energy to do before.

Take part in hobbies. Start doing something that has interested you or get back to doing hobbies or other interests that you did before you were busy caregiving.

Remember that you did the best you could at the time. Don't feel guilty about things that you could have done differently or mistakes that you made. No one's perfect.

Suggested resources

Advance Care Planning in Canada
advancecareplanning.ca offers information on what advance care planning is, how to make a plan and tips for sharing your plan with family members.

Canadian Hospice Palliative Care Association
chpca.ca provides information, resources and a national directory of hospice palliative care services.

Canadian Virtual Hospice
virtualhospice.ca provides 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 people with cancer 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.

Government benefits and services
For information on federal government services and how to apply for them, call 1-800-O-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.

> *> Benefits Finder*
> benefitsfinder.services.gc.ca
>
> The Benefits Finder is a customized list of federal, provincial and territorial programs and services you may be eligible for. It asks a few questions and uses your answers to search.
>
> *> Employment Insurance benefits*
> canada.ca/en/services/benefits/ei
>
> Find out about EI benefits and leave as well as how to apply online and submit a report.

> Employment Insurance caregiving benefits and leave
canada.ca/en/services/benefits/ei/caregiving

You can apply for EI caregiving benefits if you are providing care or support to a critically ill or injured person or someone needing end-of-life care.

> Disability benefits
canada.ca/en/services/benefits/disability

Disability benefits include disability pensions and children's benefits, savings plans and a gasoline tax refund program.

MyGrief.ca
mygrief.ca is an online resource to help people move through their grief from the comfort of their own home, at their own pace. It can help you understand your grief and approach some of the most difficult questions that may arise. It was developed by people who have experienced the death of someone important to them and grief specialists.

WE’RE HERE TO HELP

Find information you can trust

Visit cancer.ca for information on more than 100 cancer types. You’ll find topics ranging from diagnosis and treatment to managing side effects, living with cancer and reducing your risk. We also have publications, videos and webinars.

Get answers to your questions

When you have questions about diagnosis, treatment, prevention, emotional support and other services, our trained cancer information specialists can help you find answers. Call us at 1-888-939-3333. Our Cancer Information Helpline is available in English and French with an interpreter service for other languages.

Connect with someone who’s been there

Visit CancerConnection.ca to join our moderated online community. You can join discussion groups, get support and help others at the same time. It’s a safe place to connect, learn and share your experience with cancer.

Find services in your community

Our Community Services Locator (CSL) helps you find the cancer-related services you need. You can search over 4,500 listings across Canada for emotional support programs, home care, help getting to your cancer treatment, where to find a wig or prosthesis and much more. Start your search at cancer.ca/csl.

The Canadian Cancer Society works tirelessly to save and improve lives. We raise funds to fuel the brightest minds in cancer research. We provide a compassionate support system for all those affected by cancer, across Canada and for all types of cancer. Together with patients, supporters, donors and volunteers, we work to create a healthier future for everyone.

Because to take on cancer, it takes all of us.
It takes a society.

Canadian
Cancer
Society

IT TAKES A
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