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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

My Survivorship Map: A Resource & Navigation Guide Book was developed through funding from University Health Network Collaborative Academic Practice, Innovation and Research Fellowship Program and Registered Nurses’ Association of Ontario, Advanced Clinical Practice Fellowship Program.

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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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 healthcare 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 10).

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.
Videos
You can find the videos:
• At the Patient & Family Library (Main floor of Princess Margaret)
• On the internet at the website indicated

Pamphlets
Places where you can find pamphlets:
• 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 & Family Events Calendar:
• Pick the calendar up at the Patient & Family Library (Main floor of Princess Margaret)
• Visit: www.uhn.ca/PrincessMargaret Scroll down to “Classes & Activities”. Click on “See calendar”.

Hospital Resources
These support and other 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

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.

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.
Helpful Resources Throughout Your Journey

Music Therapy Program
E-mail: sarahrose.black@uhn.ca  Phone: 416-946-4501 x2494

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, BPMB-130  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

You can find more useful and helpful websites here:
www.uhn.ca/PatientsFamilies

Websites

Princess Margaret Cancer Centre
www.uhn.ca/PrincessMargaret

Adolescents and Young Adults Cancer Canada
ayacancercanada.wix.com/resources

Canadian Cancer Society
www.cancer.ca

Faces of HNC
www.facesofhnc.com

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.)

Support for People with Oral, Head & Neck Cancer (SPONHC)
www.spohnc.org

National (American) Cancer Institute
www.cancer.gov

Dana-Farber Cancer Institute

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.

General information about head and neck cancer (types of head and neck cancers, treatments, resources, etc.)
http://bit.ly/1T4PfuD

“Head and Neck Cancers: Risk Factors and Symptoms” – Video (click on Head & Neck Cancer):
http://bit.ly/1ZmyDx1

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

Video: “HPV Infection and Head and Neck Cancer”
http://bit.ly/1q3zztZ

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.
Helpful Resources Throughout Your Journey

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

Alcohol/Smoking Cessation Resources

Smoker’s Helpine
www.smokershelpline.ca  Tel: 1-877-513-5333

Nicotine Dependence Clinic
www.nicotinedependenceclinic.com  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)

Other Health Topics

Stress, Relaxation and Coping
http://www.uhn.ca/PatientsFamilies/Health_Information/Health_Topics/Pages/stress_coping_relaxation.aspx

Spiritual Care
http://www.uhn.ca/PatientsFamilies/Patient_Services/Spiritual_Care

Head and Neck Cancer Rehabilitation Resources
http://hncrehab.ca/

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.uhn.ca/PrincessMargaret
Helpful Resources Throughout Your Journey

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.

Community Services

The following is a list of community resources that are provided at no cost (free) to people with cancer and their families. The services range from support groups, education programs, exercise and wellness classes and many other supports. Check for the Wellspring and Gilda’s Club pamphlets in the Patient and Family Library.

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

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.
Sexuality, Intimacy, and Sexual Health

Sexual health is associated to overall feelings of well-being. Intimacy is the affection that people show one another and can be expressed in many ways.

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. It helps to talk to your current or future partner about the changes you have noticed in your sex life. For example, kissing for a long time may be less pleasurable now that your mouth gets dry faster. Ask your partner about taking breaks so you can drink water. You may also want to use a water based gel inside your mouth to reduce the dryness?

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)

*Drug Coverage Program for Patients with Cancer* (UHN D-5449)

Drug Coverage 101
http://bit.ly/21ALr4z

*Sex and Intimacy class*
ELLICSR - Health, Wellness & Cancer Survivorship Centre, TGH Basement, BPMB-130
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.

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 most helpful to you at this time,

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.

“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.
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.uhn.ca/PrincessMargaret

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)

- **The Princess Margaret Cancer Centre Journey App**

Download the app by searching for “Princess Margaret Cancer Journey” (PM Cancer Journey) in the Google Play or Apple App Store.
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.

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

Many patients will be admitted to 18B (or 17A/B) for their chemotherapy. Patients having weekly chemotherapy or specific types of treatments may go to the Systemic Therapy Day Unit on the 4th floor. To learn more about chemotherapy and what to expect, refer to:

- *Chemotherapy and Other Drugs Therapies booklet* (Canadian Cancer Society 301-467)
- *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 when getting your chemotherapy in the Systemic Therapy Unit on the 4th Floor.* [http://bit.ly/1ru8gKk](http://bit.ly/1ru8gKk)

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

CT Simulation and Mask Fitting

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

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.

“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.
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 > Resources > “Radiation Swallowing Exercises”

Support and services that may be helpful at this time

Pamphlets

- Coping with Cancer: Income Assistance (UHN D-3392)
- 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
You are now receiving cancer treatment. During this stage, you are most likely coming into the Princess Margaret every week day (Monday to Friday) 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).

The RNC is open Monday to Friday from 8:00am to 6:00pm. The last patient will be seen at 5:30 pm.

Getting Treatment (4-7 weeks)

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.

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 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)

Pamphlets

- **Managing the Side Effects of Chemotherapy** (UHN D-5805)
- **My Cancer Journey binder “During Treatment” section** (pages 52-64)
- **Taking Care of Your Skin During Radiation Treatment** (UHN D-5948)
- **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 *Taking Care of Your Mouth During Cancer Treatment* pamphlet for more information and mouth rinse recipes (UHN D-5653)

You can receive the best results from treatment if you:

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

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. You can also ask the staff at the 1B or 2B Reception Desk to book you into the Dietitian’s clinic. The clinic is held mornings and afternoons, Monday through Thursday.

Read: *Increasing 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 (Swelling, called lymphadema, 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 extension 5420

Remember to continue doing your:

- Swallowing exercises
- Mouth opening exercise
- Fluoride treatment
Resources that may be helpful at this time

**Classes**

- **Getting Back on Track: Life After Treatment for Head & Neck Cancer** (both parts are held at Princess Margaret 16th floor, room 728, 1:00–3:00 pm)
  
  **Part 1: Medical follow-up and emotional well-being**  
  (2nd Monday of every month)
  
  **Part 2: Nutrition & Swallowing** (3rd Monday of every month)

You will be booked into these classes about 2 months after completing treatment. This is part of your follow up care. If you need 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).

- **Reclaim Your Energy** (learn to manage your cancer-related fatigue)

- **WE-CAN Exercise Program**

**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 - Prevent and Reduce Stiffness Caused by Radiation Treatment for Patients with Head & Neck Cancer** (UHN D-8546)

“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

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

<table>
<thead>
<tr>
<th>Time after finishing treatment</th>
<th>How many follow-ups and how often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within the 1st year</td>
<td>Every 2–3 months</td>
</tr>
<tr>
<td>Within the 2nd year</td>
<td>Every 3–4 months</td>
</tr>
<tr>
<td>Within the 3rd to 4th years</td>
<td>Every 6 months</td>
</tr>
<tr>
<td>Within the 5th year &amp; beyond</td>
<td>Once a year*</td>
</tr>
</tbody>
</table>

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

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)
- Physiatrist (Rehabilitation doctor) - you need a referral from your oncologist.
- Return to Work or School - (knowing your rights and how to plan your return to work or school)

Community Services and Resources

- Wellspring — Cancer Exercise Program, Return to Work Program, Back at Work Program
  Tel: 1-877-499-9904 (toll free)  www.wellspring.ca
- Head and Neck Cancer Rehabilitation Resources
  http://hncrehab.ca/
- Exercise Programs - There is a list of other exercise programs catered toward cancer survivors on the UHN website:
  UHN Physiotherapy Programs  http://bit.ly/1TMtyMT
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 problems
- 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 and nurses 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 Do 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 for Preventing Constipation (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)
- G-Tube Feeding by Syringe (UHN D-5685)

**Imaging Information**
- Bone Scan (UHN D-3351)
- CT Scan (UHN D-3362)
- PET Scan and PET/CT Scan (UHN D-3347)

**Cancer-Related Fatigue**
- Reclaim Your Energy: Coping with Cancer Related Fatigue (UHN D-5622)
- Feeling Zapped? (UHN D-5559)
- Mental Fatigue and What You Can Do About It (UHN D-5561)

**Nutrition**
- Increasing Calories and Protein to Your Diet (UHN D-5510)
- Eating well when you have cancer (Canadian Cancer Society 313-220)
- Eating Tips for Sore Mouth and Throat (UHN D-5806)
- What to Do When You Don’t Feel Like Eating (UHN D-5311)

**Other Resources**
- Coping with Cancer: Income Assistance (UHN D-3392)
- Driving Services to Medical Appointments (UHN D-5166)
- Natural and Herbal Products (UHN D-5011)
- Getting Back on Track: Life After Treatment for Head and Neck Cancer (UHN D-5396)
- Head & 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)
- 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

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.

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

<table>
<thead>
<tr>
<th>Medical Oncologist</th>
<th>A doctor that treats cancer using different drugs such as chemotherapy.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radiation Oncologist</td>
<td>A doctor that treats cancer using radiation therapy (high-energy X-rays).</td>
</tr>
<tr>
<td>Surgical Oncologist</td>
<td>A doctor who specializes in treating cancer with surgery.</td>
</tr>
<tr>
<td>Dentist</td>
<td>A doctor that provides dental work to prevent any problems or damage to your mouth and teeth both before and after your cancer treatment.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pharmacist</th>
<th>Medication Reimbursement Specialist 416-946-4501 x5129</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td></td>
</tr>
</tbody>
</table>

| Nurse Practitioner (NP) | 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. |

<table>
<thead>
<tr>
<th>Clinical Nurse Specialist (CNS)</th>
<th>416-946-4501 x5420</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td></td>
</tr>
</tbody>
</table>
My Healthcare Team at Princess Margaret

Patient Care Coordinator (PCC)

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 assess your needs, provide care, educate and support you throughout your treatment and recovery.

Radiation Therapist

A healthcare 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

An audiologist assesses and treats disorders related to hearing and balance.

Registered Dietitian

Ask your health care team to connect you to the dietitian or how you can contact the dietitian yourself. You do not need a referral.

Spiritual Care Counsellor

Phone: 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.

Social Worker (SW)

Phone: 416-946-4501 x4525

The SW can help with resources related to practical needs (transportation services, financial resources) but can also provide counseling and emotional support to you and/or your family.
My Healthcare Team at Princess Margaret

Speech Language Pathologist (SLP)
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.

Physiotherapist
A rehabilitation specialist who can help you safely start or modify a general exercise program, show you stretches to reduce tightness after radiation or surgery, and assist with regaining your overall mobility.

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.

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

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 specialty training program (residency) and is gaining additional expertise.
Caregiver and Family Resources

Internet Resources

Family Caregiver:

Canadian Virtual Hospice
www.virtualhospice.ca

Cancer.net
www.cancer.net/coping/caregiving

Canadian Cancer Society:
If You’re a Caregiver http://bit.ly/1yLk3Vg

Strength for Caring: www.strengthforcaring.com

• A place for teens touched by cancer to connect:
  Group Loop www.grouploop.org

Video

• Parenting Through Cancer (UHN GK775 A53 2008)

Pamphlets

• Managing Caregiver Stress (UHN D5031)
• When a Parent Has Cancer (UHN D5580)
• Activities to Help Children Cope When a Family Member has Cancer (UHN D5074)
• When someone you know has cancer (Canadian Cancer Society 301–464)

Community Services
(refer to pages 9-10 for more)

Family Services Toronto: 416-595-9618
Hospice Toronto: 416-364-1666

• If you are 18 years or younger and in a caregiving role
  Young Carers Program ycptoronto.weebly.com

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 the actual voices of the patients and survivors living with head and neck cancer documented during research conducted by Maurene McQuestion, Clinical Nurse Specialist, about patients’ experiences of receiving radiation treatment for head and neck cancer.

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 the 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.
This booklet has been made possible through an educational grant by Takeda Canada Inc. and Nestlé Health Science.


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

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

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