Cancer Journey

Planner







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/. Scan this QR
Code if you have a QR Code Reader on your phone.

Introduction

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

You will get a lot of information from your cancer care team about:

- Your cancer
- Treatment options
- Side effects
- Supports at Princess Margaret Cancer Centre and the community that you can access

You will get all of this information while coping with the news that you have cancer. Given this, it may be hard to keep track of all of the information you get at once.

Finding out you have cancer is the first step in treating it. Cancer is often treated with many treatments and treatment can take many months and even years.

For this reason, some patients and survivors refer to their time coping with cancer and treatment as the "cancer journey." The cancer journey is complex and long with difficult periods along the way.

Princess Margaret Cancer Centre staff, patients and survivors made two resources to help you on this journey:

The Cancer Journey Planner

The Planner was made to help you organize your health information and keep a record of your cancer journey. In the Planner you will find:

- Lists of questions you may want to ask your cancer care team
- Trackers and calendars to help you keep information about your cancer journey organized in one place

Bring the Planner with you to your appointments. You (or a family member or friend) can take notes to help you recall information.

The Cancer Journey Guide Book

The 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

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Use this section to write down all of the phone numbers and contact information you need.

This may include:

- Nurses
- Oncologists (cancer doctors)
- Administrative assistants
- Pharmacists
- Other cancer care providers or contact information you would like to remember

Use this section to write down the contact information of cancer care providers that you want to remember.

Note that all clinics at the Princess Margaret Cancer Centre have printed sheets with contact information. You can staple those sheets to the back cover of this planner instead of writing down the information.

Cancer care provider:	Contact information:
	Name
	Phone #
	Fax #
	Email
	Name
	Phone #
	Fax #
	Email
	Name
	Phone #
	Fax #
	Email

Cancer care provider:	Contact information:
	Name
	Phone #
	Fax #
	Email
	Name
	Phone #
	Fax #
	Email
	Name
	Phone #
	Fax #
	Email
	Name
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	Name
	Phone #
	Fax #
	Email

Residents / Fellows

Princess Margaret Cancer Centre is a teaching hospital.

During your treatment, you may see residents and fellows as well as your regular oncologist (cancer doctor). Residents and fellows are doctors in training. They may change during your treatment. There is space below to keep track of their names.

Princess Margaret Cancer Cent Outpatient Pharmacy	tre 416 946 6593	
Medication Reimbursement Specialist	416 946 2830	
Social Worker	416 946 4525	

There are many other services and cancer care providers at the Princess Margaret Cancer Centre. They are listed in the "My Resources & Support" section (page 65) of the Cancer Journey Guide Book.



My Questions

The lists of questions on the next few pages are meant to help you think about what you would like to know when you are:

- Given your diagnosis (told you have cancer)
- Going through treatment
- At the end of treatment

You can write down the questions you would like to ask at your appointments in the "My Appointments" section of this Planner (page 17). There is also space in "My Appointments" to record the answers to your questions.

My Questions

How to use this section

Read the questions on the next few pages to think about what you would like to ask your cancer care team.

Note that your appointment time is short. Be sure to ask the questions that are most important to you first. If you do not get all of your questions answered by your oncologist (cancer doctor), you can ask other members of your cancer care team. Visit the Princess Margaret Patient & Family Library to get more information.

Write down questions you would like to ask at your appointments in the "My Appointments" section of this Planner (page 17).

Just Diagnosed: List of Questions

The list of questions here is meant to help you think about what you would like to know when you are given your diagnosis (told you have cancer).

Questions to ask about cancer and treatment during your appointment

- What type of cancer do I have?
- What do 'staging' and 'grading' mean? What stage and grade of cancer do I have?
- What are my treatment options?
- What are the reasons for and against these treatment options?
- Are these treatments covered by my health insurance plan?
- Will this treatment prevent me from getting a different type of treatment in the future?
- Are there any more tests that need to be done before I can start treatment?
- Will there be tests to find out how my disease responds to treatment?
- How often will I get these tests done during and after treatment?
- How will I know if my treatment is working?
- Will you change my treatment if it does not seem to be working?

- What is the total amount of time needed to complete treatment?
- How often will I see you during treatment?
- What signs or symptoms should I tell you about?

Questions about prognosis (likely outcome) and survival

- Do you expect to cure my cancer with these treatments?
 If not, what is the goal of these treatments?
- What portion of patients with my type of cancer live five years or more?

Questions about my cancer care team

- Who are the members of my cancer care team and what is their role?
- Do I have access to a dietitian at this cancer centre?
- Do I have access to a social worker at this cancer centre?
- Do I have access to a pharmacist at this cancer centre?
- Are there any support groups for me at this cancer centre?
- Are there other services to help me and my family cope?

Questions to ask when making an appointment

- Will I be able to go to work after the appointment?
- Can I drive after the appointment?
- Should I bring someone with me?

During Treatment: List of Questions

The list of questions here is meant to help you think about what you would like to know about your treatment.

Questions to ask before your treatment appointment

- How can I prepare for my treatment appointment?
- Are there things I should know about getting this type of treatment?
- What side effects can I expect?
- What problems should I report to you? For example: fever, diarrhea (loose poo), nausea (feeling like you will throw-up), vomiting (throwing up)
- How do I reach someone if I have problems in the evening or on the weekends?
- What can I do to prevent or manage side effects?
- Have any of my medicines been added, stopped or changed, and why?
- What medicines do I need to continue and why?
- How do I take my medicine and for how long?
- Can I drive myself to and from my treatment appointments?
- Do I need to take any special safety measures at home (for example, with regard to children, pets)?
- Will I be able to do my normal activities?
- Will I feel well enough to go to work?

- Will this treatment affect my sex life?
- Will this treatment affect my ability to have children?
- Do I need a special diet during or after my treatment?
- Do you have any pamphlets about my type of cancer and treatment?
- Can you suggest any websites about my treatment?
- How will I know if my treatment is working?

Questions to ask about complementary therapies

- Are complementary therapies suitable for my cancer or symptoms?
- What are the benefits of the complementary therapy?
- What are the possible side effects?
- Can I use the therapy along with standard treatments (for example: chemotherapy, radiation therapy, or surgery)?
- Will the complementary therapy interact with food, alcohol or other prescription drugs?
- How is the complementary therapy given?
- How will I know if the complementary therapy is working?
- How much does the complementary therapy cost? Will
 my health care plan cover the cost of the therapy?
- Will the complementary therapy affect my ability to have standard treatment in the future?
- Where can I find reliable information about the therapy or other complementary therapies?

After Treatment: List of Questions

At the end of treatment, many people expect to life to go back to 'normal,' like it was before cancer. However, the effect cancer has had on you, your family and friends may persist.

You may feel many emotions like:

- Relief that treatment is over
- Fear that your cancer will come back (fear of recurrence)
- Feeling unwell from side effects that began after treatment
- Anger or guilt about the cancer
- Grief and loss for the old life or body

This section contains questions to guide you as you adjust to life after treatment.

You may have many questions about:

- Late and long-term effects of treatments
- Ways to deal with emotional ups and downs
- Diet and exercise concerns
- Practical issues such as going back to work

You will need to work with your primary care provider (family doctor or nurse practitioner) and other members of your cancer care team to find answers to these questions. Remember: no question is silly or not important.

Questions to ask after you have finished treatment

- What treatments and drugs have I been given?
- Have any medicines been added, stopped or changed, and why?
- What medicines do I need to continue and why?
- How do I take my medicine and for how long?
- What side effects should I tell you about?
- How will I know if my medicine is working?
- Do I need any follow-up care?
- Who will do my follow-up care after treatment?
- Will my cancer come back?
- What should I do to maintain my health and well-being?
- Even though I survived cancer, will I feel different physically?
- Will I have trouble getting health insurance or keeping a job because of my cancer?
- Are there support groups I can turn to?
- Will I have any side effects after treatment ends?
- What are the signs of late side effects?
- What symptoms do I need to watch for that could mean my cancer has come back?
- How can I cope with fear of recurrence (fear that cancer will come back)?

continued >

- Will I be able to return to work?
- Will I have any limits on what job duties I can do?
- Is my body able to perform the duties my job requires?
- What can I do to prepare to return to work?



My Appointments

Use this section to prepare for appointments and keep track of the information you get.

This section contains space to write down:

- Details about your diagnosis
- Instructions for your appointment
- Questions you would like to ask
- Answers to your questions and instructions from your cancer care team

My Diagnosis

The word "cancer" is used to refer to over 200 diseases that affect many parts of the body. Cancer occurs when cells in the body grow and divide without control. When cancer cells grow and divide without stopping, many types of cancers form solid tumours. Some cancers like blood cancers (for example, leukaemia or lymphoma) do not form tumours. Every patient and every cancer is different. Cancer care providers have many systems they use to describe cancers.

How to use this section

Write down details about your diagnosis (type of cancer) here during your first appointment with your oncologist (cancer doctor).

You can find more information about types of cancer at the Princess Margaret Patient & Family Library.

Diagnosis given by:
Date of diagnosis:
Cancer type
What is my cancer called?
Where is the cancer in my body?

Other information about my diagnosis:	

How to use this section

Use this section to:

- ✓ Prepare for appointments. To prepare for your appointments, ask your cancer care team:
 - How long your wait time and appointment will be
 - If there are any special instructions that you need to get ready for your appointment (for example, arrive 15 minutes early)
 - What you should bring to your appointment
- ✓ Record questions you want to ask. You can find examples of questions to ask before, during, and after treatment on pages 10, 12, and 14 of this Planner.
- ✓ Keep track of information. Write down the answers to your questions and the information you are given. This includes advice you get if you call a clinic or after hours phone line such as CAREpath.

It is hard to make sure you understand what you are told by your cancer care team about your cancer. You may feel mentally or emotionally overwhelmed by the information you are given. You also may not physically be able to pay close attention. Read the tips on the next page to help you manage the information you get at your appointments.

Get the Most out of Your Appointments

- ✓ Take notes and do not rely on your memory.

 Even in the best cases, memory can be a poor resource. Add in the stress of illness, and it can be very hard to correctly recall information.
- ✓ Bring someone with you to your appointments to take notes. This person can help you recall what your doctor said.
- ✓ Review any instructions you get before you leave. This makes sure that you take home the correct information. It also gives you the chance to ask any extra questions you have.
- ✓ Ask cancer care providers to explain any words that you do not understand. Some cancer care providers speak using medical language. It can be hard to understand what is being said if you do not understand the medical words being used. Even patients with backgrounds in health care find medical language hard to understand when they feel unwell or stressed.

The next page has an example of how to use this section. There are also extra pages for notes at the end of this Planner.

Appointment Notes (Example)

Date: <u>07/26/19</u> Cancer Care Provider: <u>Dr. Smith</u>	
Instructions for appointment:	
- Arrive 15 minutes early	
- Bring all of my medicines	
Questions I want to ask:	
- What can I do to manage fatigue?	
- Can I drive myself to my treatment appointments?	
- Will I be able to continue my normal activities?	
Notes:	
- How to deal with fatigue:	
- Get 30 minutes of exercise each day	
- Attend the cancer-related fatigue class at	
Princess Margaret or online at	
www.pmcancerclasses.ca	

Date:	Cancer Care Provider:
Instructions for appo	pintment:
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Questions I want to	ask:
Notes:	

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My Medicines

This section is to help you keep track of your medicine.

Each time you come to the Princess Margaret Cancer Centre, bring all of your medicines in their original bottles and a complete list of your medicines to show your cancer care team. This will ensure that you are not given a new medicine that is not safe to take with the medicines you already take.

My Medicines

How to use this section

Use the table on the next pages to keep track of the medicines you are taking.

Include all:



If you have allergies to certain medicines, tell your cancer care team. This will help you avoid getting a medicine that can harm you.

Questions to ask about your medicines:

- 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?

Medicine or Supplement Name and Purpose	Dosage and Date Started	How Many Taken and When	Reactions/Side Effects and Date Stopped
(Example) Atrovastatin (Lipitor), High cholesterol	10 mg Started 10/15/09	1 tablet Per day, morning	Makes me tired; given different medicine 10/30/08

Medicine or Supplement Name and Purpose	Dosage and Date Started	How Many Taken and When	Reactions/Side Effects and Date Stopped

Medicine or Supplement Name and Purpose	Dosage and Date Started	How Many Taken and When	Reactions/Side Effects and Date Stopped

Notes		



My Treatments

In this section you can write down information about your treatment plan.

There are many different types of cancer treatment. Your oncologist will discuss the treatment plan with you. This will give you the chance to ask questions to ensure that the treatment plan is right for you. Your treatment plan has the details about all of the treatments you will get.

My Treatment Plan Overview

Your cancer may be treated with many types of treatment. Common treatments that are used to treat cancer include: surgery, radiation therapy, chemotherapy, and hormone therapy.

It can be hard to take in all of the information about your treatment plan at once. Some people find it helpful to have an overview of the treatment plan and then focus on one treatment at a time.

How to use this section

Use this section to map out your treatment plan. Ask your cancer care team to help you fill out the chart. The chart can help you to map out:

- The treatments that are planned for you
- How long the treatments will take
- If you will get more than one type of treatment at the same time

To fill out the chart:

- ✓ Write out each treatment in your treatment plan in the column on the left side. This may be:
 - A medicine or drug
 - A series of radiation treatments
 - Surgery
- ✓ Shade in the months that the treatment will last.

For example, if you are taking Adriamycin (a type of chemotherapy) from April 2019 until February, 2020:

- → Shade in April 2019 and February 2020
- → Then shade in the months in between

If the treatment takes place on one specific date, for example, surgery, shade in the month that that surgery takes place. You can use different colours for different treatments.

A sample chart is filled in on the next page.

Treatment/	Year:	::											¥e	Year:										
Medicine	าลก	Leb	Mar	лфА	VaM	սոլ	լոլ	6n∀	dəs	JoO	voM	Dec	nsC	Еeb	Mar	ıdA	VaM	սոլ	լոլ	6n∀	dəs	JoO	voM	Dec
Chemo:																								
Fluorouracil																								
Epirubicin																								
Cyclophosphamide																								
Docetaxel																			V					
																					,			
Radiation																								
Surgery																								
Hormone Therapy																								

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	Mar						
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My Treatments

There are 3 main types of cancer treatment:

- 1. Systemic therapy: Systemic therapy is medicine that travels through your body to kill 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: Biological therapies are medicines that 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 treatments.

How to use this section

Use this section to record details about your treatments.

Ask your oncologist what you can expect during treatment. For example:

- What side effects you may have
- Whether you can keep working
- If there is anything you can do to reduce or manage the side effects from treatment

Find more information about different types of treatment in your **Cancer Journey Guide Book** on page 22.

Get Ready for Your Cancer Treatment

- Talk with your cancer care team about what you can expect
- ✓ Read about side effects that might occur with each type of treatment
- ✓ Talk to other cancer survivors to learn what was helpful to them
- ✓ Find out what you can do to manage the side effects.

Medicine/Drug:	
How often?	How many cycles?
Start date:	End date:
How will I get it?	
Notes:	

Medicine/Drug:	
How often?	How many cycles?
Start date:	End date:
How will I get it?	
<u> </u>	
Notes:	

Medicine/Drug:	
How often?	How many cycles?
Start date:	End date:
How will I get it?	
Notes:	

Medicine/Drug:	
	How many cycles?
Start date:	End date:
How will I get it?	
Notes:	

Other Systemic Therapy

Medicine/Drug:	
How often?	How many cycles?
Start date:	End date:
How will I get it?	
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Notes:	

Other Systemic Therapy

Medicine/Drug:	
How often?	How many cycles?
Start date:	End date:
How will I get it?	
Notes:	

Radiation Therapy

Area to be treated:	
Number of treatments:	
Start date:	_ End date:
Notes:	

Radiation Therapy

Area to be treated:	
Number of treatments:	
Start date:	_ End date:
Notes:	
Notes.	

Surgery

Type of surgery:
Date of surgery:
How long will I stay in the hospital?
Notes:

Surgery

Type of surgery:
Date of surgery:
How long will I stay in the hospital?
Notes:

Surgery

Type of surgery:
Date of surgery:
How long will I stay in the hospital?
Notes:

Notes			



Use this section to track your physical and emotional health.

Record what you are feeling each day in the Side Effects Tracker. Share the tracker with your cancer care team to help them to know how you are feeling. This helps your cancer care team know if any conditions worsen.

Your well-being and how you feel matters. Many of the symptoms and side effects you feel can be helped. Keep track of your side effects so that you can tell your cancer care team about them. Your cancer care team may be able relieve your symptoms or give you tips to help you feel better.

How to use this section

Use this section to keep track of your side effects. Write down:

- ✓ How you feel each day. How you feel includes:
 - Physical side effects, such as:
 - Feeling tired
 - Nausea (feeling like you need to throw up) or vomiting (throwing up)
 - Diarrhea (loose or watery poo)
 - Constipation (trouble having a poo)
 - Aches and pains
 - Skin changes
 - Hair growing back
 - Many others
 - Your emotional side effects, such as:
 - Anxiety
 - Sadness
 - Relief

- Guilt
- Excitement
- ✓ What you can do to manage your side effects.

For example:

- Make an appointment with your doctor
- Try a new exercise
- Go to a workshop on dealing with fatigue

Share this section with your cancer care team at each appointment. They may be able to help you reduce these side effects.

Keeping track of how you feel also helps you and your doctor notice patterns. This helps your doctor know if they should make changes to your treatment.

You can also help your cancer care team know about your symptoms by completing the Distress Assessment and Response Tool (DART). DART is a survey about your overall health, well-being and symptoms. A staff member will ask you to fill out the DART survey each time you come to Princess Margaret Cancer Centre. Use the DART survey to help you talk to your cancer care team about your symtoms. Read more about DART on page 81 in your Cancer Journey Guide Book.

How I am feeling	What can I do to manage side effects?
(Example) Date: 07/29/2019 -Feeling Very tired in the afternoon -Nausea in evening -Hopeful for blood test results Thursday	-Get a referral to the fatigue clinic -Go for a walk at lunch -Call CAREPath for advice on dealing with nausea
Date:	
Date:	
Date:	

How I am feeling	What can I do to manage side effects?
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The Monthly Calendar contains six months of calendar pages. Use these to record:

- Doctor appointments
- Other appointments, for example:
 - Peer support groups
 - Education classes
 - A consult with a dietitian
- Treatment start and end dates
- Notes and reminders

Note that you can view your University Health Network (UHN) appointments and test results on the myUHN Patient Portal website (www.myuhn.ca). Read more about the myUHN Patient Portal on page 11 of your Guide Book.

Sunday	Monday	Tuesday	Wednesday

Month		Year	
Thursday	Friday	Saturday	Key Dates:
			Notes:

Sunday	Monday	Tuesday	Wednesday

Month		Year	
Thursday	Friday	Saturday	Key Dates:
			Notes:

Sunday	Monday	Tuesday	Wednesday

Month		Year	
Thursday	Friday	Saturday	Key Dates:
			Notes:

Sunday	Monday	Tuesday	Wednesday

Month		Year	
Thursday	Friday	Saturday	Key Dates:
			Notes:

Sunday	Monday	Tuesday	Wednesday

Month		Year	
Thursday	Friday	Saturday	Key Dates:
			Notes:

Sunday	Monday	Tuesday	Wednesday

Month		Year	
Thursday	Friday	Saturday	Key Dates:
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Sunday	Monday	Tuesday	Wednesday

Month		Year	
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The Princess Margaret Cancer Foundation **UHN**