

Welcome to the Juravinski Cancer Centre

Pediatric Radiation Therapy Handbook



Thank you to our patients and families, staff and volunteers who provided comments and suggestions for this handbook.

Pediatric Radiation Therapy Working Group
Juravinski Cancer Centre
699 Concession Street
Hamilton, Ontario L8V 5C2
www.hamiltonhealthsciences.ca

Hearing that your child needs radiation as part of their cancer treatment can cause fear and uncertainty. There is a lot to learn when your child begins a new phase of cancer care.

This handbook is a guide for you during this stressful time. Here you will find information about what to expect when you come to the Juravinski Cancer Centre (JCC) for radiation therapy, and the health care team who will help your child through this journey.

The JCC and McMaster Children's Hospital are a part of the Hamilton Health Sciences' family of hospitals. We work together to provide pediatric services throughout the region. We are a world leader in education, research and cancer care. Our health care providers, staff and volunteers are the people you can turn to for information, treatment, care, and most importantly, hope.

We are here for you and your family and encourage you to take an active part in your child's care. As your child goes through treatments and appointments here at the JCC, be sure to ask any questions you may have along the way.

Please visit our website: www.hamiltonhealthsciences.ca for more information.

Pediatric Radiation Therapists
Juravinski Cancer Centre
Hamilton Health Sciences

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Parking



Many children receiving radiation treatments are coming from home. Parents may park in the:

Poplar Parking Garage – beside Juravinski Cancer Centre, enter from Poplar Avenue.



Concession Parking Garage – across from Juravinski Hospital, enter from Concession Street.

Please allow yourself plenty of time to park. For most, if not all of your child’s appointments, you will need to pay the daily maximum rate.

Daily Parking: Each 30 minutes or less costs \$3.75, with a daily maximum of \$20.00. There is no charge for the first 15 minutes of parking.

Long Term Rate Options	Details	Rate
	All passes include 24 hour in/out privileges	
5 Day Pass	Valid for 5 days within a 1 year period from the time of purchase	\$50
10 Day Pass	Valid for 10 days within a 1 year period from the time of purchase	\$100
14 Day Pass	Valid for <i>14 consecutive days</i> from the date of purchase (only available from Parking Office)	\$48.50
30 Day Pass	Valid for 30 days within a 1 year period from the time of purchase	\$250

**Prices are subject to change. Please contact the Parking Office for details.

Parking Office

Location: Concession Parking Garage, Level 1

Phone: 905-521-2100, ext. 42354

Email: parkingoffice@hhsc.ca

Hours: Monday - Friday, 8:00 AM – 4:00 PM, closed weekends/holidays

Website: www.hhsc.ca Click on Patients & Visitors, then Getting Here, then Parking & Directions.



Please speak to your social worker to determine if you are eligible for parking assistance.

Transportation

Service	Notice Required	Cost	Phone Number	Website
Wheels of Hope – Canadian Cancer Society Program	At least 3 business days	Annual registration fee. Compassionate program available for financial assistance.	1-800-263-6750	https://www.cancer.ca/en/support-and-services/support-services/transportation-on/?region=on
Cancer Assistance Program (CAP)	At least 3 business days. Must live in the Hamilton area.	No cost	905-383-9797 Ext. 106	cancerassist.ca
DARTS	At least 5 days	Call to confirm fee schedule	905-529-1717 ext.3847	hsr-bus-schedules-fares">www.hamilton.ca>hsr-bus-schedules-fares

Patient Transportation Service or Ambulance

Your child may need to come to their appointment in an ambulance or transport vehicle. In this case, your child will be taken directly to the treatment unit to wait for their appointment. Your child will be given priority for treatment so you may soon return to McMaster Children's Hospital (MCH).

Radiation Therapy

What is radiation therapy and how does it work?

Radiation therapy is the use of high energy x-rays for the treatment of cancer. It damages the ability of tumour cells to grow and multiply. Various types of cancer respond to radiation in different ways, so treatments vary with each child.

Radiation therapy is designed to damage the tumour cells, but allow normal cells to heal. Although the normal or healthy cells may be affected by the radiation therapy, these cells can repair themselves more easily than tumour cells. In addition, with careful treatment planning, the radiation treatment can be directed to the cancer while keeping it away from most normal tissues.

Your child will not become radioactive after receiving radiation therapy from a machine. There are no special precautions to take for dressing or for body waste (vomit, pee, poop). There is no danger to you or to those who come in contact with your child.

Before your child's treatment begins, you will be asked to sign a consent form for radiation therapy at the JCC. This form states that you have been informed of treatment and possible side effects that your child may get from receiving radiation therapy. Read the form carefully and ask the Doctor or Pediatric Radiation Therapist any questions you may have about treatment and possible side effects.

The Radiation Therapy Program includes:

- Radiation Treatment Planning
- Radiation Treatments
- Patient Review Clinic

Your Health Care Team

Who will give the radiation therapy?

While you are at the JCC many health care providers will be involved with your child's care, however your Pediatric Radiation Oncologist (cancer doctor) and Pediatric Radiation Therapist will coordinate your child's care during their appointments.

A team of health care providers will work together to give the radiation therapy to your child. The information that follows describes each team member and explains what they do in the treatment of your child.

Your child is the most important member of the team. We encourage you and your family to take part in their care. There is space on page 25 to write down the names of your health care team members.

The Pediatric Radiation Oncologist

This is a Doctor who is trained in the use of radiation for the treatment of cancer in children. The Doctor will work with all members of your child's health care team as they plan the treatment for your child. The Pediatric Radiation Oncologist is the person referred to as "your doctor" throughout this guide.

The Pediatric Radiation Therapist

The Pediatric Radiation Therapist is trained in all parts of your child's radiation planning, treatment and assessment. The Pediatric Radiation Therapist works closely with the your doctor as well as the team at McMaster Children's Hospital (MCH), and will see your child at least once a week. During these visits they may ask questions about your child's health history and will keep track of your child's progress during radiation therapy. You can reach your Pediatric Radiation Therapist by calling 905-870-4278.

The Treating Radiation Therapist

The Treating Radiation Therapists are the health professionals who deliver the treatment. Radiation Therapists are trained to understand the operation of the treatment machine, the treatment plan, and radiation side effects. Two Radiation Therapists will treat your child daily, and inform the Doctor or Pediatric Radiation Therapist if there is a concern.

Although you are not allowed to be in the room with your child during treatment, your child is with highly-trained staff who care about their emotional and physical needs. During treatment, the radiation therapists leave the room, but constantly watch your child on a screen and listen by two-way intercom. The radiation can be stopped at any time to allow staff to enter the room and will switch off once the treatment is finished.

Mould Room Radiation Therapist

The Mould Room Radiation Therapist is the therapist who helps determine the equipment needed to keep your child still during treatment. Mould Room Therapists and Technicians have the training and experience to construct devices quickly and safely for your child.

McMaster Children's Hospital (MCH)

Your child's primary team at MCH consists of Pediatric Oncologists, Surgeons, Nurse Practitioners, Nurses, Certified Child Life Specialists, Social Workers, Dietitians, Radiologists, Pathologists, and numerous other departments and services.

Your primary team will work closely with you and your child to plan the care and services that will meet your child's needs.

All chemotherapy, surgery, medication and psychosocial issues will be addressed through your primary team at MCH.

What will happen on your first visit to JCC?

Checking in

Radiation treatment machines and services related to the Radiation Therapy Program are located one floor below the main entrance. When you arrive at the JCC please go to the reception desk located in the Lobby on Level 0.

At the desk, the clerk will ask you for your child's health card and confirm your information. After checking in, please make yourself comfortable in The Pod, our children's waiting area located directly behind the reception desk.

The Pod

Health outcomes improve when children begin treatments in a relaxed and positive mental state that is encouraged by play. The Pod provides families with a separate area that is welcoming, safe, and entertaining for children. The Pod has children's furniture in a bright and colourful setting, in addition to wider chairs for parents who want to hold their child.



Play and positive distractions are powerful ways for children and youth to cope. A variety of toys, games, and activities has been chosen for all ages. Families are welcome to bring in their own selection of favourite DVDs and games. The Pod houses our remote controlled vehicles which can be used to transport children to treatment.

We encourage parents to use The Pod as playing can help your child cope with treatment and allow you to focus on the questions you want to ask during your child's appointment.



Your child's first clinic appointment

The first appointment could be quite long, so allow yourself a few hours. Before your child begins radiation therapy, the Doctor will talk to you about your child's treatment. This visit will include:

- a discussion of goals
- details and expected results of treatment
- the possible side effects from radiation
- your child's immobilization (your child needs to be still during treatment) and sedation needs.

You will be asked to sign a consent form before your child's treatment begins. You may need to visit several areas on this day, or be asked to return for the next steps in planning your child's treatment.

Sedation

Sometimes sedation is needed to keep younger children calm and comfortable throughout their treatment. The need for sedation is determined by your Doctor and Pediatric Radiation Therapist based on your child's age, medical history and experience with past medical procedures.



Our Radiation Oncology Department works closely with the sedation staff from MCH. The teams work together so both the radiation therapy and anesthesia are given safely and effectively.

All sedation appointments are early in the morning, as your child must have an empty stomach in order to be sedated safely. Although appointments may only take a short time, you should expect to stay for about 1 hour or more after treatment until your child is awake and can safely leave.

Positive distraction devices

The JCC is equipped to provide music during your child's planning and treatment appointments. If the treatment position allows for it, a DVD player can be brought close to the treatment bed. This serves as a distraction and helps us to lessen the use of devices to keep your child still and the need for sedation. Families are welcome to bring in their own selection of favourite DVDs and music.

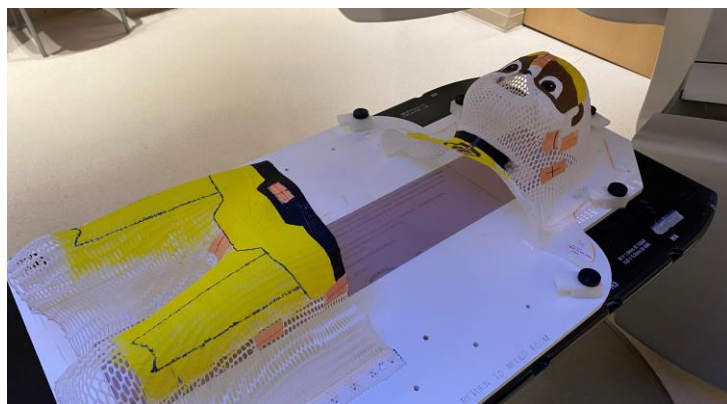
Treatment Planning

Mould Room

In order to prepare for your child's treatment, you may be taken to the Mould Room, where a device to keep them still for treatment will be made. This device is often called a cast, and is made of plastic. The cast can be painted in the character of your choosing. Your child's position for treatment and the type of equipment needed will depend on the area where the radiation will be directed. If your child does not need a cast or other body mould, your next step will be a Simulation appointment.



Mask/cast to keep the head/neck still during treatment.



Head/pelvic cast to keep the body still during treatment.

Simulation

A pre-treatment planning procedure called a Simulation will be done with your child. Radiation Therapists will perform a computerized tomography (CAT or CT) scan of the area to be treated. Simulation is done with your child in the treatment position so that your child will get an idea of what to expect during the actual treatments.

After the area for treatment is identified, coloured lines may be drawn on the cast or skin. Tiny points on the skin (the size of small freckles) may be tattooed to create a treatment position reference mark that is permanent. You may wash the area once you leave but the reference marks will remain.



CT Simulator

Treatment plan

A Planner or trained Radiation Therapist will then create a specific treatment plan for your child, under the direction of your Doctor and Medical Physicist.

Your child does not need to be present for this step, as it is all done on computers with the 3D information gathered from the CT scan. Treatment plans can vary from being simple to complex; the time it takes to design your child's plan and the number of steps needed can vary. Your child may need more than one planning/simulation session before treatment can begin. Your child will usually begin radiation treatments within 1 to 2 weeks of their planning CT scan.

Radiation Treatment

When will my child receive radiation therapy?

Your child will be given scheduled appointments for treatment, Monday through Friday. A treatment may be over several days or weeks and may start on any day of the week. There are no regularly scheduled treatments on weekends or statutory holidays.

What will happen on treatment visits?

Once you arrive at Level 0 of the JCC for the first day of treatment, you will be given a treatment schedule. You will be shown how to scan your child's barcode at the computer station and then you and your child may wait in The Pod.

Your child will then be taken to the radiation machine, where treatment will begin. The Radiation Therapists will position your child on the table. It is important that your child not move during the set-up or during the treatment itself. Actual treatment time takes only a few minutes, but the



Child's view from
the treatment bed

set-up and preparation may take another 10 to 15 minutes. Your child will be alone in the treatment room but will be watched closely through CCTV monitors and a two-way intercom for communication. The radiation can be stopped at any time to allow staff to enter the room and will switch off once the treatment has been given.

Receiving radiation is like having an x-ray taken; there is no pain or sensation involved. Your child will not see or feel anything during the treatment, but the machines may make a soft buzzing noise.



Parents' view of the treatment machine, or "Linear Accelerator"

Rewards Program

Your child is encouraged to actively participate in their radiation treatments. A personal calendar outside the treatment unit allows your child to record each completed treatment. A visit to the toy box lets your child choose an item they might enjoy, giving positive reinforcement for a job well done. On their last day of treatment, your child will be presented with a Completion Certificate signed by their team, and radiation bravery beads to continue their story.

How will my child's progress be monitored?

Patient review

Your Doctor will examine your child and review their progress with you once a week. The Pediatric Radiation Therapist will also see your child during this weekly visit. Your child's Doctor and Pediatric Radiation Therapist are available during the week if you have any questions or problems.

Your Child's Symptoms Matter

Before each of your child's weekly doctor appointments, young adolescents may be asked to:



- complete a symptom screening assessment on a personal device, computer, or tablet in the clinic waiting area
- rate the different symptoms that they may have

This series of questions will rate different symptoms about how they are feeling and their activity level.

Your child can also complete the assessment at home on the day of their in-person or virtual appointment:

<https://isaac.cancercare.on.ca>

Symptom Screening



3F Clinic at McMaster Children's Hospital (MCH)

Your child may continue to be monitored and have blood work done at MCH while undergoing radiation therapy. These appointments will be scheduled by your MCH Primary Nurse, and are often once a week.

Side Effects

Does radiation therapy cause side effects?

Even though most of the damage to healthy cells is repaired, there are some side effects of treatment that cannot be avoided. The side effects vary with each child, and may be mild or severe.

The following are some side effects that may occur during treatment to the various parts of the body. Possible delayed complications of treatment will be discussed with you as needed.

Remember that side effects from radiation will only occur in the area of the radiation treatment. Your child's Doctor and Radiation Therapists will be watching them closely and looking for signs of side effects, and will work to manage these.

Mouth or neck

Radiation to the mouth or neck may cause dryness or soreness of the mouth, taste changes, sore throat, hoarseness or difficulty in swallowing. Medications can be prescribed for any soreness that develops. Your child's teeth should be routinely checked by a dentist. You may be instructed to limit certain foods during your child's treatment.

Chest

Radiation to the chest area may cause difficulty in swallowing due to irritation of the esophagus (food pipe). This can be relieved with medication. Your child may develop a temporary dry cough. If your child develops a fever, you need to tell the Doctor or Therapist right away.

Abdomen

A child receiving abdominal radiation may experience nausea, vomiting or diarrhea. Medications can be prescribed to help control these symptoms. You may need to change your child's diet during radiation treatments. Small meals throughout the day with high calorie, high protein foods are often recommended. It is important to replace any fluids lost through vomiting.

Pelvis

Pelvic radiation may cause nausea, vomiting or diarrhea. Medications can be prescribed to help control these symptoms. An irritation of the urethra (opening where your child pees) or bladder may occur. If your child is receiving chemotherapy at the same time they receive radiation treatment, there may be a decrease in blood counts. Your child's blood counts will be taken at regular intervals and watched for any important changes.

Spine

Spinal radiation may cause nausea, vomiting or diarrhea. Medications can be prescribed to help control these symptoms. Radiation to the spine and head may result in a lowered blood count. Your child's blood counts will be taken at regular intervals and monitored for any important changes. Therapy may be temporarily stopped if your child's blood counts drop below a safe number.

Head (Cranium)

Cranial radiation usually results in loss of hair in the treatment area, often after the second week of treatment. The hair will generally begin to grow back 3 months after completing cranial radiation. Some children become sleepy when they are receiving radiation to the head. This period of sleepiness is temporary and may continue to occur up to 6 weeks after completion of therapy.

Skin

Skin reactions may be mild, such as drying or darkening of the skin in the treatment area. If the skin reaction becomes more severe, a special cream will sometimes be prescribed by your Radiation Oncologist. Avoid scratching, rubbing and pressure, and only apply lotions advised by your treatment team. Any skin changes will slowly go away within 2 to 6 weeks of completing treatment.

What are some other things I should be aware of during my child's treatment?

Activity level

Some tiredness is expected during treatment and your child should rest as needed. Allow your child to be as active as they want. There are no special limitations on activity. If there are any specific exceptions, your child's Doctor will let you know.

Bathing

You may bathe your child as necessary using mild soap and lukewarm water. Be gentle in the treated areas. Pat the skin dry with a soft towel.

Sun exposure

Avoid exposing your child's treated area to the sun. If your child should go outside, make sure they wear protective clothing and apply sunscreen. Even after completion of your child's treatment, these areas will always be more sensitive to sunlight.

When to call the JCC at 905-387-9495

Appointment change

If you need to change your appointment, please call your Pediatric Radiation Therapist at least 24 hours ahead of time. We will try our best to accommodate you. Also, if possible, please let us know if you are running late.

When to call MCH, 3F Clinic, at 905-521-2100 ext 73887

Urgent problems - Monday to Friday, from 8:00 am to 4:00 pm

If you have an urgent problem as listed below and need to speak with a member of the health care team, call MCH at 905-521-2100, extension 73887, by 4:00 pm. Describe your concern to the secretary.

Urgent problems are any changes in your child's condition, such as:

- fever of 38.3°C or higher when taken by mouth or 37.8 C or higher when taken under the arm
- signs of bleeding
- signs of infection (such as a sore throat, ear aches)
- a break in the central line
- looks unwell and you are worried
- chills
- vomiting or diarrhea
- pain
- exposure to someone with chicken pox
- unable to eat or drink
- severe headache

If your child becomes very short of breath or develops severe chest pain, call 911.

Urgent problems - after 4:00 pm or on the weekends

If you have an urgent problem, please call the On-Call Pediatric Oncologist at 905-521-5030. This is the paging department and they will transfer you to the Doctor-On-Call. Be ready to tell the Doctor about your child's disease, blood counts and current problem.

What will happen after radiation therapy is finished?

Follow-up

When your child has completed this phase of treatment, remember that radiation side effects may continue for another 1 to 2 weeks before you begin to notice a gradual improvement. Continue with any care instructions that you have been given.

The Radiation Oncologist will see you at McMaster Children's Hospital (MCH), along with your Primary Care Team. At this time, radiation side effects can be monitored and any concerns you may have will be discussed. Any further treatment, follow up testing, or imaging procedures will be arranged and discussed at MCH.

AfterCare

The Childhood Cancer AfterCare program is a follow-up care program designed to provide your family with these benefits:

- regular contact with caregivers who understand cancer and its treatments
- early detection of any late effects
- access to information related to cancer survival

Your MCH Primary Care Team will talk to you about when AfterCare should start for you. All survivors of childhood cancer who have been off treatment for two or more years may be eligible.

Services

Hummingbird Café

The Hummingbird Café on Level 0 of the JCC provides fresh brewed coffee, daily specials, sandwiches, salads and baked goods for purchase.

The Canadian Cancer Society

The Canadian Cancer Society (CCS) works very closely with the JCC. The CCS does research, offers support programs and provides information related to cancer. All these services and more are possible because of generous donors and volunteers. For more information, visit their website: www.cancer.ca



Cancer Information Service

Cancer can be difficult to understand and coping can be stressful. It helps to have someone you can talk to and trust for reliable information.

The Cancer Information Service is a confidential service for all people with cancer, their families, health care workers and the general public. Service is available in French and English. Interpreters are available for other languages.

The information you receive is confidential and tailored to your needs. A direct phone line is available in the JCC Patient and Family Resource Centre, located on Level 1, near the front entrance.

Toll-free: 1-888-939-3333 TTY: 1-866-786-3934

Email: info@cis.cancer.ca

Safety Reminders

Infection

Many of our patients have weakened immune systems. This means their body's defense systems are weak and they can get infections easily.

To protect everyone at the JCC:

- Please clean your hands at the front door
- Family and visitors that feel unwell should not come to the JCC



Call ahead of your appointment if you have been required to self-isolate or been placed in isolation at any facility or are experiencing any of the following symptoms:

- shingles
- a cold
- flu
- sore throat
- runny nose
- chickenpox
- fever
- cough
- upset stomach
- vomiting
- viral infections
- diarrhea
- open wounds
- sores or rashes

Fragrance restricted

When you come to your child's appointments, please do not wear or bring perfume, cologne, aftershave, scented hair spray or other scented products.



Latex-free environment

Please do not bring latex balloons into the JCC. If your child has a latex allergy, please let your child's Doctor know.



Privacy

At Hamilton Health Sciences, protecting our patients' privacy is a fundamental part of providing excellent care. We promise to protect and keep your child's health information private. We have rules on how health care providers can collect, use and share health information. If you would like more information about your privacy rights please ask your primary care team or ask for our handout on privacy.

Privacy Office: 905-521-2100, ext. 75122

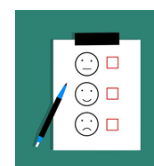
Email: privacy@hhsc.ca

Website: <https://www.hamiltonhealthsciences.ca/patients-visitors/privacy/>



Patient Experience

At Hamilton Health Sciences, we welcome your feedback. Hearing from patients and families is the best way to improve our care and services. If you have compliments or concerns about your child's care, please speak with a member of your health care team or the unit/area manager.



If you wish to share your feedback or compliments further, or feel your concerns have not been addressed, please contact the Office of Patient Experience and Feedback:

Phone Number: 905-521-2100, ext. 75240.

E-mail: patientexperience@hhs.ca

Website: <https://www.hamiltonhealthsciences.ca/patients-visitors/patient-experience-feedback/>



Resource Contact List

Canadian Cancer Society	www.cancer.ca	
Cancer Care Ontario	www.cancercare.on.ca	
Cancer Information Service	E-mail: info@cis.cancer.ca 1-888-939-3333	
Cancer Trials Hamilton	www.cancertrialshamilton.ca 905-387-9495, ext. 64417	
Hamilton Niagara Haldimand Brant Local Health Integration Network, HNHB LHIN (formerly CCAC)	www.hnhblhin.on.ca 905-523-8600 1-800-810-0000	
Hamilton Health Sciences (HHS)	www.hamiltonhealthsciences.ca 905-521-2100	
Juravinski Cancer Centre (JCC)	905-387-9495	

Ontario Cancer Trials	www.ontariocancertrials.ca	
Ontario Hospital Association	www.oha.com	
Patient & Family Resource Centre, JCC	Email: jccpfrcentre@hhsc.ca 905-387-9495, ext. 65109	
Patient Experience, HHS	905-521-2100, ext. 75240	
Parking, HHS	E-mail: parkingoffice@hhsc.ca 905-521-2100, ext. 42354	
Privacy Office, HHS	905-521-2100, ext. 75122	

Juravinski Cancer Centre Foundation

Foundation donors contribute to improved patient care, research and education at the JCC. Recent gifts have supported nursing education, research into new cancer treatment, and creating a new in-patient unit for stem cell transplantation and cellular therapy.

The Foundation is really about people. Some give of their time; others donate money. All gifts are important in reaching our goal of bringing hope to patients with cancer.

The Juravinski Cancer Centre Foundation staff is happy to meet and talk with patients and families who are interested in giving back. If you would like to learn more about the Foundation or make a donation:

Foundation Office: JCC Level 1, across from the Information Desk
Website: <https://hamiltonhealth.ca>
Phone: 905-575-6380



Tell us what you think!

Your feedback about this Patient and Family Handbook is important and your responses will help us improve.



Please email us at jccpfrcentre@hhsc.ca to give us your opinion or visit the Patient & Family Resource Centre on Level 1 to fill out a paper survey.



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Brant · Burlington · Haldimand · Hamilton · Niagara · Norfolk

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