

For patients with Head & Neck Cancer who are getting chemotherapy, radiation therapy or both.

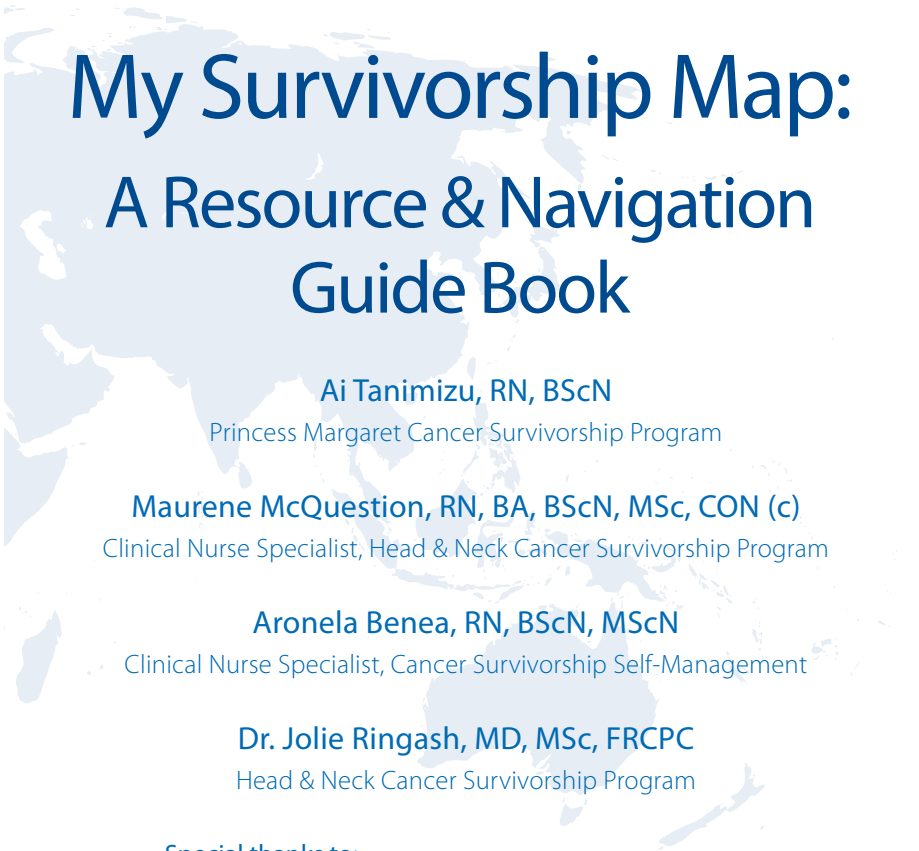


My Survivorship Map: A Resource & Navigation Guide Book

This booklet will help you:

- understand what to expect before, during, and after your treatment
- find information and resources that you may need throughout your cancer journey





My Survivorship Map: A Resource & Navigation Guide Book

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Special thanks to:

Head & Neck Cancer survivors

Head & Neck Cancer site group, Princess Margaret

ELLICSR: Health, Wellness, and Cancer Survivorship Program

Collaborative Academic Practice, Innovation and Research
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*“I will love the light for it shows
me the way, yet I will endure the
darkness for it shows me the stars.”*

- Og Mandino

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This guide is dedicated to the people who live with, through, and beyond head and neck cancer.

At the Princess Margaret, we consider a cancer survivor to be anyone who has received a diagnosis of cancer and is living with, through, and beyond the cancer journey.

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How to Use This Guide

During your cancer journey, you may need different types of resources to help you make informed choices about your treatment and care, and to give you support. Your health-care team is here to help you and your family, answer any questions you may have, and connect you with the right programs and services.

This guide will provide you with information and tips for each phase of your cancer journey, including a list of resources that can help you understand what to expect and where to get the support you may need. You can read through the whole guide or just refer to the phase you are currently in.

If you would like more resources, you can refer to the Pamphlets section (page 46).

The *Helpful Resources Throughout Your Journey* section lists resources that can be helpful at any time throughout your cancer journey (page 12).

My Cancer Journey Binder is a general binder given to all patients diagnosed with cancer. This booklet is not meant to replace the binder but to provide you with more specific information relevant to you.



After Treatment

Getting Treatment

**Preparing & Planning
for your Treatment**

Just Diagnosed

Types of Resources You Will Find in This Guide



Videos

You can find the videos at:

- Patient & Family Library (Main floor of Princess Margaret)
- On the internet at the website indicated



Pamphlets

You can find the pamphlets at:

- Patient & Family Library (Main floor of Princess Margaret)
- Wharton Head & Neck Centre (2nd floor of Princess Margaret)
- on the Princess Margaret website
- call Patient & Family Library and information can be mailed to you



Classes

For more information about a class, please check the Patient & Survivorship Education Calendar of Events:

- Pick the calendar up at the Patient & Family Library (Main floor of Princess Margaret)
- Visit www.theprincessmargaret.ca
Scroll down to "Classes & Activities".
Click on "See calendar".



Hospital Resources

These support and services are either available at the Princess Margaret or Toronto General Hospital.



Community Services

These are support groups and services in the community for cancer patients and their families. They usually offer various programs to meet practical, spiritual, emotional and physical concerns.



Internet Resources

You can find more information on the websites indicated



Healthcare Professionals

This describes healthcare professionals you will meet along your cancer journey. A description of their role can be found on page 48.

Helpful Resources Throughout Your Journey



Hospital Resources

Patient & Family Library

Princess Margaret, Main Floor, Phone: 416-946-4501 x5383

Here, you can find reliable, accurate and up-to-date information about your cancer. You can also borrow resources, use the computer (with internet access) or request a health information search. For more details — My Cancer Journey binder, page 40.

UHN Interpretation & Translation Services

Interpreters are available (free of charge) to help patients and families who prefer to communicate in another language other than English. At least one-day notice is required. Let your healthcare professional know if you would like an interpreter for your next appointment. For more details — My Cancer Journey binder, page 38.

Palliative Care Program

Phone: 416-946-4525, E-mail: popc@uhn.ca

The palliative care team can help you with management of symptoms such as pain, shortness of breath and nausea & vomiting.

In this section you can find resources that may be helpful to you throughout your cancer journey from the time you are diagnosed to the completion of your treatment and after.

Psychosocial Oncology Clinic

Phone: 416-946-4525, E-mail: popc@uhn.ca

Psychosocial Care can help you and your family cope with cancer. You can connect with a psychiatrist, psychologist, and a social worker. For more details — My Cancer Journey binder, page 44.

Adolescent & Young Adults (AYA) Program

Phone: 416-946-4501 x5579, E-mail: aya@uhn.ca

Princess Margaret's Adolescent and Young Adult (AYA) Oncology Program is committed to meeting every AYA patient's unique psychosocial and medical needs. The AYA Program can be accessed by patients that are under 39 years of age and will provide additional supportive care and counseling in collaboration with the primary oncology team.

Helpful Resources Throughout Your Journey

Music Therapy Program

Phone: 416-946-4501 x2494, E-mail: sarahrose.black@uhn.ca

Music Therapy is the skillful use of music and musical elements by an accredited music therapist to promote, maintain, and restore mental, physical, emotional, and spiritual health. Ask your healthcare team for a referral or you can self-refer to the program.

Spiritual Care Clinic

[Princess Margaret, Main floor, Phone: 416-946-3844](#)

Spiritual Care counsellors have conversations with people to help them find what is essential and of essence to them. Also, the multi-faith chapel is open on the main floor of Princess Margaret. You can drop in or book for an appointment. For more details — My Cancer Journey binder, page 46.


ELLICSR:

Health, Wellness & Cancer Survivorship Centre

[Toronto General Hospital, Basement level, BSC-021](#)

Phone: 416-581-8620

This is a comfortable place for patients, their families and friends. Patients can access health and wellness information, take part in classes, sit and relax and meet other cancer survivors here. For more details — My Cancer Journey binder, page 36.



“No matter how much money you have, you cannot change yesterday ...it’s done. It’s a done deal. You have no control of tomorrow. The sun will come up and go down and the moon will come up and go. You have no control of this moment now. Live for today and that’s what we do. Enjoy today, it’s a beautiful poem.”

-S.H.

Helpful Resources Throughout Your Journey



Websites

Princess Margaret Cancer Centre

www.theprincessmargaret.ca

Canadian Cancer Society

www.cancer.ca

National (American) Cancer Institute

www.cancer.gov

Support for People with Oral, Head & Neck Cancer (SPONHC)

www.spohnc.org

About Face Canada

www.aboutface.ca

(Canadian charitable organization that provides emotional and social support, resources and educational programs to individuals with facial disfigurements and their families.)

Adolescents and Young Adults Cancer Canada

ayacancercanada.wix.com/resources

You can find more useful and helpful websites here:

[www.uhn.ca/PatientsFamilies/Health_Information/
Health_Topics/Pages/head_neck_cancers.aspx](http://www.uhn.ca/PatientsFamilies/Health_Information/Health_Topics/Pages/head_neck_cancers.aspx)



Dana-Farber Cancer Institute

"Head and Neck Cancers: Risk Factors and Symptoms" Video:
www.dana-farber.org/Adult-Care/Treatment-and-Support/Treatment-Centers-and-Clinical-Services.aspx (click on Head & Neck Cancer)

Dana-Farber Cancer Institute (affiliated with Harvard Medical School) has videos that discuss health topics related to Head and Neck cancer, such as types of treatment, different risk factors, possible symptoms and many others.

MD Anderson Cancer Center — Information about human papilloma virus (HPV)

"HPV Infection and Head and Neck Cancer" Video:
www.mskcc.org/videos/hpv-infection-and-head-and-neck

Dr. David Pfister (Chief of the Head and Neck Oncology Service at Memorial Sloan-Kettering) talks about HPV infection and HPV related head and neck cancers in this 16 minute video.

Information Sheet

www2.mskcc.org/patient_education/_assets/downloads-english/891.pdf

This information sheet answers common questions about HPV and head and neck cancers.

Helpful Resources Throughout Your Journey



Alcohol/Smoking Cessation Resources

Smoker's Helpine

www.smokershelpline.ca Tel: 1-877-513-5333

Tobacco Addiction Treatment Clinic, Centre for Addiction and Mental Health (CAMH)

Tel: 416-535-8501 x77400

Nicotine Replacement Therapy patches

Available at the Princess Margaret Out-Patient Pharmacy (main floor) or any local pharmacies.

Alcoholics Anonymous (various locations throughout Ontario)

www.aa.org



Pamphlets

- *One Step at a Time: For Smokers Who Don't Want to Quit* (CCS 211-995)
- *One Step at a Time: For Smokers Who Want to Quit* (CCS 11-083)
- *One Step at a Time: Help a Smoker Quit* (CCS 211-997)
- *Smoking Cessation Program* (UHN D-3370)

Avoid drinking alcohol and smoking tobacco to receive the best results from treatment.



Wellness Classes

(please check the Patient & Survivorship Education Calendar of Events)

- Relaxation Therapy (learn different relaxation techniques in a group setting)
- Cancer and Your Spirit (learn about spirituality and how it can support you)
- Letting Cancer Speak (Reframe your story and spirituality in light of the diagnosis)
- Sexuality and Intimacy class



Did you pick up the monthly **Patient & Survivorship Education Calendar of Events?**

Get one at the Princess Margaret Patient & Family Library on the main floor or visit:

www.theprincessmargaret.ca

Helpful Resources Throughout Your Journey



Community Services

Wellspring – 8 locations in Ontario

Tel: 1-877-499-9904 (toll free, find your nearest location)
www.wellspring.ca

Gilda's Club – 2 locations in Ontario

Downtown Toronto:

Tel: 416-214-9898
www.gildasclubtoronto.org

Barrie:

Tel: 705-726-5199
www.gildasclubsimcoemuskoka.org



These are support groups and services in the community for cancer patients and their families. They usually offer various programs to meet practical, spiritual, emotional and physical concerns.

HopeSpring – Kitchener

Tel: 519-742-4673

www.hopespring.ca

Hearth Place – Oshawa

Tel: 905-579-4833

www.hearthplace.org

Wellwood – 2 locations in Hamilton

Juravinski Hospital Site:

Tel: 905-389-5884

www.wellwood.on.ca

Community Site:

Tel: 905-667-8870

www.wellwood.on.ca

Most programs are offered at no cost to you. Find out about their education and support programs for you and your family.

Helpful Resources Throughout Your Journey

Sexuality, Intimacy, and Sexual Health



You may feel changes in sexuality, sexual desire, or body image due to the physical and functional changes caused by the cancer or the cancer treatment. If you have any questions or concerns, please let your doctor or nurse know. They are here to help you.

Resources that you may find helpful:



Sexuality and Cancer (CCS 313-523)



Sexuality and Intimacy

Just Diagnosed

A cancer diagnosis can be scary and overwhelming. Each person's experience is unique. There is no right or wrong way to feel about a diagnosis or what it means to you.

Healthcare professionals you will meet

There are many healthcare professionals you will meet including students. Go to page 48 for a description of each.

You can organize and keep track of names and contact information for every healthcare professional you meet in My Cancer Journey binder, pages 2-5.



“Once I found out I was positive, that kind of took the wind out of my sails and put me on a kind of an emotional roller coaster for about a week. We’re now fighting an enemy that we couldn’t fight in the traditional ways...it took me about a week to really come to grips with what I was dealing with.”

~ H.H.

How to cope with a cancer diagnosis

Getting more information about your diagnosis will help you understand and be more prepared for your cancer journey.

Supportive resources can help you cope with any uncertainty and challenges of a cancer diagnosis.

To help get you started, refer to:

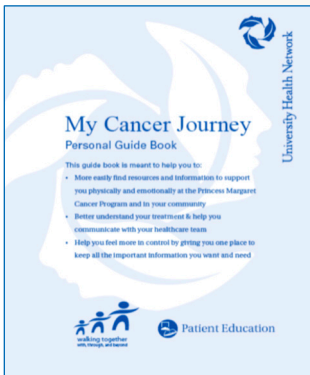
- The next page for resources that may be of most help at this time,
- Go back to page 12 for resources.

During your appointments, do not hesitate to ask questions. There is a list of sample questions in My Cancer Journey binder, pages 22–23. You can also ask your nurse what questions are frequently asked.

If you are feeling overwhelmed, you can ask a family member or friend to come to your appointments and take notes for you.

Just Diagnosed

Did you get your “My Cancer Journey” binder?



This guide book is meant to help you to:

- Understand your treatment
- Talk with your healthcare team
- Keep and organize your appointments, medications, questions to ask, important contacts, medical records, notes, and more.

Visit the Princess Margaret, Wharton Head & Neck Centre (2nd floor) to get your copy.



You can access contents of “My Cancer Journey” binder on the Princess Margaret website at:
www.theprincessmargaret.ca

Home Page > Patients & Families > The Cancer Journey > Toolkit

You may receive other pamphlets such as *What is the Radiation Nursing Clinic (RNC)* or your schedule of appointments during your clinic visit.

Resources that may be useful at this time:



Canadian Cancer Society Pamphlets

- *Living with cancer: A guide for people living with cancer and their caregivers* (CCS 311-402)
- *Living with advanced cancer* (CCS 311-404)

The resources above can be found at:



1. Princess Margaret, Patient & Family Library
(Main floor of Princess Margaret), or



2. Canadian Cancer Society website (www.cancer.ca)



My Cancer Journey Binder

- “Just Diagnosed” section

Preparing and Planning for Your Treatment (2–4 weeks)

During this time, your health care team will be working with you to prepare and plan your cancer treatment. Waiting to start treatment can be difficult. Feelings of anxiety and distress are common during this stage.

Think about what has helped you get through times of distress and uncertainty in the past. You may find talking to a supportive partner, family member or friend to be helpful.

Knowing what to expect may help you feel better. Some internet information can be wrong, confusing and can make you more anxious. Seek out reliable resources from the Princess Margaret Patient & Family Library or those suggested here.



Did you get your teeth checked by the Dentist?

Treatment for head and neck cancer can affect your dental health including your gums. Getting your teeth, gums, and dentures checked can help prevent infections and irritations in the mouth during treatment. The dentists make sure your medical treatment can be delivered safely and promptly and maintain dental health. If appropriate, you may get **fluoride treatment** to prevent cavities.

"First I was nervous not knowing anybody, but then you start to meet people in the same situation. Which makes you feel even better, and some may be a little worse off than me...It's like I'm not the only one. Like I can imagine some people say, well oh God, why me, I'm the only one. But you're not the only one, you know but you don't see it until you're around it..." ~S.D.

Chemotherapy

Chemotherapy is a way of treating cancer with the use of drug therapies.

To learn more about chemotherapy and what to expect, refer to:



- *Chemotherapy and Other Drugs Therapies booklet* (Canadian Cancer Society 301-467)
- *What is chemotherapy?* Booklet (UHN D-5194)



Chemo Questions and Concerns class
(please check the Patient & Survivorship Education Calendar of Events for a schedule)



Chemotherapy: What to expect
www.theprincessmargaret.ca/en/PatientsFamilies/ClinicsAndCentres/ChemoCentre/Pages/Chemo.aspx

All patients who will receive chemotherapy treatment will be booked for **auditory hearing tests**. Depending on your type of head & neck cancer, your medical oncologist may refer you to the **eye clinic** as well.

Preparing and Planning for Your Treatment (2–4 weeks)

Radiation Therapy

Radiation therapy is the use of high energy x-rays to kill cancer cells. Most Head & Neck patients will receive radiation treatment alone or together with chemotherapy. Your radiation treatment is individualized just for you. It takes time to design correctly for you. To learn more about radiation therapy and what to expect, refer to:



Your Radiation Therapy at the Princess Margaret Hospital (UHN D-5040)

What to Expect While Receiving Radiation Therapy for Head & Neck Cancer (UHN D-5114)



What to Expect: Radiation Treatment
www.theprincessmargaret.ca > [Head & Neck Clinic](#) > [Video Resources](#) > "Introduction to Radiation Therapy of the Head & Neck"



What to Expect While Receiving Radiation Therapy for Head & Neck Cancer — DVD (given at Wharton Head & Neck Centre)

CT Simulation and Mask Fitting

Radiation planning appointments include (but are not limited to) **CT simulation** & **mask fit** appointments for radiation therapy.



Did you get your “Getting Ready for your Radiation Treatment” checklist?

This checklist will help you organize the various appointments you may need before your radiation treatment begins. Using the checklist, your radiation oncologist and nurse will work with you to figure out which types of appointments you will need and in what order.

Ask any healthcare professional at the Wharton Head & Neck Centre (2nd floor of Princess Margaret) for the checklist.

Your simulation appointment is the first step in designing your personalized radiation therapy treatment plan. Simulation mimics a radiation therapy treatment session, but you are not given radiation during this appointment. The simulator (a special CT scanner) takes pictures of your treatment area. Your radiation team uses these pictures to design your treatments.

You will have a mask created just for you. The mask is there to help your head and neck stay in position so you can have the most effective radiation treatment. Some patients will also have an MRI simulation scan.

If you have claustrophobia (fear of enclosed spaces), this experience may be uncomfortable. Let your oncologist know ahead of time if you are afraid.

Your simulation appointment and mask fit appointment together will take about 1–2 hours. You will also have time to ask specific questions to the radiation therapists.

Preparing and Planning for Your Treatment (2–4 weeks)



Swallowing Exercises

Radiation treatment can cause jaw or tongue stiffness.

- Doing so will help you keep your ability to eat and drink during and after treatment.
- Lower your chances of having long term swallowing problems.
- Minimize the need for modified diet.
- Start before treatment and continue to up to a year after treatment.



Refer to the pamphlet:

Swallowing Exercises for Patients with Head & Neck Cancer Receiving Radiation Treatment (UHN D-5631)



To see a video on how to do your swallowing exercises, you can borrow a DVD from the Patient & Family Library

Self-Guided Exercise Program: Swallowing Exercises DVD (UHN FE380 P945 2011)



Or watch it online at:

www.theprincessmargaret.ca > Head & Neck Clinic > Video Resources > "Radiation Swallowing Exercises"

Tip: This is a great time to check into sick benefits, drug plan, transportation to and from treatment, friends or family who can help with meals, household chores, and transportation needs.

Support and services that may be helpful at this time



Pamphlets

- *Coping with Cancer: Income Assistance* (UHN D-3392)
- *Coping with Head & Neck Cancer* (UHN D-5341)
(for more support and services for Head & Neck patients)
- *Driving Services to Medical Appointments* (UHN D-5166)
- *Drug Coverage Programs Available to Cancer Patients*
(UHN D-5449)



Hospital Resources

- Princess Margaret Lodge at 545 Jarvis Street
(for patients from out of town - ask your oncologist, nurse, or social worker for more information)



Community Services

Wellspring, Money Matters Resource Centre
(for financial concerns)

Find your nearest location by calling 1-877-499-9904 or check their website at www.wellspring.ca

Getting Treatment (4–7 weeks)

You are now receiving cancer treatment. During this stage, you are most likely coming into the Princess Margaret every day to receive treatment.



Radiation Nursing Clinic (RNC)

2B, Princess Margaret

The RNC may be used by any patient who is currently on radiation treatment, planning to have radiation treatment, or for patients up to two weeks after radiation therapy is finished.

At the clinic, you will meet a Specialized Oncology Nurse and Nurse Practitioner who will assess new or changing symptoms or side effects that you may be experiencing. They can give you advice, teach you new skills, and help you with medications.

For more information about the RNC, ask any of your healthcare team or read *The Radiation Nursing Clinic* pamphlet (UHN D-5003).

Resources that may be helpful at this time



Classes

- **Head & Neck: Supporting You Through Treatment** (learn about treatment side effects, swallowing changes, and nutrition during treatment. It is important to attend

"It's because after 21 days...everything hurts, and it burns... you know. Everything is dead inside, I don't know like raw meat or whatever. I was miserable and because there is so much pain and I couldn't swallow. I mean when it's written SORE, it just means sore throat, like getting a cold. That was what I thought it would be, didn't dawn on me to wake up one morning, you swallow and it's a nightmare." ~ A.T.

this class at the beginning of treatment). Patients are usually booked in this class during first or second week of treatment. To reschedule the class, please call 416-946-4501 x2172 or x2187 (radiation reception) to reschedule your class appointment. Please have your MRN number ready (located on your blue hospital card)

- Look Good Feel Better (free, two-hour hands-on workshop offered to women to learn how to look and feel more like themselves again)
- What to Eat When You Don't Feel Like Eating



Pamphlets

- *Managing the Side Effects of Chemotherapy* (UHN D-5805)
- My Cancer Journey binder "During Treatment" section (pages 52-64)
- *Saline Soaks* (UHN D-5017) (for skin care during treatment)

Getting Treatment (4–7 weeks)



Why should I do mouth rinses?

Radiation treatment can cause cavities, mouth sores, and dry mouth.

- **Baking soda or salt water mouth rinse** can help keep your mouth clean and moist to prevent irritation and infection. You can also use flat club soda. Avoid using mouth rinses that contain alcohol such as commercial mouthwashes.
- **Mucositis mouth wash** (prescription) can help you manage pain when chewing or swallowing.



Read the *Sore Mouth and Throat* pamphlet for more information and mouth rinse recipes (UHN D-5806)

You can receive the best results from treatment if you:

- Do not drink alcohol or smoke!
- Maintain your weight and fluid intake.

“They have a CD player and you can listen to music while you’re getting treatment. So I’d go away to a different place that way, a different place mentally. That’s why I said... mental toughness is really a huge thing.” – L.L.

It is important to let a healthcare professional know what kind of side effects or distress from treatment you are experiencing. They may be able to help by suggesting tips, prescribing some medication or by referring you to resources that can help make your experience better.



Use the “Managing Side Effects” section in your My Cancer Journey binder (pages 78-84) to write down any side effects you may experience.

Having problems maintaining your weight?



Ask a member of your healthcare team to refer you to the dietitian



Read: *Adding Calories and Protein to Your Diet* pamphlet. (UHN D-5510)

After Treatment

First 3 months after finishing treatment

You have finished treatment and have reached another milestone in your journey. In the next 3 months, focus on recovering from your treatment. It is also common for recovery to take longer than 3 months.

After finishing your treatment, you may experience the following side effects:

- Mouth and throat sores
- Thickened saliva
- Pain
- Swallowing difficulty
- Changes in speech
- Fatigue
- Dry mouth (xerostomia)
- Changes in taste or smell
- Dewlap (lymphedema in the neck area)



Continue using the “Managing Side Effects” section in your My Cancer Journey binder (pages 78-84) to write down your side effects.

"...you get the information but you can't imagine that you're going to go through that. You can't imagine, you know, it's going to be like, like when Dr. X said, 'you won't have any more saliva.' Oh, I thought, well, that's okay I'll manage. But I never thought, my mouth, my throat will be that dry. I never realized all the problems I would have with eating." ~E.G.



It is important to let your health care team know what kind of side effects or distress you are experiencing. If you are experiencing issues with coping or managing your side effects after treatment, talk to a member from your healthcare team:

- Your Oncologist
- Specialized Oncology Nurse who followed up with you during your radiation treatment
- Clinical Nurse Specialist:
[416-946-4501](tel:416-946-4501) extension 5420



Remember to continue doing your:

- Swallowing exercises
- Mouth opening exercise
- Fluoride treatment

After Treatment

Resources that may be helpful at this time



Readings

- *Life after cancer treatment* (Canadian Cancer Society 313-222)
- My Cancer Journey binder, “After Treatment” section (pages 66-75)
- *Exercises for upper body during and after radiation for head and neck cancer* (this pamphlet is only available upon request to your healthcare team in clinic)



Classes

- *Getting Back on Track: Life After Treatment for Head & Neck Cancer* (both parts are held at Princess Margaret 16th floor, room 728, 1–3:00 pm)

Part 1: Medical follow-up and emotional well-being
(2nd Monday of every month)

Part 2: Nutrition & swallowing (3rd Monday of every month)

To reschedule these Getting Back on Track classes, please call 416-946-2206 (Wharton Head & Neck Clinic reception). Please have your MRN number ready (located on your blue hospital card).

- *Lebed Healthy-Steps* (10-wk gentle group exercise program)
- *Lymphedema Awareness* (learn to lower the risk of getting buildup of lymphatic fluid)
- *Reclaim Your Energy* (learn to manage your cancer-related fatigue)



Hospital Resources

(ask a member of your healthcare team for a referral)

- Function and Mobility Clinic (for neck, shoulder, and arm dysfunction after cancer treatment)
- Neurocognitive Clinic (for memory, attention, concentration concerns due to cancer treatment)
- Fatigue Clinic (for cancer-related tiredness that is not relieved with rest)



Community Services

Wellspring — Cancer Exercise Program

Find your nearest location!

Tel: 1-877-499-9904 (toll free)

www.wellspring.ca

Cancer Exercise Program, Return to Work Program, Back at Work Program

There is a list of other exercise programs catered toward cancer survivors on the UHN website

<http://www.theprincessmargaret.ca/en/PatientsFamilies/SupportServices/Pages/physiotherapy.aspx>

After Treatment

Follow-up clinic appointments


You will have routine follow-up appointments with your Oncologists (doctors who specialize in cancer). This is to monitor how you are doing after your treatment. Which oncologists will follow you will depend on your case.

How many follow-ups and how often

| Time after finishing treatment | How many follow-ups and how often |
|---|-----------------------------------|
| Within the 1 st year | Every 2–3 months |
| Within the 2 nd year | Every 3–4 months |
| Within the 3 rd to 4 th years | Every 6 months |
| Within the 5 th year & beyond | Once a year* |

*At this time, your healthcare team may discuss with you about shifting your care to the community.





“So there is a lot of adjustment that I have to make in my life. But still I find, hey, if I’m living I’m still able to eat something, I still have my friends, I still have my life, so what more can I ask? ...And later on, hopefully I’ll be able to travel. And I love life, I love reading. I love going to the movies, I love my friends. I just love life.”

-E.G.

After Treatment

Side Effects

Some long-term side effects you may still be experiencing include:

- Dry mouth
- Swallowing problems or difficulties
- Trouble opening your mouth
- Hearing loss
- Weight loss or trouble gaining weight back
- Neck stiffness
- Shoulder dysfunction
- Hormonal problems (thyroid)
- Chronic fatigue
- Bone damage to areas treated with radiation
- Teeth or gum decay
- Second cancer



It is important to continue to:

- monitor and record your side effects
- let your Oncologists know what side effects you are still experiencing and any difficulties you may have



Some patients may still be experiencing difficulty maintaining weight or swallowing difficulties.

The Post-Treatment Dietitian Clinic can help you.

- ask any member of your healthcare team for a referral.



Some patients may still be experiencing side effects from radiation treatment years after.

The Radiation Late Effects Clinic can help you

- ask your Oncologist for a referral.

Pamphlets That Are Available

Please note there are more pamphlets that are available.

If you would like some information about a specific topic, please ask the Patient & Family Library staff. Some pamphlets are also available in different languages.

Radiation Therapy

Radiation Therapy
(Canadian Cancer Society
301-477)

Saline Soaks (UHN D-5017)

*Swallowing Exercises for Patients
with Head & Neck Cancer
Receiving Radiation Treatment*
(UHN D-5631)

*What to Expect While Receiving
Radiation Therapy for Head &
Neck Cancer* (UHN D-5114)

*What to Do When Finishing
Radiation Therapy* (UHN D-5645)

*What You Need to Know About
Antioxidants and Your Radiation
Therapy* (UHN D-5021)

*Your Radiation Therapy at the
PMH* (UHN D-5040)

Chemotherapy

*Bowel Routine while Taking Pain
Medications* (UHN D-5906)

*Chemotherapy and Other Drug
Therapies* (Canadian Cancer
Society 301-467)

*Managing the Side Effects of
Chemotherapy* (UHN D-5805)

Feeding Tube Information

*What to Expect When You Are
Having a Feeding Tube Inserted
as an Inpatient* (UHN D-5792)

*What to Expect When You Are
Having a Feeding Tube Inserted
as an Outpatient* (UHN D-5746)

Tube Feeding by Gravity (UHN D-5319)

Tube Feeding by Pump (UHN D-5317)

How to Care for Your Feeding Tube
(UHN D-5685)

You can find the resources listed below either at the Patient & Family Library or the Wharton Head & Neck Centre. You can also call the Patient & Family Library at 416-946-4501 x5383 and the information can be mailed to you.

Imaging Information

Bone Scan (UHN D-3351)

CT Scan (UHN D-3362)

*PET Scan and PET/CT Scan
(UHN D-3347)*

Cancer-Related Fatigue

*Cancer Related Fatigue: What
Can You Do About It?
(UHN D-5622)*

Feeling Zapped? (UHN D-5559)

*Mental Fatigue and What You
Can Do About It (UHN D-5561)*

Nutrition

*Adding Calories and Protein to
Your Diet (UHN D-5510)*

*Eating well when you have
cancer (Canadian Cancer
Society 313-220)*

*Sore Mouth and Throat
(UHN D-5806)*

*What to Eat When You Don't
Feel Like Eating (UHN D-5311)*

Other Resources

*Coping with Cancer: Income
Assistance (UHN D-3392)*

*Coping with Head and Neck Cancer:
Hospital and Community Resources
(UHN D-5341)*

*Driving Services to Medical Appoint-
ments (UHN D-5166)*

*Facts About Natural and Herbal
Products (UHN D-5011)*

*Getting Back on Track for Head &
Neck Patients (UHN D-5939)*

*Head and Neck Cancer Information
& Support Resources (UHN D-5921)*

*Life after cancer treatment
(Canadian Cancer Society 313-222)*

*Managing Body Image Concerns
After Cancer Treatment (UHN
D-5958)*

Parking Lot Rates (UHN D-5022)

*Sexuality and Cancer (Canadian
Cancer Society 313-523)*

*Smoking Cessation Program
(UHN D-3370)*

*The Trillium Drug Coverage Program:
Fact Sheet (UHN D-5366)*

My Healthcare Team at Princess Margaret

To keep track of your healthcare team, you can write their name and contact information in My Cancer Journey binder, pages 2–5.

Medical Oncologist

A doctor that treats cancer using different drugs such as chemotherapy.

Radiation Oncologist

A doctor that treats cancer using radiation therapy (high-energy X-rays).

Surgical Oncologist

A doctor who specializes in treating cancer with surgery.

Dentist

A doctor that provides dental work to prevent any problems or damage to your mouth and teeth both before and after your cancer treatment.

Pharmacist

Medication Reimbursement Specialist

Phone: 416-946-4501 x5129

The specialist can help you apply for drug coverages and relieve the burden of financial anxiety. This person can also help you with Trillium Drug Program applications.

There are many healthcare professionals involved in your care. You may not need all their services but they are there whenever you need them. The following is a list and descriptions of the various healthcare professionals who you may meet during your cancer journey.

Nurse Practitioner

A nurse with advanced education and training who is able to manage patients for symptoms or concerns related to their cancer treatment. In the Head & Neck site, the Nurse Practitioner manages patients in the Radiation Nursing Clinic. Patients may drop in as needed and do not require a referral.

Clinical Nurse Specialist

416-946-4501 x5420

The Clinical Nurse Specialist will help you and your family manage any side effects you may have from your cancer or treatment. The CNS can also provide emotional support to help you cope and adjust to life changes as a result of your diagnosis, treatment and recovery. Ask your health care team for a referral to the CNS or you can self-refer.

Patient Care Coordinator

The Patient Care Coordinator manages the day-to-day operations of the Wharton Head & Neck Centre.

Specialized Oncology Nurse

A Registered Nurse with special training to care for patients living with a cancer diagnosis. He or she will educate and support you throughout your treatment and recovery.

My Healthcare Team at Princess Margaret

Radiation Therapist

A health care member with special training to help plan and give your radiation treatment prescribed by your Radiation Oncologist.



Ophthalmologist

A doctor who specializes in eye problems.

Audiologist

A doctor who specializes in hearing problems.

Dietitian

An expert on diet and nutrition. He or she can help you eat well during and after your treatment. Ask your health-care team for a referral.

Spiritual Care Counsellor

Phone: [416-946-4460](tel:416-946-4460)

A counsellor who is focused on supporting you emotionally and spiritually. Through conversations with you, he or she can help you find what is essential and of essence to you when you are feeling the most vulnerable.

Princess Margaret is a teaching hospital. During your treatment, you may also meet numerous medical students, residents, and fellows.

Social Worker

Phone: 416-946-4501 x4525

A healthcare professional who is focused on addressing your practical and emotional experience of cancer, and on helping you to find other resources you may need.

Speech Language Pathologist

A healthcare professional who is specially trained to help you manage any communication and swallowing problems that may be due to your diagnosis or treatment. Ask your healthcare team for a referral.

Community Care Access Centre (Home Care)

CCAC staff members can connect you with the care you need to stay at home and in your community. Ask your healthcare team for a referral.

Medical Student: student in a medical school

Resident: person who has graduated from an accredited medical school, holds a medical degree, and practices under the supervision of fully licensed physicians

Clinical Fellow: person who has completed a speciality training program (residency) and is gaining additional expertise

Caregiver and Family Resources



Internet Resources

- Caregiver Connect: www.caregiver-connect.ca
- Canadian Virtual Hospice: www.virtualhospice.ca
- Cancer.net: www.cancer.net/coping/caregiving
- Canadian Cancer Society:
 - Helping Someone with Cancer
www.cancer.ca/en/cancer-information/cancer-journey/helping-someone-with-cancer/?region=on
 - If You're a Caregiver
www.cancer.ca/en/cancer-information/cancer-journey/if-you-re-a-caregiver/?region=on
- Group Loop (a place for teens touched by cancer to connect):
www.grouploop.org
- Strength for Caring: www.strengthforcaring.com



Community Services

(refer to pages 9-10 for more)

- Family Services Toronto: [416-595-9618](tel:416-595-9618)
- Hospice Toronto: [416-364-1666](tel:416-364-1666)
- Young Carers Program (if you are 18 years or younger and in a caregiving role): ycptoronto.weebly.com

Are you taking care of someone who has cancer or you know someone who has cancer but don't know how to help? Look here for resources and support that may be helpful to you.



Video

- Parenting Through Cancer (UHN GK775 A53 2008)



Pamphlets

- *Caregiver Stress: Avoiding Burnout* (UHN D5031)
- *Coping with Cancer: Where teens, young adults and their families can go for help* (UHN D5068)
- *When a Parent Has Cancer* (UHN D5580)
- *You and Me: Activities for Parents & Children When a Parent Has Cancer* (UHN D5074)
- *When someone you know has cancer* (Canadian Cancer Society 301–464)

Check the caregiver's resource list provided by Hospice Toronto:

www.hospicetoronto.ca/PDF/Hospice_Toronto_Caregiver_Resource_List.pdf

We are committed to providing excellent patient care at the Princess Margaret.

We are a caring, creative and accountable academic hospital, transforming health care for our patients, our community, and the world.

The quotes in this booklet are Princess Margaret Cancer Centre's head and neck cancer survivors' voices and lived experiences from McQuestion, M. (2006). A qualitative descriptive study of patients' experiences of receiving primary radiation treatment for head and neck cancer. Unpublished master's thesis. University of Toronto, Toronto, Ontario.

We would like to thank the patients and family / significant others for their time and willingness to share their experience in shaping the Head & Neck Survivorship Program and in the development of My Survivorship Map. We learn from each and every one of them through our interactions and hope that this resource helps you as you recover, adapt and live with changes from the cancer and your treatment.

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