# My Surgery Map:

# A Resource & Navigation Guide Book

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#### Special thanks to:

The patients and families living with head & neck cancers

Head & Neck Cancer site group, Princess Margaret Cancer Centre

ELLICSR: Health, Wellness and Cancer Survivorship Program

Collaborative Academic Practice, Innovation &

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Registered Nurses' Association of Ontario -

Advanced Clinical Practice Fellowship Program

Head & Neck and Plastics In-Patient Unit, 6B Munk, TGH

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"Some days there won't be a song in your heart. Sing anyway."

- Emory Austin

You are receiving this booklet since you are having surgery. If your treatment also includes radiation or chemotherapy, you will receive another booklet at the time of that treatment.

My Surgery 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 Cancer Centre, 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

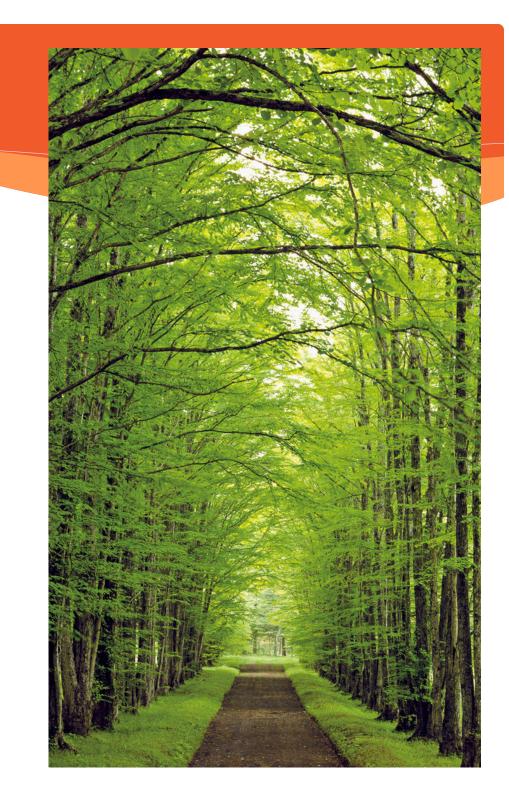
During your cancer journey, you may need different types of resources to help you make informed choices about your treatment and care, and to give you support. Your healthcare team is here to help you and your family, answer any questions you may have, and connect you with the right programs and services.

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 44).

The Helpful Resources Throughout Your Journey section lists resources that can be helpful at any time throughout your cancer journey (page 10).

The Surgery Binder is a general binder given to all patients having surgery. This booklet is not meant to replace the binder but to provide you with more specific information related to your cancer care and cancer related resources.



# Types of Resources You Will Find in This Guide



You can find the videos at:

- Patient & Family Library, Princess Margaret (main floor)
- Patient & Family Library, Toronto General Hospital (1R)
- On the internet at the websites indicated



### **Pamphlets**

You can find the pamphlets at:

- Patient & Family Library, Princess Margaret (main floor)
- Patient & Family Library, Toronto General Hospital (1R)
- Wharton Head & Neck Centre (2<sup>nd</sup> floor of Princess Margaret)



### Classes

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

- Patient & Family Library, Princess Margaret (main floor)
- Patient & Family Library, Toronto General Hospital (1R)
- Visit www.uhn.ca/PrincessMargaret 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



#### **Patient & Family Library**

Princess Margaret, Main Floor Toronto General Hospital, First Floor, Munk Wing 416-946-4501 ext. 5383 416-340-4800 ext. 5951

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 for a health information search.

#### Adolescent & Young Adult (AYA) Program

www.awacancercanada.com www.youngadultcancer.ca E-mail: aya@uhn.ca

The Adolescent and Young Adult Program addresses the unique needs of young people (39 and under) with cancer, beyond the medical aspects of care through personalized care plans and supportive counselling.

#### **Palliative Care Program**

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

The palliative care team can help you with symptom management 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.

#### **Spiritual Care**

Princess Margaret, Main floor Rm 517 416-946-4460 Toronto General Hospital, Centre for Spiritual Care 1st floor NUW Toronto General Hospital, Muslim Prayer Room, 1GW-557

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.

#### ELLICSR: Health, Wellness & Cancer Survivorship Centre

Toronto General Hospital, Munk Building, Basement Level PMB, 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.

# Helpful Resources Throughout Your Journey



#### **Princess Margaret Cancer Centre**

www.theprincessmargaret.ca

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

www.spohnc.org

#### Webwhisperers

www.webwhispers.org

Support for people with larynx cancer and other throat cancers who have laryngectomy surgery.

#### **Oral Cancer Foundation**

www.oralcancerfoundation.org

Provides information and support for people with oral cancer.

#### International Association of Laryngectomees (IAL)

www.theial.com

#### **About Face Canada**

www.aboutface.ca

1-800-665-3223

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

#### **Canadian Cancer Society**

www.cancer.ca

**National (American) Cancer Institute** 

www.cancer.gov

# Helpful Resources Throughout Your Journey



### 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.uhn.ca/PrincessMargaret

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



### **Community Support Groups**

#### Smoker's Helpline

www.smokershelpline.ca

#### Centre for addiction and Mental Health (CAMH)

 Smoking Cessation Programs - Ask for a referral from your health care team

Tel: 1-877-513-5333

#### **Alcoholics Anonymous**

www.aa.org (various locations throughout Ontario)



### **Pamphlets**

It's Never too Late to Quit (UHN D-5744)

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 211-083)

One Step at a Time: Help a Smoker Quit (CCS 211-997)

Smoking Cessation Programs Across Ontario (UHN D-5390)

# Helpful Resources Throughout Your Journey



### **Community Support Groups**

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.

#### Wellspring (8 locations in Ontario)

www.wellspring.ca

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

Wellspring is a network of community-based support centres offering programs and services that meet the emotional, social, practical and restorative needs of people living with cancer and those who care for them. Wellspring programs are offered free of charge.

Find out the closest location to you!

Head and Neck Specific Groups at Wellspring:

- Laryngectomy Support Group
- Men's Group (for men with head and neck cancer and male caregivers)

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

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.

#### Gilda's Club (2 locations in Ontario)

www.gildasclubtoronto.org

Offers activities for adults, children and families. It provides support groups, healthy lifestyle workshops, informative lectures and fun social events. Support groups include wellness groups, living with cancer and networking groups. Programs are free.

Downtown Toronto Barrie

Tel: 416-214-9898 Tel: 705-726-5199

gildasclubsimcoemuskoka.org

#### Wellwood (2 locations in Hamilton)

www.wellwood.on.ca

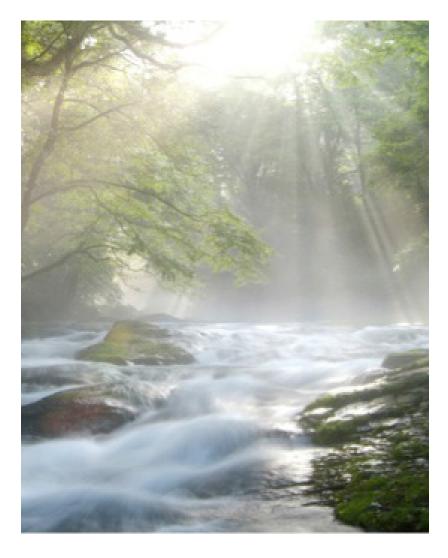
Juravinski Hospital Site Community Site

Tel: 905-389-5884 Tel: 905-667-8870

HopeSpring (Kitchener) Hearth Place (Oshawa)

Tel: 519-742-4673 Tel: 905-579-4833 www.hopespring.ca www.hearthplace.org

# 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 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
- Sexuality and Head & Neck Cancer Resource List



About Face www.aboutface.ca

1-800-665-3223



Wellspring

Gilda's Club

## **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 Surgery 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:

- page 10 for resources that may be of most help at this time
- page 10-19 for resources that you can use at any time throughout your cancer journey

During your appointments, do not hesitate to ask questions to your healthcare team.

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

## **Just Diagnosed**

#### Resources that may be helpful at this time

#### Did you get your "My Surgery" binder?



This guide book is meant to help you to:

- Understand your treatment
- Whatto expect before, during, and after your surgery
- Keep and organize your important contacts, medical records, notes, and more.

Visit the Princess Margaret, Wharton Head & Neck Centre (2<sup>nd</sup> floor) or Toronto General, Patient & Family Library (main floor) to get your copy.



You can access contents of "My Surgery" binder on the University Health Network website at:

www.uhn.ca

Home Page > Patients & Families > Surgery Patients > Online Surgery Binder

Ask about the surgery specific booklets along with My Surgery binder.

- Welcome to the Head & Neck Site Group Contact List
- Major Oral Surgery: Composite Resection with Free Flap
- Laryngectomy



### **Canadian Cancer Society pamphlets**

- Laryngeal Cancer: Understanding your diagnosis (Canadian Cancer Society 311-021)
- Oral Cancer: Understanding your diagnosis (Canadian Cancer Society 311-051)
- Thyroid Cancer: Understanding your diagnosis (Canadian Cancer Society 311-045)
- Questions to Ask about Cancer (Canadian Cancer Society 313-390)

The resources above can be found at:



 Patient & Family Libraries at Toronto General Hospital (main floor) or Princess Margaret (main floor), or



Canadian Cancer Society website www.cancer.ca

# Preparing & Planning for Your Cancer Surgery

During this time, your health care team will be working with you to prepare for your surgery. Feelings of anxiety and distress are common during this stage.

We realize that facing surgery is difficult for you, and that you need to organize a number of things in advance. We are planning that the surgery will take place at the schedule time and we want to assure you that your doctors and nurses at UHN will do everything that they can do to make sure that your surgery is performed at the scheduled time.

However, while we do our best to maintain the surgical schedule, sometimes things occur that are beyond our control, often at the last moment. For example, your surgery might be delayed or cancelled because another patient might require emergency surgery. We realize that this will cause you to be upset and inconvenienced, and we do apologize in advance should such a regrettable cancellation be necessary. Unfortunately, this situation is impossible to predict and if it does occur, we hope you will understand.

"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.

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 Patient & Family Library or those suggested here.



To learn more about oral surgery and what to expect, refer to:



*Major Oral Surgery: composite resection with free flap (UHN D-5313)* 

- This booklet can be useful for patients who are going through surgery for oral surgery.
- This booklet may be able to answer some questions you may have before surgery.

We are creating new booklets for surgery specific patient education booklets. We may have something available for you, please ask your doctor or health care professional for a copy.

# Preparing & Planning for Your Cancer Surgery

#### 1–2 Weeks Before Surgery

Your Surgical Oncologist's secretary will book an appointment for you with the Pre-Admission Clinic at Toronto General Hospital. The visit may take 2–6 hours to complete.

#### **Pre-Admission Clinic**

Tel: 416-340-3331

The Pre-Admission Department is located at Toronto General Hospital, at 200 Elizabeth Street, Eaton South Wing, Ground floor, Room # 400.

We will check how physically fit you are for the upcoming procedure. We make every effort to book your pre-admission appointment 1–2 weeks before your surgery but we may need to ask you to come in earlier or later, depending on the case.



The appointment consists of blood work, electrocardiogram (ECG), and chest x-ray.

You will also meet with the preadmission nurse who goes over information about the surgery. You may meet other members from the healthcare team at this appointment.

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



#### Readings

- Section C'Before and During My Surgery' in My Surgery binder, pages 16–32.
- Coping with Cancer: Income Assistance (UHN D-3392)
- Coping with Head & Neck Cancer (UHN D-5341)(for more support and services for Head and Neck patients)
- Drug Coverage Programs Available to Cancer Patients (UHN D-5449)
- Driving Services to Medical Appointments (UHN D-5166)
- Advanced Care Planning (Speak Up) www.advancedcareplanning.ca



### **Hospital Resources**

- Princess Margaret Lodge (for patients from out of town

   ask your surgical oncologist, nurse, or social worker)
- A tour of the inpatient unit may be an option if your are interested

# Preparing & Planning for Your Cancer Surgery



#### Your surgery has been booked.

We want to make sure you follow certain instructions so we can ensure you will have surgery on the planned date and time. Your surgery may be delayed or cancelled if you do not follow the instructions.

- ☐ Ask your surgical oncologist about using aspirin or other blood thinners before your surgery if you have not been given instructions to stop taking them.
- ☐ Stop using herbal remedies or homeopathic medications 7 days before your surgery.
- ☐ Take all your usual medications unless your doctor told you otherwise.
- ☐ Follow all special instructions explained to you during your pre-admission visit.
- ☐ Do not use any recreational drugs (such as 'pot' or 'crack') for 3 days before your surgery.

The Night Before
<ul> <li>Eat a light supper on the evening before your surgery.</li> <li>We suggest you do not eat fried foods.</li> </ul>
☐ Do NOT smoke for 24 hours before your surgery
Do NOT eat anything after midnight the night before your surgery. Do not chew or suck on candies either. Your stomach must be empty of any food when you go for your surgery.
You may have a sip of water or clear fluids up to 5 hours before your surgery. Then do not drink anything within 5 hours of your surgery.
Clear fluids are: water, apple juice, cranberry juice, clear broth, plain jello, clear soda such as ginger ale or 7-UP
Do NOT drink coffee, black coffee, tea, milk or milk products, orange juice, or alcohol.

 $If you \, have \, any \, questions \, or \, concerns \, you \, can \, contact$ 

the Clinical Nurse Coordinator at 416-340-4665

# Preparing & Planning for Your Cancer Surgery

#### The Morning of Your Surgery

Today is the day of your surgery. Feelings of being overwhelmed and anxiety are normal at this time. Your healthcare team have made all the arrangements and plans for your surgery.

#### Special instructions the morning of your surgery

- Take all your usual medications as advised unless your doctor told you otherwise. Follow all special instructions explained to you during your pre-admission visit.
- ☐ Bring your current medications to the hospital on the day of your surgery.

You may be staying in the hospital for few days. But try not to bring too much stuff with you. The key is to bring essential supplies only (such as your toiletries, a walking aid, comfortable shoes and extra socks).

#### **Surgical Admission Unit**

#### **Check-in at the Surgical Admission Unit**

- Arrive 2 hours before your scheduled surgery time.
- Make sure you bring the blue University Health Network card and your health card with you.
- The Surgical Admission Unit is on the 2<sup>nd</sup> floor of the Munk Building. You can get to the Surgical Admission Unit by using either the Munk elevators or the Eaton elevators.

## Day of Your Cancer Surgery

#### **Pre-operative Care Unit**

After you check-in at the Surgical Admission Unit, you will be taken to the Pre-Operative Care Unit (POCU).

We will prepare you for surgery at the POCU. We will give you an intravenous (IV). This is a small needle that we put in a vein in your arm. We use it to give one or all of the following:



- fluids
- antibiotics
- pain medication

After your healthcare team is ready to take you into surgery, you will be taken to the Operating Room.



## Where can your family/friends be during the whole process?

- Your family and friends can stay with you in the Pre-Operative Care Unit until you are transferred to the Operating Room.
- Once you are transferred to the Operating Room, they can wait for you at the Surgical Waiting Area on the 3<sup>rd</sup> floor of Toronto General Hospital. Family and friends are not allowed in the Operating Room or the Post-Anaesthetic Care Unit (PACU).
- Choose one person who can be in charge of communication with hospital staff and healthcare team. This person can pass on the information to your family and friends.

## **After Your Surgery**

#### Post-Anaesthetic Care Unit

After your surgery is finished, you will be taken to the Post-Anaesthetic Care Unit (PACU) or the Recovery Room. You will stay in this room until you are fully awake and stable to be transferred.





You will then be transferred to the Head & Neck and Plastics in-patient unit (Munk Building, 6B Munk, 416-340-3224).

Depending on the type of surgery you had or your condition of your health after surgery, you may be transferred to the Step Down Unit, the ICU or the 6B Munk Inpatient Unit.

The Step Down Unit is a special area within Head & Neck and Plastics in-patient unit (6B Munk). Here, we care for patients who need closer monitoring and attention. There is a nurse present with you at all times.

## **After Your Surgery**



### During your stay at or 6B Munk

6A - Consolidated Short Stay Unit (CSSU): Minor cases 1–3 day admissions

6B - ENT/Plastics/Head & Neck Surgical Units

You will meet many healthcare professionals while you are staying in the hospital. They will work together with you to meet your needs and plan your discharge for a smooth transition so you can return home or be transferred to another facility for ongoing care.

- Surgical Oncologist (surgeon)
- Patient Care Coordinator
- · Registered Nurse
- CCAC Care Coordinator
- · Register Dietitian
- Speech Language Pathologist
- Pharmacist
- Occupational Therapist
- Physiotherapist
- Volunteers





Laryngectomy: Instructions for patients going home (UHN D-5067)

Talk to a member of your healthcare team about surgery specific pamphlets!

Your nurse will go over the Discharge Checklist with you and talk about any resources that are available to you. Your nurse will also go through the checklist with you so you can go home safe and know what to do at home.

There may be some readings or pamphlets that you are interested in and want to take home. You can visit the Patient & Family Library for more information.

Your first follow-up appointment after surgery will be approximately 2 weeks after you leave the hospital.

You will be given an appointment reminder card. You need to phone your surgeon's office to book the appointment.

#### After You Go Home

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.

You may need home care (Community Care Access Centre - CCAC). It will be based on your specific needs.



For the first 2 weeks after discharge home after your surgery, contact;

- the Clinical Nurse Coordinator 416-340-4665, or
- your Surgical Oncologist's (surgeon) office

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 surgery, talk to a member from your healthcare team:

The Clinical Nurse Specialist (CNS) in the Head and Neck Cancer Program may also meet with you in the follow-up clinic at the Princess Margaret Cancer Centre to help you with the management of your symptoms, adjust to the changes following surgery and help you cope with your cancer and cancer treatment. You can contact the CNS at 416-946-4501, ext. 5420.

#### After You Go Home

#### Resources that may be helpful at this time



#### Healthcare professionals

- Speech Language Pathologist
- Registered Dietitian
- Pharmacist
- CCAC (Home Care)



#### Classes

- Cancer Exercise Program offered by Wellspring
- Lebed Healthy-Steps (10-week gentle group exercise program)
- Lymphedema Awareness (learn to lower the risk of getting swelling of lymphatic fluid)
- Reclaim Your Energy (learn to manage your cancerrelated fatigue)
- Men's Program at Wellspring



#### **Hospital Resources**

- Function and Mobility Clinic
- Neurocognitive Clinic (for memory, attention, concentration concerns due to cancer treatment)

#### Follow-up clinic appointments

You will have routine follow-up appointments with your Surgical Oncologist. This is to monitor how you are doing after your surgery.

This is a guideline of how many follow-ups and how often you will meet your oncologist after you go home. Please understand that you and your surgeon will come up with a schedule that best fits for you.

Time after finishing treatment	How many follow-ups and how often		
Within the 1st year	2–3 months		
Within the 2 <sup>nd</sup> year	Every 3-4 months		
Within the 3 <sup>rd</sup> to 4 <sup>th</sup> years	Every 6 months		
Within the 5 <sup>th</sup> year and beyond	Once a year  (At this time, your healthcare team may discuss with you about shifting your care to community.)		

#### After You Go Home

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

- Shoulder dysfunction stiffness, reduced movement or ability to lift your arm above your head
- Swallowing difficulties
- Trismus reduced mouth opening
- Fatigue
- Difficulty regaining lost weight
- Body image changes
- Facial numbness or tingling
- Facial swelling (lymphedema)



It is important to continue to:

- monitor and record any changes in your cancer health
- let your healthcare team know what side effects you are still experiencing and any difficulties you may have

Your doctor will talk to you about next steps. You may require further treatment such as radiation therapy and chemotherapy treatment. Discuss this with your surgical oncologist to see what the best plan is for you.

Follow up and make an appointment with your family doctor

Continue to look after your other health concerns (e.g. blood pressure monitoring) including screening (e.g. mammograms, prostate screening, colorectal screening)

## Pamphlets That Are Available

You can find the below resources either at the Patient & Family Library or the Wharton Head & Neck Centre

#### Surgery

- The Operating Room: A team approach to ensure your safety (UHN D-5133)
- Donating Your Own Blood for your Surgery (UHN D-3216)
- You are having surgery at Toronto General Hospital (UHN D-5248)
- Welcome to Toronto General Hospital (UHN D-5199)
- Wound Care (UHN D-2105)
- Exercises after your surgery
   (UHN D-5200) \*available in various languages
- Eating Before your surgery in Toronto General Hospital (UHN D-5306)
- Bowel Routine while Taking Pain Medications (UHN D-5906)

#### **Laryngectomy Information**

 Laryngectomy: Instructions for patients going home (UHN D-5067)

#### **Imaging Information**

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

#### **Nutrition**

- Adding Calories and Protein to Your Diet (UHN D-5510)
- Sore Mouth and Throat (UHN D-5806)
- What to Eat When You Don't Feel Like Eating (UHN D-5311)

contined on next page...

## Pamphlets That Are Available

#### **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)

#### **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 Appointments (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 and Support Resources (UHN)
- 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 Programs Across Ontario (UHN D-5390)
- The Trillium Drug Coverage Program: Fact Sheet (UHN D-5366)

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

You can contact the librarian or information specialist in the Patient & Family Library and he/she can mail a package of information to you.

# My Healthcare Team at University Health Network



There are many health care 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 health care professionals who you may meet during your cancer journey.

#### **Surgical Oncologist**

A doctor who specializes in treating cancer with surgery.

#### **Medical Oncologist**

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

#### **Radiation Oncologist**

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

#### **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.

#### **Audiologist**

A specialist in hearing testing

#### Otolaryngologist

A doctor who specializes in non cancer related ear diseases.

#### **Clinical Nurse Coordinator**

416-340-4665

A Registered Nurse who coordinates your preoperative services to ensure a seamless transition of care between home and hospital.

# My Healthcare Team at University Health Network

#### Patient Care Coordinator, Head & Neck and Plastics

A Registered Nurse in charge of the inpatient surgical unit.

#### **Clinical Nurse Specialist**

416-946-4501 extension 5420

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 with your diagnosis, treatment and recovery.

#### **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.

#### Social Worker

A healthcare team member who cam address your practical and emotional experience of cancer, and on helping you to find other resources you may need.

#### **Registered Dietitian**

An expert on diet and nutrition. He or she can help you eat well during and after your treatment.

#### **Speech Language Pathologist**

A healthcare member who is specially trained to help you manage any communication and swallowing problems that may be due to your diagnosis or treatment.

#### **Pharmacist**

An expert in safe and effective mediation use. They advise you on the proper use and side effects of your prescription and over-the-counter drugs.

#### Physiotherapist (PT)

Physiotherapists are rehabilitation specialists who help maximize your mobility and physical function.

# My Healthcare Team at University Health Network



#### Community Care Access Centre (Home Care) Coordinator

CCAC staff members can connect you with the care you need to stay at home and in your community.

#### **Spiritual Care Counsellor**

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.

#### **Hospital Volunteers**

University Health Network is a teaching hospital. During your treatment, you may also meet numerous medical students, residents, and fellows.

#### **Medical student**

Student in a graduate-level medical program

#### 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 special training program (residency) and is in medical training for a subspeciality.

## Caregiver and Family Resources



#### **Caregiver Connect**

www.caregiver-connect.ca

#### Cancer.net

www.cancer.net/coping/caregiving

#### **Canadian Cancer Society**

Helping Someone with Cancer

www.cancer.ca

If You're a Caregiver

www.cancer.ca

#### **Group Loop**

www.grouploop.org

A place for teens touched by cancer to connect.

#### **Strength for Caring**

www.strengthforcaring.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.



#### **Community Support Groups**

Refer to pages 9-10 for more.

#### **Family Services Toronto**

416-595-9618

#### **Hospice Toronto**

416-364-1666

Young Carers Program (if you are 18 years or younger and in a caregiving role): ycptoronto.weebly.com



#### Video

• Parenting Through Cancer (UHN GK775 A53 2008)

## Caregiver and Family Resources



#### **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)
- When someone you know has cancer (Canadian Cancer Society 301-464)
- You and Me: Activities for Parents & Children When a Parent Has Cancer (UHN D5074)

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

www.hospicetoronto.ca/PDF/Hospice\_Toronto\_ Caregiver\_Resource\_List.pdf



# 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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## For patients with Head & Neck Cancer who are going through surgical treatment.

