What to Expect While Receiving Radiation Therapy for Head and Neck Cancer

Information for patients who are having radiation therapy

Read this pamphlet to learn about:

• The main steps in planning radiation treatment
• How to manage common side effects
• What happens when you finish treatment
• Where to get more information

For more information on Radiation Therapy, please watch our patient education videos at www.whattoexpectrt.theprincessmargaret.ca. These videos offer a step-by-step guide to the radiation therapy treatment process. They also explain how radiation works in the body and how your team works together to deliver the highest quality treatments.
Your radiation therapy team consists of:

- your radiation oncologist (cancer doctor)
- radiation oncology nurses
- radiation therapists
- other health care team members

They will provide you and your family with care, support and information.

If you have any questions, talk to your radiation therapists at your daily treatment appointment. You can also talk to your radiation oncologist or nurse at your weekly review appointment.

Interpretation is available if you speak very little or no English. Please let us know as soon as possible that you need help with interpretation.

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**Your radiation therapy planning**

To plan for your radiation therapy treatment, you will need a CT simulation scan appointment. The CT simulation scan gives us the detailed x-ray images that are used to develop your treatment plan.

At this appointment you will have:

- your treatment mask made
- your planning CT scan with your treatment mask on

You may also need:

- a MRI
- an IV contrast with your scan

An IV contrast is a dye that is injected into the vein in your arm. This helps us see the vessels in your neck.
Once your treatment plan is ready, you will start your treatment.

On the day of your CT simulation scan appointment, go to level 1B (one floor below the main floor) of the Princess Margaret Cancer Centre. Check in at the reception desk.

At that time we will take your picture and save it in your file. That way we know who you are when you come for treatment. When you are done, have a seat in the waiting room. Your radiation therapist will come and meet you in the waiting room.

You can expect to be here for about 1 hour for this appointment

What to expect at your CT simulation scan appointment

- Your radiation therapists will explain what will happen during the appointment. Ask any questions you may have.
- If you need to have an IV contrast during your CT simulation scan, you will get a consent form to complete. Read the form carefully and ask any questions you may have. If you have an allergy to contrast dye, tell your radiation therapists and radiation oncologist right away.
- Your customized treatment mask will be made, along with any other devices that you need for treatment. The treatment mask moulds around your head and neck area. It helps us place you into the same position for treatment each time. You will wear it during your CT simulation scan and during your treatment.
- You will have your CT simulation scan with your mask on and any other devices you need. If you are having an IV contrast, your radiation therapists will start the IV contrast during your CT scan. Your therapists may also give you instructions to follow for your CT scan.
- After your CT scan, your therapists will give you your green appointment card and radiation therapy pamphlets. If you’ve had an IV contrast with your CT scan, you will also get an IV contrast information card.
- If you are to have a MRI, ask your therapists where you need to wait for your MRI.
Your doctor, physicist and radiation therapist will use the information to plan your treatment.

## Your radiation therapy treatment

### When do I get my first radiation therapy appointment?

You get your first radiation therapy appointment at the time of the CT simulation scan. Or you will get a phone call a few days after your CT simulation scan with the date, time and place of your appointment.

### Where do I go for my radiation therapy?

You get your radiation therapy on level 2B (2 levels below the main floor) of the Princess Margaret Cancer Centre. Check in at the reception desk on level 2B when you arrive. The staff there can show you how to check in.

### Can I choose when I have my radiation therapy appointments?

A large number of patients are treated every day. Because of this, we may not be able to give you the times that you ask for. Your radiation therapists will try to help you if you have special reasons for needing an exact time.

### What to expect at your radiation therapy appointment

Your radiation therapists will bring you into the treatment unit and position you on the treatment table in your treatment mask. They will check the measurements from your treatment plan. They will take a Cone Beam CT scan (sometimes called a “mini CT”) to check that you are in the same position every day.
This process takes a few minutes and once your position has been checked and any changes have been made, you will have your radiation treatment. During treatment the radiation machine slowly will rotate around you on the treatment table.

**How long is the course of treatment?**

A course of radiation therapy treatment for head and neck cancer may last from 4 to 7 weeks. Most patients get a single treatment each day but some will get 2 treatments a day. Your radiation oncologist will discuss with you the recommended schedule to best manage your cancer.

**How long is the appointment?**

You should plan to be at the hospital for 30 to 60 minutes each day you have your radiation therapy treatment. The treatment takes about 20 minutes. Most of this time is used to make sure you are in the right position for treatment.

**Will I see the oncologist (cancer doctor) during my radiation therapy appointment?**

You meet with your radiation oncologist and nurse once a week during your course of radiation therapy. They can answer your questions and talk to you about any concerns that you may have. Tell them about any side effects you have.

At your treatment appointment, you can also talk about your side effects with your radiation therapists. If you need help managing your side effects, we may send you to the Radiation Nursing Clinic (RNC). At the RNC, you will see our Radiation Nursing Team.
How to manage common side effects from radiation therapy

Some common side effects are listed below. However you may also have other side effects. Tell your radiation oncologist, radiation therapists, oncology (cancer) nurse what side effects you have.

Skin changes
You may have changes to your skin in the treatment area. This is a normal side effect and will get better.

- After 2 to 3 weeks of treatment, your skin may feel irritated: warm, red, swollen, dry and tight, itchy
- In later weeks, areas of your skin may have dry, flaky patches.
- Near the end of your treatment, areas of your skin may be open and moist.
- The skin in the area being treated will begin to heal about 2 to 3 weeks after finishing your radiation treatments. It should heal within 1 to 2 months.

To learn how to care for your skin, see the pamphlet “Taking Care of Your Skin During Radiation Therapy”

Changes to nose lining and skin on lips
The lining inside your nose and the skin on your lips are very thin and sensitive. If your treatment includes these areas, you may need to care for them a bit differently than other areas of your skin. The tips below are only if your lips or nose are being treated directly with radiation.
Do these things if your lips or nose are irritated:

- Use a sterile (germ-free) water-based lubricating gel such as E-Z Lubricating Jelly or Surgilube. You can buy them at a pharmacy. Don’t use a moisturizing cream.
- Use a clean cotton swab to gently apply the gel.
- Try saline soaks to help soothe and clean these areas. It may be harder to apply than to other areas of the body.
- Use a clean squirt bottle to gently put saline inside the nose. Do this over a sink. Tilt your head forward to let the saline run into the sink.
- Try products such as Nasa Mist or a Neti Pot if you find a squirt bottle too hard to use. Your treatment team can help you find what works best for you.
- **Do not try to force saline past any blockages you have.**

**Hair loss**

Hair loss from your radiation treatment only happens in areas affected by the radiation. For example, you may lose some facial hair or some hair on the scalp if is in the treatment area. You may also lose hair in both areas. In most cases this hair will grow again within 6 months of finishing treatment. In some cases the hair may stay thin or not grow again.

If your scalp is irritated, wash with a gentle, unscented shampoo (such as baby shampoo). Read the pamphlet “Taking Care of Your Skin During Radiation Therapy”. This pamphlet will help you take care of these areas. It also includes advice about shaving.

**Dry mouth**

If your saliva glands are in the treatment area, radiation can cause you to have less saliva and thicker saliva. These changes usually begin during the first and second week of treatment and continue throughout treatment. Your mouth may become dry and sticky, making it harder to swallow.
Talk with your doctor about what might help. Try the mouth rinses without medicine on pages 11 and 12 to clean and remove thick saliva.

How much dryness you have and how long this lasts will depend on your radiation treatment plan. In some cases your saliva slowly improves after treatment but some dryness may be permanent.

**Taste changes**
If your tongue or saliva glands are in the treatment area, your sense of taste may change. You may find that food tastes different or you may lose your sense of taste.

These changes can begin in the first and second week of treatment and continue throughout treatment. Changes in taste usually improve 6 to 12 months after radiation treatment is done. Some changes may be permanent.

**Sore throat and trouble swallowing**
Your mouth and throat may become dry, irritated or swollen during treatment. This may include areas on your:
- tongue
- floor or roof of your mouth
- inside of your cheeks
- areas around your gums
- your lips

The exact area depends on where you get your radiation treatment. If you notice any signs or symptoms of a swallowing problem, it is important that you share this with your doctor or a member of your health care team.

These changes usually begin in the first or second week of treatment and continue throughout treatment. How much and how long they last depends on your radiation treatment plan.

Healing inside your mouth may take a few months after your last radiation treatment. Your health care team can help explain what to expect.
**Hoarse voice (raspy or strained) or losing your voice**
If your throat and voice box are in the treatment area, you may get dryness and swelling in the area. This may affect your voice. These changes can begin in the first or second week of treatment and continue throughout treatment. These changes usually improve 1 to 3 months after treatment.

If your voice box is being treated with radiation, you may lose your voice for a period of time. This is because of swelling in the voice box.

**What if I have trouble eating and drinking?**
Dryness, swelling and pain in your throat and voice box can make it hard to drink and eat. Many patients have to change what they eat and drink and use:

- pain medicines
- mouth rinses with medicine (medicated)
- mouth rinses without medicine (see the list of mouth rinses without medicine on pages 11 and 12)

These temporarily help with eating and drinking during this difficult time.

In some cases, you may need intravenous (IV) fluids. These are fluids that are put directly in your veins. You will need IV if you become dehydrated (your body loses too much water).

Sometimes a feeding tube may be needed. Your radiation oncologist may recommend a feeding tube at the start of treatment. If this is the case for you, your radiation oncologist and nurse will talk to you about it.
Here are some general care tips to start.

**Do these things if you have changes in your mouth:**

- Keep caring for your mouth with:
  - a recommended mouth rinse (without medicine) on pages 11 and 12.
    (Do not use regular mouthwash. It may irritate your mouth and throat.)
  - gentle cleaning
  - instructions you get from our dental team

- Our dental team may recommend that you use oral fluoride trays every day. This is very important for the long term prevention of tooth decay. If you find these fluoride trays uncomfortable to use while you are on treatment, talk to your radiation oncologist.

- Sip water or use a spray bottle to keep your mouth and throat moist.

- Use pain medicine you get from your doctor that makes it easier to eat. For example, Mucositis Mouthwash (medicated) is often used 15 to 20 minutes before you eat or drink. This numbs the area and helps you swallow.

**Do these things if you have changes to your voice:**

- Use a recommended mouth rinse (without medicine) on pages 11 and 12.
- Rest your voice as much as possible.
- Keep the air moist in your home by using a cool mist humidifier. At night, place it close by your bed or put a bowl of water in your bedroom to keep the air moist.
Recommended mouth rinses (without medicine)

You can choose to gargle with any one of the mouth rinses below. All of these mouth rinses work well. They will help to soothe, clean and remove secretions from the mouth. Choose the one you find the most soothing and easy to use.

1. Flat Club Soda
   • Open any brand of store-bought Club Soda.
   • Leave it open until the soda is “flat” or no longer fizzes. The bubbles should be gone.

2. Baking soda and water
   • Dissolve 1 level teaspoon of baking soda in 2 cups (500 ml) water.
   • Stir until the baking soda is dissolved.

3. Salt and water
   • Dissolve 1 level teaspoon of salt in 2 cups (500 ml) of warm water.
   • Stir until the salt is dissolved.

4. Baking soda, salt and water
   • Dissolve ½ level teaspoon of baking soda and ½ level teaspoon of salt in 2 cups (500 ml) of warm water.
   • Stir until the baking soda and salt are dissolved.

How to store and use mouth rinse (without medicine):

• Allow the solution to cool to room temperature before you use it.
• Store the mouth rinse in a clean, covered container. Store at room temperature.
• Always make a new batch of mouth rinse every 24 hours. Old mouth rinse is less helpful and may contain germs.
• Rinse and gargle (but do not swallow) and spit out to soothe your mouth and clear out thick saliva.
• Do not swallow any of the mouth rinses except for the flat club soda. You can swallow a small amount of the flat club soda to clear the back of your throat.
• Use as often as possible (every hour if you can), especially before and after meals.
## Do these things to eat well during treatment:

- Use the Swallowing Exercise instructions (see pamphlet or video).
- Eat your normal food. Switch to softer foods if eating becomes hard.
- Try different foods if you have taste changes. Some may taste better than others.
- Eat 5 or 6 small meals each day instead of 3 large meals.
- Stock up on foods that are easy to make and easy to eat.
- Carry a snack with you when you come for treatment. If your treatment appointment is delayed, you will be able to eat.
- Get some light exercise and fresh air. These may help your appetite.
- If eating hot or cold food irritates your mouth or throat, try them at room temperature.
- Use gravy, sauces and cream soups to make food moist. This will make it easier to eat.
- Take your pain medicine and use your medicated mouth rinses your doctor has prescribed (ordered). These will make it easier for you to eat.
- Use meal supplements (such as Ensure or Boost) if you are having trouble eating solid food.
- If you have a feeding tube, use it to get the right amount of water and food. Follow the instructions your doctor and dietitian gave you.
- Ask a member of your health care team for a referral to a dietitian if you need more suggestions

## Do these things if your mouth and throat are irritated:

Avoid alcohol and smoking.

Be careful with foods that may irritate your mouth and throat such as:

- very spiced (hot) foods
- highly acidic foods (such as oranges, tomatoes)
- foods with a rough texture foods (such as chips, nuts, raw vegetables, toast)
**Do these things to drink well during treatment:**

- Use the Swallowing Exercise instructions (see pamphlet or video).
- You could get your fluids in many ways, for example: water, juices, milk, soups, ice cream, popsicles, tea, fluid supplements (such as Ensure).
- Carry a bottle of fluid with you all the time. Take small sips often.
- If you have a feeding tube, use it to get the right amount of fluid.
- Ask a member of your health care team for a referral to a dietitian if you need more suggestions.

**Will I get tired while on treatment?**

Fatigue (feeling very tired) is a common side effect of radiation therapy. The level of fatigue varies with each person. Fatigue often begins early in treatment. It can slowly increase during treatment. It usually gets better 1 to 2 months after treatment is done. Do your usual activities if you feel well enough to do so.

**Do these things if you are feeling fatigue:**

- Pace yourself. Break jobs down into smaller parts.
- Ask for help with activities you do every day that makes you tired or you find hard to do.
- Pick a relaxing activity. For example, walk or do a light physical activity or hobby. Pick something that you are able to do every day.
- Plan time to rest before and after activities.
- Keep a regular sleep routine.
- Rest during the day as needed.
- Get enough food and fluids. See the tips in this resource.
Will I get constipated?

You can get constipated (trouble having a bowel movement) from changes in what you eat. You can also get constipated from the side effects of some opioid pain medicine such as codeine and morphine. If you are taking opioid pain medicine, you may need to take another medicine at the same time to prevent constipation. This is called a “bowel routine”. It may include a stool softener (such as Colace) and laxatives (such as Senokot and Lactulose).

Your doctor and nurse case manager will help you manage your pain medicine and bowel routine medicines.

What if I am having trouble managing my side effects from treatment?

If you need help managing a side effect from treatment, you can talk to your radiation oncologist or nurse during your weekly review appointment. You can also talk to your radiation therapist at your treatment appointments and you can visit the Radiation Nursing Clinic (RNC) to manage your pain and symptoms. The clinic is on level 2B, behind the main reception.

The clinic is open Monday – Friday from 8:00 am to 5:30 pm. You will need to check in with the 2B main reception desk.

You do not need an appointment to be seen at the clinic.
What to expect when you finish radiation therapy

Near the end of your treatment, we will give you 2 booklets:

• “Questions to ask before you finish your radiation treatment”
• “Getting Back On Track: for head and neck patients who have completed or about to complete their cancer treatment”

You will be given a follow-up appointment to see your radiation oncologist at your final weekly review appointment. You will see your radiation oncologist a few weeks or months after your treatment is finished.

At your final weekly review appointment, ask your doctor or nurse about registering for the “Getting Back on Track” classes.

After treatment finishes, some of your side effects may carry on and get worse before they start to get better. This is normal. Continue to follow your health care team’s instructions until you feel better. Call the hospital once you are finished with your treatment, if you have any questions or concerns.

Where to get more information?

Princess Margaret Cancer Centre
Patient & Family Library on the main floor.
Phone: 416 946 4501 extension 5383
Email: patienteducation@uhn.ca

For information about treatment and services at the cancer centre.
Some other resources:

**Wellspring**
Phone: 416 961 1928 or toll free 1 877 499 9904

**The Canadian Cancer Society**
Phone: 416 488 5400 or call toll-free 1 800 268 8874

**Community Care Access Centre (CCAC)**
Phone: toll-free 310 2222 (310 CCAC) You do not need to dial an area code.

The development of patient education resources is supported by the Princess Margaret Cancer Foundation.