University Health Network

# My Cancer Journey

## Personal Guide Book

This guide book is meant to help you to:

- More easily find resources and information to support you physically and emotionally at the Princess Margaret Cancer Program and in your community
- Better understand your treatment & help you communicate with your healthcare team
- Help you feel more in control by giving you one place to keep all the important information you want and need

walking together
with, through, and beyond

Patient Education

# My Cancer Journey

## Personal Guide Book

Everyone knows that if you have been given a diagnosis with the word 'cancer' in it, the effect can be devastating. Most people feel as if they are reeling: they feel upset, bewildered and off-balance. This booklet is designed to help you get your balance back, and we hope you'll find it easy to use.

The binder is divided into six sections PLUS there is a "ROAD-MAP" of your treatment plan on the back pages. In that way, you can work with your healthcare team to map out your treatment plan and then you'll be able to see at a glance what the next stage of your treatment is.

This binder is a place to keep all the brochures, pamphlets and information sheets that you'll collect and be given over the next few weeks, and also a single place to keep all of your contact numbers (e.g. clinics, nurses, appointment desk, x-ray, etc).

To help you, the first page of each section is marked with a thick bar of colour and a tab so that you can find what you need quickly. The Table of Contents on the next page will outline the six sections of this binder.

# Table of Contents

MY CONTACTS .................................................. Page 1

This is the place to write down all the phone numbers for your appointments, nurses, doctor's offices etc.

MY CALENDAR .................................................. Page 7

This can be your appointments diary – so you can keep track of clinic appointments, tests, scans, treatments etc.

JUST DIAGNOSED .................................................. Page 17

This section is the first stop on the way to finding out what's available for you and which services, programs and resources may be helpful. It's a good overview of what the Princess Margaret Cancer Program and the community has on hand to offer you and how to make the contacts that will be most useful.

DURING TREATMENT .................................................. Page 51

In this section you can write down information about your own health, your treatment schedule, your appointments, allergies and so on. This section may also be useful for you to show to and share with your family doctor (and any other health care professional).

AFTER TREATMENT .................................................. Page 65

There are services and support programs that may be helpful to you after you've finished your treatment. In this section you'll find places to write down some information to help you create your own support plan – a Survivorship Care Plan. Making a Care Plan can help you get the maximum value from your follow-up visits.

MANAGING SIDE EFFECTS .................................................. Page 77

In this section you can find information to help you cope with side effects you may experience before, during and after your cancer treatments.

ROAD MAP .................................................. Page 87

The Road Map is a place where you can work with your healthcare team to map out your treatment plan and then you'll be able to see at a glance what the next stage of your treatment is and also have a record of the treatments you've had.

# My Contacts

This is the place to write down all the phone numbers for your appointments, nurses, doctors offices and so on.

# My Personal and Contact Information

## Personal Information

Name________________________________________________

Street Address___________________________________________

City_______________ Province________________ Postal Code___________

Home Phone_____________________ Cell Phone______________________

Email________________________________________________

## Emergency Contact

Name_____________________________ Relationship________________

Street Address___________________________________________

City_______________ Province ________________ Postal Code___________

## My Healthcare Team

### Princess Margaret Cancer Program Contacts

The Princess Margaret Cancer Program is a teaching hospital. During your treatment, in addition to seeing your regular oncologist and other healthcare professionals, you may also see numerous residents and fellows. They may rotate during your treatment. We have provided space for you to keep track of their name(s).

**Princess Margaret Cancer Program** Phone #______________________

**Surgical Oncologist**

A Doctor who specializes in treating cancer with surgery.

Name________________________

Phone #______________________

Fax #________________________

Email________________________

**Surgical Oncology Secretary**

Name________________________

Phone #______________________

Fax #________________________

Email________________________

**Registered Nurse Case Manager**

Surgery

Name______________________________
Phone #____________________________
Fax #______________________________
Email______________________________

**Medical Oncologist**

A Doctor who specializes in treating cancer with chemotherapy and hormone blocking treatments.

Name______________________________
Phone #____________________________
Fax #______________________________
Email______________________________

**Medical Oncology Secretary**

Name______________________________
Phone #____________________________
Fax #______________________________
Email______________________________

**Registered Nurse Case Manager**

Medicine

Name______________________________
Phone #____________________________
Fax #______________________________
Email______________________________

**Radiation Oncologist**

A Doctor who specializes in treating cancer with radiation therapy.

Name______________________________
Phone #____________________________
Fax #______________________________
Email______________________________

**Radiation Oncology Secretary**

Radiation

Name______________________________
Phone #____________________________
Fax #______________________________
Email______________________________

**Registered Nurse Case Manager**

Name______________________________
Phone #____________________________
Fax #______________________________
Email______________________________

**Radiation Treatment Unit #**

Name____________________________
Phone #__________________________
Fax #____________________________

**Resident(s) / Fellow(s)**

____________________________________
____________________________________

| | |
|---|---|
| **PMH Pharmacy** | 416-946-6593 |
| **Medication Reimbursement Specialist** | 416.301.7137 |
| **Dietitian** | 416-946-4501 ext 5528 |
| **Social Worker** | 416-946-4525 |

There are many other health care providers at the Princess Margaret Cancer Program to help you, such as social workers and dietitians. They are listed on pg 30 and 42-44 in the 'Just Diagnosed' section under 'My Resources and Support Services'.

Use this page to keep track of your important non-PMH health related contacts.

## My Non-PMH Contacts

### Family Doctor

Name______________________________
Phone #___________________________
Fax #______________________________
Email______________________________

### Other Specialist

Name______________________________
Phone #___________________________
Fax #______________________________
Email______________________________

### Child Care

Name______________________________
Phone #___________________________
Fax #______________________________
Email______________________________

### Community Care Access Centre (CCAC)

Your CCAC connects you with the care you need at home and in your community.

Name______________________________
Phone #______310-2222___________
Fax #______________________________
Email______________________________

### Other Hospital Clinic

Name______________________________
Phone #___________________________
Fax #______________________________
Email______________________________

### Other Pharmacy/Drugstore

Name______________________________
Phone #___________________________
Fax #______________________________
Email______________________________

# My Calendar

You've got some of your appointments on your PMH appointments card – and in this section you can write down other appointments as well, and keep track of what's been arranged for you.

Please note that the wait times can vary for appointments, so leave time between one appointment and another. If you are calling, remember to have your Medical Record Number (MRN) handy. Your MRN can be found on your blue hospital card.

To be better prepared for your appointments, ask your healthcare team:

- Approximately how long your wait time and appointment will be
- If there are any special instructions that you need to get ready for your appointment
- What should you bring to your appointment.

# January-March

Year:____________________

| Dates | Appointments | Notes |
|---|---|---|
| **January** | | |
| **February** | | |
| **March** | | |

# April-June

Year:

| Dates | Appointments | Notes |
|---|---|---|
| **April** | | |
| **May** | | |
| **June** | | |

# July-September

Year:____________________

| Dates | Appointments | Notes |
|---|---|---|
| July | | |
| August | | |
| September | | |

# October-December

Year:____________________

| Dates | Appointments | Notes |
|---|---|---|
| **October** | | |
| **November** | | |
| **December** | | |

# January-March

Year:____________________

| Dates | Appointments | Notes |
|---|---|---|
| **January** | | |
| **February** | | |
| **March** | | |

# April-June

Year:____________________

| Dates | Appointments | Notes |
|---|---|---|
| **April** | | |
| **May** | | |
| **June** | | |

# July-September

Year:

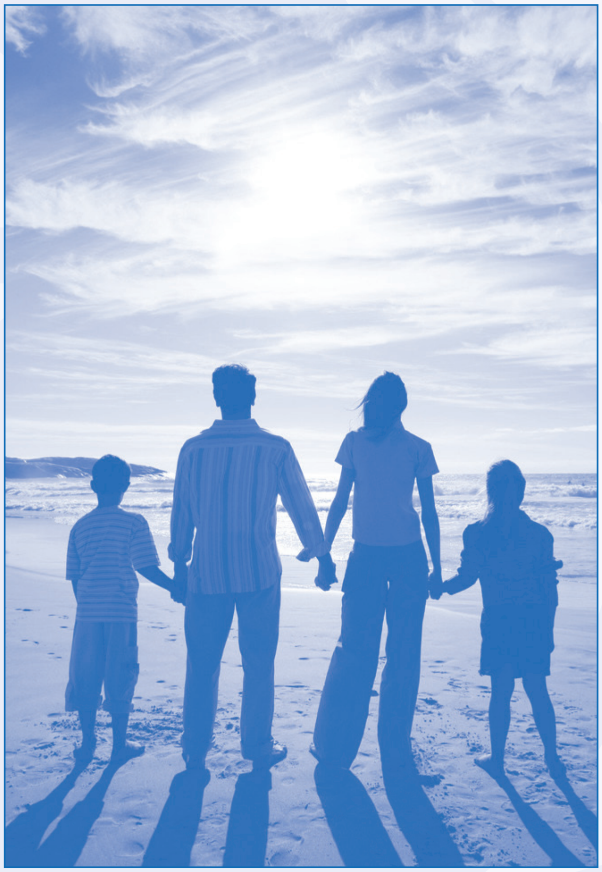
| Dates | Appointments | Notes |
|---|---|---|
| July | | |
| August | | |
| September | | |

# October-December

Year:____________________

| Dates | Appointments | Notes |
|---|---|---|
| **October** | | |
| **November** | | |
| **December** | | |

# Just Diagnosed



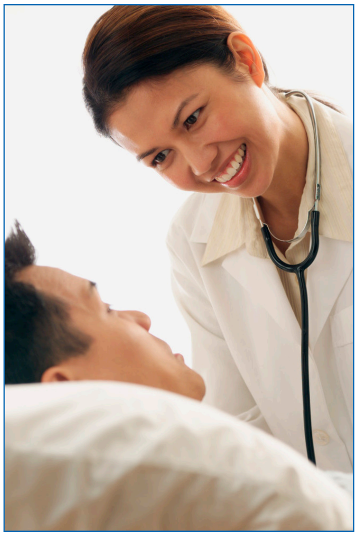
This section is the first stop on the way to finding out what's available for you and which services, programs and resources may be helpful. It's a good overview of what the Princess Margaret Cancer Program and the community has on hand to offer you and how to make the contacts that will be most useful.

The effects of cancer can be felt before you start treatment, while you're in treatment and after treatment. This binder has a section called Managing Side Effects for your easy reference throughout your cancer journey.

# "How Much Do I Need To Know"

## How much information should you get from your doctor?

**This is a difficult question – and the answer very much depends on you and your doctor.**



To put it simply there is no 'one size fits all' amount of information that every single patient wants or needs to have about her or his condition and treatment.

Some people like to know all of the details, other people much less – and in most cases the amount of information you want will change as time goes by: you might not want to know everything to start with, but might want more details later on.

You are welcome to bring a family member or friend with you to your appointments to help you remember or write down information that you get as it can be difficult at times to absorb all of the information on your own.

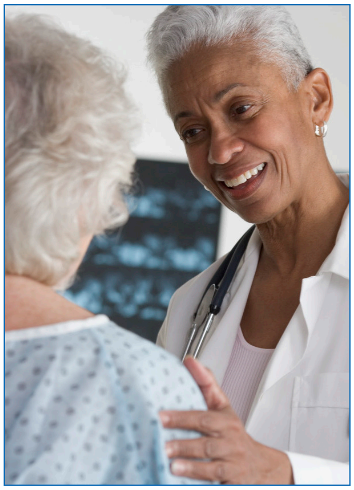
Even though clinics are often very busy, the goal of your healthcare team is to support you. To help you to get the details that you want and need: (a) ask for the details that you really want to know, and (b) realize that you've got several chances to get more information – you don't have to get all the details at once, particularly if you can't cope with it all at one time.

So make sure that you have a good general picture of the situation, if that's what you want. Perhaps the most important details are (a) the type of cancer (b) the grade of the cancer (i.e. what it looks like under the microscope in terms of how aggressive it is and so on) (c) the stage that the cancer is at (d) whether it has spread to any distant parts of your body or not, and (e) what treatment is recommended for your situation (i.e. chemotherapy, radiation, surgery or a combination of these). Please ask your healthcare team to write the overall plan down on the back page of this binder. We hope that this 'road-map' will be a useful general guide to things that are going on now and things that are going to happen in the future.

## Communicating with Your Healthcare Team

It is important to feel comfortable communicating with your healthcare team along your cancer journey. A lot depends on the nature of your cancer treatment of course – you may only meet individual members of that team on one or two occasions (e.g. in the blood lab or for a diagnostic test), or you may end up knowing others for many years after treatment (e.g. your oncologist or clinic nurse). Either way, they are somehow involved in your health care during a time when you are facing cancer, and being able to communicate with your healthcare team is a very important aspect of that care.

Before being diagnosed with cancer, many of us don't know much about the disease or treatment, or about the people who work in cancer-related health centres and communities. There are a lot of questions and a lot of information that need to be shared on both sides. Patients with cancer need to know the details of their particular cancer, prognosis, treatment options, financial considerations, support resources and more. Your healthcare team needs to know your medical history, how you're tolerating treatment, your insurance concerns and support needs, to name a few. If you may be feeling anxious and overwhelmed to begin with, it can be even harder to think about how to communicate with your healthcare team to ensure you get the answers you need, and they get the information that they require to treat you properly.



Fortunately, **you and your healthcare team are united by one common goal:** to treat your cancer as effectively as possible. It is helpful to remember this if you are feeling intimidated in the hospital environment or when it sometimes feels like “us versus them”. Clinics can get busy and tensions can run high, but you’ve been building successful relationships all of your life so you have a lot of skills already to help you get the care that you need. Think about what works in other areas of your life: sometimes a smile or a kind word can make all the difference in establishing a connection with someone you’ve just met or don’t see frequently. Other times you may need to stand up for yourself if you feel you’re not getting all of the facts that are important to you. If you don’t feel that you have enough energy to do that, consider asking a friend or family member to help you get what you need.

Most importantly, you and your healthcare team will always come back to the goal of treating your cancer and helping you get through the treatment process. Some additional tips for communicating with your healthcare team are listed below.

## Tips for Communicating with Your Health Care Team

- **Be yourself!** Everyone has natural and unique ways of communicating with people, whether with humour or stories or curiosity about others – these skills will serve you just as well during treatment as they do everywhere else.
- **Establish a connection** with a member of your healthcare team based on a common interest, even if it’s just talking about the weather (it’s a great topic!).
- Try to be **as specific as possible** when asking questions, and keep asking until you get the answer that you need.
- **Be open and honest** about what you’re experiencing physically and emotionally so that you can be treated appropriately and get the support that is necessary.
- **Enjoy the relationships** that can develop between you and like-minded members of your healthcare team – when your health is at stake, these relationships can be very special.

## Tips for when you call the hospital

- Your MRN# is your medical record number. Have it available when calling the hospital.
- Leave your MRN#, Name, Daytime Telephone Number and your concern on the answering machine (available Monday – Friday 9am – 5pm).
- If you need to reschedule your appointment, please call to change/cancel the appointment(s).
  - o Appointment Hotline: 416-946-2938
- Contact your oncologist(s) at his or her office for the following concerns:
  - o Letter/Form completion, documentation, fax to family doctor, etc
  - o Referral appointment to other Specialist
- Contact your Nurse Case Manager(s) for the following concerns:
  - o Change in health and questions regarding your plan of care
- On Weekends and After Hours, for medical concerns, call the Princess Margaret Cancer Program at 416-946-2000 and ask for the doctor on call or call your family physician's office.
- 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 Hospital.

### Tips for you when you are coming in for a clinic visit

**Bring:**

- Your health card and blue hospital card
- Your pharmacist and family doctor contact information
- A complete medication list of all your medications in their original bottles with labels, including herbal remedies and vitamins
- Any daily medications you may require during your visit (e.g. pain, diabetic medication)
- A list of concerns regarding your treatment plan and care
- A family member or friend if you require assistance
- A snack/drink and something to read if you need to wait (e.g. a book, magazine)
- Your "Cancer Journey Binder" so that you can read through it, take notes and your keep health information in one place

Come in 1½ hours earlier for blood work before your actual clinic appointment if you are on Chemotherapy.

## Just Diagnosed

It is likely that you have many questions for your healthcare team during this time. This list is to help you think about what you'd like to know. Your appointment time is short. Ask the questions that are most important to you first to ensure that there is time for them to be answered. Many questions can be answered by other members of your healthcare team or with the help of the Librarian in the Patient & Family Library on the main floor of the Princess Margaret.

### Questions for my healthcare team

**Questions to ask when making an appointment:**

- Can I return to work after this appointment?
- How long will the appointment be?
- Can I drive after the appointment?
- Should I bring someone with me?

## Questions to ask about the disease and treatment during the appointment:

- What type of cancer do I have?
- What do ‘staging’ and ‘grading’ mean?
- What stage is my cancer?
- What are the pros, cons and side effects of these treatment options?
- What are the expected survival rates with these treatments?
- Are these treatments covered by my health insurance plan?
- Will receiving this treatment prevent me from receiving a different type of treatment in the future if I need it?
- Are there any more tests that need to be done before starting treatment?
- Will there be tests to determine how my disease responds to the treatment?
- How often will these tests be done during and after treatment?
- Will you change my treatment if it does not appear to be working?
- How long will the treatment last?
- How often will I see you during and after treatment?
- What signs or symptoms should I bring to your attention to help you observe my treatment and evaluate my response to treatment?

## Questions about prognosis and survival:

- Do you expect a cure from these treatments? If not, what is the goal of this therapy?
- What percentage of patients with my type of cancer live five years or more?

## Questions about my healthcare team:

- Do I have access to a dietitian at this hospital?
- Do I have access to a social worker at this hospital?
- Are there any support groups available at this hospital?
- What other services are available to help my family and I cope with the disease?

This is a place where you can write down questions that you'd like to ask and record the answers.

Name of health care team member____________________________________________
Date______________________________ Time___________________________________
Location______________________________________________________________

Question 1

________________________________________________________________________

Answer(s) to question 1

________________________________________________________________________

________________________________________________________________________

Answered by_____________________________________________________________

Question 2

________________________________________________________________________

Answer(s) to question 2

________________________________________________________________________

________________________________________________________________________

Answered by_____________________________________________________________

Question 3

________________________________________________________________________

Answer(s) to question 3

________________________________________________________________________

________________________________________________________________________

Answered by_____________________________________________________________

Question 4

________________________________________________________________________

Answer(s) to question 4

________________________________________________________________________

________________________________________________________________________

Answered by_____________________________________________________________

Name of health care team member____________________

Date____________________ Time____________________

Location____________________

Question 1

Answer(s) to question 1

Answered by____________________

Question 2

Answer(s) to question 2

Answered by____________________

Question 3

Answer(s) to question 3

Answered by____________________

Question 4

Answer(s) to question 4

Answered by____________________

# My Resources & Support Services

We are all different! And the way in which each of us gets the most benefit and support is as individual as all the other things in life. Just as we all have different tastes and preferences when it comes to music, food, books and so on, we all may have different ways of getting help when we need it.

Perhaps the most important thing to realize first of all is this, there's nothing wrong in asking for help. The majority of people have some difficulty in coping with any diagnosis that has the word 'cancer' in it. That's not a sign of weakness – it's simply due to the associations attached to the word 'cancer' in today's society. So there's nothing wrong with knowing what's available for you and using the resources that are accessible if they are likely to be helpful to you.

So have a look at the list of services on the next few pages; and for support if you think it would help.

| Page # | Service<br>For complete descriptions of each service and contact information, see pages 29-50 | Fee Charged | Referral Needed |
|---|---|---|---|
| 29 | **Caring Voices**<br>Check out www.CaringVoices.ca to chat with other people affected by a diagnosis of cancer and health care professionals. | Free | No |
| 30 | **Clinical Nutrition Services**<br>Treatment often affects your appetite and/or your ability to eat. A dietitian can help you to discover more appetizing food to eat in a healthier way. | Free | No |
| 32 | **Community Resources**<br>There are many resources available in your community; page 32 lists a few agencies and programs that might be helpful to you. Visit the Patient & Family Library to find out more about resources in your community. | Free | No |
| 34 | **Drug Coverage**<br>Find out what drug coverage options are available for you. | Free | No |
| 36 | **ELLICSR Health, Wellness and Cancer Survivorship Centre**<br>A comfortable place where you, your family members, friends and caregivers can come to get information on health and wellness, participate in a class or program, meet other survivors or sit and relax before or after your appointments. | Free | No |
| 38 | **Information Desk**<br>The Princess Margaret Hospital Information Desk can help you with general information about the hospital. | Free | No |
| 38 | **Interpretation Services**<br>If you or your family member needs an interpreter, Interpretation Services can help you. This is a free service but at least one-day notice is required. | Free | Yes |
| 39 | **Managing Your Cancer Journey**<br>These classes are for you and your family to help guide and support you as you deal with your cancer experience and manage other parts of your life. | Free | No |

*continues >*

| Page # | Service<br>For complete descriptions of each service and contact information, see pages 29-50 | Fee Charged | Referral Needed |
|---|---|---|---|
| 40 | **Patient & Family Library**<br>The Patient & Family Library loans materials about cancer including books, videos, DVDs, magazines, tapes and CDs to patients and their families. | Free | No |
| 42 | **Pharmacy Services**<br>There is no fee for pharmacy consultations. Fees may be charged as appropriate for medications. | Free | No |
| 43 | **Physiotherapy Services**<br>Physiotherapy Services are available in some clinics. If you are having difficulties as a result of your treatment, please speak to your doctor. | Speak with your doctor | Speak with your doctor |
| 44 | **Princess Margaret Hospital Lodge**<br>The Princess Margaret Hospital Lodge offers hotel-style rooms for patients and their families that come to Toronto for cancer treatment. | Yes | No |
| 44 | **Psychosocial Oncology & Palliative Care (POPC)**<br>The Psychosocial Oncology & Palliative Care program can help you and your family to cope with cancer. Medical referrals are required for psychiatry and psychology. You can self-refer to speak with a social worker. | Free | Yes – Medical<br>No – other consults |
| 47 | **Virtual Tour**<br>**http://www.uhn.on.ca/PMH/virtual_tour/index.asp** Take a virtual tour of the Princess Margaret before coming to your appointment. The Tour is available in 7 languages. | Free | No |
| 47 | **The Wig Salon and Accessories Boutique** is conveniently located on the 3rd floor of the Princess Margaret, providing a valuable service to patients in a supportive, private atmosphere. | No fee charged for consultation however there is a fee for the wigs | No |
| 48 | **Recommended Websites**<br>Visit the recommended websites for additional online support. | Free | No |

# www.caringvoices.ca

Caring Voices

## What is Caring Voices?

Caring Voices is an online community for cancer survivors that was developed at the Princess Margaret. At the Princess Margaret, a “survivor” is anyone affected by a diagnosis of cancer, including patients, caregivers, family members, friends and healthcare professionals. You will find them all on caringvoices.ca

## How to Join Caring Voices

1. Go to www.caringvoices.ca
2. Click on Register
3. Follow the steps to complete your profile
4. Start connecting with other survivors

If you have questions about Caring Voices please contact the Caring Voices project lead at caringvoices@rmp.uhn.on.ca

## Features of Caring Voices

### Resource Library

You will find professionally reviewed resources about a variety of cancer-related topics that range from diagnosis to treatment to emotional support.

### Events

An event is a scheduled online chat that is live and is lead by a community member, survivor, or healthcare professional. To see upcoming Events, click on the “Events” tab on the Caring Voices home page. All you have to do to join an event is register on Caring Voices or, if you are already a member, login and click on the title of the event that you’d like to join.

### Chats & Forums

Chats and forums provide a way of sharing your stories or experiences with other Caring Voices members online. In a Chat you can send messages to people in real-time. Forums are like bulletin boards that are used to post questions, experiences or resources for other members to read and reply to at any time.

### People Matching

The people matching feature of Caring Voices lets you find other members of the community. When you register for Caring Voices you complete a profile that includes information about yourself and your experience with cancer. If you choose, you can share this information with other members so that they can connect with you. This is a great way to make friends on Caring Voices.

## Clinical Nutrition Services

A Registered Dietitian is available to address your nutrition concerns relating to your treatment.

**During treatment, these issues may include:**

- Weight loss
- Eating to help manage symptoms, e.g. nausea, diarrhea, swallowing difficulties, loss of appetite and fatigue
- Maintaining good hydration (fluid intake)
- Assessing whether you need to follow a therapeutic diet e.g. diabetic diet, low fat diet, low potassium diet, low sodium diet and many others
- Assessing whether it is safe to continue with certain complementary or alternative diet therapies

Towards the end of the treatment or after treatment, nutrition issues may include:

- Eating for wellness
- Maintaining a healthy weight

## How to Contact a Registered Dietitian at PMH

To contact a Registered Dietitian associated with your cancer site or program, please ask your healthcare team to make a referral.

## Services offered include:

### Individual Counseling

Those who have specific nutrition issues and would like their nutrition status assessed can make an appointment with a Registered Dietitian who is associated with their cancer site or program.

### Group Classes

- What to Eat When You Don't Feel Like Eating - This class focuses on ways to increase your intake when you don't have an appetite. It is offered through the Patient & Family Library.

There are other nutrition classes that are specific to a cancer site or program. Please ask a member of your healthcare team for more information or pick up a Calendar of Events from the Patient and Family Library.

## Additional Resources

- The dietitians at PMH 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. It is available to purchase at the Outpatient Pharmacy as well as for lending from the Patient & Family Library.

# Community Resources

There are many organizations that provide support to you and your family. Come to the Patient & Family Library, located on the main floor of Princess Margaret Hospital, to find out about them, browse the collection or ask a library staff member for help.

## Canadian Cancer Society Volunteer Drivers

If you are getting treatment at Princess Margaret, you can get free transportation to and from your cancer-related appointments. Service may be limited based on driver availability. The 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. For more information or to book transportation in the Toronto area, call 416-480-7901 ext 4012. For out of town transportation, call 1-888-939-3333.

## 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 join with others to build social and emotional support as a supplement to medical care. Gilda's Club also welcomes long-term cancer survivors and those who have lost someone to cancer. Free of charge, Gilda's Club offers support and networking groups, lectures, workshops and social activities in a non-residential, home-like setting. The Gilda's Club philosophy is based on the belief that a diagnosis of cancer affects the whole family, as well as friends, and that no one should have to face cancer alone.

Gilda’s Club Greater Toronto
110 Lombard Street, Toronto, Ontario
Telephone: 1-800-GILDA-4-U
Website: www.gildasclubtoronto.org

## Wellspring

Wellspring is an innovative network of centres providing high-quality cancer support, education and coping skills to a growing number of individuals, family members and professional caregivers in Canada. Wellspring programs are free of charge and open to individuals and caregivers who are coping with any type of cancer, at any stage. They include individual and group support, coping skills, expressive therapies, energy work, and educational workshops and presentations and are housed at warm, non-institutional Wellspring centres.

Telephone: 1-877-499-9904
Website: www.wellspring.ca

# Drug Coverage

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

It is important to know what kind of drug coverage you have as early as possible. Knowing your drug coverage options can help you plan ahead and prevent delays in your treatment.  Use this flow chart to find out what you need to know before your doctor gives you a prescription.

if you have

| Type of Insurance You May Have | What You Need to Know |
|---|---|
| Private insurance (such as plans through work, your spouse or other family members) | **Who to ask:** Your employer or plan provider<br>**What to ask:** If your prescription is covered, what percentage you will pay for each prescription, and if you have to pay up front<br>**What to bring to the pharmacy:** Show the pharmacist your drug card to fill your prescription. |
| A valid Drug Card from: Ontario Works, Home care, Ontario Disability Support Program | **Who to ask:** A medication reimbursement specialist, social worker or pharmacist<br>**What to ask:** If your prescription is covered, how the plan pays the prescription cost and what you will pay for each prescription<br>**What to bring to the pharmacy:** Show the pharmacist your valid drug card to fill your prescription. |
| No insurance at all | **Who to ask:** A medication reimbursement specialist, social worker or pharmacist<br>**What to ask:** How to apply to the Trillium Drug Program, the details of coverage and what you will pay for each prescription<br>**What to bring to the pharmacy:** Once you are approved, show the pharmacist your OHIP card to fill your prescription. |
| Coverage as a senior (65+) | **Who to ask:** A pharmacist<br>**What to ask:** When you qualify for coverage, if your prescription is covered, and what you will pay for each prescription<br>**What to bring to the pharmacy:** Show the pharmacist your OHIP card to fill your prescription. |

## How can a Medication Reimbursement Specialist help me?

A PMH medication reimbursement specialist is a drug coverage expert who can help you understand how your coverage works and what options you may have. If you need:

- help figuring out how your coverage works
- advice on how to move forward with planning
- more information about patient assistance programs

Then, call the number below to book an appointment.

## Who to contact with your questions

### Medication Reimbursement Specialist

(by appointment only)
Yvonne Ta
Princess Margaret Hospital Outpatient Pharmacy
Gift & Health Shop, Main Floor Room 514
416-301-7137
yvonne.ta@uhn.on.ca

### PMH Social Workers

Psychosocial Oncology & Palliative Care
(by appointment only)
16th Floor, Room 718
416-946-4525

## Community Resources

### Wellspring Money Matters Resource Centre

(by appointment only)
Women's College Hospital (76 Grenville St, Toronto)
416-323-6400 ext 4240

You can also visit the Patient & Family Library on the main floor for a more detailed pamphlet about your drug coverage options.

walking together
with, through, and beyond

# ELLICSR

## Collaborative Centre for Health, Wellness & Cancer Survivorship

### What is ELLICSR?

ELLICSR is a comfortable health, wellness and cancer survivorship centre, located on the basement level of the Toronto General Hospital.

ELLICSR is a place where you, your family members, friends and caregivers can come to get information on health and wellness, participate in a class or program, meet other survivors or sit and relax before or after your appointments.

### ELLICSR has:

- A Resource Library with a collection of books you can borrow, a computer, and wireless Internet access. The ELLICSR librarian can help you find the information you need.
- 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.

For more information about activities and programs taking place at ELLICSR, pick up the monthly Patient & Survivorship Education Calendar of Events from the ELLICSR Resource Library or call 416.581.8453.



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

## Directions:

**TTC:** Take the Queen's Park subway exit on the University line. Exit on University Ave south-east side and walk to the University Ave entrance at TGH.

From the College subway station (Yonge line) take the streetcar Westbound to University Ave, walk south to TGH.

Enter TGH using the University Avenue entrance. Take the West elevators (near Starbucks) down to the basement level (B), turn right. ELLICSR is ahead on your right hand side.

**Hours of Operation:**

Monday – Friday

8:30 am – 4:30 pm

# Information Desk

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

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

**Telephone:** 416-946-4501 Ext. 4558 or 4559.

# Interpretation Services

## UHN Medical Interpreters

University Health Network is committed to ensuring effective communication throughout the continuum of care for patients with limited English and patients who are Deaf, deafened and hard of hearing.

The department of Interpretation and Translation Services offers professional medical interpreters (face-to-face and phone interpreters) in over 150 languages, including Spanish, Cantonese, Mandarin and American Sign Language, to help patients communicate with their healthcare team.

Access to phone interpreters is available at all three sites of University Health Network, 24 hours a day, 7 days a week.

If you would like an interpreter, please ask your care provider to contact Interpretation Services.  If you need an interpreter, ask your care provider to contact Interpretation Services at (416) 603-5979 Ext.6400 between 8:30 am and 4:00 pm. One-day notice is required to make an appointment.

This service is provided free of charge.

# Managing Your Cancer Journey

Managing Your Cancer Journey is a series of two classes developed to help guide and support you as you deal with your cancer experience and continue to manage the other parts of your life. In these classes you will have an opportunity to identify sources for support, learn how to navigate the healthcare system, and strengthen your understanding of your cancer diagnosis by speaking with healthcare professionals. The two classes are (1) Balancing Life with Cancer; and (2) Medical Information I need to Know. Each of the classes last 1.5 - 2 hours and are professionally led by the Survivorship Program's social worker and a medical oncologist. You can attend Class 1, Class 2 or both, at any time during your cancer experience.

## Benefit / Goals

By participating in the Managing Your Cancer Journey classes you will have the opportunity to identify what your individual and family needs are for support, education and information. You will build skills that will assist you during your cancer experience. Specific benefits and goals of each class are:

### (1) Balancing Life with Cancer

You will learn how to address difficulties in coping and address ways in which to balance your life to fit your current needs. You will learn where to find the support, education and information to address your current needs. You will also strengthen your understanding of the supports available to you at Princess Margaret Hospital and in the community.

### (2) Medical Information I need to Know

You will strengthen your understanding of cancer and its treatment, and learn how to communicate effectively with your healthcare team. In this class you are given the opportunity to have your medical questions answered by a medical oncologist at Princess Margaret Hospital.

**How to attend:** You can register for a class by calling the Patient Education department at 416-946-4501 ext 5090; no medical referral is necessary.

# The Patient & Family Library

The Patient & Family Library is here to help you and your family find reliable, up to date and accurate information about cancer to help you make educated health decisions, maintain healthy behaviours and better cope with your diagnosis and treatment. The Library is located on the main floor in the lobby of Princess Margaret Hospital.

The Patient and Family loans materials about cancer including books, videos, DVD's, magazines, tapes and CDs to patients and their families. The Library also provides patients and their families with access to computers that are connected to the Internet and the Princess Margaret Hospital Intranet. To contact the Library, call at (416) 946-4501 ext. 5383.
See also www.uhn.ca/pmh/services/library.asp

## Resource Library

The Patient & Family Library has a large collection of materials that are available for you, your family and the visiting public free of charge. For example, the library has pamphlets on a wide variety of cancer and health related newsletters and magazines. We also have medical reference books, which are available for use in the Library.

## Computers Available for Patient use throughout Princess Margaret Hospital

There are two computers available for patient use in the Patient & Family Library and there are many more located throughout the hospital clinics in the Patient & Family Resource Centres. The computers can be used for personal Internet research and to run the Oncology Interactive Education Series (OIES) CD-ROMs. The Patient & Family Library provides a list of Internet sites that have been reviewed and approved by the Patient Education Librarian. You can pick up the list from a volunteer in the Patient & Family Library.

## Search Request Form

Patients, friends, family members and staff can request health information that is tailored to their needs by filling out the Search Request Form, available at the Patient & Family Library and on the Patient Education website. The Librarian of the Patient & Family Library or a trained volunteer will search for information according to the details provided on the Search Request Form. Once the search request is complete, the information can be sent to the requestor by post, email or can be picked up in the Patient & Family Library in the lobby of the Princess Margaret Hospital.

## Information Pamphlets

A wide variety of pamphlets containing useful information on various types of cancer and supportive services offered through Princes Margaret and community services are available free of charge for patients and their caregivers.

The Patient Education Program works with health professionals to produce up-to-date, reader-friendly patient education materials.
These pamphlets are available on the Internet at:
www.uhn.ca/Patients_&_Visitors/health_info/topics/a.asp

## Patient & Survivorship Education Calendar

There are many sessions and programs 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 (found in your clinic, the library or the patient education website) for times and dates of the sessions.

### The Education Sessions include:

- Cancer Related Fatigue
- Chemo Questions?
- Clinical Trials 101
- Eating Healthy During Breast Cancer Treatment
- Eating Well After Breast Cancer Treatment
- Finding Health information Online

- Lymphedema Introduction
- Managing Your Cancer Journey*
- Nutrition for Wellness After Treatment for Breast Cancer
- Prostate Cancer Information Session
- Radiation Therapy: Answering Your Questions
- What to Eat When You Don't Feel Like Eating

*See Full description on page 39.

**Phone the Patient Education Coordinator for more details 416.946.4501 ext 5090.**

### The Patient Education & Survivorship Program 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

Phone the Patient Education Coordinator for more details 416.946.4501 ext 5090.

## Pharmacy Services

The PMH pharmacy consists of inpatient, daycare and outpatient services. At the inpatient units and outpatient pharmacy, there are pharmacists available to check patient drug orders for suitability, drug-interactions, and to address other drug-related questions ranging from herbal products to drug coverage. Please dial 416-946-2000 and ask for the appropriate department/personnel as required:

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

# Physiotherapy Services

Physiotherapy Services are available in some clinics with a Doctor's Order. If you are having mobility difficulties as a result of your treatment, please speak to your doctor about this option. You may be able to consult with a physiotherapist both while undergoing treatment and/or after treatment is completed.

## The Role of the Physiotherapist includes:

- Assessment and recommendations regarding range of movement, stretching, and strengthening.
- Tips to relieve common side effects of surgery and treatment, such as numbness, feeling of tightness or "pulling" on movement, poor balance, coordination, posture.
- Further information about activity guidelines, walking aids.
- The Physiotherapist is also an Assisted Devices Program Authorizer for any needs that develop as a result of your cancer and treatment.
- Referral to ongoing specialized rehabilitation if more physiotherapy follow-up sessions need to be arranged.

# Princess Margaret Hospital Lodge

The Princess Margaret Hospital Lodge, located at 545 Jarvis Street, is a unique place for cancer patients who come to Toronto for cancer treatment. It is a self-care ambulatory facility with 24 hour nursing support for patients during the active phase of their cancer treatment. The PMH Lodge provides accommodation and services at reasonable rates for patients and when space permits for family members. Please call the booking office for further details, 416-413-7402.

# Psychosocial Oncology & Palliative Care (POPC)

The Psychosocial Oncology & Palliative Care Program is available to help you and your family cope with cancer and maintain quality of life while facing this illness. All the services are free. Our team includes physicians, psychiatrists, psychologists, social workers, oncology nurses, spiritual care counsellors and an early childhood education specialist. A medical referral is needed for the psychology and psychiatry service.

**Contact Information:**

Psychosocial Oncology & Palliative Care
16th Floor
Tel. (416) 946-4525
E-mail: pop@uhn.on.ca

## Children's Services

The Magic Castle is a free childcare service for children and grandchildren of patients undergoing treatment at Princess Margaret Hospital. An early childhood educator provides an atmosphere of safety and fun, allowing children to express themselves through play and creativity. It is located on the main floor of the Princess Margaret Hospital.

## Discharge Planning

Our team can help you with discharge planning to ensure a safe and timely discharge home from the hospital, or with making arrangements for transfer to an alternate level of care i.e. a long-term care facility, inpatient rehabilitation program, continuing complex care facility, or a palliative care unit.

## Family Counselling

Patients and family members may both benefit from support. We can see the whole or parts of the family to help in a variety of ways: individual counselling can help with adjusting to illness; couple counselling can help with relationship and sexual problems that can arise as a result of illness; when a friend or family member has cancer, consultation with parents can help them know how they can help their children cope; adult family members can also be seen individually to assist with coping when a loved one is facing cancer.

## Income Support and Drug Coverage

There are a number of supports for patients facing a cancer diagnosis. To learn about the private options and government programs and how to apply, PMH has available a comprehensive booklet titled Coping with Cancer: Income Supports. This booklet is available in the Patient & Family Library on the main floor (416-946-4501 x5383), and in the Psychosocial Oncology and Palliative Care Program on the 16th floor (416-946-4525). In addition, you can meet with a Social Worker through Psychosocial Oncology to discuss drug coverage options.

## Palliative Care

Palliative care is the active, total care of patients when disease is no longer responsive to curative treatment. Palliative Care focuses on pain and symptom control and addresses the psychological, social and spiritual needs of patients and families.

## Resource Counselling

Staff can help guide you through important decisions regarding practical concerns, navigate the health and community systems, arrange needed services in the hospital and the community and overcome barriers to recommended care and services.

## Spiritual Care Services

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

## Stress Reduction

Stress can make the process of coping and recovery more difficult. We can help identify specific causes of stress and teach you skills to help you cope more effectively, for example: mindfulness-based stress reduction training; problem-solving regarding job-related issues, practical concerns, financial concerns, adaptation to the healthcare system, and changes in patient functional level.

## Treatment Counselling

Our team can help you adjust to your illness, prepare for treatment and cope with side effects. Specific coping strategies may decrease anxiety about treatment or the impact of side effects following treatment.

## Treatment of Depression and Anxiety

Staff with specialized expertise in the diagnosis and treatment of depression, anxiety and other psychological disturbances can assist with counselling and/or with medication.

# The Virtual Tour

You can take a virtual tour through Princess Margaret Hospital before your first appointment. The Virtual Tour was designed specifically to make you and your family feel more comfortable and less nervous when visiting the Princess Margaret Hospital for the first time.

The Virtual Tour is currently available in six languages:

- English
- Cantonese
- Mandarin
- Spanish
- Italian
- Portuguese

www.uhn.ca/PMH/virtual_tour/index.asp

# Wig Salon & Accessories Boutique

The Wig Salon and Accessories Boutique is located on the 3rd floor of the Princess Margaret Hospital (PMH), in room 642, providing a service to you in a supportive, private atmosphere. The Wig Salon staff recognize that hair loss is one of the most public side effects of some cancer treatments and are committed to supporting you through your cancer journey. We can help you find a look that you like and feel comfortable in.

Before starting treatment you may want to prepare yourself by searching for a wig and hair alternatives (scarves, hats and turbans). This allows you time to find a wig specialist you feel most comfortable with. During this search you may want to bring a favourite photograph of yourself and ask a family member or friend whose opinion you value to help you with your choice. They can provide you with support and a valuable second opinion. When choosing a wig, take your time to decide and make sure to choose a wig that suits your lifestyle needs, as wig sales are final.

www.uhn.ca/Clinics__&_Services/services/wig_salon/index.asp

### GOOD TO KNOW

You can obtain a prescription from your doctor as some insurance companies provide coverage for a “hair prosthesis”. If you don’t have coverage through your insurance, you are eligible to claim the cost of the wig when you file your income tax (as a health expense), and receive a refund for a portion of the cost.

Call 416-946-6596 to arrange for a free private consultation with a wig specialist. Please note there is a charge for wigs, hats & accessories.

## Recommended Websites

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

🍁 = Canadian website

### American Cancer Society

www.cancer.org

The web site for this US community-based voluntary health organization provides current information, new cancer treatment developments and detailed information on a wide variety of different types of cancers.

### American Institute for Cancer Research Online

www.aicr.org

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

### BC Cancer Agency 🍁

www.bccancer.bc.ca

This comprehensive cancer control program offers helpful information for patients, caregivers, and their families. Particularly useful is the information section on Complementary & Alternative Therapies.

### Canadian Cancer Society 🍁

www.cancer.ca

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

### Cancer Care Ontario 🍁

www.cancercare.on.ca

Cancer Care Ontario (CCO) is the provincial government's principal adviser on cancer issues. This bilingual site offers information about prevention and screening, publications, professional training and continuing education, treatment and supportive care, and more.

### Cancer.gov Cancer Information

www.cancer.gov/cancer_information

This service from the National Cancer Institute (US) acts as a gateway for up to date information on cancer. This site provides information on: Types of Cancer, Treatment, Clinical Trials, Genetics, Causes, Risk Factors, Prevention, Testing, Coping etc.

### CaringVoices 🍁

www.CaringVoices.ca

Caring Voices is an online community for cancer survivors. Supported by the Princess Margaret Cancer Program, Caring Voices provides quality survivorship information and allows you to chat with other cancer survivors across Canada.

### Oncolink

www.oncolink.com

Founded in 1994 by the University of Pennsylvania, this site provides comprehensive information about specific types of cancer, updates on cancer treatments, news about research advances, and more.

### Ontario Cancer Trials

www.ontariocancertrials.ca

A collaboration between the Canadian Cancer Society and the Ontario Cancer Research Network, this site allows you to search specifically for cancer trials taking place in Ontario treatment centres. A user-friendly site with helpful glossary and frequently asked questions. The site also allows you to sign up for automatic trial updates.

### University Health Network – Health Information

www.uhnpatienteducation.ca

This site represents health information gathered by professionals at the three hospitals comprising the University Health Network. The “List of Topics” allows you to search for information by the name of the condition and “Support & Information Groups” directs you to community agencies that specialize in different areas.

### 211 Ontario.ca

www.211Ontario.ca

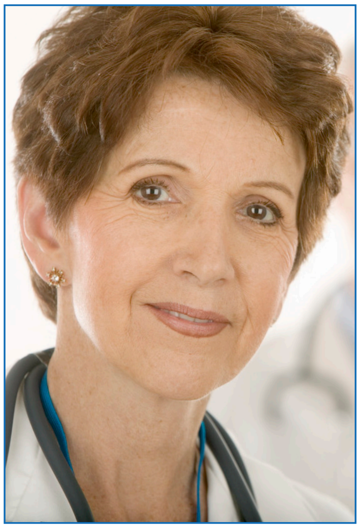
211Ontario.ca is your connection to information about community, social, health and government services in Ontario. This website provides you with accurate and up-to-date information about child care, language classes, job searches, housing, emergency shelters, services for persons with disabilities, home support, legal assistance, financial assistance and much more.

# During Treatment

In this section you can write down information about your own health, your treatment schedule, your appointments, allergies etc. This section may also be useful for you to share with your family doctor (and any other healthcare professional). You will be given pamphlets about your specific treatments and these can be filed in this section if you'd like to keep your treatment information in one place.

The effects of cancer can be felt before you start treatment, while you're in treatment and after treatment. This binder has a section called **Managing Side Effects** for your easy reference throughout your cancer journey.

# During Treatment



There are a lot of questions listed on the next page. The list is to help you think about what you'd like to know. Your appointment time is short. Be sure to prioritize your questions. Many questions can be answered by other members of your healthcare team and can be found in the Princess Margaret Patient & Family Library or with help from the Librarian.

## Questions for My Healthcare Team

Preparing for the experience of cancer treatment can reduce anxiety and stress. Write down any questions you have for the healthcare team before your appointment.

### Get ready for your cancer treatment by:

- Talking with your doctor about what you can expect
- Reading about side effects that might occur with each type of treatment
- Talking with other cancer survivors to learn what was helpful to them in the waiting room or online at www.caringvoices.ca
- Finding out what can be done to manage the side effects

### Before your treatment sessions, ask questions such as:

Once a treatment is selected:

- How can I prepare for the treatment session?
- Are there things I should know about going through this type of treatment?
- What are the expected side effects?
- What problems should I report to you? (Fever, diarrhea, nausea/vomiting, etc.)
- How do I reach someone if I have problems in the evening or on the weekends?
- What can I do to prevent or control side effects that I experience?
- Can I drive myself to and from the treatment?
- Do I need to take any special precautions at home (in regards to children, pets)?
- Will I be able to continue my normal activities/can I go to work?
- Will this therapy affect my sex life?
- Will this therapy affect my ability to have children?
- Do I need a special diet during or after my treatment?
- Do you have any printed materials about my type of cancer and treatment?
- Can you recommend any websites concerning my treatment?

This is a place where you can write down questions that you'd like to ask and record the answers.

Name of health care team member________________________________________

Date__________________________ Time_______________________________

Location__________________________________________________________

Question 1

Answer(s) to question 1

Answered by_____________________________________________________

Question 2

Answer(s) to question 2

Answered by_____________________________________________________

Question 3

Answer(s) to question 3

Answered by_____________________________________________________

Question 4

Answer(s) to question 4

Answered by_____________________________________________________

Name of health care team member______________________________

Date____________________ Time____________________

Location________________________________________

Question 1

________________________________________________

Answer(s) to question 1

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Answered by________________________________________

Question 2

________________________________________________

Answer(s) to question 2

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Answered by________________________________________

Question 3

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Answer(s) to question 3

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Answered by________________________________________

Question 4

________________________________________________

Answer(s) to question 4

________________________________________________

________________________________________________

Answered by________________________________________

# Understanding Your Prescription Medications

It is important to keep your doctors/nurses/pharmacists providers informed about any medications you are taking and to ask questions about how multiple medications may interact with one another. Use the practical tips below to help you better understand your medications.

**Practical Tips:**

#1. Be proactive; write down as many questions as possible before seeing your doctors, nurses and pharmacists. Be sure to have all your questions about your medications answered during your appointments.

#2. Use the tables in My Medications section of this binder on page 58-59 to update and disclose all your prescription and non-prescription medications (for example, over the counter drugs, vitamins, eye drops, inhalers, patches and sprays) to your doctors, nurses and pharmacists and alert them about your medications history and medication allergies (if applicable).

#3. Update your doctors, nurses and pharmacists about recent medication/strength/direction changes (including discontinuation of your medication) initiated by you or your prescribers. Tell them how you are taking your medications.

#4. Whenever applicable, provide your community pharmacy contact information to your pharmacist.

#5. Schedule an appointment with a member of the outpatient pharmacy team as part of the MedsCheck program.

## MedsCheck Program

The MedsCheck Program, is a service available through the Princess Margaret Hospital Outpatient Pharmacy to help you manage your medications. This service is available to you to help you better understand your medications.

## During this appointment, you will be able to:

- Check what your medications are for
- Check that you are taking your medications properly
- Discuss any problems that you may have with your current medications
- Get advice about taking your medications properly

For further details, please speak directly with any pharmacist and please be sure to bring all your medications with you to this appointment.

# My Medications

This section is to help you keep track of your medications. Bring all your medications or a list of medications with you each time you come to the hospital. This will ensure that you are not given a new medication that is not safe to take with any existing medication. Use the table below to keep track of the medications you are taking (including prescription, over-the-counter medications, herbals and vitamins). If you have allergies or react to certain medications, tell your doctor, nurse or pharmacist. This will help you avoid getting a medication that can harm you.

Bring a copy of your most up-to-date list of medications to each of your appointments.

| **Medication Name and Purpose** | **Dosage and Date Started** | **How Many Taken** | **When do you take it? (Check all that apply)** | | | **Reactions/ Side Effects and Date Stopped** | **Prescribing Doctor's Name** |
|---|---|---|---|---|---|---|---|
| | | | **Morning** | **Afternoon** | **Evening** | | |
| Example: Atrovastatin (Lipitor) High cholesterol | 10 mg Started 10/15/09 | 1 tablet per day | | ✓ | | Makes me tired; Changed meds 10/30/08 | Dr. Peter Monty; family Physician |
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| Medication Name and Purpose | Dosage and Date Started | How Many Taken | When do you take it? (Check all that apply) | | | Reactions/ Side Effects and Date Stopped | Prescribing Doctor's Name |
|---|---|---|---|---|---|---|---|
| | | | Morning | Afternoon | Evening | | |
| Example: Atrovastatin (Lipitor) High cholesterol | 10 mg Started 10/15/09 | 1 tablet per day | | ✓ | | Makes me tired; Changed meds 10/30/08 | Dr. Peter Monty; family Physician |
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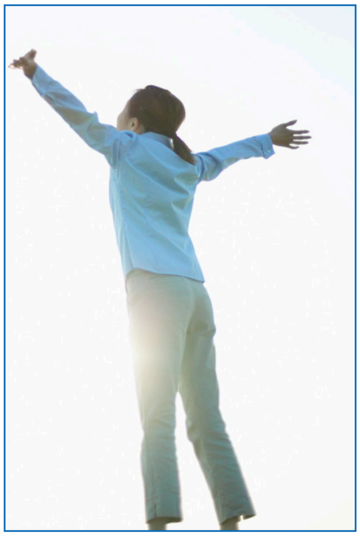
# Knowing About Your Cancer Treatments & Side Effects

It's important to know what possible side effects to expect from your cancer treatments, and how to manage them. Use the table below to discuss the type of treatment you may receive, what possible side effects you can expect and how to manage them. If you experience any side effects from your treatments, it's important to let your doctor or nurse know. Use the table below to write down some notes so your healthcare team can know how best to help you. See also the section at the back of this binder called "Managing Side Effects".

| Type of Treatment | What can I expect? | What can I do to manage or prevent side effects? |
|---|---|---|
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

# Caring for Myself



In addition to the physical effects of cancer and it's treatment, there are also the emotional and practical effects. When first diagnosed with cancer the focus tends to be on the medical aspects of the illness. Very quickly it becomes clear that this medical diagnosis also affects other parts of life, such as your family, finances, friendships, household tasks, and your ability to sleep and so on.

Many survivors who have completed treatment have commented that it is important that you pay attention to all of these areas of your experience with cancer. In particular, you need to take care of yourself, ask for extra support and adjust your commitments to account for the time and energy involved in participating in and recovering from treatment. There is nothing wrong in asking for help; it is simply a reflection of how much a diagnosis of cancer demands. If you haven't attended the "Managing Your Cancer Journey" course yet at Princess Margaret, schedule it into your calendar as it can give you very practical tips to help you manage your cancer journey including helping you prepare to manage your daily life with the extra demands of treatment. You are welcome to bring a family member or friend to the class. Call 416-946-4501 x5090 for more information and see page 39 of this binder.

Remember to refer back to the "Just Diagnosed" section where the supports and programs offered at the Hospital and in your community are listed. Also, visit the Patient & Family Library. You might be surprised to find out about free transportation to your appointments from the Canadian Cancer Society or free childcare at the Hospital while you are in your appointment and there are even free services available to help you with house cleaning while getting chemotherapy.*

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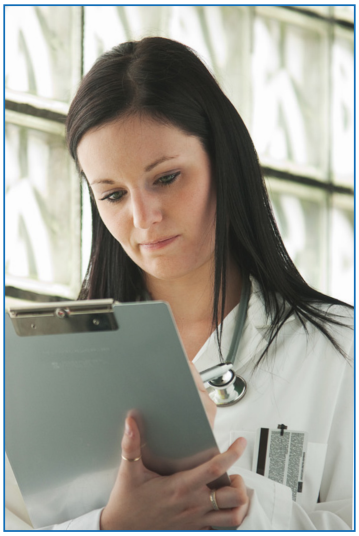
*Adapted with permission from the "Getting Back on Track" booklet which was fully funded by the Canadian Breast Cancer Foundation - Ontario Region and developed in partnership by the Canadian Breast Cancer Foundation - Ontario Region and Princess Margaret Hospital.



# Waiting for Results

At various stages in your cancer journey, you may find yourself waiting to hear the results of a test that you've had. It could be a blood test, CT scan, X-ray, biopsy, nuclear medicine image, or any of the many other types of tests that are used to detect cancer and the side effects of treatment. This waiting period can be very challenging, and is sometimes referred to by patients as "scanxiety," a combination of the words 'scan' and 'anxiety'.

"Scanxiety" is very real, and very normal to experience. You may notice that it changes slightly depending on the type of results you're waiting for. For example, if you are just being diagnosed, your fear of the unknown may be greater if you're unsure about treatment options and how your life may change with a diagnosis of cancer. While you're going through treatment, the result of a test may indicate whether your treatment is working or not. After treatment is finished, your concerns may be more around relapse or confirmation of a side effect, i.e. infertility or organ damage. Often there is a lot riding on these results, including the possibility of celebrating remission or the relief that can come with the diagnosis of unexplained symptoms.

In any case, waiting for results can be a hard time for many people. While everyone handles waiting differently, consider the following to help you out:

## 1. Acknowledge Your "Scanxiety" and Anticipation of Results

- Sometimes trying to ignore how you are feeling takes more energy than being aware of your feelings
- You can try talking to a friend or relative who listens well (chances are they may be feeling anxious too, and relieved that you're talking about it)

- You may prefer to write in a journal instead, where you can express your thoughts without having to go anywhere or share them with anyone
- Counselors, social workers and other community resources are also available to speak to about how you are feeling (See the "My Resource & Support" section for more information)

## 2. Prepare for Receiving Your Results

- It is helpful to mark the date in your calendar on which you expect to receive your results, and if you will receive them by phone or in a follow-up appointment with your doctor – this gives you something to focus on (if you're not sure when or how you will be getting your results, you can ask your doctor or nurse)
- Prepare a list of questions that you think you may have when you receive your results: what information do you need? (sometimes it is helpful to think back on when you last got a result for something, and what you needed to find out then or want to ensure you find out this time)
- Who do 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? (E.g. provide a ride to the appointment, write questions/answers down, give you some time to process the results you receive) Make sure you tell your family and friends what you need! (and be open to the fact that they may need to seek support from other resources too)

## 3. What Has Helped You Before?

- If you find it helpful to keep busy with work or other activities while you're waiting, try and plan to have something set up during this time
- Some people find it difficult to sleep while they're waiting for results – you may want to speak to your family doctor or nurse practitioner about this, or seek support from other resources
- "Scanxiety" can also make it difficult to concentrate on work or other

activities – it's important to do what works best for you during this time, and care for yourself as much as possible (which 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 or watching a game with friends, whatever you like best)
- Think about what has worked for you in the past when you've waited for something important, or ask others for ideas

As difficult as the waiting period can be, the results will come. In the meantime, it is important to help yourself get through the waiting in the best way that is possible. This may include acknowledging how you are feeling, preparing for the results, and using what has worked in the past or trying new ways to deal with the wait so that you are most comfortable.

# After Treatment

There are services and support programs that may be helpful to you after you've finished your treatment. In this section you'll find places to write down some information to help you create your own support plan – a Survivorship Care Plan. Making a Care Plan can help you get the maximum value from your follow-up visits.

The effects of cancer can be felt before you start treatment, while you're in treatment and after treatment. This binder has a section called Managing Side Effects for your easy reference throughout your cancer journey.

# Charting Your Course: Seeking Information

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

No matter what your style, at times over the next year you may wish you had a guide to help you.  This binder can be your guide. Remember to refer back to the "Just Diagnosed" section to look up programs in the Hospital and in your community that you can take for support.*

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* GBOT Booklet (Get info from NKQ)

Adapted with permission from the "Getting Back on Track" booklet which was fully funded by the Canadian Breast Cancer Foundation - Ontario Region and developed in partnership by the Canadian Breast Cancer Foundation - Ontario Region and Princess Margaret Hospital.

# After Treatment Questions

You may have many questions about the after-effects of treatments, ways to deal with emotional ups and downs, diet and exercise concerns or practical issues such as returning to work. You will need to work with your family doctor and nurse as well as your oncology team to find answers to these questions. Remember: no question is silly or trivial.

To help you to know what you can expect once cancer treatment ends, these are some sample questions to ask your healthcare team.*

## What treatments and drugs have I been given?

You can ask your doctor to provide a written record detailing the type of cancer you had, what treatments and drugs you received, and the potential side effects of these treatments. You can also record this information in your My Cancer Journey Binder.

## Do I need any follow-up care?

You can ask your doctor about what kinds of screening or tests you should be receiving once your treatment is complete. Also ask for a schedule of when you should be following up with your primary care or oncology provider to have these performed. Add these dates to your calendar to remind you about follow-up care.

## Will I get cancer again?

You can ask your doctor about the risks of secondary cancers or recurrent cancers and what signs or symptoms you should look for.

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

You can ask your healthcare team about maintaining a healthy diet and routine exercise. You can also ask about

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* Institute of Medicine of the National Academies: “Cancer Survivorship Care Planning”, Fact Sheet November 2005.

whether you should inform close relatives about a risk of cancer and need for cancer screening.

## Even though I survived cancer, will I feel differently physically?

Cancer treatment has a different effect on everyone, and for some survivors, there are serious side effects from treatment. You should be aware of the possible short and long-term effects that may arise. Radiation could affect a person's heart, stamina, or fertility. You should ask your doctor how your treatment could affect your long-term health and mental functioning. There are many programs in the community to help you manage these side effects. See the "My Resource & Support" section for more information.

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

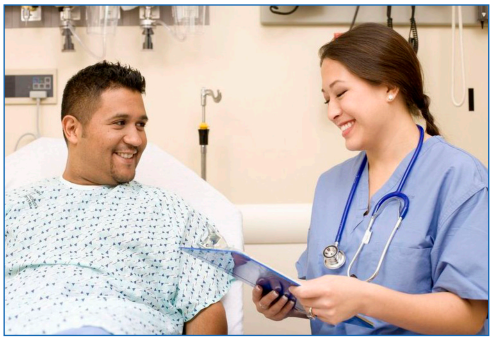
Having cancer can affect access to health or life insurance, the ability to keep a job, as well as job mobility. You can ask your healthcare team for information about what resources are available if you face employment discrimination or are unable to access or keep health and life insurance.

## Are there support groups I can turn to?

Your doctor or nurse should be able to provide a useful list of community or nationally based cancer-related organizations or other groups that can offer support or information on survivorship issues and challenges.

## Now that I've finished treatment who on the team will be responsible for monitoring my care?

Find out who will be the main point of contact working with your primary care provider to coordinate follow-up care related to your cancer treatment.



This is a place where you can write down questions that you'd like to ask and record the answers.

Name of health care team member____________________________________

Date________________________ Time____________________________

Location____________________________________________________

Question 1

Answer(s) to question 1

Answered by_________________________________________________

Question 2

Answer(s) to question 2

Answered by_________________________________________________

Question 3

Answer(s) to question 3

Answered by_________________________________________________

Question 4

Answer(s) to question 4

Answered by_________________________________________________

Name of health care team member________________________________________________

Date________________________________ Time________________________________________

Location________________________________________________________________________

Question 1

________________________________________________________________________________

Answer(s) to question 1

________________________________________________________________________________

________________________________________________________________________________

Answered by_____________________________________________________________________

Question 2

________________________________________________________________________________

Answer(s) to question 2

________________________________________________________________________________

________________________________________________________________________________

Answered by_____________________________________________________________________

Question 3

________________________________________________________________________________

Answer(s) to question 3

________________________________________________________________________________

________________________________________________________________________________

Answered by_____________________________________________________________________

Question 4

________________________________________________________________________________

Answer(s) to question 4

________________________________________________________________________________

________________________________________________________________________________

Answered by_____________________________________________________________________

# After Treatment:
# What You May Be Feeling Now

Until now, doctors, nurses and other health professionals have guided you on your cancer journey. From your earliest tests, through your diagnosis and your treatment, these professionals provided you with information and helped you make choices. You probably learned to trust them. You shared yourself with them and may have made some friends along the way.

Now that you cancer treatment is over you are entering a new stage in your journey. It is perfectly normal to worry about your future and you may not want to give up the connection to your healthcare team. Even though your family and friends may be willing to help, you may feel that you need the expertise of healthcare professionals to guide you along the way.

# What You Need to Know Now

All of the health professionals who guided you along your way are still available to support you if you need them. In fact, most will tell you to call them if you have any questions about treatment after-effects, new symptoms or other issues. They can also help you link with other trained professionals who are skilled in helping cancer survivors move into their life after treatment.

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

### You will see your healthcare team less often

You will still need to have medical appointments, but these visits will become fewer because you don't require active treatment. Now your check-ups will be shared among your oncologists and your family doctor. You may not need to see all of these professionals regularly, but they will be available if you need them.

### The size of your team will become smaller

You will not see as many health professionals as you did during active treatment.

### Your family doctor will coordinate your care

It is important that you have a family doctor, someone that you see regularly rather than seeing a few different doctors. He/she will look after your health in partnership with your cancer health team. If needed, other medical professionals and social workers are there for you.

### Your relationship with team members may change

Your nurse may become a more important source of information after your cancer treatment ends. Your Nurse Case Manager will be available by telephone and at your follow-up clinic visits.

Note: Find out who you Nurse Case Manager is. She/he can help steer you in the right direction so that you get the help that you need.*

## You and Your New Healthcare Team

### 1. The “Star Player” – You

You have learned a lot about how the healthcare system works and how you like to be treated. You are the most important member of your healthcare team and should continue to be part of all decisions.

### 2. Your Family Doctor

You will need one family doctor who works closely with you, does a complete physical check-up every year and manages your general health. He/she will also need to help you keep track of your physical, emotional and social needs, and make sure that your healthcare is

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*GBOT Booklet (Get info from NKQ)

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arranged in a timely manner. You will need to make sure that he/she is aware of all your medical appointments and the results of any tests. If you can, you should ensure that a copy of all reports and visits to specialists are sent to your family doctor.

### 3. Your Registered Nurse

Nurses can be your most helpful guides within the healthcare system. They can help you meet your physical, emotional and practical needs. Today, there are many different types of nurses who help patients and their families. The key nurses that you will relate to now will probably be the nurses who work with your family doctor and perhaps an oncology nurse.

At the Princess Margaret, your Nurse Case Manager will be a key contact for you. Your Nurse Case Manager works together with your oncologist. If you forget who your Nurses is, you can call your oncologist's office to find out.

### 4. Your Oncologist(s)

You may continue to see your medical, surgical and/or radiation oncologists. Each oncologist will do a physical examination that relates to the treatment that he/she gave you.

### 5. Your Social Worker

A social worker is available to help you with your psychological and social well-being and help you and your family resume your daily life.

### 6. Your Peer Support Group

You may wish to take advantage of local support groups that are available in your community. For a complete list of these groups, check with your social worker or the Princess Margaret Patient & Family Library.

### 7. Other Members of Your Healthcare Team

Dietitian: A healthcare professional with the expertise to counsel you on matters of nutrition and diet.

**8. Patient Flow Coordinator:** An individual who works in the Clinics at Princess Margaret and will continue to book your medical appointments as needed.

**9. Psychiatrist:** A doctor who provides psychiatric evaluations and interventions and who can also prescribe medicine.

**10. Psychologist:** A healthcare professional with a doctorate in psychology who provides psychological services but does not prescribe medicine.

**11. Volunteers:** People who volunteer their time to work at the Princess Margaret. Volunteers can help you find information you need.

## Providing the Best Possible Information to Your Family Doctor

Keep up-to-date records of all the medical care you receive for cancer and other conditions because future decisions about your care may depend on how you have been treated in the past. Notes from your clinic visits should be automatically sent to you family doctor – check with your healthcare team to ensure that this is happening. If you move or go to several different doctors, you are the only one who will have your complete health history.

### Make sure that you keep your family doctor up to date on:

- Any medications that you are taking now (including over-the-counter medicines such as pain killers, laxatives, as well as nutritional supplements, vitamins, minerals etc.). Your family doctor will need this information to avoid problems when prescribing new medicine for you.
- Whether you are considering herbal therapies. Herbs may affect your body the same way that drugs and medications do so consult your doctor before starting to ensure that they are safe and right for you.

- When your next surveillance test is due (like a mammogram, PSA test etc).
- Which specialists are still seeing you.
- Any fear or concerns that you have, especially those that might affect your recovery.
- Any lifestyle changes such as if you quit smoking, changed your diet or exercise routine etc.
- How you feel. Do you have any symptoms or changes that are worrying you?

# Managing Side Effects

In this section you will find information to help you manage the effects of cancer that you might experience before, during and after your cancer treatment. You can keep pamphlets or information sheets with tips on what to expect and how to manage side effects here.

# Noticing My Own Changes

Whether you are just diagnosed, starting treatment or if your treatment is over, you may be noticing some changes within yourself. You may be dealing with physical side effects of your cancer, it's treatment, and you may be experiencing some emotions that you're unsure how to handle. It is important to be aware of and monitor any physical issues you have, and it can be just as helpful to notice how you're feeling emotionally and how your feelings change over time as well.

The next section is about managing your physical and emotional health as you go through your cancer journey, and includes two tables for you to identify what you are experiencing at different stages of your recovery. This will help you make sure you get the assistance you need when you need it. It is also good to track how you're feeling over time so that you can notify your healthcare and community service supports if any conditions worsen, or celebrate your progress as they improve.

## Physical Side Effects

There may be short and long term physical side effects as a result of your treatment. You should talk to your doctor about what you can expect, and make sure your health team is aware of everything that you're experiencing so that you can get the care that you need.
Some common side effects include:

- Fatigue
- Aches and Pains
- Fertility changes
- Hair re-growth
- Other

If you experience any symptoms that may be related to your cancer, follow up with your doctor as soon as possible. Also, it is important to attend all of your scheduled check-ups.

# Dealing With Your Emotions

After treatment is also the time that many people really start to process their cancer experience and how it may have changed them. You may be thinking about your life differently in terms of what's important for you now. It is helpful to take time to notice these changes, and talk or write about how you want to handle them going forward.

Everyone experiences different emotions and has different emotional needs relating to their cancer survivorship. Many people continue to feel anxious after treatment, and worry about recurrence. This is completely normal, as are all of the other emotions you may be feeling. It is important for you and your family and friends to acknowledge these emotions and it can be very helpful to talk to others who have been through cancer treatments and who may be feeling the same thing. There are also many different ways to get the support that you and your family and friends need as you're dealing with these emotions. Some examples are listed below.

## Ways to manage:

- Speak to your doctor
- Talk to a counselor
- Join a support group
- Chat with cancer professionals and others who have experienced cancer on Caring Voices
- Volunteer
- Get involved with the cancer community
- Keep a journal
- Try a workshop: meditation, yoga, writing

See the "My Resource & Support" section for more information.

The following sections provide space to write down the different physical and emotional effects you may be experiencing. You may find it helpful to re-visit these notes every so often to update them as needed.

**What physical effects am I experiencing after treatment?** (E.g. fatigue, aches, pains, fertility changes, hair re-growth, other)

| Months/ Years After Treatment | Physical Effects | How would I like to address any issues? (E.g. make appointment with doctor, try new exercise) | How have I dealt with these issues? (E.g. followed up with doctor, attended a workshop on dealing with fatigue) |
|---|---|---|---|
| 3 months | | | |
| 6 months | | | |
| 1 year | | | |
| 2 years | | | |
| 3 years | | | |

## What am I experiencing emotionally after treatment?

(E.g. anxiety, anger, sadness, relief, frustration, guilt, excitement, determination, other)

| Months/ Years After Treatment | Emotional Effects & Needs | How would I like to address any issues? (E.g. make appointment with counselor, join support group, try new exercise/ meditation, write in a journal) | How have I dealt with these issues? (E.g. visited counselor, attended a workshop on survivorship, took up yoga, journalled on a weekly basis) |
|---|---|---|---|
| 3 months | | | |
| 6 months | | | |
| 1 year | | | |
| 2 years | | | |
| 3 years | | | |

# Cancer-Related Fatigue

Cancer-Related Fatigue (CRF) is a common side effect of your cancer treatment BUT did you know that you might feel tired long after your treatment is finished?

## What is Cancer-Related Fatigue (CRF)?

- CRF is a feeling of being very tired that is not caused by daily activity and does not go away with rest or sleep.
- Descriptions include feeling: "worn-out", "exhausted" or "heavy and slow".
- CRF happens during treatment for cancer and may last for months after treatment is finished.

## How common is Cancer-Related Fatigue?

- CRF is a common symptom of cancer, and a side effect that occurs during and after cancer treatment.
- 60-96% of people on treatment for cancer experience CRF.
- For about one-third of people, CRF can last for many months after treatment.

## How will Cancer-Related Fatigue affect me?

Cancer-Related Fatigue can affect many parts of your life. It can:

- Make you feel like you have little or no energy or motivation for your everyday activities.
- Change your mood and the way you feel about yourself.
- Affect your ability to work (paid or unpaid) your regular hours and days.
- Affect your relationships with people in your life.

## How can I manage Cancer-Related Fatigue?

- Learn more about CRF: come to the Cancer Related Fatigue Class (check the Patient Education Calendar for dates and location)

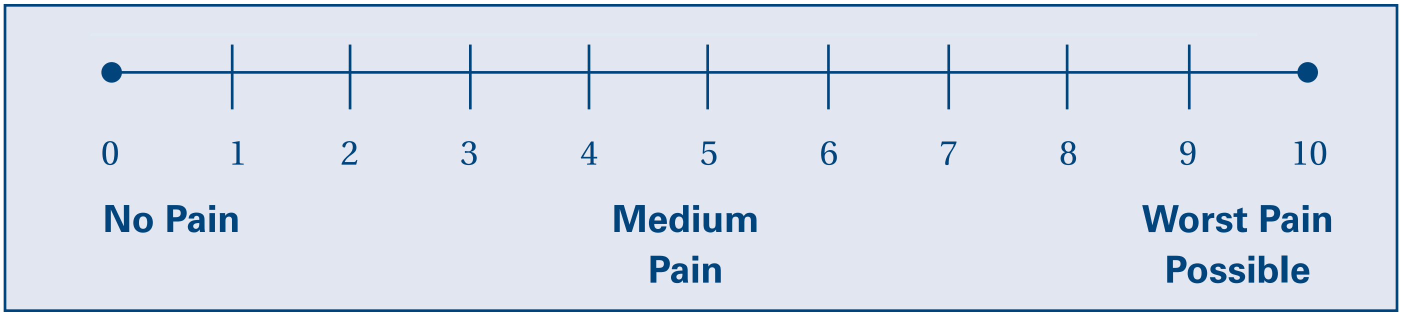
- Plan and prioritize your activities so that you can balance caring for yourself, free time, and household tasks/work in your day.
- Schedule rest breaks: Balance periods of rest and work. Pace yourself and take rest breaks throughout the day. Keep naps to less than an hour if needed.
- Ask for help with tasks and only do what you can. Remember that you can say “No”.
- Work towards regular exercise: Start slowly and add more exercise a little at a time. For example, start with 5 minutes of brisk walking 3 times a week then increase by 2 minutes each week.
- Make healthy eating choices: Spread your calories throughout the day, drink lots of liquids and eat a varied diet to work towards a healthy weight.
- Keep a regular schedule for going to bed and getting up.
- Talk to your doctor: Tell your doctor about your symptoms.
- Remind yourself that it is OK to relax.
- Check the Patient & Family Library for pamphlets relating to CRF.

# Managing Your Pain

Every person feels pain in a different way and coping with pain can be hard work. If you experience pain, tell your doctor or nurse so you can be helped.

## When describing your pain, make sure you tell your healthcare team:

- When and how often you have pain
- If you have noticed that a particular activity brings on pain
- How severe your pain is by rating it on a scale (you may use the scale below to rate your pain)
- How you treat the pain – be sure to mention any medications you are taking to relieve the pain



Use the space below to make notes on any changes to the pain you experience. There are many ways to control your pain, speak with your healthcare team to determine the best ways to provide you with extra relief and comfort from your pain.

Notes

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# Road Map

The Road Map is a place where you can work with your healthcare team to map out your treatment plan and then you'll be able to see at a glance what the next stage of your treatment is and also have a record of the treatments you've had.

# The Road Map (Plan) of My Treatment

### Radiation Treatment (Planned Treatments approx.)

| Area to be Treated | How Many? | Will Start | Will Last | Will End |
|---|---|---|---|---|
| | | | | |
| | | | | |
| | | | | |

### Chemotherapy (Planned)

| Initials | Drugs | How Often | How Many | Will Start | Will End |
|---|---|---|---|---|---|
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

### Surgery (Planned)

| Type of Surgery | When | Notes |
|---|---|---|
| | | |
| | | |
| | | |

### Other Therapy (e.g. Endocrine, Biologic)

| Drug | Duration | Will Start | Will End | Notes |
|---|---|---|---|---|
| | | | | |
| | | | | |
| | | | | |

# The Road Map (Plan) of My Treatment

## Radiation Treatment (Planned Treatments approx.)

| Area to be Treated | How Many? | Will Start | Will Last | Will End |
|---|---|---|---|---|
| | | | | |
| | | | | |
| | | | | |

## Chemotherapy (Planned)

| Initials | Drugs | How Often | How Many | Will Start | Will End |
|---|---|---|---|---|---|
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

## Surgery (Planned)

| Type of Surgery | When | Notes |
|---|---|---|
| | | |
| | | |
| | | |

## Other Therapy (e.g. Endocrine, Biologic)

| Drug | Duration | Will Start | Will End | Notes |
|---|---|---|---|---|
| | | | | |
| | | | | |
| | | | | |