

# **Chemotherapy and Other Drug Therapies** *A guide for people with cancer*



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We would like to thank the people who shared their personal experiences with us. To protect their privacy, and with their permission, we have changed their names.

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### About this booklet

This booklet was written to help you understand the different kinds of drug therapies used to treat cancer. Drug therapies – or treatments – include chemotherapy, hormonal therapy and targeted therapy.

You can use this booklet as a guide as you:

- get ready to start treatment
- cope with side effects during treatment
- continue to take care of yourself after treatment

For some of you, the information in this booklet may be enough. For others, it will be only a starting point. Either way, it can help you prepare for what lies ahead and help make it easier to talk with your healthcare team and your family and friends.

Throughout the booklet, you'll hear from Canadians who've been where you are now. Their stories may not be the same as yours, but their words are offered here to help you understand that you're not alone and that you can work with your healthcare team to manage side effects and get the care and support you need.

> Chemo's not easy. I'm not trying to say that anything's easy there. But remembering what it's actually doing for you, right, it's a life-saving thing, so you put up with a lot more. ~ Jackson

# Working with your healthcare team



Treating cancer is a team effort. Your healthcare team will work together to help you during and after treatment. They are there to help you and your family cope with both the physical and the emotional effects of cancer treatment and to help you find your way through the healthcare system. Together, you can work with your team to get the best care possible.

### Getting to know your healthcare team

My surgeon was the one who gave me a timeline and laid everything out – he even drew a little picture, which we kept. And then I spoke with the oncologist, who explained the process of chemo, the benefits of it and the risks involved, and the odds of survival with and without it for the kind of tumour I had. I trusted him right away. ~ Jackson

Your healthcare team is a group of professionals who work together to treat your cancer. But you are the most important member of the team, along with your family and friends. You should be informed and consulted at every stage of care. Any of these people may be part of your healthcare team:

A medical oncologist is a doctor who diagnoses and treats cancer using chemotherapy, hormonal therapy and targeted therapy.

A surgical oncologist is a doctor who performs biopsies and surgeries or other procedures to diagnose or treat cancer.

A nurse gives care in the hospital or at your home. Nurses often have the most contact with you. They answer questions, give medicine and provide emotional support. Oncology nurses and oncology nurse practitioners have special training in caring for people with cancer.

A pathologist looks at tissue samples taken from the body to diagnose illness or see how the cancer is responding to the treatment. A pharmacist prepares drugs and other medicines and explains how they work. An oncology pharmacist specializes in chemotherapy and other cancer drugs.

A physiotherapist or occupational therapist works with you to restore or maintain physical fitness. They can help when you have a hard time moving around or doing daily activities. An occupational therapist can also help you return to work, adjust your work activities and suggest how to modify your home to make things easier while you have treatment or deal with side effects.

Psychiatrists and psychologists are mental health specialists. They can help you and your family understand and cope with feelings, thoughts, worries and behaviours.

A registered dictitian can answer your questions on nutrition and eating well throughout your treatment and recovery. They can help if your treatment makes it hard to eat, if you have problems gaining or losing weight or if treatment makes foods taste different.

A social worker helps you and your family cope with cancer and its treatment. Social workers can provide counselling or refer you to counselling, support groups, financial help and other resources.

A spiritual care worker offers support and prayer according to your spiritual and religious needs.

Your family doctor or general practitioner (GP) provides general healthcare to you and your family. Your GP plays an important part in continuing your care, especially after your cancer treatments are over.

### Talking to your healthcare team

Oh, my healthcare team – if I called up to ask about something I wasn't sure about, they would come up with an answer. And if somebody wasn't available right there and then, they would be back to me within minutes. They were absolutely marvelous. There was no question too dumb to ask. ~ Diya

The people on your healthcare team are experts on cancer. But you are the expert on *you*. Help your healthcare team get to know more about you, not just your cancer. For example, tell them how much information you need – whether you want to learn more or if you're getting too much.

Tell your team how you're feeling. Share with them any fears or concerns you have about treatment or side effects so they can help you. Be honest, open and direct with your team. It's one of the best ways to get good care.

You may want your healthcare team to know things about your life away from the cancer centre – for example, that you live alone, that you have young children or that travelling to and from the hospital is hard for you. Tell them if you plan to continue working or studying during treatment or if you have special events coming up like a trip, wedding or graduation.

Talk to the healthcare team about any cultural or spiritual practices that are important to you. If you prefer to communicate in another language (including sign language), ask about an interpreter. If an interpreter isn't available during your visit, bring a friend or family member who can translate for you.

Before you meet with your healthcare team, you'll likely have a lot of questions. It can be helpful to make a list of your questions before your appointments. You may want to bring a family member or close friend with you. They can take notes or record the visit and help you remember what was said. Doctors and other members of the healthcare team need to communicate effectively with you too. It's part of their job to provide you with the information you need to make decisions about care. This includes clear explanations of all available treatment options and the benefits and risks of each. You may want them to explain things several times.

Keep in mind that it takes time to develop a good relationship with your healthcare team. If you find anyone on your team hard to talk to, tell them. And if the relationship with your doctor isn't working, you may be able to find a new doctor.

My oncologist was delightful. She was the kind of person who had empathy and all those qualities that are so important when you're going through this. But the surgeon was too busy looking good, in my opinion. He didn't listen, didn't seem to take my symptoms seriously. You need to find ways around those things if they happen. If you feel that you're not being listened to, you need to talk to somebody else. ~ Pedro

#### During your visit

- Ask all your questions. If you don't understand something, ask the doctor to explain. Repeating what was said in your own words can help make sure you understand.
- Get the information in print or find out how to access it online. Fact sheets with clear language and pictures can help you remember important information at home.
- Tell your doctor about anything new that has come up since your last visit. Your doctor and nurse need to know about new symptoms and changes in how you feel. They won't know unless you tell them.

### After your visit

- Review your visit to help remember what was said. Look at your notes and discuss the visit with the person who went with you.
- Make a list of any new questions you may have or questions you forgot to ask.
- Keep important information like test results, appointment dates, instructions, addresses and phone numbers in one place where you can find it easily, like in a 3-ring binder or an expandable folder with tabs. Or keep folders on your tablet or laptop.

I kept everything in a big binder: all my notes, all the pieces of paper they gave to me. So much information comes at you in a very, very short amount of time and it's really hard to keep track of it all. It really helped, especially later in chemo when I got into the chemo fog and was not remembering things very well. ~ Christa

#### Know who to contact

Always know who you can contact if you have any questions during and after treatment. Ask who you should call or what you should do in an emergency or if you notice any unexpected side effects. Find out how to contact someone after office hours. Keep these phone numbers nearby.

### **Questions to ask**

You may want to ask your healthcare team some of these questions before starting drug treatment:

- What treatments do you recommend for me?
- Are there other ways to treat my type of cancer?
- What is the goal of this treatment?
- When will I start treatment?
- What are the chances that the treatment will work? And how will we know if the treatment is working?
- What will we do if the treatment doesn't work?
- What are the risks and side effects of this treatment? Are any side effects permanent?
- Are there any clinical trials (research studies that test new ways to treat or manage cancer) for my type of cancer?
- Will I have to pay for any of the drugs?
- Will I be able to work while on treatment?

#### Worried or afraid?

It's normal to be concerned or anxious about cancer treatments. But you may be afraid of a side effect that can be easily managed or that actually won't happen with your type of treatment. If you're worried, talk to your healthcare team.

"I think it's always scary. I mean, you're facing the unknown. It's like one of those games of blind faith, where you fall backward because someone promises to catch you, and you really have no idea of whether it's going to work. But 14 years later, I'm still here." ~ Diya

# Using drugs to treat cancer



### **Different drug treatments**

There are many different drug treatments for cancer. They work in different ways to destroy cancer cells, stop them from spreading or slow their growth.

- Chemotherapy destroys cancer cells or makes them less active.
- Hormonal drug therapy changes the levels of certain hormones in your body to slow the growth of cancer cells or destroy them.
- **Targeted therapy** changes the way cancer cells behave this stops them from growing and spreading.
- **Supportive drugs** prevent, manage or relieve side effects caused by cancer or cancer treatments.

You may need only one type of treatment. Or your doctor may recommend a combination of different treatments. Sometimes drugs are used to shrink a tumour before other treatment is given, such as surgery or radiation therapy. Sometimes they are given after surgery or radiation to destroy any cancer cells that have stayed in the body. Different treatments can be given at the same time – for example, chemotherapy may be given at the same time as radiation.

Your doctor will explain which treatments you'll be getting and the goals of your treatment. The goals of your drug treatment may be to:

- Cure the cancer destroy all the cancer and reduce the chances that it will come back.
- Control the cancer stop it from spreading, slow it down or destroy cancer that has spread to other parts of the body.
- Prevent the growth or spread of cancer.
- Relieve symptoms of cancer and help you feel better if the cancer cannot be cured.

### How does your doctor decide what drugs to use?

I thought I knew a fair bit about cancer before I was diagnosed, but I found out that what I thought I knew was a thimbleful in a 10-gallon pail. I thought chemo was just chemo: well, it's not. The chemo was made for my body weight, my cancer, my conditions, my everything. ~ Diya

Your healthcare team will suggest a treatment plan just for you. Sometimes 2 people with the same cancer can be given different treatments and different drugs. The treatment you get depends on:

- the type of cancer you have
- where it is in your body
- the stage and grade of the cancer
- your age, sex and general health
- other medical problems you might have
- whether you've had chemotherapy or other drug therapy before
- your personal wishes (preferences)

If you have preferences about drug treatment, talk to your healthcare team about what's important to you. For example, let them know if you're afraid of needles or find it hard to swallow pills. There may be different ways to give the treatment or they can give you tips on taking the drugs. Telling your healthcare team about your wishes can help them make decisions that are right for you.

#### The cost of medicines

You may be concerned about the cost of drugs and how you will pay for them. Sometimes your treatment plan includes drugs that are not paid for by the government or hospital.

Your healthcare team can help you understand what costs are covered and tell you about programs that can help you pay for your medicines.

Some Canadians can have all or part of the cost of their medicines covered by private insurance plans (3rd-party insurance), provincial or territorial drug benefit programs, or federal programs for certain groups of people. Each province or territory has different rules.

"The chemo in the hospital was covered, but all the other drugs – the morphine, the antinausea pills, the drugs for constipation – I had to pay for all of those myself because I'm self-employed and don't have a medical plan. It was very expensive. Thank goodness I had money put away for retirement, but I had to use most of that. So now I'm at the stage of rebuilding my business." ~ Pedro

"We were lucky. What wasn't covered by the provincial healthcare plan, my husband's drug plan covered. I also had critical illness insurance, which helped with things like flying family in to help out when we needed it." ~ Christa

### How do you know the drugs are working?

Your healthcare team will check how you're doing and how well the treatment is working. At each visit, they'll ask you how you feel and give you a physical exam. They may do medical tests such as blood tests.

You will likely have tests done before starting treatment, such as blood tests, urine tests, imaging scans or heart tests. As you continue with treatment, your team will compare new test results with the old results to see how the treatment is working. Your healthcare team will tell you what the test results mean. Ask questions about anything you don't understand.

Side effects are usually not a sign of whether the drug treatment is working or not. They are different from person to person and from drug to drug.

### How drugs are given

Different drug treatments are given in different ways. Drug treatments may be given at the hospital or cancer clinic, taken at home, or both. How and where they're given depends on the type of cancer you have and which drugs are used. Drug treatments may be given:

- by mouth (orally) pills (tablets or capsules) or liquids that you swallow
- intravenously (IV) drugs that drip slowly through a tube into your vein
- by injection a needle in a muscle in your arm, leg or hip, or just under the skin in your arm, leg or stomach, or in some other part of your body
- topically a cream that you rub onto your skin

Pills, liquids and creams are usually taken at home. Your healthcare team will tell you when and how to take pills and liquids. Read the labels and the information you've been given before you leave the hospital.

Topical chemotherapy treats the cells where the cream is applied, and very little of the drug is absorbed into the body. Sometimes a cream is given for skin cancer. Staff at the hospital will tell you how to apply it at home.

Needles and IV drips are usually given in a hospital or clinic, but you may also be able to take these at home, either by yourself or with a nurse coming in to give you the medicine. Some drugs can be given only intravenously in the hospital or clinic. A nurse will put a thin needle into a vein on the back of your hand or lower arm. The IV needle attaches to a plastic tube with a bag of liquid at the end of it. IV treatment can last from 15 minutes to several hours. Most people get IV treatments as an outpatient (you won't stay overnight). Others may need to stay in the hospital for a few days.

IV treatment can also be given through catheters or ports, sometimes with pumps, so you don't have a needle put into your vein at each treatment session.

- A catheter is a soft, thin tube that goes into a large vein in your arm or your chest. The other end of the tube stays outside your body. The drugs are given through a special needle that fits into the catheter. Catheters are also used to take blood.
- A port is a small disc made of plastic or metal that goes under your skin. It attaches to a catheter that's threaded to a large vein, usually in your chest. A needle goes into the port to give you drugs or to take blood.
- Pumps can be attached to catheters or ports to control how much and how fast the drugs go in. A pump is small, so you can go home with it.

Catheters and ports are put in by a nurse or doctor and stay there until all of your IV drug treatments are done. Catheters and ports are used if you need many treatments over a long period of time or if the drugs irritate the vein. Your nurse will give you instructions on how to take care of your catheter, port or pump.

### Interactions with other medicines

Your healthcare team will ask you about any other medicines or supplements you're taking. These medicines could interact with your drug treatment. They may affect how the treatment works or cause side effects.

Take a written list of your drugs or take the drugs in their original containers with you when you meet with your healthcare team. Include all types of drugs on your list:

- prescription drugs (your pharmacist can give you a list of prescription drugs you're taking or have taken recently)
- over-the-counter drugs (for example, cough syrup or pain or allergy medicine)
- vitamin or mineral supplements
- · herbal remedies and other natural health products

For each drug, vitamin or supplement, your doctor or nurse needs to know:

- the name
- the reason you take it
- how much you take (the dose) and how often
- how long you've been taking it

During treatment, talk to your doctor before taking any new medicine, supplements or herbal remedies.

### Questions to ask about drug treatment

- Which drugs will I get and how will they be given?
- When will my treatment begin?
- Where will I have my treatments?
- How many treatments will I have? How often? Over what period of time?
- Should someone drive me to and from treatments?
- Is there anything I should do before treatment starts, such as visiting the dentist?
- Can I drink alcohol (beer, wine, spirits) during treatment?
- Are there any special foods or liquids I should or should not eat or drink?
- Will treatment affect my sex life or my fertility?

### Chemotherapy

Chemotherapy (sometimes called chemo) uses drugs to destroy cancer cells. Some chemotherapy drugs are given on their own. But more often, several chemotherapy drugs are given together. Chemotherapy may also be given together with other drug treatments.

Today, many different kinds of chemotherapy and combinations of chemotherapy drugs are used to treat cancer. The drugs you get for chemotherapy may be different from the drugs someone else gets. Even if you get the same drugs as someone else, your body may react to them differently. So the way you feel during treatment may be very different from how others feel.

### How chemotherapy works

Chemotherapy drugs travel through the blood to target cancer cells and damage them. The drugs slow or stop the cancer cells from growing, increasing or spreading to other parts of the body.

But chemotherapy doesn't damage only cancer cells – it also damages healthy cells. The healthy cells that chemotherapy damages are usually in the:

- bone marrow (which makes blood cells)
- hair follicles
- lining of the mouth
- digestive system (for example, the throat and stomach)

Damage to these healthy cells can cause side effects, like hair loss, nausea or mouth sores. But different chemotherapy drugs have different side effects.

Luckily, damage to healthy cells is usually temporary. They can repair themselves over time and the side effects often go away once treatment is over.

Your doctor or nurse will explain your chemotherapy treatment plan to you. You may also meet with the pharmacist, who'll tell you about the drugs you'll get and their side effects. You may need some tests before starting chemotherapy.

### How long does chemotherapy last?

Each chemotherapy treatment plan has a different schedule. How long you get chemotherapy depends on:

- your type and stage of cancer
- the goal of the treatment
- the drug or combination of drugs
- your overall health
- how your body reacts to the chemotherapy

You may get chemotherapy in a series of treatment sessions, or cycles. Each treatment session is followed by a rest period, when you won't get any chemotherapy. This rest period gives your body time to recover and build new healthy cells.

I was supposed to have chemo every 3 weeks, but I didn't stay on that schedule very often. Things happen throughout chemo. You get an infection, or you start to get sick and your white blood cell counts go down too low and then they have to delay you. I think only 2 of my 6 treatments were on schedule. So just because they say it's going to be every 2 weeks, every 3 weeks, don't get your heart set on that. ~ Christa

#### What you can expect

You may receive chemotherapy treatments at a cancer clinic, in a hospital, at home or in your doctor's office – or some combination of these. Most of the time, you won't have to stay in a hospital overnight.

I had chemo at home and in the hospital. I'd do my blood work the day before at the hospital, then start the cycle with an IV in the hospital and spend about 4 or 5 hours there. Then they gave me a series of pills and prescriptions that I would take over the next couple of weeks. Then a week with no pills, then the cycle would start again. ~ Jackson

Before each treatment session, you will likely see your doctor or nurse and have blood tests and a physical exam. Sometimes you can have these tests in your home or in a clinic near you a day or 2 before your treatment.

Once the tests show that you're in good shape to have chemotherapy, a pharmacist will prepare your drugs. You may also get some medicine before chemotherapy that prevents nausea or allergic reactions – sometimes you'll take this the day before. The nurse may also give you fluids that help some drugs work better. If your treatment is taken by mouth or is a cream, you may pick up your drugs at the pharmacy and take them at home.

It can take a while to prepare your treatment. If you get the treatment in a hospital or clinic, bring something to help pass the time. You may also want to bring drinks and snacks. You'll usually get chemotherapy while sitting in a comfortable chair or lying on a bed. Your nurse will put in an IV needle or attach it to a port or catheter if you have one.

When the chemotherapy session is done, the nurse will take out the IV and talk with you about possible side effects, including which side effects you should report right away and which ones can wait until your next appointment.

Ask questions if you're not sure about anything or you're worried. Your healthcare team is there to help and support you.

Side effects from chemotherapy can happen any time during, immediately after or a few days or weeks after chemotherapy. Possible side effects include nausea and vomiting, constipation or diarrhea, fatigue, appetite changes, hair loss, a sore mouth or throat, memory changes, and muscle and nerve problems.

Side effects can usually be reduced or managed and can sometimes be prevented. Tell your doctor about the side effects you're having. You may need to change the dose or type of chemotherapy you're taking if your side effects are severe. Your doctor may also prescribe supportive drugs, like antinausea medicine, to help. Side effects usually go away once chemotherapy is done, but some may be permanent.

> My cancer clinic offered a "chemo school" for everyone who was going to be starting chemo for all types of cancer. It was about an hour and a half long, and it pretty much explained how chemo works and everything that was going to happen. That was really useful. ~ Christa

### Safety precautions

Chemotherapy drugs are very strong. It takes a few days for your body to get rid of the drugs. During that time, your body fluids (such as urine and vomit) have very small amounts of the drugs in them. Once this waste is outside your body, it can damage or irritate your skin and be harmful to other people and pets around you.

#### > TIPS

- Keep chemotherapy medicine out of reach of children.
- Use the toilet sitting down (both men and women). This cuts down on splashing.
- Flush the toilet twice with the lid down after using it. Consider wearing gloves to clean the toilet seat after each use.
- Wash your hands with soap and warm water after using the toilet. If possible, use a separate toilet for a few days after treatment.
- Wear waterproof, throw-away gloves when cleaning up body fluids like vomit.
- Sheets and clothing that have body fluids on them should be washed separately from other clothes and laundry. You may be told to wash clothes twice. Wear disposable gloves when handling laundry during this time. If the soiled laundry cannot be washed right away, seal it in a plastic bag until you can wash it.
- If you use disposable adult diapers, underwear or sanitary pads, seal them in plastic and throw them out with the regular trash.
- Use a condom during sex. You need to protect your partner, since there may be some chemo drugs in semen and vaginal fluids during and just after your treatment.

Following these precautions when you have chemotherapy will make things safer for you and the people around you.

### Hormonal drug therapy

Hormones are chemicals made naturally in the body or artificially in a lab. They travel in the blood and control the activity or growth of certain cells. Some cancers need hormones to grow. Hormonal therapy can slow down or stop the growth of the cancer cells or kill these cells. In some cancers, hormonal therapy may work as well as chemotherapy or better than chemotherapy.

### How hormonal drug therapy works

Hormonal therapy adds, blocks or removes hormones from the body to slow or stop the growth of cancer cells that are dependent on hormones. Different types of hormonal therapies treat different types of cancer. And different hormonal drugs work in different ways.

Hormonal drug therapy is often combined with other cancer treatments. Sometimes it's used before or after other treatments.

Your healthcare team will check to see if you are a good candidate for hormonal drug therapy. They will choose the type of hormonal drug therapy and suggest how it should be given. The length of treatment depends on the type of cancer you have and your response to treatment. The drugs may be used for only a short time or for as long as the drugs are working.

### What you can expect

Hormonal therapy drugs can be given as pills that you take at home or as injections you get in your doctor's office or clinic. Sometimes both pills and injections are used.

Hormonal therapy drugs affect hormone levels throughout your whole body and may cause side effects. Possible side effects include nausea and vomiting, swelling or weight gain, fertility problems and less interest in sex. Women may experience hot flashes, breast swelling and treatment-induced (early) menopause or menopausal symptoms. Men may have temporary or permanent difficulties with erections as well as hot flashes, breast swelling and fatigue.

I started on hormonal therapy after surgery and chemo for breast cancer. The drugs have put me into early menopause. It's been really rough on my body, but I'm coping a bit better now. ~ Christa

Side effects can usually be reduced or managed. They often start to go away as your body gets used to the change in hormone levels. Tell your doctor about the side effects you're having. You may be able to change the time of day you take your medicine, the dose or the type of medicine to help you cope more easily with the side effects. Side effects usually go away once hormonal drug therapy is done, but some may be permanent.

### Targeted therapy

Targeted therapy uses drugs to target specific molecules (for example, proteins) that help cancer cells grow. The drugs stop the cancer cells from growing and spreading but limit the harm to healthy cells.

### How targeted therapy works

Targeted therapies use many different types of drugs to target different molecules. Each drug works differently. Some examples are:

- Tyrosine kinase inhibitors block certain proteins that help cancer cells grow.
- Apoptosis-inducing drugs help destroy cancer cells. These drugs can help chemotherapy work better.
- Monoclonal antibodies bind to proteins that are specific to cancer cells to destroy them or slow down their growth.
- Hormonal drug therapy is also a targeted therapy because it targets cancer cells that contain specific hormones.
- Immunotherapy can be considered a targeted therapy because it uses a person's immune system to find and destroy specific cancer cells.

### What you can expect

Targeted therapy may be used alone or together with other cancer treatments. Some targeted therapy drugs are taken as pills, while others are given by needle into a vein. Some targeted therapy drugs must be given in the hospital. Others can be taken at home. You may get targeted therapy in a series of treatment sessions, or cycles. Each treatment session is followed by a recovery period.

In general, the side effects from targeted therapy are fewer and less severe than side effects you may experience with chemotherapy. Which side effects you have will depend on the drug and dose you're getting. You may experience flu-like symptoms, diarrhea or fatigue. Some people may get skin problems including redness, itching, dryness or a rash. Talk to your healthcare team about which side effects you may have with the therapy offered.

### **Supportive drugs**

Supportive drugs are sometimes given along with cancer treatments. Some supportive drugs help protect cells and organs from damage caused by treatment. Others help reduce certain side effects or even prevent them from happening.

These are some of the supportive drugs used:

- Anti-emetics help reduce or prevent nausea and vomiting. There are many different antinausea drugs. They may be given by injection or as pills, suppositories or skin patches. They may be taken before or after chemotherapy.
- Bisphosphonates help protect your bones from pain or weakness caused by cancer or cancer treatments. Bisphosphonates may be given as pills or by injection and may cause side effects – such as more pain at first, problems digesting food, flu-like symptoms or changes in kidney function.
- Colony-stimulating growth factors help the bone marrow make red or white blood cells or platelets. They are given as injections just under the skin.
- Steroids may be used with drug treatments to help them work better. They may be given by IV or taken as a pill. Steroids can also help reduce allergic reactions to certain treatment drugs, to control pain and nausea or to help improve your appetite. But steroids can cause side effects, such as stomach upset, changes to your blood-sugar levels, increased appetite or changes to your mood.

Tell your healthcare team about any side effects you have. There may be a supportive drug that can help you cope.

## Cancer treatment at home



I'd get an IV in the clinic on a Tuesday and then take a week of pills at home, then get another IV in the clinic and another week of pills at home. And then 2 weeks off to recover. I had to take something like 30 or 32 pills a day, some in the morning, some in the afternoon, some with food, some on an empty stomach. I realized that my mind was feeling a little boggled and I wasn't sure I could keep track. So I got a notebook, a scribbler, and I wrote down all of my pills and when I was supposed to take them. And I would check them off, so that by the end of the day I knew I had taken everything. I did that for 6 months. ~ Diya

More and more drug treatments for cancer are being taken at home. Your healthcare team will explain to you when and how to take your pills or injections. But sometimes it can be hard to stay on your drug treatment plan when you're doing it on your own.

Here are things you can do to make it easier to take your medicine at home.

- > TIPS before starting cancer treatment at home
  - Get written instructions. Your nurse or pharmacist should give you clear, easy-to-understand instructions to take home with you. Instructions usually include information about what each medicine looks like, when and how often to take it, and whether you need to take it on an empty stomach or with food or liquid. If your medicine is taken as an injection, the instructions may include drawings to show you how to store and use the medicine.
  - If English is your 2nd language, write the instructions in your native language. If you have poor vision, create your own label by writing the medicine's name and instructions in a larger text. Braille labels are also available from most pharmacies.

- Ask any questions you have while you're with your healthcare team. Write down the answers or ask someone to take notes for you.
- Understand why you're taking the medicine. Knowing why you're taking it can help you to continue taking the drug and get you through the side effects.
- Know what to expect. Find out what side effects you may have and when, and what you can do to manage them.
- If you're taking pills, it may help to use a pill box to keep them organized. But check with your pharmacist first. They may tell you to keep your cancer medicines in their original containers.

#### Know what to do if you miss a dose

At the start of your treatments, ask your healthcare team what you should do if you forget to take a dose of your drug. For example, if you forget to take a pill in the morning, ask if you should take it later in the day or wait until the next day.

### > TIPS taking cancer treatment at home

- Take your medicine exactly as you were told to. Always take the prescribed dose at the right time. Follow the instructions about taking the drug before or after meals or with liquids.
- Wash your hands with soap and water before and after taking your medicine.
- If you have to take medicine during the night or when you nap, set an alarm so that you don't miss a dose. If you're taking pills, put the dose and a glass of water on your bedside table so you don't have to get up.
- If you take your medicines only once a day, check with your pharmacist or nurse about whether you can take them just before bedtime to avoid some side effects like nausea.
- Make taking your cancer treatment a part of your usual routine. If you take your drug daily, take it at the same time as another activity you do each day, like brushing your teeth in the morning. If you take your medicine once a week, choose a day and mark it on your calendar. Calendars on your computer or smartphone can give you automatic reminders.
- Keep a drug diary. Record each dose you take and when. You may also want to record any side effects you think the drug may have caused. Bring the diary to follow-up visits with your doctor.
- Plan ahead when going on a trip. Take along your medicine in its original container. For air travel, pack your drugs in your hand luggage in case your checked luggage is lost. Take extra medicine in case you stay longer than expected. You may also want to take a note from your doctor explaining that you have been prescribed the drugs.

If you need injections, you may have to go to a hospital or cancer clinic. But some injections can be taken at home. A nurse may come to your home to give them to you or to teach you and your family how to give them.

#### > TIPS taking injections at home

- Check the syringe to make sure you have the correct dose.
- Before injecting, wipe your skin with a sterile alcohol swab. Let the area dry for 30 seconds before injecting.
- If you're worried about pain or discomfort from the needle, ask your healthcare team about using an anesthetic cream to numb the skin before an injection.
- If the needle touches anything that isn't sterile before you use it, throw it away and start over with a new needle.
- Use a different place on the body for each shot. For shots under the skin (subcutaneous injections), use a place at least 2.5 cm (1 inch) away from the place you used before.
- For shots into a muscle (intramuscular injections), ask your healthcare team for a picture or chart of safe places on the body.
- Watch for signs of infection, including redness, warmth, swelling, pain or oozing at injection sites or a fever of about 38°C (100°F) or higher.
- Be careful around used needles and syringes. Get a needle disposal box from your pharmacist or hospital. Ask the pharmacist for information on how to return used needles.

- > TIPS especially for caregivers
  - Learn how to give the medicines if the person you're caring for can't do it.
  - Help keep track of when to take the next dose.
  - If you help with shots, be careful to not stick yourself with the needles. Before you start the injection, have the used needle disposal box nearby. Drop the needle and syringe into the box as soon as you're finished.
  - Know who to call in case you have questions or if there's an emergency. Keep phone numbers for the cancer clinic and the healthcare team nearby.

#### When to call the healthcare team

- You are about to run out of your medicine and need a refill.
- You spill or lose medicine, miss a dose or vomit a dose.
- Someone else takes your medicine.
- You have redness, warmth, swelling, drainage, pain or burning at an injection site.
- You have a fever of about 38°C (100.5°F) or higher.
- You have uncomfortable side effects, such as nausea, vomiting, diarrhea or pain.
- You can't take your medicine for any reason.

*"I always felt that if I had a question at home I could just call the nurses at the chemo clinic. And I did, a lot. I have all the phone numbers. I was able to call the pharmacy too. Whatever I needed, I could always call."* ~ Christa

# Managing side effects


Any medicine can have side effects, but it's hard to know if or when they might happen to you. This is especially true for cancer drugs. Which side effects you may have depends on:

- your treatment schedule
- the drugs you get
- how your body reacts
- your general physical health

Different drugs cause different side effects and everyone reacts differently. A certain drug may make one person feel sick, while someone else may feel nothing at all.

Researchers are always testing new cancer treatments that have fewer side effects. So some types of newer drugs are easier to cope with than drugs used in the past. And today there are also more drugs available that help manage side effects.

You know, in the movies, everyone with cancer is so sick all the time. But there are newer treatments now that have fewer side effects, and the images haven't caught up with that. ~ Christa

Your healthcare team will explain which side effects are more likely to happen and when they may start. They'll suggest ways to deal with any side effects you may have.

You and your healthcare team can better manage your side effects if you keep track of them. Keeping track of your side effects can help you:

- notice when a new side effect appears or something unexpectedly gets worse
- decide with your doctor if you need to change your treatment or dose
- be able to continue to take your drugs

### When side effects happen and how long they last

Side effects can happen any time during your treatment. Some may happen as soon as you start taking the drugs. Others may appear a few days later or may not start until after you've taken the drugs for a while.

Some side effects can cause other side effects or make them worse. For example, if you have trouble sleeping, you'll be very tired. Being tired can make it harder to cope when you're feeling afraid or anxious. Tell your healthcare team about all the side effects you're experiencing. Helping to manage one problem may also help relieve others.

Most side effects go away after treatment is over, but others may take longer to go away or may be permanent.

### Questions to ask about side effects

- What side effects can I expect right away?
- What side effects can I expect later?
- How serious are these side effects?
- How long will these side effects last?
- Will all the side effects go away when treatment is over?
- What can I do to manage or ease these side effects?
- What can my doctor or nurse do to manage or ease these side effects?
- When should I call my doctor or nurse about these side effects?

If you have the slightest change, tell your doctor. If that change persists without any relief, tell your doctor. If they don't listen, tell another doctor. Tell your GP. Tell your oncologist. Tell your chemo oncologist. Tell the nurse. Make sure that it's being dealt with. At my cancer centre, they always said if I couldn't handle it, to call and come in. Use the hotline. I did. I called, and I went in when I needed to. ~ Pedro

### ALERT – Allergic reaction

Signs of a life-threatening allergic reaction to a treatment drug include:

- wheezing or trouble breathing
- developing sudden or severe itching
- breaking out in a rash or hives
- swelling of the face, eyes, tongue or throat

If you have any of these signs, go to your nearest emergency room.

# Anemia

Anemia is when you don't have enough red blood cells. Red blood cells carry oxygen to all parts of your body. When you don't have enough, your body tissues don't get enough oxygen to do their jobs properly.

Some treatments can reduce your red blood cells and cause anemia. If you have anemia, you'll be very tired and may be dizzy or short of breath. You may have pale skin and feel weak or cold. The symptoms will go away as your body produces more red blood cells. Anemia may happen in between treatment sessions or once treatment is done. If you feel very tired, tell your healthcare team right away.

If your body needs help to build up your red blood cells, your doctor may:

- change the drug dose you get in each treatment
- offer you medicine to increase your red blood cells
- suggest a blood transfusion
- delay treatment
- > TIPS
  - Move slowly to avoid getting dizzy. When you get out of bed, sit on the side of the bed for a while before you stand up.
  - Eat foods that are high in iron, such as green, leafy vegetables, liver and cooked red meats. A dietitian can help you choose foods that may help you feel better.
  - Limit some of your activities. Do only what you have to or what is most important to you.

# Anxiety

Anxiety is feeling afraid, overwhelmed or very worried. Feeling anxious when you have cancer is normal, but if your anxiety becomes worse and starts to take over your thoughts and your daily life, tell your healthcare team. They can recommend someone you can talk to or give you medicine that can help.

Some anxiety can be caused or made worse by certain chemotherapy drugs as well as some hormonal therapies, steroids and pain medicines.

### > TIPS

- Talk with someone you trust.
- Write down your thoughts or talk to other people with cancer.
- Try relaxation techniques or complementary therapies, such as acupuncture, massage, meditation or yoga.

Meditation helped me through all of it. I really tapped into meditation and yoga, into mindful breathing, to get through. I did certain breathing techniques before and after surgery. ~ Christa

It can also help to:

- eat well
- get enough sleep
- be active
- limit or avoid caffeine and alcohol
- spend time with people who make you laugh

### **Appetite changes**

My wife experimented with what we called "calorie cocktails," these thick milkshake concoctions designed to keep my calorie count up. I'd have a pint glass at breakfast and another at lunch and it would often take me a couple of hours to drink those because of the nausea. Getting enough calories felt like a full-time job. ~ Pedro

You may notice changes to your appetite during treatment. These changes may be caused by your drug treatments. The changes may also be caused by other side effects of your treatment. You may not feel like eating because of nausea or because you have a sore or dry mouth. Fatigue, stress or worry can make you want to eat more or less than usual. You may find that you suddenly like or dislike certain foods. These cravings or dislikes may change from day to day.

Some chemotherapy drugs can even change your sense of taste and smell. Foods may have less taste than usual, taste sweeter than usual or have a bitter or metallic taste.

Food definitely tasted different. There was a very metallic
taste to the food. I found things that I could eat. I was like a pregnant woman. I ate pickles like crazy and salty things, like sardines. I was really into salads with olive oil and balsamic vinegar. Maybe I was attracted to such strong flavours to get past the metallic taste. ~ Jackson

You may lose your appetite or find that you're not interested in eating. Having cancer and being treated for it may mean that your body needs more energy. If you don't meet your body's energy needs with food, you may lose weight.

For other people, weight gain can be a problem. Certain chemotherapy, hormonal drug therapy and supportive drugs may make you gain weight. Your healthcare team can help if this becomes a problem. I gained weight. I think it was the steroids I took before each chemo – at those points I was craving and eating foods that I hadn't eaten in 10 years. I was of the frame of mind that my body was going through a lot of things and if I had a craving for a food I was just going to eat it. I would worry about getting my body back and getting my health back after I was done with this. ~ Christa

#### > TIPS when food tastes different

- Rinse your mouth before and after eating to help clear your taste buds.
- Eat foods cold or at room temperature to reduce strong tastes and smells.
- Use plastic cutlery and glass cooking pots if foods taste metallic.
- Try different foods and seasonings to make food taste better. For example, add spices, try tart foods or add sugar.
- Suck on lemon candies or mints or chew gum to get rid of bad tastes that remain after eating.

I could not use metal cutlery because the metal taste made me sick. So I carried plastic cutlery with me everywhere I went. I would get out my own little plastic fork and knife and spoon. ~ Diya

- > TIPS when you lose your appetite
  - Choose foods and drinks that are high in protein and calories. Eat smaller amounts every couple of hours.
  - Keep quick and easy snack foods in your cupboards so that they're ready to eat when you are.
  - Eat your favourite foods at any time of the day. Eat breakfast foods at suppertime if you feel like it.
  - Eat well when your energy level is highest. Make the most of your good days.
  - Be active if you can. A walk before meals can help your appetite.
- > **TIPS** when you feel hungry and are gaining weight
  - Eat smaller portions and plan your meals around vegetables, fruit, whole grains and legumes, like chick peas. These are low in calories and high in fibre so they help you feel full.
  - · Limit salty foods. Salt causes the body to retain (hold onto) water.
  - Cut back on butter, margarine, mayonnaise and salad dressing. These have a lot of fat and calories.
  - Choose lower-fat milk and dairy products either skim milk or no more than 2% milk fat (MF). Choose hard cheeses with no more than 20% MF.
  - Don't skip meals. This may cause you to overeat later.
  - Be more active if you can. Physical activity can lessen some of the side effects of chemotherapy and can limit weight gain.

# Bladder, kidney and urinary tract problems

The kidneys and bladder take waste from your body, including waste from the drugs you're taking. Some chemotherapy drugs may irritate the bladder or damage the kidneys. They may make your urine change colour, look cloudy or smell different.

You may be asked to give urine and blood samples regularly to check how well your kidneys are working. Kidney and bladder problems usually go away when chemotherapy is over. But sometimes damage to the bladder or kidneys can be permanent.

#### > TIPS

- Drink plenty of fluids. Ask your healthcare team how much fluid you need each day. Try water, juice, herbal teas, caffeine-free soft drinks, broth, ice cream, soup and gelatin. These are all examples of fluids.
- Drink fluids in small sips throughout the day. Drinking too much at one time may upset your stomach.
- Empty your bladder often. This may help prevent urinary tract problems.
- Check with your healthcare team before drinking wine, beer or other alcohol. Alcohol can make you dehydrated and can interact with certain medicines. It may change how the medicine works or cause side effects.

# What to watch for – Signs of a bladder or kidney problem or a urinary tract infection

- a burning feeling when you urinate
- · a reddish colour or blood in your urine
- the need to urinate often
- not being able to urinate at all
- a feeling that you must urinate right away
- a fever or chills (especially chills that make you shake)

Call your healthcare team if you have any of these signs.

# **Bleeding and bruising**

Some chemotherapy drugs and targeted drug therapies can cause your body to make fewer platelets. Platelets are cells that help the blood to clot. Without enough platelets, you may get bruises even when you haven't bumped into anything. You may bleed easily from your nose or in your mouth or get a rash of tiny red dots.

Your platelet levels are checked during treatment. If you don't have enough platelets, you may need a platelet transfusion or your doctor may change your drug dose.

Some over-the-counter medicines, such as cold remedies, pain relievers, vitamins or herbal remedies, can also affect your platelets. Talk to your healthcare team before taking any over-the-counter medicines. Also let them know if you're thinking of using a complementary therapy that uses pressure or massages your body, such as acupuncture, shiatsu, yoga or chiropractic therapy.

- Use a very soft toothbrush or cotton swabs to clean your teeth. Soften the brush with hot water before each use.
- Be very gentle and careful when flossing. Avoid areas that bleed easily. Your healthcare team may recommend that you not floss until platelet counts return to normal.
- Use a lip balm to keep lips moist and prevent cracking.
- Be very gentle when blowing your nose.
- Use an electric shaver instead of a razor.
- Use pads instead of tampons during menstruation.
- Avoid contact sports and other activities that might result in an injury.
- Be extra careful when you use a knife, scissors or any sharp tool.
- Wear gloves if you're working in the garden.
- Take steps to prevent constipation to avoid rectal bleeding.

#### What to watch for - Signs of a low platelet count

- bruising easily or red spots under your skin
- bleeding from your gums or nose
- · a lot of bleeding or long-lasting bleeding from a small cut or injection site
- · blood in your urine, which may look pink, red or brown
- blood in your stool or black-coloured stool
- · vomiting blood or vomiting something that looks like coffee grounds
- vaginal bleeding that is different from and lasts longer than your normal menstrual period

Call your healthcare team if you have any of these signs.

# Blood pressure changes

Some drugs can make your blood pressure go up or down. This is not a common side effect. You probably won't notice if your blood pressure is a bit higher or lower than normal. But high blood pressure increases your risk of headaches, heart problems, stroke and kidney problems. Low blood pressure increases your risk of dizziness, falling and fainting. Your healthcare team will check your blood pressure regularly during treatment.

#### > TIPS

- Get up slowly so you don't get dizzy.
- Stay as active as you can.
- Make healthy food choices and drink less alcohol and caffeine.
- If you smoke, get help to quit.
- Try to reduce stress it can cause your blood pressure to rise.

# Breast swelling or tenderness

Some hormonal drug therapies can cause breast swelling or tenderness. This side effect can happen in both men and women. It usually goes away when treatment is over. Some people may get a low dose of radiation to the breast tissue to prevent breast swelling or tenderness before hormonal drug therapy starts.

# Constipation

Constipation means you're not having bowel movements as often as you used to. Your stool becomes hard and dry, and having a bowel movement can be difficult or painful.

Changes in your normal bowel movements may be caused by the cancer itself, drug treatments for cancer or other drugs you're taking to manage nausea, diarrhea, depression, blood pressure changes or pain. Constipation can also happen because you've changed your eating habits, you're drinking less liquid or you're less active.

If you're constipated, your healthcare team may suggest a stool softener or laxative. Talk to your healthcare team before taking an over-the-counter laxative.

> I took stool softeners for constipation. They worked. Sometimes it took a couple of days, and a lot of pills, but they did work. ~ Pedro

- Add more fibre to your diet a little at a time. Examples of foods with high fibre are whole grain breads and cereals, vegetables, fruit (including dried fruit), legumes, seeds and nuts.
- Drink plenty of liquids throughout the day. Try water, fruit or vegetable juices, teas and lemonade. Hot or warm liquids like cocoa, tea or lemon water can also help.
- Be more physically active if you can. Just taking a walk can help.

# Depression

Depression means feeling sad, hopeless, tearful or discouraged or feeling the loss of pleasure in nearly all activities. All of these feelings can come and go. But it could be a sign of clinical depression if:

- the feelings become worse or last a long time
- you also feel worthless or guilty or have regular thoughts of death or suicide
- you also have changes in appetite, weight or sleep or have a hard time thinking
- the feelings start to take over your thoughts and negatively affect your daily life

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

#### What to watch for – Possible signs of depression

- feeling hopeless or worthless
- crying a lot
- not sleeping or sleeping too much
- overeating or having no interest in eating
- thoughts of harming yourself

Talk to your healthcare team if you have any of these signs of depression.

- Talk to someone who's had a cancer experience similar to yours – it can help you cope with depression and reduce your fears.
- Share your worries and concerns with your healthcare team. Try not to keep your feelings inside.
- Let family and friends help you.
- Look to your spiritual faith for comfort to keep you going in difficult times.
- Eat well and be as active as possible.
- Follow a regular sleep schedule.
- Avoid alcohol it can make depression worse.

# Diarrhea

Diarrhea means you have soft, loose or watery stools more than 3 times in a day. You may also have cramps and bloating or feel an urgent need to have a bowel movement.

Some drugs can cause diarrhea. Diarrhea can also be caused by infections or drugs used to treat constipation. It's important to tell your healthcare team if you have diarrhea because it can cause other problems, such as fatigue, weight loss or dehydration (the loss of too much water from the body). Talk to them before taking any over-the-counter medicine for diarrhea. They can tell you what to take and when, depending on what's causing the diarrhea.

### > TIPS

- Eat small meals and snacks often throughout the day.
- Drink plenty of fluids that are non-carbonated and caffeine-free, such as water, sports drinks and clear broth. This helps prevent you from becoming dehydrated.
- Limit greasy, fried, spicy and sugary foods.
- Avoid sugarless gum and candies made with sorbitol because it acts like a laxative (makes you have a bowel movement).
- Stay away from foods that are natural laxatives, such as prunes, prune juice, rhubarb and papaya.
- Choose foods that are low in fibre white bread and pasta, ripe bananas, mashed or baked potatoes without the skin, meat, poultry and fish.

#### What to watch for

Talk to your doctor if your diarrhea:

- lasts for more than 24 hours
- · causes pain in your abdomen (stomach or middle area)
- causes cramping

Keep a record of the number, amount and appearance of your bowel movements for your doctor. And tell the doctor if you also have a dry mouth, dizziness, less urine than usual or dark urine.

# Dry mouth, throat and nostrils

All of a sudden you realize how many foods are really dry. So what are you going to do about it? I have to process virtually every meal with skim milk. As a result of that I can eat bread, I can even eat toast when I drink milk with it. Peanut butter is my favourite food. ~ Pedro

A dry mouth means you don't have enough spit (saliva) to keep your mouth wet. Talking, chewing and swallowing can be hard when your mouth and throat feel dry. Some drugs can make your mouth, throat and nostrils very dry.

If you have a dry mouth, throat or nostrils, your healthcare team may suggest artificial saliva for your mouth or products to keep your nostrils moist.

My nostrils got very dry and cracked. I had to use some sort of moisturizing cream on them. ~ Christa

- Sip on club soda or ice water to help loosen saliva. You can also try sucking on ice chips or popsicles.
- Take sips of fluid when you eat to make chewing easier.
- Avoid alcohol and tobacco.
- Use vegetable juices, broth or milk to blend with food to make it easier to swallow. You can also blend foods into a purée.
- Keep your mouth clean by using a soft-bristle toothbrush and rinsing your mouth throughout the day.
- Use a cool-mist humidifier at night.

### Fatigue

By the 3rd cycle of chemo, I started feeling drained and tired. I would just sit down in a chair, and my eyes would close and I'd fall asleep anywhere, with any amount of noise. It didn't matter. I'd go out with my wife and we'd be among other people, and I would just go off into the living room and sit in a chair by myself and have a little snooze. But I also had a really good community around me of my friends, and everybody knew what I was going through, so it was fine. ~ Jackson

Fatigue is a feeling of being very tired. You may feel weak, heavy or slow, and you may have trouble concentrating or remembering things. Fatigue is different from feeling tired after a long day. It may not get better with rest or sleep.

Chemotherapy, hormonal drug therapy and targeted therapy can all cause fatigue. Other things can add to your feeling of fatigue, such as low blood counts, the effort of going to many medical appointments, and stress and worry. Dealing with other side effects like pain, trouble sleeping and changes to your eating can also make you feel very tired.

Fatigue usually goes away over time after cancer treatment ends. For some people, it can take a long time to go away completely.

Most people experience fatigue during drug treatment. Tell your healthcare team when you feel most tired, when you have energy and if sleeping helps you feel rested or not. It's possible that you may need medicine, a nutritional supplement or a blood transfusion.

#### To help with fatigue

Regular daily exercise such as a brisk walk, building up to an hour per day, is the best way to lessen fatigue. You can push your body to do more as long as you don't get dizzy or have chest pain or a fast heartbeat.

- > TIPS
  - Try to schedule appointments or activities you enjoy when you have the most energy. Write down when you feel most tired and when you have more energy.
  - Plan ahead. Do the things that mean the most to you first. Plan rest periods before activities. Ask about a flexible work schedule or reduced hours if you're still working during your treatment.
  - Drink plenty of fluids, especially water. If your appetite is poor, eat when you feel the most hungry. It helps to have 5 or 6 small snacks throughout the day instead of 3 large meals.
  - Rearrange your home so that many activities can be done on one floor.
  - Ask your healthcare team to suggest exercises or activities that may be right for you. Moderate activity can actually give you more energy.
  - Rest when you need to. Take short naps of 10 or 15 minutes rather than longer naps during the day. Too much rest, as well as too little, can make you feel more tired. Save your longest sleep for the night. If you have trouble sleeping at night, avoid napping during the day.
  - Let others help. Ask friends and family to grocery shop, cook, help clean up or babysit when you feel most tired.
  - Keep in touch by phone, email or social media if you don't have the energy to meet in person.

# **Fertility problems**

Fertility problems for a man mean he can't get a woman pregnant. For a woman, they mean she can't get pregnant or can't carry a pregnancy to term. Some chemotherapy and hormonal therapy drugs can cause temporary fertility problems. And sometimes they can cause permanent fertility problems.

But not all chemotherapy or hormonal drug treatments lead to temporary or permanent infertility – it depends on which drugs you're taking, your age and your general health.

- For men, some drug treatments may cause the body to make less sperm or make damaged sperm. Damaged sperm may not be able to fertilize a woman's egg.
- For women, certain drug treatments may cause the ovaries to stop releasing eggs or to release fewer eggs. For some women, the ovaries start releasing eggs again when treatment ends and their periods return to normal. For others, the damage may be permanent. Damage to the ovaries can cause you to experience the side effects of early menopause. Your healthcare team can help you manage these side effects.

Fortunately, there are many fertility options for both men and women. You can preserve your fertility by freezing sperm, eggs or embryos (an egg fertilized by sperm) until you're ready to try to have children. Fertility preservation lets you decide later whether you want to try to have children.

#### > TIPS

- Plan ahead for a family. If you plan to have children in the future or think you might want to, talk to your doctor before starting treatment so that you have as many fertility options as possible.
- Use birth control. Even if you're planning for a family, it's very important that you use condoms during and after chemotherapy and during hormonal therapy – for safety and to avoid pregnancy. The effects of cancer treatments on an unborn child are not known. Chemotherapy drugs can stay in your system for a while after your treatment has ended, so talk to your doctor about when it's safe to stop using birth control after your treatment is over.

#### If you're pregnant when cancer is found

If you're pregnant when your cancer is found, it may be possible to delay treatment until after the baby is born. If you need treatment sooner, your doctor may suggest waiting until after the first 3 months of pregnancy. In some cases, you might need to think about ending the pregnancy if your doctor feels your treatment cannot wait. You and your doctor will then discuss the risks and benefits of this very personal decision.

### Hair loss

I lost every hair on my body. I even lost my nose hairs and ear hairs, which made my ears so sensitive that you couldn't talk loud in the room with me because it felt like you were screaming in my ear. All my life, my hair was blonde and poker-straight. When it grew back in, it was black and curly. I love the waves. So out of every bad comes a little good, I guess. ~ Diya

Some chemotherapy drugs – but not all – can cause hair loss or thinning of the hair. Some hormonal or targeted therapies can sometimes make your hair thinner or dry. Your healthcare team can tell you if the drugs you're taking may cause your hair to change or fall out.

Hair loss from certain chemotherapy drugs usually starts 2 or 3 weeks after treatment begins. It may start gradually or your hair may come out in clumps. You may also notice that your scalp feels tender. It can take about a week for all your hair to fall out. Hair loss can happen anywhere on the body – your head, eyelashes, eyebrows and body hair (including pubic, chest and underarm hair).

Hair loss is usually temporary. Your hair may begin to grow back while you're still having treatment or it may take 3 to 6 months after treatment to start growing back. Some people find that their new hair is slightly different in colour or texture than before treatment.

- > TIPS before treatment
  - Get a short haircut or shave your head. Use an electric shaver rather than a razor to prevent cutting your skin.
  - Visit a wig specialist. Choose a wig before your hair falls out. That way, you'll be able to find a close match to your own hair colour and style more easily. Ask your healthcare team about wig services near you.

- Ask your insurance company if it will cover the cost of a wig. If not, you can deduct the cost as a medical expense on your income tax return. Some cancer support groups also have free wig fittings and "wig banks."
- Prepare your family and friends. People close to you, especially young children, may need to be reassured when they see that you are losing your hair.

The wig place I went to was fantastic – the lady who helped me was just great. But if I had to do it over again, which I hope I never do, I probably wouldn't have bothered with the wig. I only wore it a few times. I went through my treatments in the summer and it was hot, so I mostly wore scarves and hats. ~ Christa

#### > TIPS during treatment

- Be gentle with your hair. Use a mild shampoo and a soft hairbrush. Put your hair dryer on low heat or let your hair dry naturally.
- Avoid colouring, perming or straightening your hair during treatment. Ask your healthcare team when you can start these activities again.
- Protect your scalp from the sun. A wide-brimmed hat or scarf can help. Use a sunscreen with a sun protection factor (SPF) of at least 30 on your scalp when you are outside.
- Stay warm during cooler weather. Try wearing a scarf, turban or hat.
- Use a satin pillowcase. Satin creates less friction than cotton and may be more comfortable for you when you sleep.
- Talk about your feelings. Hair loss can be hard to accept for some people. Share your fears and worries with your healthcare team, someone close to you or with others who've been there.

# Hand-foot syndrome

Some chemotherapy drugs can cause hand-foot syndrome. The skin on your hands and feet may appear red, may be more sensitive than usual and may tingle or feel numb. The palms of your hands and the soles of your feet can get very dry and begin peeling. This can be uncomfortable and affect your day-to-day activities. Your healthcare team may delay your treatment or adjust your medicine to prevent hand-foot syndrome from getting worse.

### > TIPS to prevent hand-foot syndrome

- Put moisturizer on your hands and feet often, especially in all creases. Or ask your pharmacist or nurse about other things you can use.
- Avoid hot water. Use warm water in the shower or bath instead.
- Avoid doing a lot of activities that cause rubbing or pressure with your hands, such as holding tools, typing on a keyboard, playing musical instruments or driving.
- Do not use Band-Aids on your hands or feet.
- Put your feet up whenever possible.
- Wear loose-fitting clothes and comfortable shoes with cushioned soles. Don't walk barefoot.

#### > TIPS to manage hand-foot syndrome

- Place the palms of your hands or the bottoms of your feet on an ice pack or a bag of frozen peas to help relieve the pain.
- Put gel insoles into your shoes for more cushioning.
- · Soak your hands or feet in Epsom salts and lukewarm water.

### Infections

You're more likely to get infections if you don't have enough white blood cells. White blood cells are part of your body's immune system. They defend your body against viruses and destroy bacteria. Many chemotherapy and some targeted therapy drugs lower the number of white blood cells in your blood.

Your healthcare team will check your white blood cells often during your treatment. If you don't have enough white blood cells, they may suggest:

- a drug to help increase your white blood cells
- an antibiotic to fight infection
- delaying your treatment for a period of time
- a lower dose of drugs

#### ALERT - Watch for signs of infection

- a fever, especially over 38°C (100°F)
- unusual sweating
- a burning feeling when urinating
- a severe cough or sore throat
- chills or shivering

Call your healthcare team right away if you have any signs of infection.

### > TIPS

• Wash your hands often, especially before eating and after going to the bathroom. Carry a small bottle of hand sanitizer for when you can't get to a sink.

I had 2 little kids at home, so we talked to them a lot about handwashing and how it was important to keep me from getting sick. I had a big jug of hand sanitizer right by the back door, and I had a little sign on the back door asking everyone to please wash or sanitize their hands before coming in. Pretty much everyone respected that. ~ Christa

- Avoid crowds, especially during cold and flu season. Stay away from anyone who has a cold, the flu or an infectious disease. Ask people not to visit if they or their family members have a cold, flu or other infection.
- Check with your healthcare team about vaccinations. Depending on your treatment, there may be some vaccinations you should avoid and others you should have.
- Use an electric shaver instead of a razor to prevent cutting your skin.
- Clean cuts, scrapes or burns right away with warm water and soap, and cover with a bandage. Do not squeeze or scratch pimples, or cut, bite or chew the cuticles of your nails.
- Shower or have a bath daily using warm (not hot) water. Gently pat your skin dry rather than rubbing it briskly. Use a moisturizer or oil if your skin becomes dry or cracked to soften it and help it heal.
- Clean your anal area gently but thoroughly after a bowel movement.
- Use medical devices properly. If you have a catheter or port, follow instructions carefully and always wash your hands before handling the device.
- Avoid cleaning up after animals, such as cleaning cat litter boxes or birdcages. Wash your hands after touching animals.

Even if you're very careful, your body may not be able to fight infections when your white blood cell count is low. Check your temperature for a fever at least once a day or as often as your doctor or nurse tells you to. Find out how to reach your healthcare team after office hours and on weekends. If you have to go to a hospital emergency department, tell them that you're being treated for cancer.

#### Flu-like symptoms

Not all flu-like symptoms mean you have an infection. Some targeted therapies and chemotherapy drugs can make you feel like you have the flu. You may feel tired, lose your appetite or have muscle aches, a headache, nausea, a slight fever or chills. Ask your healthcare team if flu-like symptoms are normal with your treatment.

# Memory loss and trouble concentrating

It's normal to have problems with your memory sometimes, like forgetting where you put your glasses or why you went into a room. But you may find that it's harder to concentrate (focus) or remember things since being diagnosed with cancer. Perhaps you're forgetting things more often or can't remember simple things like the name of a good friend. Doing a couple of things at once (multi-tasking) may be hard. You may get easily distracted or confused.

> A couple of times while I was driving at night, I wasn't focused and sometimes I didn't see pedestrians. And I said to my wife, "I think I'm going to take myself off the road at night for a while." It just didn't seem safe. But it got better. Now I do drive at night. ~ Jackson

Memory changes (sometimes called brain fog or chemo brain) can be caused by treatments like chemotherapy and hormonal drug therapy. Memory loss may also be a side effect of other medicines, such as drugs to control pain or nausea, antidepressants, steroids or sleeping pills. Other things that can also affect your thinking are stress, anxiety, depression, changes in routine, fatigue and poor nutrition caused by lack of appetite.

Your memory may improve after treatment is over, but you could notice problems for a year or longer after your treatment. It can help to tell your family and friends what you're going through, so that they understand if you forget things you normally wouldn't.

- Plan activities that need the most concentration for times of the day when you're most rested.
- Keep track of things by making lists. Use a calendar. Put reminders on your smartphone or electronic calendar or use a notebook or organizer. Make lists of the things you want to do or remember.

If I don't write something down, it's just gone. It frustrates my wife to no end. So, part of the new normal is recognizing that you need to do things in a slightly different way. And for me, that means I have to write things down. ~ Pedro

- Ask a family member or friend to help you remember things. They can go with you to appointments and listen, take notes and ask questions.
- Say it out loud. Saying things out loud helps you organize your thoughts better, slow down and process more deeply. You will be more likely to remember what you set out to do.
- Try to be more active. It can help you be more alert.

### Menopausal symptoms

Menopause is a time in a woman's life when her hormone levels drop and she stops getting her period. Most women start to notice changes in their late 40s to early 50s.

Some drug treatments for cancer, like chemotherapy and hormonal drug therapy, can cause early menopause (also called treatment-induced menopause). Depending on your age and the drugs you're taking, menopause caused by cancer treatments may be permanent or temporary. For some women, hormone levels and monthly periods come back after treatment is done. The younger you are, the more likely you are to have your period again.

Menopause caused by cancer treatment happens more suddenly than natural menopause. You may experience:

- mood changes, irritability or depression
- vaginal dryness (which can make it painful or uncomfortable to have sex)
- loss of interest in sex
- hot flashes and sweating (often made worse by taking hormonal drugs such as tamoxifen)

- problems sleeping
- memory loss and problems with concentration
- loss of bone density (osteoporosis)
- weight changes

#### For men

Men do not go through menopause, but men who have hormonal treatment for cancer may have similar symptoms (for example, hot flashes). Some of the information in this section may help men as well.

### > TIPS

- Choose lightweight clothing. Wear it in layers if you're having hot flashes so you can take layers off.
- Avoid caffeine and alcohol.
- Be as active as you can.
- Eat well and maintain a healthy body weight.
- Use a water-based vaginal lubricant when having sex.
- Use an estrogen suppository, cream or gel around the vulva. This may help with severe dryness.

#### What to watch for - Vaginal dryness and infection

Vaginal dryness can make sex uncomfortable or painful, and you may be more likely to get bladder or vaginal infections. Call your healthcare team right away if you think you have an infection.

### Muscle and nerve problems

The thing that's really bothered me the most is my feet. I used to be a runner, but I can't anymore because you just feel like you're falling over. Now my toes and the front of my feet are numb. In the wintertime I put a heating pad in my bed because they just feel numb and cold, and that makes it difficult to fall asleep. But this year I'm going to try skiing again. I found that you can actually buy boots that have heaters built in. That might be an option for me. ~ Jackson

Some drugs can make your muscles feel weak or make you lose your balance. They can affect your nerves, causing numbness or a tingling (pins and needles) or burning feeling in your hands or feet. It may be hard to do up buttons or open jars. Your legs may feel numb and you may have trouble walking. Some people may have sudden, sharp or stabbing pain.

Usually, these side effects are temporary. But for some people, they may last for several months after treatment is over or be permanent. Let your healthcare team know if you have any symptoms of weak muscles, numbness or tingling in your fingers or toes. They may decide to change your treatment or dose to help prevent permanent nerve damage.

The pain in the balls of my feet was so violent that I had trouble sleeping. The only thing that would stop the pain was to get up and stand. I couldn't lie flat for long periods of time. They reduced my chemo to deal with the side effects. ~ Pedro

### > TIPS

- Be careful with sharp objects so you don't cut yourself.
- Move slowly and use handrails when you go up and down stairs.
- Use no-slip mats in the bath and shower.
- In your house, keep all areas clear so you don't trip.
- Protect your feet with shoes, socks or slippers.
- Use gloves when taking food out of the freezer.
- Test the water temperature with a thermometer before taking a bath.
- Check the bottom of your feet for cuts or other wounds.

#### What to watch for - Signs of muscle or nerve problems

- tingling, burning, weakness or numbness in your hands or feet
- feeling colder than normal
- sensitivity to hot and cold or being less able to feel hot and cold
- pain when walking
- weak, sore, tired or achy muscles
- · trouble picking up objects or buttoning your clothes
- shaking or trembling
- being clumsy and losing your balance
- hearing loss

Call your healthcare team if you have any of these problems.

### Nausea and vomiting

My vision going into chemo was that I'd just be vomiting all the time. So I was surprised when they told me that if I got sick more than 2 or 3 times I needed to get to the hospital, that the antinausea drugs were so good now that I shouldn't be getting sick. ~ Christa

You might be worried about chemotherapy and other drug treatments making you feel sick (nausea) or causing you to throw up (vomiting). Some chemotherapy, hormonal drug therapy and targeted therapy drugs can cause nausea and vomiting. Nausea can happen right after you start taking the drugs or several hours or days later. Pain medicine, constipation or dehydration may also cause nausea.

It's easier to prevent nausea than to treat it once it starts. Talk with your healthcare team before treatment begins about your risk of experiencing nausea. They can prescribe antinausea drugs to prevent or reduce this side effect.

There are many different antinausea drugs. They can be given by injection or as pills, suppositories or skin patches before or after treatment. Different antinausea drugs work for different people, and you may need more than one drug to feel better. Work with your healthcare team to find the drugs that work best for you.

Sometimes antinausea drugs can have side effects of their own, such as sleepiness, general fatigue or problems concentrating.

- Instead of big meals, eat smaller meals and snacks more often throughout the day.
- Nibble on dry foods like crackers, toast, dry cereals or bread sticks every few hours during the day.
- Avoid foods that are very sweet, greasy, fried or spicy or that have a strong smell.

- Sip water and other liquids (flat ginger ale, sports drinks, broth) throughout the day. Cool liquids may be easier to drink than very hot or very cold liquids.
- Let other people do the cooking.
- After eating, avoid lying down for at least half an hour. Relax sitting up or with your head and shoulders raised on pillows.
- If you feel nauseated, take slow, deep breaths through your mouth.
- Distract yourself by listening to music, watching a movie or talking to family or friends.
- Consider relaxation techniques or complementary therapies, such as deep breathing, acupuncture or guided imagery.

Some people feel nauseated before treatment because they feel anxious and expect to be sick. This is called anticipatory nausea. To avoid it, try relaxation techniques or antinausea medicine.

> TIPS for avoiding anticipatory nausea

- Lie down in a quiet place for 15 to 30 minutes before treatment begins.
- Place a cool cloth over your eyes before you receive your chemotherapy drugs.
- Talk to someone. It can keep your thoughts away from feeling sick.

#### ALERT – What to watch for

If you can't stop vomiting or can't keep liquids down for more than 24 hours after your treatment (even if you're taking antinausea drugs as directed), call your healthcare team.

#### Cannabis (marijuana)

Cannabis is legal in Canada. But research studies do not yet give a clear answer about the effectiveness of smoking cannabis to relieve pain. Talk to your healthcare team about the benefits and risks of using cannabis.

# Sexual problems

I had a lot of other things going on, and sex was pretty low down on my list. It was a pretty dull year in that respect, but it's getting better, slowly. ~ Jackson

Some drug treatments, such as chemotherapy and hormonal drug therapy, can cause sexual changes. For women, changes in hormone levels may lead to vaginal dryness and early menopause. Men can get erectile dysfunction (impotence) from changes in hormone levels, reduced blood supply to the penis and damage to the nerves that control the penis.

You may find that your interest in sex and intimacy changes during treatment and for some time after treatment. The physical and emotional stress of having cancer and treatment can also affect your sexuality. You might:

- be worried about changes in your appearance
- be coping with side effects of treatment, including fatigue and pain
- feel anxious about your health, family or finances

Remember that there are many ways to express your sexuality. Touching, holding and cuddling may be all that you want for a while. Try to talk openly about how you're both feeling. Together, you and your partner can discover your changing needs and find out what gives both of you pleasure. If talking to each other about sex and cancer is hard, a counsellor may be able to help you talk more openly. You feel like crap, right, so you don't really feel like the sexiest being on earth. Still, we kept things going as best we could because that's part of the relationship as well and we didn't want to lose it. ~ Christa

Treatment may bring different challenges for people who aren't in a relationship. Being single and dealing with sexual changes can be especially difficult. Having a network of friends and family can help you feel less alone. If you're having a hard time on your own, share your feelings with a close friend or a counsellor.

#### Want more information?

Our booklet *Sex, Intimacy and Cancer* has more details on managing possible problems for men and women.

### Skin and nail changes

Some chemotherapy drugs can cause skin rashes, redness, itching, dryness, peeling or acne-like blemishes. A rash usually starts within a few weeks of starting treatment. It may start as a redness or a warm feeling like a sunburn. The colour of your skin may become darker. Some drugs may make your fingernails and toenails become darker, yellow, brittle or cracked. These skin conditions usually go away once treatment is over.

Skin rashes caused by targeted therapy are most likely to appear on the face, neck, upper back or chest. After a few days pimples may appear and your skin may be tender and itchy. The pimples may look like acne, but they aren't. Your healthcare team can suggest a treatment specific to your rash.

Both chemotherapy and targeted drug treatments can also make your skin very sensitive to the sun.

- > TIPS
  - Wash often with a mild, unscented soap to reduce your risk of skin irritation and infections.
  - Have a bath in warm water instead of hot. Hot water dries out your skin. Gently pat your skin dry rather than rubbing it.
  - Use a moisturizer or oil to soften your skin and help it heal if it becomes dry or cracked. Look for moisturizers that don't have alcohol in them. Your healthcare team or pharmacist can suggest some.
  - Do not use anti-acne skin products. They have chemicals that can dry out your skin.
  - Do not squeeze or scratch pimples.
  - If your skin feels itchy or irritated, instead of scratching, try gentle massage or pressure on the area or rub it with a soft cloth. You can also apply a cool, damp cloth to itchy areas.
  - Keep your nails short and clean. Use cuticle cream or cuticle remover on your nails instead of cutting the cuticles.
  - Protect your nails by wearing gloves when washing dishes, gardening or doing other work around the house.
  - Use an electric shaver instead of a razor to prevent cutting your skin. If you do cut or scrape your skin, clean the area at once with warm water and soap.
  - Protect your skin from the sun by wearing a wide-brimmed hat and clothing that covers your arms and legs. Apply sunscreen with a sun protection factor (SPF) of at least 30 when you go outside. You may need to use something like zinc oxide to fully block out the sun.

#### What to watch for

If you have any redness, pain, burning or swelling on your skin where the drugs were injected, talk to your healthcare team about what to do.

### Sleep pattern changes

My sleep patterns changed. I'd sleep for a couple of hours in the afternoon, then I'd be wide awake at 2 or 3 in the morning. My wife is a sound sleeper, so I could turn on the TV and not bother her. But after going through all of this, I'm a little bit more in tune with my body. Now, if I get tired, I just have a quick nap. ~ Jackson

Having trouble sleeping (insomnia) is a common problem during treatment. You may have insomnia if you:

- are unable to fall asleep
- wake up often during the night
- wake up very early and can't go back to sleep

Pain, anxiety, depression and some medicines can affect your sleep. Insomnia makes it harder to cope with other side effects of treatment. It can affect your mood and energy level, cause fatigue and make it hard to think and concentrate.

- Take only short naps during the day. If you need to rest, nap for only 15 to 20 minutes.
- Be as active as you can during the day.
- Go to bed and get up at the same time every day.
- Relax before bedtime have a warm bath, listen to soothing music or read.
- Avoid alcohol, drinks with caffeine or smoking for several hours before bedtime.
- Make sure your bed, pillows and sheets are comfortable.
- Block outside light with blinds or drapes if needed, or use a sleep mask.
- Get up and go into another room if you're tossing and turning in bed. Read or watch TV until you feel sleepy enough to return to bed.

### Sore mouth or throat

Some chemotherapy and targeted therapy drugs can give you painful sores in your mouth or throat or on the tongue and lips. Sometimes these sores can become infected or can make eating, drinking or swallowing painful. Your healthcare team can prescribe medicine to help reduce the pain.

### > TIPS to avoid getting mouth sores

- Visit your dentist and get any needed dental work done before you start treatment.
- Suck on ice chips before and during drug treatment.
- Keep your teeth and gums healthy. Your family doctor or dentist can suggest gentle ways of cleaning your teeth. Ask your healthcare team about flossing. You may need to floss gently. Or you may have to avoid flossing if your mouth is sore or your blood counts are low.

### > TIPS when you have mouth sores

- Keep your mouth clean. Use a very soft-bristled brush or cotton swab to clean your teeth.
- Remove dentures often to give your gums a rest. Keep dentures clean.
- Eat foods that are lukewarm or cool in temperature. Hot foods can irritate your mouth and throat.
- Keep your mouth moist by sipping water throughout the day.
- Limit foods that are tart, salty or spicy or have rough edges (like toast or hard tacos).
- Choose foods that are moist, soft, bland and easy to chew or swallow, like soup, mashed potatoes, cooked cereals, yogurt and eggs.
- Rinse your mouth often. Try a few different rinses to see what works best for you. Ask your healthcare team or pharmacist to recommend mouthwashes that are alcohol-free. Your healthcare team may also have a recipe for you to make yourself. Salt or baking soda mixed with water or club soda is cheaper than store-bought mouthwashes.
## Swelling and puffiness

I retained a lot of water in my feet. They were always sore and it made it difficult to get around. Toward the end of the chemo, it was all I could do to take my dog for a 10-minute walk. I went for some reflexology. Did it make a difference? I don't know, but it sure is nice when your feet are sore just to have a foot rub. ~ Christa

Swelling or puffiness in the face, hands, feet or stomach may be a sign that you are keeping too much fluid in your body (fluid retention). Certain chemotherapy, targeted therapy and hormonal therapy drugs can cause your body to keep or hold onto fluids. Fluid may build up around your lungs and heart, causing you to cough, be short of breath or have an uneven heartbeat.

Other drugs you're taking – such as pain medicine, bisphosphonates and steroids – can also cause swelling or puffiness.

> TIPS

- Avoid adding salt to your meals. Salt causes the body to hold onto water.
- Prop up a swollen arm or leg on pillows.
- Ask your doctor about medicine to reduce the water in your body.

# Life during treatment



The thing about being a person going through cancer treatment is that you have to focus on yourself. You have to do what you need to do. You have to be patient with yourself. You have to listen to your body, and you have to talk to your doctors. You have to say, "This is how I'm feeling. Am I nuts or is that OK?" You need to do the things that are important to you and feel right for you. ~ Pedro

For most people, day-to-day life changes during treatment and for a while after. You and your family will probably focus on managing each day – getting to hospital appointments on time, having tests and dealing with any physical and emotional side effects of treatment. You may have to reduce your work hours or take a break from working altogether.

Your family role and responsibilities may have to change while you focus on getting better. Sometimes you'll just need to rest while others take care of chores. It may be harder to find time to see friends – and you may need to cancel plans on days when you're not feeling well.

Being active and eating well can help you feel better and cope. Talk to your healthcare team about what's right for you during treatment.

According to my doctors, one of my best therapies was the fact that I had a Siberian husky. She was a beautiful dog and she had to walk, and I have always been a big exerciser. And the first thing I had to do every morning was put on my winter jacket over my PJs and put on my big snowmobile boots and go out for a walk. The doctor said that was likely a really good thing, because I knew I had to get out of bed for her. ~ Diya

It can also help to stay organized, manage any stress you're experiencing, look after work or financial concerns and get support when you need it.

## Staying organized

The healthcare system and your treatment aren't simple. You've probably seen many different healthcare professionals from different departments. And you've probably been given handouts, names and phone numbers, website addresses and important papers. It can help to keep everything organized in one place, such as in a binder or electronically on your computer.

### > TIPS

- Use a calendar to keep track of all your appointments, when to take medicines and any side effects you may have.
- Ask for copies of all your medical reports and test results and keep them with you.
- Ask your pharmacist for a printed list or an electronic file of your medicines.
- Keep copies of your health insurance documents if you have additional coverage.

This may seem like a lot of work, but it can be very useful when you have questions or when you see a new member of your healthcare team.

## **Managing stress**

Dealing with cancer and treatment can be stressful. It's normal to have a wide range of feelings during treatment. You may also be tired, which can make it even harder to cope with your feelings. But your emotional health is just as important as your physical health.

Some people feel sad or depressed because of the changes cancer has caused. Others feel down because they're frightened about the future. Whatever is making you feel stressed, it's important to get the support you need. It helped to have goals to focus on, things I wanted to return to. Like having good food was one goal – when would I be able to have a great hamburger again? When would I be able to enjoy a nice glass of wine? I would look forward to getting on the golf course again, to be able to walk more than 100 metres, even mowing the lawn. ~ Pedro

### > TIPS

- Some people find it helpful to talk about their feelings with a counsellor, a spiritual care worker or a social worker. Talking to someone who's had a cancer experience similar to yours can also help you cope.
- Do things you enjoy. Finding pleasure in the things you do will help give you back your sense of control.
- Keep a journal or diary or start a blog during treatment. Writing down your thoughts and feelings can help relieve anxiety. A journal is also a good place to write positive feelings that you can return to when you're feeling down.
- Get up and move. Regular physical activity even very gentle movement can make you feel better, calmer and more in control.
- Learn a relaxation method. Meditation, deep-breathing exercises or guided imagery can help you relax. Other complementary therapies like acupuncture, hypnosis or massage can also be useful.

I took up meditation, and I'm still practising it, and I really enjoy it. It just clears your mind and clears your thinking. It helps keep me calm during the day. When I was ill, I would use it to get me out of today, looking toward tomorrow. ~ Jackson

Recognize that recovery takes time. Even if you don't feel well today, you may find that, in time, you start to feel better.

Sometimes the symptoms of stress and anxiety can be severe. If you feel stressed most of the time, talk to your healthcare team. They may be able to teach you some self-help methods, refer you to a counsellor or support program or prescribe medicine for anxiety.

## Work and financial matters

Some people are able to keep working while they have treatment. But other people may need to stop working. Think about your finances before you start treatment. You may need to plan ways to support yourself or your family. Whether you need to take time off work will depend on:

- the type of treatment you have
- what side effects you have (if any)
- the type of work you do
- your financial needs

### Working while in treatment

I had some short-term disability coverage, but that ran out after my 2nd round of chemo, so I had to go back to work. My employer was absolutely magnificent. I made out a schedule for my manager of the days during my chemo cycle where I knew I felt OK, and he would book me for those days. That's how I coped financially. ~ Diya

Many people are able to keep working during treatment. Working while in treatment can help your self-esteem and remind you that you're a valued employee, boss or co-worker – not just a cancer patient. The contact with and support of others at work may make you feel better.

## > TIPS

- Plan treatments late in the day or just before the weekend to give yourself time to recover.
- Explore work options like flexible work hours, working from home or other changes to your work schedule.
- Reduce your hours. Consider working part time while you're in treatment.
- Share your workload. There may be some parts of your work or other duties that can be divided among co-workers.

### Taking time off work

I wanted to work but I couldn't. I would have been useless at work. So I ended up having a year off and I had insurance coverage, but you still don't make what you used to make. So you're on a different budget. But we made do. ~ Jackson

You may need to take time off work to rest and recover while in treatment and afterwards. If you're an employee, talk to your employer or human resources department about sick leave or leave without pay.

It can be hard to know if or when to go back to work. Going back soon after treatment ends can be helpful if you're eager to get back to your normal routine or if you need the income. But it can take a long time to recover fully from treatment for cancer. It may be many months before you feel ready to return to work. You may decide to work part time or to change the type of work you do. It's important to do what's right for you.

#### Discrimination is against the law

Some people with cancer can face problems when they try to continue working while in treatment or when they go back to work or get a new job after treatment. If you feel that you have been discriminated against, you can contact the Canadian Human Rights Commission in your province or territory at 1-888-214-1090 or chrc-ccdp.ca.

### Your finances

Whether you continue to work or take time away from work, cancer can affect your finances. You may have to pay for help around the house, childcare, or drugs or therapies not covered by provincial or private health insurance plans.

Extra expenses, loss of income and growing debt can leave you feeling worried about how you'll manage financially. Start by finding out if you have health insurance – either private disability insurance or insurance through your employer. Ask your insurance broker or your human resources department about the terms and conditions of your coverage. They can tell you what your insurance will pay for, what you will need to pay for yourself and when you can get your coverage. For example, many policies have a waiting period before disability coverage starts.

There are other people you can talk to:

- Account managers at your bank, personal financial planners or advisors can help you budget your money and help you decide whether you should use equity in your home, RRSPs or other investments.
- An accountant can tell you about the expenses you can claim. You are allowed to claim many of your medical, disability and attendant care expenses on your tax return. Visit the Canada Revenue Agency website at cra-arc.gc.ca.
- Social workers can help you find out more about financial assistance programs in your province or territory or about government benefits, such as Employment Insurance (EI) sickness benefits and Canada Pension Plan (CPP) disability benefits. Most hospitals and treatment centres have a social worker on staff.
- Don't forget about friends and relatives. You may know a bookkeeper, credit officer or accountant who might be willing to help you organize your finances.

#### For information on government services

For information on government services and how to apply for them, contact Employment and Social Development Canada at 1-800-O-Canada (1-800-622-6232) or visit canada.ca.

## **Getting support**

I can't say enough good things about the people that helped me – the doctors and surgeons, the cancer centre, my employer, the people I worked with. I know that I wouldn't have gotten through without their support. ~ Diya

There are many sources of help available for people with cancer. You don't have to go through this alone.

## Family, friends and community

Your family, friends and community can support you emotionally by being there and listening. They can also help by doing practical things to make your life easier, like doing housework or yardwork, cooking meals, taking care of children or walking the dog.

If you're having trouble asking for or accepting help, remember that many people really want to support you. Sometimes people don't know what to do when someone is ill, and helping you is one way for them to feel useful.

> I had friends offer to do laundry and cleaning and everything else. If I had to do it over again, I would have been more open to accepting help. Really, if somebody wants to come over and do your laundry, lay down on the couch and let them do your laundry. It's not the end of the world. ~ Christa

You can also ask members of your healthcare team about services in your community that can provide support.

## Counsellors

If you're having trouble coping with cancer and its treatment, you may find it helpful to talk to a counsellor, like a psychologist, psychiatrist, spiritual care worker, nurse or social worker. Some cancer centres offer free counselling to people with cancer and their families. Ask a member of your healthcare team about counselling services that are available to you.

## **Other support**

Consider joining a support group or talk with a cancer survivor in person, on the phone or online. Talking with others who've had similar experiences can be helpful. Try more than one option to see which one works best for you.

> I actually started to look forward to having that chemo visit at the hospital every 3 weeks, because I met a core group of people who were all going through treatment for various types of cancer. We would all be in there every 3rd week, and we'd make sure, we'd purposely pick the same days, so we could be there together. It was my little support team. That's where I got the real conversations, with the other patients. ~ Jackson

#### Talking to someone who's been there

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

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

#### Want to connect with someone online?

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

## For the caregiver

A cancer diagnosis affects more than just the person with cancer. As a caregiver, you may feel unprepared or overwhelmed and may not know what is expected of you. It helps to be able to communicate well with the person who has cancer. And it's important to take good care of yourself too.

There are many different ways to be a caregiver. You may help with daily activities, such as getting to a doctor or preparing meals. You may help with physical care, like bathing and dressing. It can also mean helping the person cope with feelings that come up during this time.

Good communication - talking honestly with each other - can help.

- > TIPS on talking
  - Be a good listener. When the person with cancer wants to talk, listen. Try to hear what they mean but may not be able to say. You can ask if you're understanding them correctly. You might say, "It sounds like what you're trying to say is ... Is that right?"
  - Silence is okay. You don't always have to talk. If someone stops talking, it may mean that they are thinking about something sensitive. You may want to hold the person's hand. Other times, there may be nothing that needs to be said. It's enough that you are there.
  - Say what you feel. You're allowed to say things like, "I find this difficult to talk about," or "I don't know what to say." Your needs, emotions and concerns may be different from those of the person you're caring for. But they are important too. Share them with someone – the person you're caring for or someone else.
  - Laugh a little. People with cancer don't want to talk about their illness all the time. It's OK to watch a funny movie or TV show together and enjoy life, even when someone is ill.

## Taking care of yourself

If there was something like a Christmas dinner, instead of staying at home and having to be with me all the time and feel sorry for me, my wife got comfortable going without me. It took a while for her to get used to that, but then she realized that I didn't mind, that I was just going to sleep anyway. We always think about the patients, but it's about the people around the patients as well. ~ Jackson

Caregivers are often so focused on the person they're caring for that they forget to care for themselves. It's important to pay attention to your own emotional and physical health as well. You can give good care only when you also care for yourself.

## > TIPS on taking care of yourself

- Try to stay healthy. Eat well. Drink plenty of water. Get enough sleep. Take a nap once in a while if you need to.
- Go to your own medical checkups and remember to take your own medicines.
- Be active every day. A simple walk outdoors can do good for the mind as well as the body.
- Take a break and do something just for you. Read, take a relaxing bath or watch a movie. Choose an activity that you enjoy.
- Accept help from other people. You don't have to do everything on your own. Family and friends can run errands, babysit, help with household chores or prepare a meal.
- Go online and search for "helping calendars" to schedule chores and people's visits.
- Accept your emotions. It's normal to feel stressed, guilty, angry, sad or other emotions when you're caring for someone with cancer. It may help to talk with your family or friends or a professional counsellor.
- Remember that you are not alone. Connect with others by joining a support group or talking with another caregiver in person, over the telephone or online.

#### Want more information?

Our booklet *Coping When You Have Cancer* has more details that can help you manage.

# After treatment



During treatment you're busy. You've got your appointments, you're looked after and you're doing this and you're doing that and you know what's coming next. Your whole life revolves around this disease, right? And then, all of a sudden, it's just like, OK, you're done, bye-bye, have a nice life. ~ Christa

As the end of your treatment nears, you may look forward to getting on with your life. But getting back on track can take time. Completing treatment often causes strong emotions – relief, joy, fear, uncertainty and anxiety, among others. One moment you may feel happy that treatment is over and ready to get on with the things you've put on hold. The next moment you may feel afraid and left alone with no doctor or nurse to talk to. This is normal. Be patient with yourself and give yourself time to find the best way to work through these emotions.

> I still go and see the nursing staff. Every time I go in for my follow-up appointments, I go into the clinic and have a chat, and I take them a box of chocolates at Christmas. They were a big part of my life, and I want to see them, yeah. And I think it's also good for them. I think that they like to see the results of their care. ~ Jackson

Not everyone will have difficulties after their treatment finishes. But for many people, moving on isn't easy. Knowing what to expect after treatment can help you and your family deal with issues that may come up and any changes that you may have to make. To help prepare for the end of treatment:

- Ask your doctor what you can expect after treatment. Understand what changes or long-term side effects may affect your daily life.
- Connect with other people who've been there. Talking to other cancer survivors after treatment can help a lot. Many people find it helpful to join a support group.

# Keep all your healthcare providers informed about your cancer history

If you see healthcare professionals other than your cancer specialists (for example, dentists, dietitians or complementary practitioners), it's very important that you tell them you've had cancer. It may affect their decisions about the care they provide.

Now that treatment is over, give yourself time to cope with physical and emotional changes. Allow time for your friends, family and caregivers to adjust as well. Sometimes, friends and family may expect things to get back to normal and that you can simply move on. Keep in mind that people around you may not even realize what you're going through. They may not be able to understand how cancer and treatment has affected you and that your recovery takes time.

If you feel comfortable, talk to your family, friends and co-workers. This will help them understand how you feel.

> You have days for quite a long time where you're fatigued or you're just not feeling well. Sometimes you feel almost guilty because people don't understand – you look like you, and you sound like you, and oh, you don't have cancer anymore so what's wrong with you? Why can't you do this? Why can't you do that? Why are you laying on your couch? I think more people need to understand that getting back into life and healing from cancer takes longer than the actual treatment stage. ~ Christa

## Follow-up care

When your treatment is done, you'll likely have regular checkups to keep track of how you're doing and to make sure any health issues or other problems are found and dealt with early. Follow-up care helps you and your healthcare team follow your progress and your recovery from treatment. At first, you might meet with one of the specialists from your healthcare team. Later on, it may be your family doctor.

> I am now more sensitive to my body, and I'll go to the doctor and say, 'This doesn't feel normal and it bothers me.' Whereas before the cancer, I probably would've thought, 'Oh, it'll go away.' ~ Pedro

The schedule of follow-up visits is different for each person. You might see your doctor more often in the first year after treatment and less often after that. After treatment has ended, you should report new symptoms or symptoms that don't go away to your doctor right away, without waiting for your next scheduled visit. Depending on the type of cancer you had, you may need to have blood tests, x-rays, scans or other medical tests.

Your doctor will examine you and ask how you've been feeling. Tell your doctor how you feel mentally as well as physically. Talk about any side effects you still have.

Tell your doctor about:

- new medicines you are taking (including over-the-counter medicine such as painkillers, laxatives and nutritional supplements)
- herbal therapies and other complementary therapies you may be thinking of trying
- lifestyle changes you've made or would like help with, such as quitting smoking, exercising or eating well
- names of new doctors or specialists you may have started seeing

I was going for follow-up care every 3 months, and now they just put me on the 6-month program. I like to think I don't get nervous before the appointments, but I do. I do. ~ Jackson

### Questions to ask about follow-up care

- Who will be taking care of my follow-up care?
- Where do I go for follow-up care?
- How often will I see the doctor?
- What symptoms should I be watching for?
- What should I contact you about right away?
- What other long-term side effects might I have? Is there any treatment for them?
- How will my family doctor be involved?
- What can I do to reduce the chances of cancer coming back?

## When cancer cannot be cured

When cancer cannot be cured, the focus of care changes. You may receive chemotherapy or other drug treatment to help you feel better. You may be treated for pain, nausea, shortness of breath or other symptoms.

#### Want more information?

Our booklet *Advanced Cancer* is for people and their caregivers when cancer is unlikely to be cured.

## Late and long-term side effects

It can take time to get over the effects of your cancer treatment, both physically and emotionally. Some problems will disappear quickly. Others can take weeks, months or even years to go away. These are called long-term effects. For some people, there may be permanent effects or late effects. Late effects are problems that appear a long time after treatment finishes.

Your healthcare team can help you understand what late or long-term effects you may need to be prepared for and who can help you manage them. Here are some of the late or long-term side effects you may face:

- fatigue
- fertility problems
- heart (cardiac) problems
- lung problems
- swelling in certain parts of your body (lymphedema)
- memory and concentration problems
- loss of bone mass (osteoporosis)
- 2nd cancers

Whether you have permanent, late or long-term effects depends on the type and stage of cancer as well as the type of treatment you had. Everyone is different. Someone who had the same type of cancer and treatment as you may recover faster or slower. You may have side effects that they didn't. Your body will cope with treatment and recovery in its own way.

Five years later, I'm still going through it. I have chemo head – I don't have the memory I used to have. I can't skate because of my leg. I can't carry anything up and down stairs. Chemo has created a new normal and what I've had to do is adapt to it and not lament the loss of anything but instead celebrate where I'm at and keep winning. ~ Pedro

Some late and long-term effects may be made worse by other health problems that you had before you were diagnosed with cancer, like diabetes, arthritis or heart problems. It's important to ask for medical help for any problems that you may have.

Late and long-term effects can cause strong feelings. Finding the best way to work through them can take time and patience.

### Want more information on life after treatment?

Our booklet *Life after Cancer Treatment* can help you understand more about late and long-term effects and healthy living after cancer treatment.

# Moving forward



I went through a time where I didn't know what was wrong with me, and then I realized I was grieving. I was grieving the loss of my life before cancer. You need support for the transition back into life after cancer, because it's not the same. Is it better? Is it worse? I've chosen to make it better, but it's a hard transition. ~ Christa

Now that treatment is over, give yourself time to cope with physical and emotional changes.

Life after cancer treatment is a time of adjustment and change. You may move between the positive and the negative, relief and fear, joy and grief. You may find that you have different interests and attitudes about life. During times of doubt, it can help to remember that life after cancer treatment is a process, not an event. It can take time to come to terms with all that has happened to you and with the uncertainties of the future.

Just as your experience of treatment was your own, the way you adjust to life after treatment will be unique too. There's no right or wrong way to feel about the impact that cancer has had on your life. The challenge for survivors is to celebrate the joys of the present and get on with living – and to recognize when they need help and ask for it.

> I made a couple of decisions very early on. And probably the most important decision I made was that if I survived this and got through this, I was going to give back. I wanted to give back to cancer agencies and cancer patients wherever I could. Also, I got a tattoo on my forearm. It's a reminder of where I'm coming from, of this 2nd chance at life. ~ Jackson





# Canadian Cancer Society We're here for you.

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

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



**Ask** a trained cancer information specialist your questions about cancer.

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



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

Visit CancerConnection.ca.



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

Visit cancer.ca.

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

### Tell us what you think

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

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## What we do

The Canadian Cancer Society fights cancer by:

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

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



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