

# Cancer Journey

Guide Book

This Guide Book is meant to help you:

- Find resources and information at Princess Margaret Cancer Centre and in your community
- Understand your treatment
- Help you speak with your cancer care team

# Cancer Journey

## The Cancer Journey Guide Book

At Princess Margaret Cancer Centre, we know that finding out you have cancer can make you feel overwhelmed, afraid, numb or anxious.

This Guide Book was made to help you find:

- Information to help guide you throughout your cancer journey
- Tips from other cancer patients
- Details about resources you can find at Princess Margaret Cancer Centre and in the community

### Did You Know?

You can get the **Cancer Journey** resources online or on your smartphone.

#### Smartphone/Tablet App



Download the **Princess Margaret Cancer Journey App** from:

- **Google Play** if you have an Android phone/tablet
- **The App Store** if you have an iPhone/iPad

#### Website



Visit: [www.uhn.ca/PrincessMargaret/PatientsFamilies/Cancer\\_Journey/](http://www.uhn.ca/PrincessMargaret/PatientsFamilies/Cancer_Journey/). Scan this QR Code if you have a QR Code Reader on your phone.

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# Just Diagnosed

When you are first diagnosed (told you have cancer), you may have a lot of questions. You may also feel overwhelmed by the amount of information you are getting.

This section has tips to help you:

- Cope with all the information you will get
- Talk with your cancer care team
- Prepare to call Princess Margaret Cancer Centre
- Prepare for appointments



## How Much Do I Need To Know?

How much information should I get from my oncologist (cancer doctor)?

This is a hard question and the answer very much depends on you.

There is no perfect amount of information for every person. Each person wants to learn a different amount about their cancer and treatment.

Some people like to know all of the details. Other people prefer much less. In most cases, the amount of information you want will change over time. You might not want to know much to start with, but later on, you might want to know more.

Bring a family member or friend with you to your appointments. A family member or friend can help you recall or write down information that you get. It can be hard to absorb all of the information on your own.

Although clinics can be very busy, your cancer care team is here to support you. To get the details that you need:

- ✓ Ask for the information that you most want to know right now.
- ✓ Know that you will have many chances to get more information. You do not have to get all the information at once.

For a good general picture of your cancer and treatment, the most important details may be:

- Your type of cancer
- The grade of your cancer (what your cancer cells look like under a microscope and how fast they are growing)

- The stage of your cancer (how large the cancer tumour is and how much it has spread)
- Whether your cancer has spread to any other parts of your body
- What treatment your oncologist (cancer doctor) recommends for you (for example, chemotherapy, radiation, surgery or a mix of these treatments)

You can write down these details in the **“My Diagnosis”** (page 18) and **“My Treatment”** (page 54) sections of your Cancer Journey Planner.

## Talk With Your Cancer Care Team

Your cancer care team uses the information they have about your cancer and the information you give them to inform your treatment plan. You may only meet some members of your cancer care team one or two times (for example, in the blood lab or for a diagnostic test such as a biopsy). Or, you may end up knowing members of your cancer care team for years after treatment ends (for example, your oncologist or clinic nurse). How well you are able to talk with your cancer care team is key to getting the care that is best for you.



Before being diagnosed with cancer, many people do not know much about cancer or its treatments. Many people also do not know much about the types of health care providers who work in cancer centres and what supports are available to them. This is normal.

As a patient, you may need to know about:

- The details of your cancer
- Your prognosis (outlook)

- Your treatment options
- Financial supports
- Support resources available to you (for example, support groups, classes)

Your cancer care team also needs to learn about you to best treat your cancer.

Your cancer care team needs to know:

- Your medical history
- How you are feeling
- Any financial concerns related to cancer treatment
- Your support needs, and more (for example, getting to your appointments, referral to other cancer care providers)

Remember that you and your cancer care team will always come back to the goal. This goal is to treat your cancer and help you get through treatment. More tips for talking with your cancer care team can be found in the “**Tips from Patients**” section of this book (page 47).



## Tips for Calling Princess Margaret Cancer Centre

- ✓ For emergencies, go to your local emergency department or to the Emergency at the Toronto General Hospital. Be sure to tell the emergency staff that your cancer is being treated at Princess Margaret Cancer Centre. Note, Princess Margaret Cancer Centre does not have an emergency department.
- ✓ If you have a care or concern about how you are feeling, call the site telephone line to talk to the Specialized Oncology Nurse. Leave your OHIP number (found on your health card), name, daytime phone number, and your concern on the answering machine. The answering machine is available Monday to Friday, from 9 am to 4:30 pm. You will be given the number for the site telephone line on your first visit.
- ✓ For medical concerns on weekends and after hours, you can:
  - Call CAREpath to talk to a Specialized Oncology Nurse. You can reach CAREpath at 1 877 681 3057. Read more about CAREpath on page 69 of this Guide Book.
  - Call your primary care provider's office (your primary care provider is your family doctor or nurse practitioner).
- ✓ Call your clinic if you need to change or cancel your appointment.
- ✓ Contact your oncologist (cancer doctor) at their office if you need:
  - Any forms or letters filled
  - Access to your medical records or information sent to your primary care provider
  - A referral to another specialist

## Tips for Coming in for a Clinic Visit

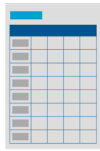
When you come in for a clinic visit, bring:



- Your OHIP card



- The contact information of your pharmacist and primary care provider (family doctor or nurse practitioner)



- A complete list of all your medicines. This includes over-the-counter drugs, herbals, minerals, vitamins, and eye, ear, and nose drops.



- All of your current medicines in their original bottles. This includes over-the-counter drugs, herbals, minerals, vitamins, and eye, ear, and nose drops.



- A list of questions you have about your treatment plan and care



- A family member or friend to take notes and help you remember what was said in your appointments. You can also bring a family member or friend to keep you company.



- A snack or drink and something to read if you have to wait (for example, a book or magazine)



- Your Cancer Journey Planner. You can write down your list of questions and list of medicines in your Planner. You can also use your Planner to take notes at appointments.

# myUHN Patient Portal

myUHN is a secure website for patients of University Health Network (UHN). UHN is a health care and research organization made up of four health care centres. These centres are: Princess Margaret Cancer Centre, Toronto General Hospital, Toronto Western Hospital, and the Toronto Rehabilitation Institute.

The myUHN website lets you see your appointments and results from all UHN hospitals and clinics as soon as they are ready. With myUHN, you can access your personal health record anywhere, anytime on a computer, smartphone or tablet. Ask for a registration code when you check in for your next appointment or call myUHN Support at 416 340 3777.

What will I see in myUHN Patient Portal?

With myUHN, you can:

- ✓ See your UHN appointments and receive appointment reminders
- ✓ See your UHN lab results dating back to 2008
- ✓ See your UHN reports, such as pathology and imaging reports, and clinic notes dating back to May 1, 2015
- ✓ Find links to education resources, medical dictionaries and other helpful websites
- ✓ Share your health information with others

## Contact the myUHN Patient Portal Team

For questions about sign in, registration, registration codes or using myUHN:

**Phone:** 416 340 3777

**Email:** [myUHN@uhn.ca](mailto:myUHN@uhn.ca)

**Hours:** Monday to Friday, 9 am to 5 pm

# My Cancer Care Team

Your cancer care team is the group of health care providers who treat your physical and emotional health when you have cancer. This team may include:

The “Star Player” – You

You are the most important member of your cancer care team and should be part of all decisions.

Your Oncologists (Cancer Doctors)

Oncologists are doctors who specialize in treating people with cancer.

There are three main types of oncologists:

- **Medical oncologists** treat cancer with medicines, such as chemotherapy.
- **Radiation oncologists** treat cancer with radiation therapy.
- **Surgical oncologists** treat cancer using surgery.

You may have more than one oncologist on your cancer care team, depending on your treatment plan.

Oncology Nurses

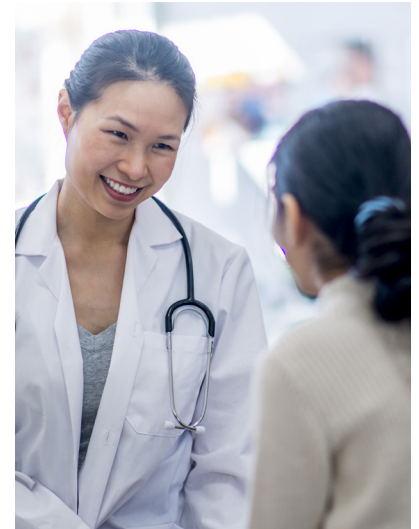
Oncology nurses are registered nurses who specialize in the care of people with cancer. They:

- ✓ Provide pain and symptom management
- ✓ Care for inpatients (patients who stay overnight in the hospital)
- ✓ Provide care and support during your review and follow-up appointments

Nurses often have the most contact with people being treated for cancer. They can provide you with information, emotional support and practical support.

Your Primary Care Provider (Family Doctor or Nurse Practitioner)

Your primary care provider manages your general health. Your primary care provider should do a complete physical check-up every year. They will also help you keep track of your physical, emotional and social needs after treatment.



Social Worker

A social worker can help you with your mental and social well-being. They can help you and your family resume your daily life.

Dietitian

A dietitian is a health care provider who can counsel you on matters of nutrition and diet.

Patient Flow Coordinator

A Patient Flow Coordinator is someone who works in the clinics at Princess Margaret Cancer Centre. They will book your appointments and check you in for your appointments.

Psychiatrist

A psychiatrist is a doctor who treats your mental and emotional health. A psychiatrist will come up with a treatment plan and can prescribe medicine.

Psychologist

Psychologists treat mental and emotional health, and do not prescribe medicine.

Pharmacist

Pharmacists are health care providers who can help you learn about your medicines. Pharmacists can teach you how to take your medicines safely and help you notice side effects.

## Medical Professional Trainees

The Princess Margaret Cancer Centre and the other hospitals of the University Health Network are teaching hospitals. Medical professional trainees who are gaining experience may be part of your cancer care team.

- **Students** are people who are training to become medical professionals such as doctors, nurses, or pharmacists. Most students will be in their final year of school.
- **Residents** are doctors who are qualified to practice medicine but are training to become specialists, such as pediatricians. Residents can spend between 1 and 5 years training to become specialists after graduating from medical school.
- **Fellows** are specialists who have finished residency. Fellows go through further training to become experts in their chosen area – for example, pediatric oncology.

## Volunteers

Many people volunteer their time to work at Princess Margaret Cancer Centre. Volunteers can help you find information you need.

## Other Members

There may be many other people on your cancer care team. Find out about the resources available to you in the “**My Resources and Support**” section of this book (page 65). Visit the **Princess Margaret Patient & Family Library** to learn more about different cancer care providers.



# During Treatment

In this section you can find information to help you when you are going through treatment.

This section has tips to help you:

- Understand your medicine
- Care for yourself
- Cope when you are waiting for test results
- Understand common cancer treatments

# Understanding My Prescription Medicine

It is important to keep your cancer care team informed about any medicines you are taking. Ask questions about how different medicines can interact with one another. Use the practical tips below to better understand your medicines.

## Tips for Understanding Your Medicines

- ✓ Be ready with questions. Write down as many questions as you can before seeing your cancer care team. Be sure to have all your questions about your medicines answered during your appointments. Questions to ask about your medicines include:
  - Have any medicines been added, stopped or changed, and why?
  - What medicine do I need to continue and why?
  - How do I take my medicine and for how long?
  - What side effects should I watch out for?
  - How will I know if my medicine is working?
- ✓ Use the tables in the “**My Medicines**” section (page 43) of the Planner to list your prescription and non-prescription medicines. Include:



- Prescription medicines (medicines ordered by a doctor)



- Over-the-counter medicines (medicines you can buy in a pharmacy or drug store without a prescription)

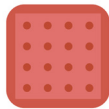




Vitamins, minerals and herbals



Eye, ear and nose drops



Patches



Inhalers



Sprays



Cannabis

Tell your doctors, nurses and pharmacists about any medicines you take and if you have any allergies.

- ✓ Update your doctors, nurses and pharmacists about any changes to medicines you take. This includes telling them if you have stopped taking a medicine and why. Tell them how and when you are taking your medicines.
- ✓ If you get your medicines from your local pharmacy, give your cancer care team the pharmacy's contact information.



## Caring for Myself

As well as the physical effects of cancer and treatment, there are also emotional and practical effects. When you are first diagnosed with cancer, there tends to be a focus on the medical side of the illness. But a cancer diagnosis also affects other parts of your life. This can include your family, finances, friendships, household tasks, and being able to sleep.

Many cancer survivors who have finished treatment have said that it is important to notice all of these areas throughout your cancer journey. You need to take care of yourself, and ask for extra support as you need it. Adjust your commitments to account for the time and energy it takes to go through treatment. There is nothing wrong in asking for help. It simply reflects how much a cancer diagnosis demands.

Refer to the **“My Resources & Support”** section (page 65) to find the supports and programs offered at Princess Margaret Cancer Centre and in your community. The **Princess Margaret Patient & Family Library** has many resources and information. Learn about rides to appointments by the Canadian Cancer Society, or free childcare at Princess Margaret Cancer Centre during your appointments. There are even free house cleaning services while you are getting chemotherapy.

Read the **“Tips From Patients”** section of this book (page 47) for advice from other cancer patients on how to care for yourself.

# Waiting for Results

At different stages in your cancer journey, you may have to wait to hear the results of a test. It could be a blood test, CT scan, x-ray, biopsy, nuclear medicine image, or one of many other tests used to detect cancer and the side effects of treatment. This waiting period can be very hard. Some patients refer to this feeling as “scanxiety,” a blend of the words “scan” and “anxiety.”



“Scanxiety” is a very real and very normal feeling. You may notice that the feeling changes based on the type of results you are waiting for. If you are just being diagnosed, you may fear the unknown. This fear may be greater if you do not know about treatment options or how cancer affects your life.

During treatment, you may worry about test results that tell you if your treatment is working or not. After treatment, your concerns may focus on cancer coming back or side effects. These results can often have a big impact on you. This includes the chance of celebrating remission (that your cancer has gone away) or the relief of knowing what is causing symptoms.

In any case, waiting for results can be a hard time for many people. You may find that the following tips help:

## 1. Acknowledge your “scanxiety”

- ✓ Notice your feelings. Sometimes, trying to ignore your feelings takes more energy than being aware of your feelings.
- ✓ Try talking to a friend or family member who listens well. They may feel anxious too, and relieved that you are talking about it.
- ✓ You may want to write in a journal instead of talking about your scanxiety. This way you can express your thoughts without having to go anywhere or share them with anyone.

- ✓ Talk to counsellors, social workers or support groups about how you are feeling. See the **“My Resources & Support”** section (page 65) for more information.

## 2. Prepare for getting your results

- ✓ Mark on your calendar when you expect to get your results. Note if you will get them by phone or in a follow-up appointment with your doctor. This gives you something to focus on. If you are not sure when or how you will get your results, ask your doctor or nurse.

You can also see your results online on the myUHN Patient Portal. myUHN is a secure website for patients of University Health Network (UHN). The website lets you safely see your appointments and results from all UHN sites as soon as they are ready. Read more about myUHN on page 11 of this Guide Book.

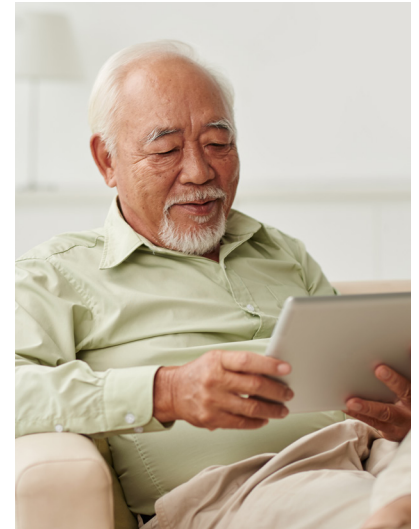
To see your results on myUHN Patient Portal:

- Ask for a registration code when you check in for your next appointment
  - Call myUHN Support at 416 340 3777
- ✓ Prepare a list of questions that you think you may have when you get your results. What information do you need? Try to remember what you needed to know the last time you got a result. This can help you make sure you find out this time.
  - ✓ Think about who you want with you when you receive your results. Would you like to bring a friend or family member? What would you like them to do to help out? For example, they could:
    - Give you a ride to the appointment
    - Write questions and answers down
    - Give you some time to process the results you receive

Make sure you tell your family and friends what you need. Understand that they may need to seek support too.

### 3. Do what has helped you before

- ✓ It may help to keep busy with work or other activities while you are waiting. Try and plan to have something to do during this time.
- ✓ It can be hard to sleep while you are waiting for results. Speak to your primary care provider (family doctor or nurse practitioner) if it is hard to get enough sleep.
- ✓ “Scanxiety” can make it hard to focus on work or other things. Do what works best for you during this time. Care for yourself as much as possible. Caring for yourself can include:
  - Getting more rest
  - Light exercise
  - Talking or writing about how you are feeling
  - Seeing a show
  - Listening to music
  - Reading
  - Sharing a laugh
  - Watching a game with friends
  - Whatever you like best
- ✓ Think about what has worked for you before while waiting for something important, or ask others for ideas.



As tough as the waiting period can be, the results will come. In the meantime, help yourself get through the waiting the best way you can. It may help to:

- ✓ Notice and accept your feelings
- ✓ Prepare for the results
- ✓ Use coping methods that have worked in the past
- ✓ Try new ways to deal with the wait

# Common Cancer Treatments

## How is cancer treated?

Each type of cancer is different. The way cancer is treated is based on the cancer type as well as details about your health. These details include:

- Your cancer type, size and where the cancer is in your body
- If your cancer is in one spot or if it has spread
- Your age and how healthy you are
- If it is best to:
  - Remove the cancer
  - Slow the growth of the cancer
  - Manage symptoms of the cancer

The 3 main types of cancer treatment

**1. Systemic therapy:** Systemic therapy is medicine that travels through your body to treat cancer cells wherever they are. Systemic therapies include:

- **Chemotherapy:** Chemotherapy uses different kinds of medicines to kill cancer cells.
- **Hormone therapy:** Hormone therapy is a way to slow down the growth of your cancer. A hormone is a chemical in your body that helps different parts of your body know how to work or grow.
- **Targeted cancer therapy:** Targeted cancer therapies use medicine to block the specific molecules that help cancer cells grow and spread.
- **Immunotherapy:** Immunotherapy uses your immune system to find and kill cancer cells.
- **Biological therapy:** A biological therapy is a medicine that is most often made by living cells, instead of chemical processes. Biological therapies are used to kill cancer cells or stop them from growing.

**2. Radiation Therapy:** Radiation therapy, also called radiation treatment, uses high energy x-rays to kill cancer cells.

**3. Surgery:** Surgery is a type of treatment in which an area of the body is cut open to remove cancer.

For some types of cancer, people may get 1 or 2 types of treatment or all 3 types of treatments. Ask your cancer care team to explain details about your treatment plan.

## Chemotherapy

What is chemotherapy?

Chemotherapy is a systemic therapy and is a common type of cancer treatment. You may hear chemotherapy referred to as “chemo”.

Chemotherapy uses different kinds of medicines to kill cancer cells.

There are more than 100 types of chemotherapy medicines. Depending on your cancer, your chemotherapy treatment may include one medicine or combine many chemotherapy medicines.

Many people may be worried about getting chemotherapy. But learning about what chemotherapy is, how it works and what to expect may help you feel less fearful. Chemotherapy can be used on its own or with other treatments like radiation therapy. The treatments you get, and in what order you get them, are based on details about your cancer.

Chemotherapy can be used to:

- ✓ Kill cancer cells
- ✓ Slow the growth of cancer
- ✓ Keep cancer from spreading
- ✓ Help manage cancer symptoms, like pain
- ✓ Cure cancer

The goal of your chemotherapy treatment will depend on details about your health and your cancer. Ask your medical oncologist (a cancer doctor trained in giving systemic therapies) what the goal of your treatment is.



How does chemotherapy work?

Chemotherapy kills cells that multiply or grow quickly, like cancer cells. Unlike radiation therapy and surgery, which can target specific areas, chemotherapy works throughout the whole body. That is why chemotherapy is called a systemic therapy. Chemotherapy travels through your blood to reach cells over your entire body, or system.

Chemotherapy destroys cancer cells, but it also damages normal, healthy cells. These are the normal cells most likely to be damaged from chemotherapy:

- Blood cells
- Cells in the gut
- Cells in the mouth
- Hair cells
- Reproductive cells (cells that are needed to produce children)

The damage to normal, healthy cells is the reason for many of the side effects of chemotherapy. Normal cells that are damaged can be repaired or replaced when new healthy cells grow. Because normal, healthy cells can be replaced, most side effects are short-term and will go away after chemotherapy ends.

What side effects might I have?

Each person reacts in their own way to chemotherapy. Even people who are taking the same kind of chemotherapy may react in a different way. Talk to your medical oncologist (cancer doctor) or nurse about what side effects to expect.

Side effects depend on:

- The type of chemotherapy you will get
- The dose (amount) you get
- How your body reacts to the chemotherapy



The most common side effects of chemotherapy are:

- Cancer related fatigue
- Low blood counts
- Nausea (feeling like throwing up) and vomiting (throwing up)
- Diarrhea (loose or watery poo)
- Constipation (trouble having a poo)
- Mouth sores
- Hair loss
- Skin and nail changes
- Brain fog (trouble thinking)

There are many ways to prevent or reduce some of these side effects. Speak to your cancer care team about what you can do to manage side effects of chemotherapy. Visit the **Princess Margaret Patient & Family Library** for more information.

## Radiation Therapy

What is radiation therapy?

Radiation is a common treatment for cancer. Radiation therapy uses high energy x-rays to kill cancer cells. Radiation therapy is called a local treatment. Local means the radiation affects the part of the body that is being treated. Radiation may be combined with other types of treatment.

Radiation therapy can be used to:

- ✓ Kill the cancer cells
- ✓ Slow the growth of the cancer
- ✓ Help manage cancer symptoms, like pain



The goal of your radiation treatment will depend on details about your health and your cancer.

How will I get radiation therapy?

There are 3 ways to get radiation therapy:

- 1. External beam radiation therapy:** External beam radiation therapy uses machines that aim radiation beams directly at the cancer.
- 2. Internal radiation therapy,** also called brachytherapy: Internal radiation therapy, or brachytherapy, places radiation inside your body or close to your cancer.
- 3. Ingested/injected radiation therapy:** Ingested/injected radiation therapy uses a pill (ingested) or a needle (injected) to deliver the radiation.

What side effects might I have?

The side effects you may get from radiation treatment depend on the type of treatment you have and where the treatment is done in your body. Ask your cancer care team what side effects you can expect from your radiation treatment.

## Surgery

Surgery is a type of treatment in which an area of the body is cut open to remove cancer.

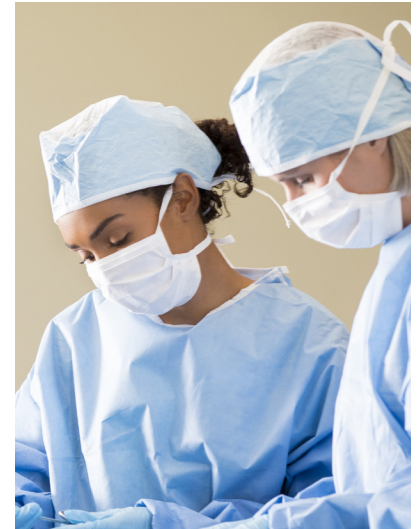
Cancer surgery can be used to:

- ✓ Prevent cancer
- ✓ Diagnose cancer
- ✓ Stage cancer
- ✓ Treat cancer

Preventing cancer

Some people may have a high risk for cancer. If you are at high risk, your doctor may suggest surgery to help reduce and prevent the risk of cancer. This type

of surgery is called preventative or prophylactic surgery. During surgery, a surgical oncologist (a surgeon trained in cancer surgery), may remove the body tissue or body part that is likely to develop cancer. Even though there is no sign of cancer at the time of surgery, removing the tissue or body part before it can develop cancer helps prevent or reduce the chance of cancer.



### Diagnosing cancer

Diagnosing cancer means finding the cause of an illness or disease. In some cases, surgery may be the only way to find out if someone has cancer and the kind of cancer. During surgery, the surgeon removes a small piece of tissue called a sample. The sample is sent to the lab where it is tested to find out if the sample contains cancer and what type of cancer it is. This process is called a surgical biopsy.

### Staging cancer

Staging cancer means finding out how much cancer there is and how far it has spread in the body. During surgery, the surgeon will remove tissue and lymph nodes near the cancer. The surgeon will have these tissue samples and lymph nodes examined in a lab to learn about the cancer. Knowing the stage of the cancer is vital to deciding treatment plans.

### Treating cancer

Surgery may be your main treatment if:

- The cancer is only in one part of the body
- The tumour or cancerous tissue can be totally removed

However, you may have other treatments like chemotherapy or radiation as well. During surgery, the surgeon will remove the tumour or cancerous tissue. The surgeon will also remove a small amount of normal tissue around where the cancer was (called the surgical margin). By removing some of the normal tissue, the surgeon can ensure that no cancer cells are left behind.

Sometimes, if not all the cancer can be removed, surgery is still done. The surgeon will try to remove as much of the cancer as possible. This is called debulking surgery. Your doctor may then treat the cancer that remains with radiation, chemotherapy or other treatments.

What side effects might I have?

The side effects and risks you may have from surgery depend on:

- Where the surgery is done in your body
- The type of surgery
- Your overall health

Most side effects will go away after surgery, but some may be long term or permanent.

Possible side effects of surgery include:

- Sore throat
- Pain
- Nausea (feeling like you might throw up)
- Vomiting (throwing up)
- Bruising or bleeding
- Swelling
- Fatigue
- Scarring
- Loss of movement or feeling

It takes time to recover from surgery. You may feel tired or weak after having surgery. Before your surgery, your cancer care team will talk to you about how to deal with pain, and they may give you a prescription (medicine ordered by a doctor) for medicines to take afterwards. Tell your cancer care team if you have any side effects you think may be from surgery. Your cancer care team can help improve many side effects with treatment.

## Complementary Therapies

What are complementary therapies?

Complementary therapies are used with standard cancer treatments. Standard cancer treatments are proven methods of treating cancer (for example, chemotherapy, radiation therapy, and surgery). Complementary therapies most often do not involve surgery or medicines. These therapies tend to be a natural approach to improving health and well-being.

Many people use complementary therapy during and after cancer treatment. People treated for cancer may use complementary therapy to:

- ✓ Relieve side effects of cancer treatment and stress
- ✓ Take an active role in improving their health and wellness

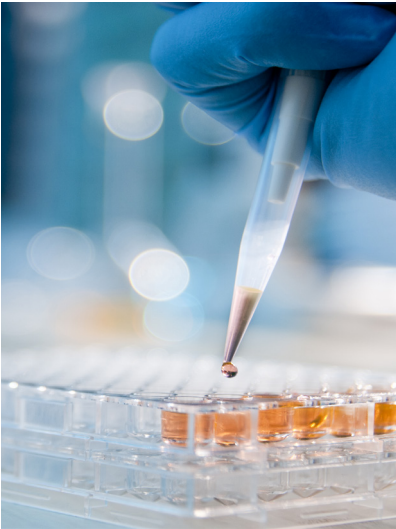
There are many types of complementary therapy. Some examples of complementary therapies include:

- Music therapy
- Natural and herbal products
- Acupuncture

Some complementary therapies can make your side effects worse or prevent your treatment from working. Talk to your doctor before you use complementary therapies. Your doctor can help you find a complementary therapy that is right and safe for you.

What about alternative therapies?

Alternative therapies are different than complementary therapies. Complementary therapies are used **with** standard cancer treatments. Alternative therapies are used **instead of** standard cancer treatments. Alternative therapies have **not** been proven to treat cancer. If you delay standard treatment to use an alternative therapy, the standard treatment may not work as well. Talk to your cancer care team if you are thinking about taking an alternative therapy.



## Clinical Trials

What are clinical trials?

Clinical trials are research studies that involve people. Clinical trials look for new ways to prevent, detect or treat cancer. Clinical trials may also explore ways to improve quality of life for cancer patients. Every treatment used today is the result of past clinical trials.

How can I find a clinical trial that's right for me?

Princess Margaret Cancer Centre is a research hospital, so you may be asked if you would like to join a clinical trial or research study. You can also ask your doctor if there are any clinical trials you could be involved in. Being in a clinical trial or research study is always your choice.

There are many clinical trials taking place at Princess Margaret Cancer Centre. Each clinical trial is designed to include patients with specific traits. "Inclusion criteria" are the traits patients must have to join a clinical trial. "Exclusion criteria" are traits that prevent patients from joining a clinical trial. Inclusion and exclusion criteria:

- Help to keep patients safe
- Help the researchers find the answer they are looking for

There are many websites that list current clinical trials. If you find a clinical trial you want to join, tell your doctor. Your doctor can help you know if the clinical trial could be a good fit for you.

Find a Clinical Trial

- **At Princess Margaret Cancer Centre:** <https://bit.ly/2Hly94A>
- **In Canada:** [www.canadiancancertrials.ca](http://www.canadiancancertrials.ca)

For more information about clinical trials, and what to consider when you join, visit: [www.uhn.ca/PrincessMargaret/PatientsFamilies/Patient\\_Family\\_Library/About\\_Clinical\\_Trials](http://www.uhn.ca/PrincessMargaret/PatientsFamilies/Patient_Family_Library/About_Clinical_Trials)



# Managing Side Effects

Cancer treatments can cause side effects. There is much that you can do to manage your side effects while you are getting treatment. Ways that you can manage side effects include things like:

- Drinking water to stay hydrated
- Being sure to eat enough to keep up your strength
- Noticing symptoms to report to your cancer care team

# How I Am Feeling

You may be dealing with physical side effects of your cancer or treatment. You may be feeling emotions that you are unsure how to handle. Be aware of any physical issues you have and note how your emotions and feelings change over time.

Keeping track of how you feel helps you and your oncologist (cancer doctor) notice patterns. This helps your oncologist know if they should make changes to your treatment or do something to reduce side effects. It is also good to track how you are feeling over time. This way, you can let your cancer care team know if any conditions worsen or improve. The **Cancer Journey Planner** includes a **Side Effects Tracker** (page 69) to help you track your side effects.

## Physical Side Effects

There may be short and long term physical side effects as a result of your treatment. Every patient has different side effects. Talk to your doctor or nurse about what side effects you can expect. Make sure your cancer care team is aware of how you are feeling so that you can get the care that you need.

Some common side effects include:

- Fatigue (feeling of tiredness that lasts a long time and that does not go away with sleep)
- Aches and pains
- Nausea (feeling like you might throw up)
- Vomiting (throwing up)
- Hair loss

**If you notice any new or different symptoms, tell your oncologist as soon as possible. Attend all of your scheduled check-ups. This is to make sure that your oncologist is aware of any changes that may be related to your cancer.**



## Cancer-Related Fatigue

Cancer-related fatigue is the most common symptom felt by people with cancer. Since most people with cancer feel fatigue, read below for tips to manage fatigue.

What is cancer-related fatigue?

Cancer-related fatigue is a feeling of being tired that can last a long time and does not go away with rest or sleep. Most of the time, fatigue is worse during treatment. For some patients, it can last for months or even years after treatment is over. Fatigue can make you feel:

- Very tired, weak, heavy or slow
- Like you cannot think or remember things
- Worn out
- Like you do not have the energy to see people or do things you love

What causes cancer-related fatigue?

Cancer-related fatigue may be caused by:

- Cancer itself
- Cancer treatments
- Anemia (low number of red blood cells in your body)
- Nausea (feeling like you might throw up) and vomiting (throwing up)
- Pain, depression or anxiety
- Not enough physical activity and exercise
- Not getting the right nutrients
- Other medical problems
- Fatigue before treatment
- Medicines
- Emotional distress
- Sleep problems



## How Can I Manage Cancer-Related Fatigue?

- ✓ **Be active.** Exercise is the best way to make your fatigue better. Try to get 30 minutes of moderate (not too easy or too hard) exercise on most days. Talk to your cancer care team about how to exercise safely.
- ✓ **Improve your sleep.** Talk to your cancer care team about problems that may disturb your sleep, like depression, anxiety and stress.
- ✓ **Manage stress and emotions.** You can help manage your fatigue by talking to someone about your feelings or doing activities to relieve stress and anxiety.
- ✓ **Pace Yourself.** Use your energy wisely to do the things that are most important to you.
- ✓ **Eat well.** Eat healthy foods and lots of variety to have more energy. To stay hydrated, drink at least 6 glasses of water or other liquids every day (unless your doctor told you to drink more or less).

When should I talk to my cancer care team?

Tell your cancer care team how you are feeling at every appointment. They want to know about your fatigue. Do not be afraid to ask about your questions and concerns.

Tell your cancer care team right away if you have any of these symptoms:

- Feeling dizzy, loss of appetite or falls
- Fatigue that is suddenly much worse
- Sudden shortness of breath or a fast heart beat
- Bleeding that cannot be explained or bleeding that does not stop
- Anxiety, depression or feelings of not coping well

For more information, visit the **Princess Margaret Patient & Family Library** to get pamphlets relating to cancer-related fatigue. Read how cancer survivors have dealt with the effects of cancer and fatigue in the “**Tips From Patients**” section of this Guide Book (page 47).

## Find Information on Managing Physical Side Effects

Each person’s cancer journey is different, and each person will have different side effects. Use the resources below to find information on the side effects of:

- Chemotherapy
- Radiation
- Surgery
- Many other therapies

### Resources

#### **Princess Margaret Cancer Answers**

Princess Margaret Cancer Answers is an online special search engine designed for people with cancer. It can help you find trusted health information from Princess Margaret Cancer Centre and other organizations around the world. Find pamphlets, websites, videos and more by typing in keywords such as “chemotherapy side effects.”

**Website:** [www.pmcanceranswers.ca](http://www.pmcanceranswers.ca)

#### **Princess Margaret Patient & Family Library**

The Patient & Family Library has a large collection of print and digital materials about cancer. These materials are available for you, and your family to borrow free of charge.

To contact the Library:

**Phone:** 416 946 4501 ext. 5383

**Email:** [patienteducation@uhn.ca](mailto:patienteducation@uhn.ca)

## Cancer Education Class Calendar

Find classes, events, and activities for patients and family in the Cancer Education Class Calendar. See the calendar for times and dates of the sessions.

Pick up a monthly calendar:

- In your clinic
- In the Patient & Family Library
- On the Princess Margaret Cancer Centre website at [www.uhn.ca/PrincessMargaret/PatientsFamilies/Pages/events\\_calendar.aspx](http://www.uhn.ca/PrincessMargaret/PatientsFamilies/Pages/events_calendar.aspx)

You can also take many cancer classes online at [www.pmcancerclasses.ca](http://www.pmcancerclasses.ca).

Contact the **Princess Margaret Patient & Family Library** for more details:

**Phone:** 416 946 4501 ext. 5383.

See the “**My Resources & Support**” section of this Guide Book on page 65 for a full list of resources available at Princess Margaret Cancer Centre.

Find a list of recommended websites on page 102.

# Dealing With My Emotions

Everyone has different emotions and emotional needs relating to their cancer journey. Some people keep feeling anxious after treatment, and worry about their cancer coming back. This is normal, as are all of the other emotions you are feeling. You and your family and friends should take note of these emotions. You may want to talk to others who have been through cancer treatments and may be feeling the same thing. There are many ways to get the support that you and your family and friends need as you are dealing with these emotions. Some examples are listed below.

## How to Manage Your Emotions

- ✓ Speak to your cancer care team
- ✓ Talk to a counsellor
- ✓ Join a support group
- ✓ Volunteer
- ✓ Get involved with the cancer community
- ✓ Keep a journal
- ✓ Attend a workshop: meditation, yoga, writing

See the **“My Resources & Support”** section (page 65) for more information. You can find tips from cancer survivors on coping with cancer in the **“Tips From Patients”** section (page 47) of this book.

Keep track of your daily physical and emotional side effects in the **“Side Effects Tracker”** section (page 69) of your Planner.





# After Treatment

The effects of your treatment can last long after the treatment has finished. This section contains information on how to get the best care possible after you have finished treatment.



## Charting Your Course: Seeking Information

Some people who have been through cancer treatment feel like they cannot get enough information. After their treatment is over, they have time to think. They often have questions about what has happened to them. On the other hand, some people would rather not focus on what has happened. They prefer to let their cancer care team advise them as needed.

**Refer to the “My Resources & Support” section (page 65) to look up programs at Princess Margaret Cancer Centre and in your community to support you.**



# After Treatment Questions

You may have many questions about life after cancer treatment. You may have questions about:

- How to deal with your emotions
- Diet and exercise
- Practical issues such as going back to work

You will need to work with your cancer care team to find answers to these questions. Remember: no question is silly or not important.

Below are some sample questions to ask your cancer care team.\* These questions can help you to know what you can expect once cancer treatment ends.

What treatments and medicines have I been given?

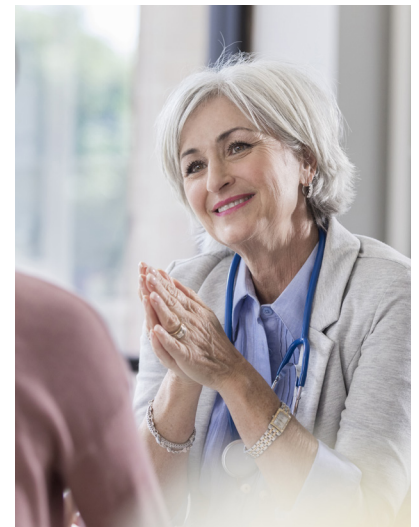
Ask your oncologist to provide a written record of:

- The type of cancer you had
- The treatments and medicines you had
- The side effects of these treatments

You can record this information in your **Cancer Journey Planner**.

Do I need any follow-up care?

Ask your oncologist about screening or tests you need once your treatment is complete. Ask for a schedule of when you should follow up with your primary care provider (family doctor nurse practitioner) or oncologist to have these tests done. Add these dates to your calendar to remind yourself about follow-up care.



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\*From the Institute of Medicine of the National Academies: "Cancer Survivorship Care Planning", Fact Sheet November 2005.



Will I get cancer again?

Ask your oncologist about the risks of getting a secondary cancer (another type of cancer) or recurrent cancer (the same type of cancer). What signs or symptoms should you look for?

What should I do to maintain my health and well-being?

Ask your cancer care team about eating a healthy diet and exercise.

Even though I survived cancer, will I feel different physically?

Cancer treatment has a different effect on everyone. For some people, there are severe side effects from treatment. Be aware of the possible short and long-term effects that may arise.

Some treatments can affect a person's heart, energy, or fertility (being able to get pregnant or to get someone pregnant). Ask your oncologist how your treatment could affect your long-term physical and mental health.

There may be a program in your community to help you manage these side effects. See the **"My Resources & Support"** section (page 65) for more information.

Will I have trouble getting health insurance or keeping a job because of my cancer?

Having cancer can affect:

- Access to health insurance or life insurance
- The ability to keep a job
- How easy it is to move between jobs

Ask your cancer care team for information about resources available to you if you are:

- Treated unfairly in your job due to your cancer

- Treated unfairly when applying to jobs due to your cancer
- Unable to access or keep health insurance and life insurance
- Looking for support for going back to work

Are there support groups I can join?

A member of your cancer care team can provide a list of organizations or groups that can offer information on issues you may face after treatment. Visit the **Princess Margaret Patient & Family Library** to get information about support groups.

Now that I have finished treatment, who on the team will monitor my care?

Find out from your cancer care team who will be in touch with your primary care provider. This team member will arrange follow-up care related to your cancer treatment. Follow-up care is the health care you have after cancer treatment has finished. Follow-up appointments will involve regular check-ups with your oncologist or primary care provider.

## My Cancer Care Team After Treatment

Until now, doctors, nurses and other cancer care providers have guided you on your cancer journey. From your earliest tests, through your diagnosis and treatment, these people gave you information and helped you make choices. You probably learned to trust them and may have made some friends along the way.

Now that your cancer treatment is over, you are entering a new stage in your journey. It is normal to worry about your future. You may not want to give up your connection to your cancer care team. You may feel that you need the expert advice of your cancer care team to guide you further.

Everyone on your cancer care team is still there to support you, if you need them. In fact, most will tell you to call them with any questions about side effects after treatment, new symptoms, or other issues. Your cancer care team can also help you connect with other health care providers who can help you move forward after treatment.

However, a few things will change now that you have finished your treatment.

You will see your cancer care team less often

You will still need to have medical appointments with you cancer care team, but these visits will be fewer. This is because you do not need active treatment. Now your oncologists and primary care provider will share the job of giving you your check- ups. You may not need to see all of these cancer care team members as often, but they will be available if you need them.

The size of your team will become smaller

You will not see as many cancer care providers as you did during treatment.

Your primary care provider will coordinate your care

You will need to have a primary care provider (family doctor or nurse practitioner). Your primary care provider is the one person you will see on a regular basis rather than seeing a few different doctors. Your primary care provider will look after your health with your cancer care team. If needed, other cancer care providers are there for you.

Your relationship with team members may change

Your Specialized Oncology Nurses may become a more important source of information after your cancer treatment ends. Your Specialized Oncology Nurses will be available by telephone and at your follow-up clinic visits.

Your nursing team can assist you in getting the help that you need. To speak to a Specialized Oncology Nurse, call the site telephone line. You will be given the site telephone line number on your first visit.

# Get Your Cancer Information to Your Primary Care Provider

Keep up-to-date records of all the medical care you get for cancer and other conditions. Future decisions about your care may depend on your past treatments. Notes from your clinic visits should be sent to your primary care provider (family doctor or nurse practitioner). Check with your cancer care team to ensure that this happens. If you move or go to several different doctors, you are the only one who will have your complete health history.

### Share access to your myUHN Patient Portal

Give your primary care provider access to your myUHN Patient Portal by making them a “Shared Access User.” This allows them to see your health information that is in your myUHN Patient Portal. You can choose what information you want your primary care provider to see, and how long they can see it.

To make your primary care provider a Shared Access User:

1. Your primary care provider must register for their own myUHN account. All Shared Access Users must register for their own account, even if they are not a UHN patient.
2. Send your primary care provider a shared access invitation by clicking “Send invite” in the “Shared Access” section in myUHN.

Keep your primary care provider up-to-date on:

- Any medicines that you are taking now. This includes over-the-counter medicines such as pain killers, laxatives (medicine to help you poo), as well as nutritional supplements, vitamins, minerals and herbals.
- When your next check-up test is due (for example: a mammogram, PSA test, Pap test).

- Which specialists you are still seeing.
- Any fear or concerns that you have.
- Any lifestyle changes you have made (for example: quitting smoking, changing your diet, changing how you exercise).
- How you feel. Do you have any symptoms or changes that are worrying you?



# Tips from Patients

This section has been shortened and adapted from the **Toolkit by Patients for Patients**. The content of this section is based on the experiences of cancer survivors (patients, their families and friends). Find out what has helped other survivors in their journey with cancer.

Find the full toolkit in the Princess Margaret Cancer Journey app or webpage ([www.uhn.ca/PrincessMargaret/PatientsFamilies/Cancer\\_Journey/](http://www.uhn.ca/PrincessMargaret/PatientsFamilies/Cancer_Journey/)).

# Access Services

Many people rely on the hospital to take care of them when they are most ill but the hospital may not provide everything people need when facing a serious disease like cancer. In the sections below, cancer survivors provide insight into what you and your support circle can do to access the supports and services you might need at different stages through your cancer journey.

## Get Access to the Best Health Care

Many survivors talk about the tension they felt when they asked their doctor for a second opinion or referral to a specialty cancer hospital like Princess Margaret Cancer Centre. Survivors have explained that some doctors may take offense at these requests and this made them feel awkward and sometimes prevented them from getting answers.

You have the right to ask questions and talk about access to quality treatment. If your cancer care team does not seem to respect your right to ask questions and express concerns, consider finding someone who is more compatible with your views. You should be at ease speaking with your doctor about any doubts in your cancer care. It is best to do this before treatment begins because once treatment starts, changing cancer care providers or hospitals can interrupt or delay your treatment.



## Find Resources

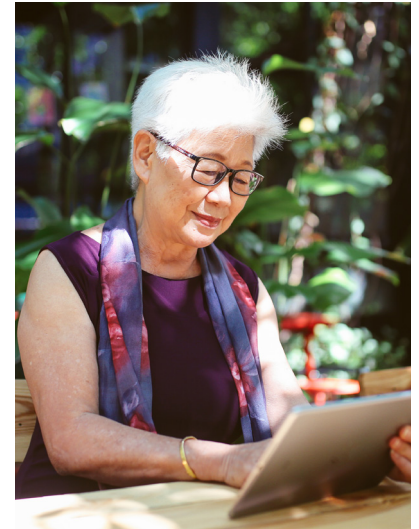
Community services and other survivors (peers) have helped many people during and after their cancer treatment. You can find support through classes and programs for cancer survivors. Survivors have shared the positive effects that yoga, laughing, being around good friends or meeting other survivors had on them. What will help you is up to you to explore because everyone is different. Do not be afraid to try something new.



Many resources for financial help, health information and support classes and programs can be found through the **Princess Margaret Patient & Family Library**. Read about the Library on page 94 of this Guide Book.

## Get Informed

Cancer and its treatment are complex. Cancer care providers do not always provide the answers you need in a way you can understand, or when you are ready to hear or absorb it. Getting informed means learning what information you want (and do not want) and knowing how to find it.



## Manage Information Overload at Your Appointments

Survivors explain that a lot of important medical information is given to patients when they first learn that they have cancer. You are not alone in feeling rushed or that you cannot manage the amount of information you are getting in your appointments.

### How to Manage Information

- 1. Get as much information as you can in writing. Bring a notepad and pen to every appointment.** Use the “Appointment Notes” (page 20) in your Planner if you think this would be useful. Ask for pamphlets or handouts to read later.
- 2. Ask your health care provider to slow down, repeat information and do not be afraid to ask questions.** If you do not know what to ask, then ask your cancer care provider to tell you what other people have asked about the topic.

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- 3. Take time to read through the pamphlets your cancer care team gives you.** If you have questions after reading the pamphlets, call your cancer care team to discuss or leave a message for a call back.
- 4. You are entitled to a second opinion if you feel you need one.** Since some health care providers may take offense to this, you can ask your family doctor to organize the second opinion instead of your cancer care team.
- 5. Bring family or friends to your appointments to help you digest information.** Sometimes having a family member or friend present can also remind your cancer care team that you are a person who is loved and cared for by others.

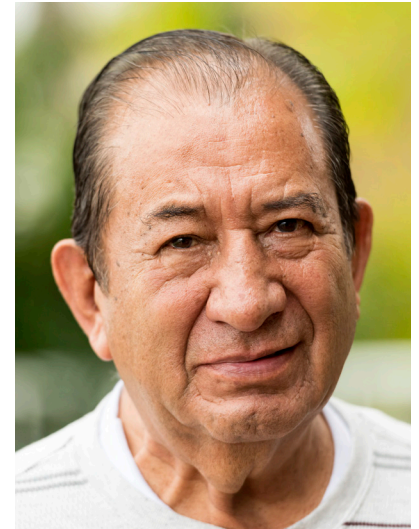
## Find Information from Other Cancer Survivors

Health related information can often be found in clinics, in pamphlets in waiting areas, in patient and family libraries and on the Internet. Information about living with cancer in the context of everyday life is often the biggest information gap because it is not addressed by the health care system. For many people, other survivors are the best source of information about everyday life with cancer.

Some survivors view support from other survivors as the best way of being informed. Places like the Canadian Cancer Society (CCS) and Gilda's Club offer a peer matching program where you can connect with other survivors that have things in common with you. Some other ways of meeting with other survivors are through various online community networks of cancer survivors on Twitter and Facebook.

# Find Strength

Finding strength is moving forward even when you feel afraid, sad and unsure. Strength can come and go; it is not constant. Finding strength is being able to live with feeling scared or uncertain about what will happen next. Finding strength is not forcing an upbeat viewpoint. It is accepting that the cancer experience is hard and that it can feel like too much to deal with at times.



Finding strength can also mean letting go of control and being open. For friends and family members, finding strength may be coping with the health care of a loved one while sometimes feeling sad and helpless.

## Ways to Find Strength

People find the strength to face cancer in diverse ways. You can find strength in yourself, in others, or in things you can do.

Some ways to find strength are:

Be aware of your feelings and needs

- ✓ Get to know yourself and share your feelings with others
- ✓ Work through your feelings of frustration or fear
- ✓ Believe in and be honest with yourself
- ✓ Set limits for yourself and others
- ✓ Tell others what you are thinking and feeling
- ✓ Use humour
- ✓ Find new meaning in life based on what you have been through
- ✓ Know that cancer is not a failure; you did not cause your disease

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Reach out to people around you

- ✓ Ask for help and support when you need it
- ✓ Build a support circle of family, friends, work colleagues, fellow survivors or health care providers
- ✓ Attend support groups to meet people going through cancer
- ✓ Make a bond with other survivors so you feel less alone and can learn from each other

Do things you enjoy or that make you feel good

- ✓ Read, paint, watch TV, play a game: do something you enjoy that helps you feel normal or distracts you from cancer
- ✓ Learn to relax during times of stress by trying meditation, exercise, yoga, breathing techniques, or massage

Finding strength can help protect you from everyday stress, anxiety and depression. Caring, positive relationships and sharing with others can be helpful during a time of stress and can relieve some of the pressure on you. Simple acts, such as making meals, being social and being active can be healing and help you feel more like yourself.

Many people who find strength after a cancer diagnosis feel a sense of growth and new meaning in life after they have gone through the hardest of times.

# Focus on Yourself

There are “little things” you can do that can help you cope during difficult times. These “little things” can include everything from small actions to certain ways of thinking. Cancer survivors have found that the following things help.

## Listen to Yourself

After a cancer diagnosis, other people may offer you help and advice. You may also feel like others expect you to act or feel a certain way. It is important for you to learn to listen to yourself and your needs.

Although learning to listen to yourself sounds simple, many survivors find it hard. With many demands like work and family-life, we often leave little time for our own needs. Give yourself time to learn how to put your needs first by taking time for regular “check-ins” with yourself. Block off some personal time so you can get in touch with yourself, your needs, and the little things that matter to you.

## Form Special Connections

Many survivors describe someone or something that they formed a special connection with and turned to when taking time for themselves. This special connection can help you cope with changes and any challenges you may experience. Taking time for yourself can bring a sense of feeling normal or an escape when things get difficult. It can also help make the good times better.

Special connections can be made through:

- **Others**, such as your family, friends or another person who is in a similar situation as you
- **A place**, like your backyard or any other part in your home you call your own or your “safe place”



- **An object**, such as a comb and the routine of combing that can be a symbol of hair growing back after treatment
- **An activity or routine**, like painting, listening to music or doing a familiar routine like waking up and making coffee
- **Nature**, like a nature reserve or park
- **Spirituality or faith**, such as a beliefs, values, or religion

## Accept What You Can't Control and Slow Down

Most people like being in control of their lives. After a cancer diagnosis, many things can be out of your control, from your everyday routine to changes to your mind and body. Many survivors say that their first reaction was to try taking back control. This meant forcing themselves to do things that were too much. In retrospect, they say the better approach is to: "...Let go of the things you cannot control and control the things you can."

Accepting what you cannot control takes time, but letting go of the need for control can help you slow down and allow you to find inner peace. Survivors explain that simple things they do but often take for granted or little things they look at every day but do not really "see" or appreciate, become more clear and meaningful.

## See a Positive Change in Yourself

A cancer diagnosis can seem to "flip your life upside down". It can also lead to great personal growth and change. Some people may not see the positive changes in themselves or feel how empowering this change can be until later on in their cancer experience. This growth can happen over a short or long period of time.

One survivor said, "**Amidst a chaotic schedule of treatments and a bevy of family and friends, we had to learn to be self-reliant and fend for ourselves.**" This independence can foster self-confidence and a deep sense of spirituality, and can be empowering.

# Build Your Support Circle

Complex treatments, side effects and appointments can be hard to manage when you feel weak or stressed. You may find that having a support circle of people to help you can make a difference in how you feel. Your support circle can help fill in the gaps when you are not feeling your best and can make things easier.

You may be surprised by who becomes part of your support circle. You can choose people to be in your support circle from any part of your life. Sometimes, family members are a good choice but for some people it is simpler to get support from people who are less close to you. People who are close to you may be feeling concerned about you. This can make it hard for them to provide support. Sometimes, a cancer diagnosis can cause a feeling of distance between loved ones. It may take time for those closest to you to be able to help.

You can have a support circle with just a few people or your circle could include many people but perhaps with smaller roles. Some people like their support circle to be planned with clear roles, while others prefer to let it grow naturally.

## What Should I Look for in a Support Person?

Who is able to help depends on many things. This includes their personality and level of empathy, and also the amount of free time they have or if they have a skill, like being a good cook or being able to drive.

You may also meet people in your cancer care team who may help you with your needs. These people may play a special role in helping you talk about and understand your needs and can connect you to the right resources.



## How Do I Build a Support Circle?

There are 5 steps to building a support circle:

- 1. Make a list of your needs.** Take some time early on to think about what you really need. Make a list of all the support you will want or need. You may want to include a “gatekeeper” on your list. This is a person who can help you politely answer emails and phone calls, and send updates to your friends and family on days when you are not feeling up to it.
- 2. Match people with your needs.** Once you have a list of needs written down, match your needs with what you think each person will be good at. Some people have found it helpful to create 2 support groups – 1 for emotional support and 1 for practical support.
- 3. Share with your support people.** Sharing your feelings and needs with people can be hard. Some survivors found it easier to share with others during activities that are part of their normal routines, like visits to the gym or over a cup of coffee.
- 4. Set up an easy way to connect with the whole group.** This may be really helpful for times when you have less energy. Your gatekeeper may be able to help you with these ideas:
  - Regular group emails to all caregivers. Weekly or monthly emails are helpful to update everyone. This will allow everyone to know how you are doing without adding more to your to-do list.
  - Group calendars, like Outlook or Google. Set up a calendar with all the appointments and tasks that you need help with. Allow everyone in your support circle access so they can sign up for tasks.



- Create an interest group (for example, knitting) with your support circle. This will allow you and your support circle to spend time together without always focusing on your health.
- 5. Give thanks.** Many survivors note that it is important to thank the people who are helping you. Small things go a long way. For example, writing a card or making extra soup to share are great ways to show you care about them too.

## What Should I Do When a Loved One Has Trouble Showing Support?

Feeling like you have a loved one who does not want to be there for you can be very hard. But some survivors find it helpful to try to understand why loved ones may be having a hard time showing their support. People may stay quiet for many reasons. Your relationships with people may change, but if or when it feels right, you can try to connect again after a while.

Caregiving is a special kind of skill. Not everyone copes well with being uncertain about a loved one's well-being. They may avoid the topic to lessen the pain. It may take them a while to work through their feelings.

# Partner in Your Care

Being a partner can be summed up by the phrase: **“Do not do anything to me without including me.”** Being a partner means that you are involved in all decisions about your care. Your cancer care team tells you what to expect, answers your questions in language that you understand, and respect your wishes about your care.

Partnering in your care can:

- ✓ Help you feel more comfortable and in control
- ✓ Lead to better outcomes
- ✓ Help solve problems faster



## Benefits of Partnering

The benefits to having a strong partnership with your cancer care team include:

- **Better communication.** Being a partner in your care makes it easier to tell your cancer care team about how you are feeling, and easier for them to tell you about things that can help you.
- **Higher level of comfort.** People who are partners in their care feel more comfortable because they know that they can talk to their cancer care team and that they will listen to and respect what they say.
- **Problems are solved more quickly.** Most people experience side effects or other difficulties during cancer treatment. If you have a strong partnership with your cancer care team, you can tell them about these difficulties and find a solution more quickly.
- **Greater sense of control.** When you are a partner in your care you know that the other members of your cancer care team will respect your wishes. This gives a greater sense of control and helps you feel more comfortable at a difficult time in your life.

## How to Partner in Your Care

To build a strong partnership with your care team:

- ✓ **Be open about what you want.** Let your cancer care team know that you want to be involved. When your team members see that you want to be a partner, they will start to work with you and involve you more.
- ✓ **Try something different.** Each person has their own way of dealing with other people. If you find it difficult to work or communicate with one of the members of your cancer care team, try a different approach instead of repeating the same thing.
- ✓ **Keep trying.** Some members of your cancer care team may not respond when you first reach out. Don't give up. If you can't get an answer from one person, try asking someone else and build a connection with that person.
- ✓ **Communication is key.** Open communication is the key to being a partner in your care. Talk to your cancer care team about what you are experiencing. Ask questions, and keep asking questions until you get an answer you understand. Do not be afraid to ask people to explain or repeat something as many times as you need.

## Handle Barriers to Partnering

Although it is good to have a strong partnership with your cancer care team, it can be difficult to create one. There may be barriers you need to overcome, including:

- **Medical appointments are often very short.** Many people feel rushed during their appointments. Doctors may not have the time to listen to questions or concerns. Try talking to nurses or other health care provider if you have questions that your doctor has not answered.

- **Medical information can be very complex.** Some cancer care providers use medical language when they talk to patients. This language can be hard for people to understand without a medical background. If you cannot understand what anyone on your cancer care team is saying ask him or her to use simpler language.
- **There are different styles and schools of thought about how health care providers should work with patients.** Some cancer care providers are happy to partner with patients and work with them. Others feel that patients should simply do what they are told. In the end your ability to get what you need from your cancer care team comes down to communication and cooperation.

## Give Back

Giving back can have a wide-reaching impact on you, those around you and cancer care overall. Giving back can be driven by a desire to help, by things you are grateful for in your life, or by something you had to struggle through.

For some, giving back is viewed as a way of repaying a “debt” for what they have been fortunate to receive. Some find that giving back is a way to address gaps in their own cancer care like being overwhelmed with the news of having cancer, not knowing what to expect or wanting

more information and not knowing where to find it. For others, it is a source of hope and courage in overcoming cancer and a sense of purpose in helping others.

Giving back can be helpful to the giver and the receiver. Many people give back to help others, but find that they have also gained. For some, it allows them to be more open about what they went through and get in touch with their feelings. For others, giving someone



else hope helps them gain control over their life and look at their experience in a different way.

## How to Give Back

- ✓ Get involved in volunteer organizations.
- ✓ Give your time to help create support groups.
- ✓ Join a committee or panel. This can be a useful way to connect, inform, and make lasting changes that will help those in need.
- ✓ Share your story. The success and challenges you faced are an important source of information for others. This can include supporting others in advocating, sharing what worked and did not work for you and services and support you found helpful.
- ✓ Support others. Connect one-on-one with others living with cancer to develop a relationship and support system. In the words of one survivor: “You are not walking alone. There is a special kind of support that only other cancer survivors can provide.”

Survivors have said that telling their story took away the feeling that their life is defined by their cancer experience. They explained that giving back asserts that “You are more than your cancer” and that “I had cancer, but the cancer doesn’t have me.”

## Make Healthy Choices

When it comes to healthy living, there is no single meaning. One of the first things to come to mind when people think of “healthy living” is eating healthy foods and getting exercise. But healthy living also includes other things you do that make you feel good. Other cancer survivors describe what a healthy lifestyle means to them in the following sections.



## How to Live a Healthy Lifestyle

### Put yourself first

When you have cancer, it is important to take care of yourself first. When you're feeling tired or overwhelmed, don't try to "work through" it. Take the time to rest and relax so you don't wear yourself out.

Some cancer survivors found it helpful to:

- ✓ Give yourself permission to stop and relax.
- ✓ Make time for yourself.
- ✓ Say "no" to things that would create more stress in your life.
- ✓ Ask for help to get things done.
- ✓ Find activities that give you peace of mind, like meditation, deep breathing, yoga, or art.

### Enjoy life

It is OK to feel sad, angry or frustrated, but it is also OK to feel happy, pleasure, or joy. As one cancer survivor put it: "Find ways to have fun even when you're in a miserable place."

Find small ways to add a little joy to your day:

- ✓ Find ways to laugh and smile every day, like wearing a goofy wig or dancing around your home. You may even make other people laugh too.
- ✓ Learn to appreciate every moment, even the winter.
- ✓ Do something you enjoy – reading, bird watching, working on your computer, ceramics, singing, anything – to take your mind off what you are going through.
- ✓ Try something new that you have never had the courage to try before.

- ✓ Get outside and play.
- ✓ Find time to smell the flowers and notice the world around you.

### Take care of your body

Knowing what to do to eat right and stay active can be confusing. Instead of following the trends, or feeling guilty, take a more balanced approach and enjoy everything in balance and do things that make your body feel good. You can also get information from a health care provider that has knowledge and experience working with people with cancer.



Some cancer survivors found it made them feel better to:

- ✓ Eat balanced amounts of a wide variety of food, and savour every bite.
- ✓ Eat as many vegetables as you can, but leave a little room for treats every now and then (and do not feel guilty about eating them).
- ✓ Take your fitness routine to the next level, no matter if you are a beginner or an expert.
- ✓ Try using deep breathing techniques to relieve pain or energize yourself.
- ✓ Lower your exposure to chemicals, like those in cleaning and personal care products.
- ✓ Know that you did not cause your cancer. Taking care of yourself is not about making up for the past, it is about getting through cancer and feeling healthy in mind, body and spirit.

### Get support from other people

Do not feel like you need to manage cancer by yourself. You are not alone. Family, friends, and cancer care providers can offer you support by helping you through tough times or helping you with everyday tasks.

Some cancer survivors found it helpful to:

- ✓ Accept offers of help from family, friends, and even well-meaning strangers.
- ✓ Surround yourself with the people who make you feel loved and good about yourself. Spend less time with those who do not.
- ✓ Join a support group for people affected by cancer. No matter how supportive your family and friends may be there are some things about living with cancer that they will not be able to understand.
- ✓ Talk to a counsellor, social worker, or psychologist, even if you do not think you need the extra support. You can share your deepest, darkest thoughts with a professional without worrying about upsetting them.

Let go

Give yourself permission to let out your feelings. This can help you feel like a weight has been lifted off your shoulders. Another part of letting go is realizing that some things are not worth worrying about. As one survivor said, "I do not stress if the household chores were not done properly. After what I have been through, it is not important to me anymore."

Some cancer survivors found it helpful to:

- ✓ Give yourself permission to cry and let your feelings out.
- ✓ Try using art or writing to express yourself.
- ✓ Let go of worries about the things you cannot control.
- ✓ Know what is really important to you, and let go of the rest.

No matter what choices you make, pursue the healthy lifestyle choices that feel right for you.





# My Resources & Support

Use this section to find out what services, programs and resources are available for you. This section provides a good overview of what Princess Margaret Cancer Centre and the community has to offer. You can find information here that will help you make the contacts that will be most useful.

# My Resources & Support

We are all different. How each of us gets support is as unique as all other things in life. Just as we all have different tastes when it comes to music, food and books, we all have different ways of getting help when we need it.

Perhaps the most important thing to realize is that there is nothing wrong in asking for help. Most people have some trouble coping with any diagnosis that has the word 'cancer' in it. That is not a sign of weakness. It is simply due to the connections drawn from the word 'cancer' in our world today.

Review the list of services and resources available to you on the next few pages, and find out how to contact them.

# Services

For complete descriptions of each service and contact information, see pages 69-105

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CAREpath is an after-hours telephone service that allows you to speak with an oncology (cancer) nurse.	
<b>Clinical Nutrition Services</b> .....	<b>70</b>
A Registered Dietitian can help you to find more appetizing food to eat in a healthier way.	
<b>Community Resources</b> .....	<b>72</b>
There are many resources available in your community. Page 72 lists a few agencies and programs that might be helpful to you.	
<b>Department of Supportive Care</b> .....	<b>76</b>
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A comfortable place to get information, participate in a class or program, meet other survivors or sit and relax.	
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Service	Page #
<b>Interpretation Services.....</b>	<b>88</b>
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<b>Medical Imaging.....</b>	<b>89</b>
Find out who to contact about your medical imaging tests and appointments.	
<b>Pharmacy Services.....</b>	<b>90</b>
Pharmacy services can help you understand your medicines and make sure that they are safe for you.	
<b>Physiotherapy Services.....</b>	<b>91</b>
A physiotherapist can help you if you have mobility problems as a result of your treatment.	
<b>Princess Margaret Cancer Answers.....</b>	<b>92</b>
Princess Margaret Cancer Answers (PM Cancer Answers) is a search engine website to help you find cancer information you can rely on.	
<b>Princess Margaret Cancer Centre Lodge.....</b>	<b>94</b>
The Princess Margaret Cancer Centre Lodge is a place to stay for Princess Margaret Cancer Centre patients getting active cancer treatment.	
<b>Princess Margaret Patient &amp; Family Library.....</b>	<b>97</b>
The Patient & Family Library is here to help you and your family find reliable and up-to-date information about cancer.	
<b>Smoking Cessation.....</b>	<b>100</b>
Find resources and programs to help you quit smoking.	
<b>Wig Salon &amp; Accessories Boutique.....</b>	<b>101</b>
Provides a valuable service to patients in a supportive, private atmosphere.	
<b>360° Clinic Tours.....</b>	<b>102</b>
Tour the clinic spaces online before you come to Princess Margaret Cancer Centre.	
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Recommended websites for online information and support.	

# CAREpath

If you need help managing symptoms of cancer treatment after clinic hours, call CAREpath. CAREpath is an after-hours telephone service that allows you to speak with an oncology (cancer) nurse. The oncology nurse can help you better manage your symptoms at home.

Your cancer clinic will give you a one-page sheet with information about your cancer treatment and diagnosis (details about your cancer). The oncology nurse will need this information to help you. This one sheet contains your personal information so keep it in a safe place.

CAREpath is only available when Princess Margaret Cancer Centre clinics are closed. To talk to an oncology nurse:

1. Call CAREpath at 1 877 681 3057.
2. An operator will answer your call.
3. Your call will go through to an oncology nurse.

If the nurse is not able to take your call, you will get a call back within 15 to 20 minutes. After your call, the nurse will send a note to your clinic. If you need to follow-up with your cancer clinic, your clinic will have all the information about your call. If you have any questions about CAREpath, ask a member of your cancer care team.

## Contact CAREpath

**Phone:** 1 877 681 3057

**Hours:**

- Monday to Friday, 5 pm to 8:30 am
- Saturday, Sunday and Holidays: available 24 hours (all day and all night)

# Clinical Nutrition Services

Every patient's cancer journey is unique and every patient will have different needs for their diet. A Registered Dietitian can help you maintain or improve your nutrition before and after treatment.

During treatment, diet concerns may include:

- Losing or gaining weight without trying
- How to eat to manage symptoms (such as, loss of appetite, taste and smell changes, nausea, or swallowing problems)
- Whether you need to follow a special diet (such as, a diabetic diet, low fat diet, low potassium diet, low sodium diet)
- If it is safe to stay on certain alternative diet therapies
- Nutrition after cancer treatment

## Services Offered by Registered Dietitians

### Group Classes

Classes are led by a Registered Dietitian, and provide a setting for group discussion. For general questions about healthy eating, a group class may be best for you. There are other nutrition classes that are tailored to a cancer type or program.



Find classes, events, and activities for patients and family in the Cancer Education Class Calendar. See the calendar for times and dates of the classes.

Pick up a monthly calendar:

- In your clinic
- In the Patient & Family Library
- On the Princess Margaret Cancer Centre website at [www.uhn.ca/PrincessMargaret/PatientsFamilies/Pages/events\\_calendar.aspx](http://www.uhn.ca/PrincessMargaret/PatientsFamilies/Pages/events_calendar.aspx)

You can also take many cancer classes online at [www.pmcancerclasses.ca](http://www.pmcancerclasses.ca).

Contact the **Princess Margaret Patient & Family Library** for more details at 416 946 4501 ext. 5383.

### Individual Counselling

Based on your treatment, you may have problems that make it hard to eat or drink. In this case, you may need one-on-one counselling with a dietitian.



## Additional Resources

The dietitians at Princess Margaret Cancer Centre co-wrote a cookbook called “**Goes Down Easy: Recipes to Help You Cope with The Challenge of Eating During Cancer Treatment.**” It is a practical cookbook for people living with cancer and their caregivers. Buy it at the outpatient pharmacy or online at [www.amazon.ca](http://www.amazon.ca), or borrow it from the Patient & Family Library.

### Contact a Registered Dietitian at Princess Margaret Cancer Centre

Patients at the Princess Margaret Cancer Centre can talk to a Registered Dietitian working in cancer. The dietitian will help decide if a group class or a one-on-one counselling session is best for you. **Ask a member of your cancer care team to refer you.**

# Community Resources

There are many organizations that can support you and your family. Visit the **Princess Margaret Patient & Family Library** to find out about them. Browse the library collection or ask a staff member for help.

## Wheels of Hope Transportation Service, Canadian Cancer Society



**Canadian  
Cancer  
Society**

If you are getting treatment at Princess Margaret Cancer Centre, you can get transportation to and from your cancer-related appointments. If there are not enough drivers, service may be limited. This service can also be arranged if you live out-of-town. A telephone with a direct line to the transportation office of the Canadian Cancer Society is located at the Information Desk on the Main Floor across from the Murray Street entrance.

Contact Wheels of Hope

**For more information or to book transportation:**

**Phone:** 1 888 939 3333

**Website:** <https://www.cancer.ca/en/support-and-services/support-services/transportation-on/>

## Gilda's Club Greater Toronto

Gilda's Club Greater Toronto is a place where men, women, teens and children with cancer – along with family and friends – can come together to share social and emotional support. Gilda's Club also welcomes long-term cancer survivors and those who have lost someone to cancer.



Gilda's Club offers the following in a home-like setting:



- Support and networking groups
- Lectures
- Workshops
- Social activities

The Gilda's Club philosophy is based on the belief that a diagnosis of cancer affects the whole family, as well as friends. They believe that no one should have to face cancer alone. Gilda's Club programs are free of charge.

Contact Gilda's Club Greater Toronto

**Location:** 24 Cecil St, Toronto, ON M5T1N2

**Phone:** 1 800 GILDA 4 U or 416 214 9898

**Website:** [www.gildasclubtoronto.org](http://www.gildasclubtoronto.org)

## Wellspring

Wellspring is a place that provides high-quality cancer support, education



and coping skills to patients and family members. Wellspring programs are free and open to patients and caregivers coping with any type or stage of cancer.

Wellspring programs include:

- Individual and group support
- Coping skills
- Expressive therapies
- Energy work
- Educational workshops and presentations

These programs are housed at warm and inviting Wellspring centres.

Contact Wellspring

**Phone:** 1 877 499 9904

**Website:** [www.wellspring.ca](http://www.wellspring.ca)

## Cancer Chat Canada

Cancer Chat Canada is a free online support for all Canadians affected by cancer. This includes patients, survivors, caregivers and families. Chat groups are led by professionals. Groups meet once a week for 90 minutes for about 8 to 10 weeks in a live chat room.

Register for upcoming groups by filling out the online registration form.

**Website:** [cancerchat.desouzainstitute.com](http://cancerchat.desouzainstitute.com)

## Peer Match Program, Canadian Cancer Society

The Peer Match Program is a free telephone-based service for Canadians diagnosed with cancer or caregivers of someone with cancer. You can speak one-on-one with trained volunteers who have had a similar cancer experience. Register online to find someone who can help you cope during your cancer experience.

Contact the Peer Match Program

**Website:** [match.cancer.ca](http://match.cancer.ca)

## Meals on Wheels

Meals on Wheels is a services that delivers meals to people who are unable to buy or prepare their own meals. There are more than 180 places in Toronto and Greater Toronto Area that provide this service. There is a fee.

Contact Meals on Wheels

**Website:** [www.mealsonwheels.ca](http://www.mealsonwheels.ca)

## The Nanny Angel Network

The Nanny Angel Network provides free in-home childcare for mothers with cancer. For four hours a week, professional childcare providers volunteer their time, so mothers can rest, go to appointments or simply have some time for themselves. The Nanny Angel Network service is free and open to

all mothers in the GTA diagnosed with cancer with children aged 12 and under.

Contact the Nanny Angel Network

**Phone:** 416 730 0025

**Email:** [info@nannyangelnetwork.com](mailto:info@nannyangelnetwork.com)

## Discounted Parking Passes

Princess Margaret Cancer Centre does not have its own parking lot. You are eligible to buy a discounted parking pass for the Sinai Health System parking lot, at 40 Murray Street, if you:

- Are a Princess Margaret Cancer Centre patient
- Have a family member who is getting treatment in Princess Margaret Cancer Centre
- Are a visitor to Princess Margaret Cancer Centre

The price of the pass\* depends on the number of the days you would like a parking pass for:

- 5 Days Pass: \$60.00
- 10 Days Pass: \$130.00
- 30 Days Pass: \$390.00

\*Parking pass prices are accurate as of Fall 2019 and may change.

# Department of Supportive Care

The Department of Supportive Care team can help you and your family cope with cancer and maintain your quality of life. All services are free. The Department of Supportive Care team includes:

- Physicians
- Psychiatrists
- Psychologists
- Social workers
- Oncology nurses
- Physiotherapists
- Occupational therapists
- Kinesiologists
- Registered massage therapists
- Dietitians
- Expressive arts therapists
- An early childhood education specialist

For some services, you may need a medical referral.

## Cancer Rehabilitation and Survivorship (CRS)

The Cancer Rehabilitation and Survivorship (CRS) program provides many services to support you during and after your cancer treatment. The CRS program is an outpatient program. This means you will not stay at Princess Margaret Cancer Centre overnight to access the program.

Below is a list of reasons you may be referred to the CRS program:

- Loss of range of motion
- Weakness
- Feelings of pain, tingling, numbness

- Balance issues and falls
- Fatigue (feeling tired)
- Lymphedema (swelling)
- Changes in appetite and diet concerns
- Trouble with activities of daily living
- Help with returning to work or school
- Sexual health (less interest in sex, vaginal dryness, pain with sex, body image issues)
- Psychosocial-help (emotions and coping, relationship changes, fear of cancer recurrence)
- “Brain fog” (poor memory, attention or focus)
- Help with exercise

The CRS program services can help you:

- ✓ Live with the late and long-term effects of your cancer treatment
- ✓ Improve your function
- ✓ Improve your health and quality of life
- ✓ Get better with help from a large rehabilitation team

The CRS team provides 3 different types of care:

1. Cancer Rehabilitation and Exercise Program (CaRE)
2. Specialized Rehabilitation
3. Community and Wellness Programs

You must be referred to the CRS program by a doctor. This doctor can be any doctor caring for you. However, the reason you are referred must be cancer-related. Your referral is a paper form that can be found online at: <https://bit.ly/2HNWepq>. Your doctor must fill out this form.

Ask your doctor to send your referral by fax to 416 946 4549.



## Palliative Care

Palliative care treats the whole person: body, mind and spirit. The Palliative Care team helps patients and families improve their quality of life when facing cancer. Palliative care is active, total care. Palliative care aims to prevent and treat pain and other physical symptoms. This care also addresses your mental, emotional, spiritual and social needs.

Palliative care can be helpful through all stages of illness. Early on, it can help make cancer treatments and side effects easier to manage. The program can also provide emotional and social support. At later stages, it can:

- Reduce suffering
- Help you carry on with daily life
- Help you plan for the care at the end of life

## Psychosocial Oncology

The Psychosocial Oncology Clinic can help you and your family maintain the best possible quality of life.

### Counselling and Emotional Support

At the Psychosocial Oncology Clinic, the team includes:

- Social workers
- Music and art therapists
- Psychologists
- Psychiatrists

The team provides counselling and therapies to help you and your family:

- ✓ Cope with cancer
- ✓ Reduce stress
- ✓ Improve emotional well-being

The clinic offers many services to help you and your family while you are a patient at Princess Margaret Cancer Centre. The clinic can also give you support for up to three years after your treatment.

The staff are trained to help people facing cancer. They can help you and your family cope with the emotional distress of cancer diagnosis and treatment. The clinic offers counselling, meeting with an expert, and medicine for patients and family members.

### Income Support

Patients facing cancer have many tools to get financial (money) support. Princess Margaret Cancer Centre has created a booklet called **“Coping with Cancer: Know How to Get Financial Help.”** In this booklet, you can find information about private options like workplace insurance, government programs, and how to apply. You can find this booklet in the Patient & Family Library (416 946 4501 ext. 5383), and in the Psychosocial Oncology reception area (416 946 4525). You can also get this booklet online by going to [www.pmcanceranswers.ca](http://www.pmcanceranswers.ca) and typing in **“Coping with Cancer: Know How to Get Financial Help.”**

### Discharge Planning

Discharge planning ensures you leave the cancer centre safely and at the right time. Discharge planning can also help arrange transfer to a different level of care. Social workers can help you with discharge planning along with the other members of your hospital cancer care team. This may include transfer to:

- A long-term care facility
- An inpatient rehabilitation (rehab) program
- A continuing complex care facility
- A palliative care unit

### Resource Counselling

Resource counselling can help you:

- ✓ Make decisions about practical concerns

- ✓ Find your way through the health and community systems
- ✓ Arrange services you need At Princess Margaret Cancer Centre and the community
- ✓ Overcome problems in getting care and services

### Child Care – The Magic Castle

The Magic Castle is a free childcare service for children, up to 12 years old. A registered early childhood educator and Princess Margaret Cancer Centre volunteers provide a safe and fun space. Children can express themselves through play and creative expression. The Magic Castle is on the main floor of the Princess Margaret Cancer Centre.

### Spiritual Care Services

Spiritual care visitors offer spiritual guidance and comfort to patients, families and staff of all faiths and backgrounds. The multi-faith chapel is always open and is located on the main floor.

## Contact the Department of Supportive Care

### Cancer Rehabilitation & Survivorship

**Location:** 2<sup>nd</sup> floor

**Phone:** 416 946 4501 ext. 2363

**Fax:** 416 946 4549

### Palliative Care

**Location:** 5<sup>th</sup> floor

**Phone:** 416 946 2135

### Psychosocial Oncology

**Location:** 16<sup>th</sup> Floor

**Phone:** 416 946 4525



# The Distress Assessment and Response Tool (DART)

The Distress Assessment and Response Tool (DART) is a review of your overall health, well-being and symptoms. DART will ask you questions about:

- Your common physical symptoms
- Practical concerns
- Emotional concerns

A staff member will ask you to complete the DART survey each time you come to the Princess Margaret Cancer Centre. This will ensure you get the best care possible. All of your information will be kept private and will only be shared with your cancer care team.

Complete the DART survey at every visit. Completing the survey will help your cancer care team:

- ✓ Talk to you about your most important concerns and symptoms
- ✓ Plan care that is right for you
- ✓ Find the help you and your family need

Complete the DART survey either on an iPad or computer in your clinic, or on paper. The paper version is available in 35 languages.

**Speak to your cancer care team if you have questions about the DART survey.**



# Drug Coverage and Financial Help

## How Drug Coverage Works: A Guide to Your Drug Coverage Options

Knowing your drug coverage options as early as possible can help you plan ahead and prevent delays in your treatment. Use the chart on the next page to find out what you need to know before your doctor gives you a prescription.

## How can a Medication Reimbursement Specialist help?

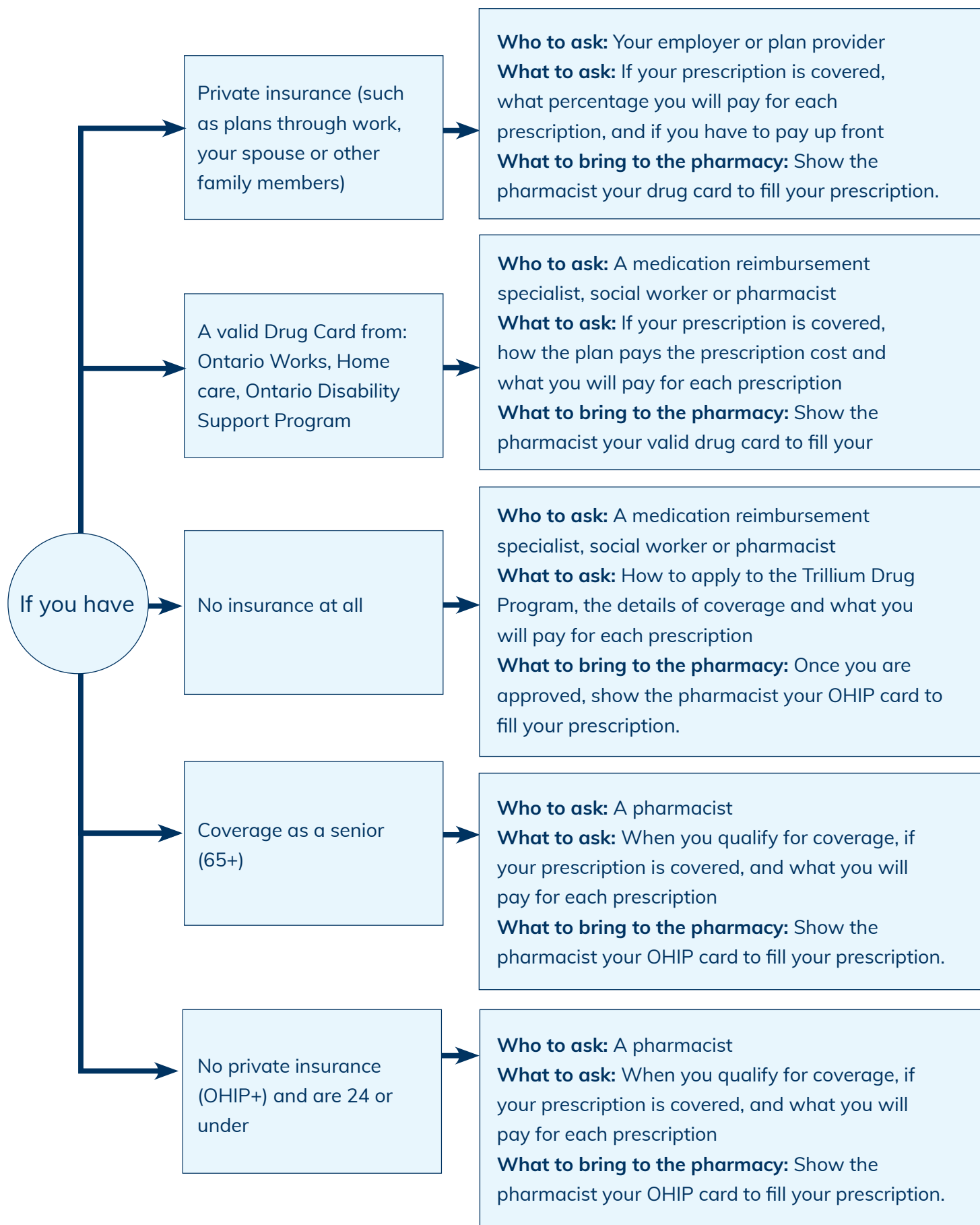
A Princess Margaret Medication Reimbursement Specialist is a drug coverage expert who can help you understand how your coverage works and what your options are. Make an appointment with a Medication Reimbursement Specialist if you need:

- Help knowing how your coverage works
- Advice on how to move forward with planning
- More information about patient assistance programs

Contact the Medication Reimbursement Specialist Office, or Princess Margaret social workers with questions.

## Type of Insurance You May Have

## What You Need to Know



## Contact a Medication Reimbursement Specialist

Medication Reimbursement Specialist Office

**Hours:** Monday to Friday, 9 am to 4 pm

**Phone:** 416 946 2830

**E-mail:** pmh-mrs@uhn.ca

## Contact a Princess Margaret Social Worker

Psychosocial Oncology & Palliative Care

**Location:** 16th Floor, Room 718

**Phone:** 416 946 4525

(by appointment only)

## Other Resources

Wellspring Money Matters Resource Centre

Wellspring's Money Matters Resource Centre gives patients access to individual financial counselling, and helps direct patients through government and agency income and support programs (by appointment only).

**In person:** Contact your local Wellspring centre.

**Website:** [www.wellspring.ca/mmonline](http://www.wellspring.ca/mmonline)

Trillium Drug Program

The Trillium Drug Program helps people who have high prescription drug costs but a low household income. It covers all drugs approved under the Ontario Drug Benefit (ODB) program. Learn how to apply online or through a Princess Margaret Cancer Centre Medication Reimbursement Specialist.

**Phone:** 416 648 3038 or 1 800 575 5386 (toll free)

**Website:** [www.ontario.ca/page/get-help-high-prescription-drug-costs](http://www.ontario.ca/page/get-help-high-prescription-drug-costs)

**You can also visit the Patient & Family Library for information about your drug coverage options.**

# ELLICSR Centre for Health, Wellness & Cancer Survivorship



# ELLICSR

## What is ELLICSR?

ELLICSR is a comfortable health, wellness and cancer survivorship centre. Visit ELLICSR in the basement level of the Toronto General Hospital (TGH).



ELLICSR is a place where you, your family members, friends and caregivers can:

- ✓ Get information on health and wellness
- ✓ Join a class or program
- ✓ Meet other survivors
- ✓ Sit and relax before or after your appointments

ELLICSR has:

- A Library with books you can borrow, a computer, and wireless internet access
- A Teaching Kitchen where you can watch cooking demonstrations and learn how to cook healthy foods.
- A Gym where you can get moving and have fun with other cancer survivors



Come find out how you can be part of the ELLICSR community.

## Directions

ELLICSR is on the basement level of Toronto General Hospital (TGH) in the Peter Munk Building. To get to ELLICSR, enter TGH through the University Avenue entrance (585 University Avenue, Toronto). Take the Munk elevators (near Starbucks) down to the basement level (B). Turn right to walk down the hallway. ELLICSR is ahead on your right hand side.

## Contact ELLICSR

### **Location:**

Toronto General Hospital  
585 University Avenue  
Peter Munk Building, Basement, Room B PMB 130

**Phone:** 416 581 8620

**Hours:** Monday to Friday, 8:30 am to 4:30 pm

To find out about programs at ELLICSR, pick up the monthly Cancer Education Classes Calendar from the ELLICSR Patient & Family Library at Princess Margaret Cancer Centre. You can also call 416 581 8620.

# Genetic Testing Services

What is genetic testing?

Genetic testing is a blood or saliva (spit) test that looks at your genes. Genetic testing looks for mutations (changes) in your genes. A gene mutation is a change in a gene that stops the gene from working as it should. Some gene mutations can cause cancer. Hereditary (inherited) cancer means a gene mutation is passed from one generation to another.



How can genetic testing help me?

Genetic testing can help you:

- ✓ Know why you have cancer
- ✓ Decide your cancer care
- ✓ Know your risk of getting other cancers
- ✓ Make choices about cancer screening

How can genetic testing help my family?

If you have a gene mutation, your family members may also have this gene mutation. Genetic testing may be offered to your family members. This testing helps your family members know if they have a higher risk for cancer.

## Familial Cancer Clinic

You can talk to a genetic counsellor at the Familial Cancer Clinic at Princess Margaret Cancer Centre. A genetic counsellor will talk with you about whether your cancer is inherited. A genetic counsellor can also work with your family members to reduce their risk of getting cancer.

**You need a referral from your doctor to become a patient at the Familial Cancer Clinic. Talk to your doctor if you have questions about genetic testing.**

# Information Desk

The Princess Margaret Cancer Centre Information Desk is on the Main Floor across from the Murray Street entrance. Staff at the desk can help you with general information about Princess Margaret Cancer Centre.

## Contact the Information Desk

**Phone:** 416 946 4501 ext. 4558 or 4559

**Hours:** Monday to Friday, 8:30 am to 4:30 pm

# Interpretation Services

## Medical Interpreters

University Health Network (UHN) aims to make sure that all patients understand their health information. This includes patients with limited English or who are deaf, deafened and hard of hearing.

The Department of Interpretation and Translation Services at UHN offers professional medical interpretation (face-to-face and phone interpreters) in over 150 languages. These languages include:

- American Sign Language
- Cantonese
- Italian
- Mandarin
- Portuguese
- Spanish
- Vietnamese

Access to remote interpretation is available at all UHN sites (including Princess Margaret Cancer Centre), 24 hours a day, 7 days a week.

**If you need an interpreter, ask a cancer care team member to contact Interpretation Services for you.**



# Medical Imaging

The Joint Department of Medical Imaging (JDMI) is a joint effort between University Health Network (UHN), Women's College Hospital, and Sinai Health System.

**Note that not all Medical Imaging tests are done at Princess Margaret Cancer Centre.** Know which hospital your test will take place at.

Medical Imaging tests offered through JDMI include:

- Breast Imaging
- Computed Tomography (CT) Scans
- General Radiography (X-Ray)
- Magnetic Resonance Imaging (MRI)
- Positron Emission Tomography (PET) Scans
- Ultrasound
- Many more

Be sure to arrive on time and follow the instructions you are given for your test. Contact your oncologist's office or clinic directly for questions about your appointment or how to prepare for your test. For more information about your test visit: [www.uhn.ca/JDMI](http://www.uhn.ca/JDMI).



## Contact Medical Imaging

To ask about, change, or cancel your Medical Imaging appointment, phone:

- **Princess Margaret Main Booking Office:** 416 946 2889
- **MRI Booking Office:** 416 946 2026
- **Medical Imaging Central Booking Office:** 416 340 3384



# Pharmacy Services

The Princess Margaret Cancer Centre pharmacy consists of inpatient, daycare and outpatient services.

Pharmacists can:

- ✓ Check drug orders to make sure they are correct for you
- ✓ Make sure your medicines are safe to take with each other
- ✓ Address other questions about medicine ranging from herbal products to drug coverage

## Contact the Pharmacy Services

**Phone:** 416 946 2000

Ask for the right department/personnel as required:

- **Inpatient pharmacy:** For inpatients who have questions about their treatment while staying Princess Margaret Cancer Centre
- **Daycare pharmacy:** For patients receiving chemotherapy from chemo daycare
- **Outpatient Pharmacy:** For questions about your take home medicines (located on the main floor of Princess Margaret Cancer Centre, at the University Ave entrance)
- **Drug Information Pharmacist:** For drug specific inquiries
- **Medication Reimbursement Specialist:** For questions regarding drug coverage

# Physiotherapy Services

Physiotherapy Services are available in the inpatient units. If you have mobility problems as a result of your treatment, speak to your nurse or a doctor about physiotherapy.

A physiotherapist can:

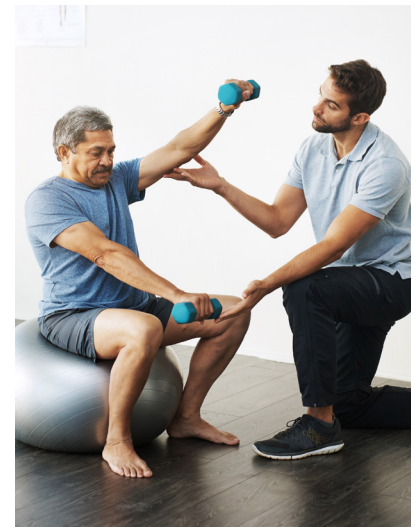
- ✓ Assess and give advice on movement, stretching, and strengthening
- ✓ Give tips to relieve common side effects of surgery and treatment.

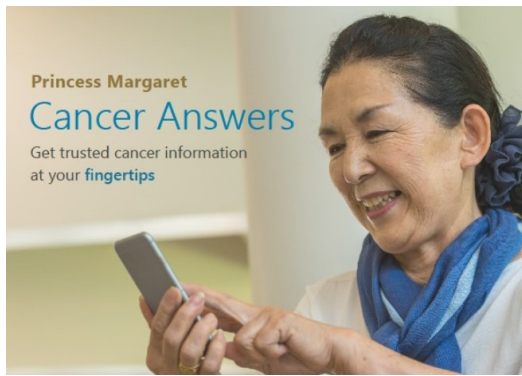
Examples of these side effects are:

- Numbness
  - Feeling of tightness or “pulling” on movement
  - Poor balance
  - Changes in posture
- ✓ Provide information about exercise and activity guidelines, and recommend walking aids
  - ✓ Help provide access to personal assistive devices for any needs you have that are a result of your cancer or treatment (physiotherapists are Assisted Devices Program Authorizers)
  - ✓ Refer you to a specialized rehabilitation program to arrange more physiotherapy follow-up sessions, if needed

If you are an outpatient (you are not staying at Princess Margaret Cancer Centre overnight) you may be able to consult with a physiotherapist both during and after treatment at the Cancer Rehabilitation and Survivorship (CRS) Program.

**You will need a referral from your doctor for these services. You can also visit a physiotherapist at a clinic in the community.**





# Princess Margaret Cancer Answers

Princess Margaret Cancer Answers (PM Cancer Answers) is a search engine website to help you find cancer information you can rely on. PM Cancer Answers includes content

developed by Princess Margaret Cancer Centre, Canadian Cancer Society and other verified cancer organizations.

Many people rely on a Google search or other Internet search engines to find answers to their cancer questions. Many search results are confusing, and the reliability of these results (whether they are based on science or opinion) is often unknown. This can leave many people feeling unsure about the information they find online.

Princess Margaret Cancer Answers is easy to use and can be accessed on a desktop computer, smartphone or tablet. A large search bar lets users search for a certain topic. Users can also explore the site by browsing defined categories, such as:

- Types of cancer
- Cancer journey phase
- Medical tests and treatments
- Caregiving
- How to manage side effects
- Food and nutrition
- Community resources

The trusted information can be found in many forms, including:

- Brochures in PDF format
- Videos
- Audio books/CDS
- Links to other websites

Visit Princess Margaret Cancer Answers

**Website:** [www.pmcanceranswers.ca](http://www.pmcanceranswers.ca)

# Princess Margaret Cancer Centre Lodge

The Princess Margaret Cancer Centre Lodge is a place to stay for Princess Margaret Cancer Centre patients getting cancer treatment. Treatment includes chemotherapy, radiation therapy, or stem cell transplant. The Lodge offers shared twin rooms, meals, and transportation to Princess Margaret Cancer Centre appointments at a low cost. Family members can stay at the Lodge with you if space permits. There is a fee for family members who stay at the Lodge.



The Lodge is open on weekends. Note that rooms are not locked and you are advised not to bring valuables while staying at the Lodge. Talk to your cancer care team to learn how to register.

## Eligibility

To stay at the Princess Margaret Cancer Centre Lodge, you must be:

- At least 16 years old
- Referred to the lodge by a member of your cancer care team
- Able to manage your own personal care and medicines
- Able to attend appointments at Princess Margaret Cancer Centre on your own
- Able to walk up and down at least one flight of stairs without help
- Getting cancer treatment such as radiation therapy, chemotherapy, or stem cell transplant
- Living outside the Greater Toronto Area (Toronto, Mississauga, Brampton, Richmond Hill, Vaughan, Markham)

## Check-in Hours

Check-in hours are:

- Monday to Thursday: 7:30 am to 9:30 pm
- Friday: 7:30 am to 3:00 pm
- Sunday: 2:00 pm to 9:00 pm

## Transport to Princess Margaret Cancer Centre & Sunnybrook Health Sciences Centre

A free shuttle bus runs between the Lodge, Princess Margaret and Sunnybrook on Monday through Friday during regular clinic hours. The shuttle schedule is available at the Lodge.

## Meals

If you stay at the Lodge, you are given 3 meals a day, Monday to Friday. These meals are included in the Lodge fee. Note that there is no meal service is available on weekends.

### Contact The Princess Margaret Cancer Centre Lodge

**Location:** 545 Jarvis Street, Toronto, ON

**Phone:**

- Main Line: 416 413 7400
- Booking Office: 416 413 7402
- Fax: 416 413 7418

**Email:** [pmlodge@uhn.ca](mailto:pmlodge@uhn.ca)

# Princess Margaret Patient & Family Library

The Patient & Family Library is here to help you and your family find reliable and up-to-date information about cancer. Knowing this information can:

- ✓ Help you make informed health decisions
- ✓ Maintain healthy habits
- ✓ Better cope with your diagnosis and treatment

Library services are free and health information is available in multiple languages.

The Patient & Family Library can help you and your family:

- ✓ Find online and printed information about:
  - Cancer
  - Diagnostic tests (for example, biopsies)
  - Treatment options
  - Managing side effects
  - Recovery
  - Well-being
- ✓ Create tailored health information packages to meet your needs.
- ✓ Find free health education programs, social and emotional supports and wellness groups at Princess Margaret Cancer Centre and in your community.

The Patient & Family Library loans out resources about cancer to patients and their families. Resources include books, videos, DVDs, CDs, audiobooks and eBooks.

Anyone can borrow resources. You must show a valid piece of identification (ID) with your name and current address to register and borrow resources.

## Patient Education Pamphlets

The Patient & Family Library has a very large number of free pamphlets and booklets on many types of cancer, health topics and support services. All resources in the Library have been chosen to meet the needs of patients and family.

The resources provided by the Library should not replace a visit with your cancer care provider

## Information in Other Languages

You can request health information and resources in any language. Library staff will help you find trusted health information in the language of your choice.

## Computers Available for Patient Use

Computers and iPads are in the Patient & Family Library for patient use. You can use the computers for personal use to connect with family and friends. You can also use the computers to check the Patient Portal to see your appointments, test results and clinic notes when they are ready. The Patient & Family Library has a list of up-to-date cancer websites and apps that have been approved by the Patient & Family Librarian. Pick up the list at the Princess Margaret Patient & Family Library.

## Search Request Form

Patients, friends, family members and staff can request tailored health information by filling out the Search Request Form. Search Request Forms are found in the Patient & Family Library. The Librarian will search for information based on your needs. Once the search request is complete, the information can be sent to you by mail, e-mail or you can pick it up from the Library.

## Cancer Education Class Calendar

There are many classes that you can take to help you cope, prepare for treatment, and manage your daily life. The classes are also open to friends and



family members. See the monthly calendar for times and dates of the sessions.

Pick up a monthly calendar:

- In your clinic
- In the Patient & Family Library
- On the Princess Margaret Cancer Centre website at [www.uhn.ca/PrincessMargaret/PatientsFamilies/Pages/events\\_calendar.aspx](http://www.uhn.ca/PrincessMargaret/PatientsFamilies/Pages/events_calendar.aspx)

You can also take many cancer classes online at [www.pmcancerclasses.ca](http://www.pmcancerclasses.ca).

Princess Margaret Cancer Centre also offers support programs that include:

- Brain Tumour Support Group
- Focus on Healing Through Movement
- Head Wrap Workshop
- Healing Journey Program
- Healthy Steps
- Look Good Feel Better Program
- Man to Man Prostate Cancer Support and Resources
- Mindfulness Based Stress Reduction Program for Coping with Stress and Anxiety
- Relaxation Therapy
- Renewed Strength

Contact the Princess Margaret Patient & Family Library

**Phone:** 416 946 4501 ext. 5383

**Hours:** Monday to Friday, 8:30 am to 4:30 pm

# Smoking Cessation

## For Patients Who Smoke: Quit Smoking to Get the Best from Your Cancer Treatment

Did you know that quitting smoking can help your treatment work better? When you quit smoking during your cancer treatment you will:

- ✓ Help your body respond to treatment better
- ✓ Help your body heal faster after treatment
- ✓ Improve some of your side effects
- ✓ Lower your risk of your cancer coming back
- ✓ Lower your risk of getting a second cancer

How can quitting smoking help your treatment?

- If you are having surgery, quitting smoking lowers your risk of infections. Quitting smoking can reduce complications during or after surgery.
- If you will be getting radiation therapy, quitting smoking can help reduce side effects. When you smoke the oxygen levels in your blood are lower. Radiation therapy works best when your blood oxygen level is normal.
- If you will be getting chemotherapy, quitting smoking can make chemotherapy drugs work better. Cigarette smoke has over 7000 chemicals and some of those can make chemotherapy drugs less effective.

**Quitting smoking and tobacco can be hard, but the benefits start right away and can last a long time.**

## Get the support you need to help you quit smoking

Using both counseling and medicine works and can increase your chance of success.

### UHN Outpatient Pharmacies

You can ask for help from a UHN pharmacist to quit smoking. Services include in person, telephone or email consults using tools, counseling and medicines (if needed) to help you quit. Tell your cancer care team if you are trying to quit. There are three outpatient pharmacies at UHN that you can choose from.

#### **Princess Margaret Cancer Centre Outpatient Pharmacy**

**Location:** 610 University Avenue Main Floor - Room M633

**Phone:** 416 946 6593

#### **Toronto General Hospital Outpatient Pharmacy**

**Location:** 585 University Avenue, 1<sup>st</sup> Floor Norman Urquhart Wing - Room 2

**Phone:** 416 340 4075

#### **Toronto Western Hospital Outpatient Pharmacy**

**Location:** 399 Bathurst Street, Main Atrium

**Phone:** 416 603 5800 ext. Q-U-I-T (7-8-4-8)

Nicotine Dependence Clinic,

Centre for Addiction and Mental Health (CAMH)

Experts at CAMH can help you get the treatment and services you need to help you quit smoking and using tobacco products. Services include one-on-one consults, reviews of your health, group counselling, and consults on medicines to help you quit. You may also get Nicotine Replacement Therapy for free up to 6 months a year as part of the “STOP” program.

**Location:** 175 College Street

**Phone:** 416 535 8501 ext. 77400

**Website:** [www.nicotinedependenceclinic.com](http://www.nicotinedependenceclinic.com)

For more information to help you quit smoking and using tobacco:

Quit Smoking to Improve Your Cancer Treatment (eLearning)  
Access a 5-minute eLearning course about how quitting smoking improves your cancer treatment.

**Website:** [www.theprincessmargaret.ca/quitsmoking](http://www.theprincessmargaret.ca/quitsmoking)

Smokers' Helpline Online Quit Program,  
Canadian Cancer Society  
Sign-up at [www.smokershelpline.ca](http://www.smokershelpline.ca) to find a community of quitters and Quit Coaches to help you quit smoking. Visit their website for online support and resources including a personal Quit Plan, tailored e-mails and other online services.

Princess Margaret Patient & Family Library  
Visit the library to ask for more information about how to quit smoking or using tobacco.

**Location:** 610 University Avenue

**Phone:** 416 946 4501 ext. 5383

Princess Margaret Cancer Answers  
Cancer Answers provides high quality cancer information that you can trust. Search for more information about how to quit smoking or using tobacco.

**Website:** [www.pmcanceranswers.ca](http://www.pmcanceranswers.ca)

Quitting smoking is one of the best things a patient can do to help their cancer treatment.

# Wig Salon & Accessories Boutique

The Wig Salon and Accessories Boutique is on the 3<sup>rd</sup> floor of the Princess Margaret Cancer Centre, in room 642. The Wig Salon can help you in a supportive, private setting. As hair loss is the most public side effect of cancer treatment, the Wig Salon staff are here to support you through this time.



Before starting treatment, you may want to start searching for a wig and hair alternatives (scarves, hats and head wraps). This gives you time to find a wig specialist you feel most at ease with. During this search you may want to bring a favourite photo of yourself. You can also ask a family member or friend to help you choose. They can give you support and a valuable second opinion. When you choose, take your time to decide. Make sure to choose a wig that suits your lifestyle needs, as wig sales are final.

## Good to Know

Some insurance companies provide coverage for a “hair prosthesis.” Get a prescription from your doctor for a wig if your insurance provides this coverage. If you do not have coverage through your insurance, you are able to claim the cost of the wig when you file your income tax (as a health expense). You will get a refund for a portion of the cost of the wig. Call 416 946 6596 to arrange for a free, private consultation with a wig specialist. Note that there is a charge for wigs, hats and accessories.

## Contact the Wig Salon & Accessories Boutique

**Location:** 3<sup>rd</sup> Floor, Room 642

**Phone:** 416 946 6596

# 360° Clinic Tours

Before you come to Princess Margaret Cancer Centre, you can tour the clinic spaces online. The Princess Margaret Online 360° Clinic Tour is a series of 360° images. This will let you see the clinics and the other nearby areas before you visit Princess Margaret Cancer Centre. These clinic tours were designed to make you and your family feel more comfortable and less nervous when visiting Princess Margaret Cancer Centre for the first time.

**You can view the 360° tour by visiting the Princess Margaret Cancer Centre website. Search for the clinic you will visit – the 360° tour for the clinic will be on the clinic's webpage.**

# Recommended Websites for Information and Support

The following websites offer various resources that may be helpful to you and your family.

 = Canadian website

American Cancer Society

[www.cancer.org](http://www.cancer.org)

The American Cancer Society is a US health organization. Their website provides current information, new cancer treatment news, and detailed information on many different types of cancers.

American Institute for Cancer Research Online

[www.aicr.org](http://www.aicr.org)

The American Institute for Cancer Research is a leading charity in the field of diet, nutrition and cancer prevention. The information found here could help you reduce cancer risk for you and your family.

BC Cancer Agency 

[www.bccancer.bc.ca](http://www.bccancer.bc.ca)

This website offers helpful information for patients, caregivers, and their families. There is a section on Complementary & Alternative Therapies that may be especially useful.

Canadian Cancer Society 

[www.cancer.ca](http://www.cancer.ca)

The Canadian Cancer Society (CCS) is a national community-based organization of volunteers. The French and English website offers information on types of cancer and support services. View recent news articles or statistics or link to the CCS provincial websites.

Cancer Care Ontario 

[www.cancercareontario.ca](http://www.cancercareontario.ca)

Cancer Care Ontario (CCO) is the Ontario government's leading adviser on cancer issues. This French and English website offers information about:

- Prevention and screening
- Research
- Treatment
- Supportive care, and more

CancerConnection.ca by the Canadian Cancer Society 

[www.cancerconnection.ca](http://www.cancerconnection.ca)

[CancerConnection.ca](http://www.cancerconnection.ca) is an online community for anyone facing cancer. You can post messages on the discussion board, respond to what others have written, add pictures, start a personal journal and speak with other cancer survivors and caregivers. To register for this online community, complete the registration on their website.

National Cancer Institute

[www.cancer.gov](http://www.cancer.gov)

This service from the National Cancer Institute in the US provides up-to-date information on cancer. You can find information here on:

- Types of cancer
- Treatment
- Clinical trials
- Genetics
- Causes
- Risk factors
- Prevention
- Testing
- Coping, and more



Oncolink

[www.oncolink.org](http://www.oncolink.org)

Oncolink was founded in 1994 by the University of Pennsylvania. This website provides information about specific types of cancer, updates on cancer treatments, news about new research, and more.

Ontario Cancer Trials 

[www.ontario.canadiancancertrials.ca](http://www.ontario.canadiancancertrials.ca)

This website is a joint effort between the Canadian Partnership Against Cancer and the Ontario Institute for Cancer Research. This website lets you to search for cancer trials taking place in Ontario treatment centres. There is a helpful glossary and frequently asked questions. You can also sign up for automatic trial updates here.

Princess Margaret Cancer Answers 

[www.pmcanceranswers.ca](http://www.pmcanceranswers.ca)

Princess Margaret Cancer Answers is a search engine designed for cancer patients. It can help you find trusted health information from Princess Margaret and other organizations around the world.

University Health Network – Health Information 

[www.uhnpatienteducation.ca](http://www.uhnpatienteducation.ca)

This website offers health information from the hospitals of the University Health Network. The “Health Information” section allows you to search for information by topic, body part or system, type of treatment, and get information in other languages.

211 Ontario.ca 

[www.211Ontario.ca](http://www.211Ontario.ca)

[211Ontario.ca](http://www.211Ontario.ca) gives you information about community, social, health and government services in Ontario. This website provides accurate and up-to-date information about:

- Child care
- Language classes

- Job searches
- Housing
- Emergency shelters
- Services for persons with disabilities
- Home support
- Legal help
- Financial help and much more



The Cancer Journey resources are made possible with funding from

The Princess Margaret  
Cancer Foundation  **UHN**