CHORDOMA
FOUNDATION

Radiation Therapy for Chordoma in Canada

A PATIENT GUIDE

A guide to radiation treatment, particle therapy questions, and access pathways for Canadian patients

This guide is for education and decision support. It is not medical advice. Treatment decisions should be made with your radiation oncologist and care team.

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What Matters Most

Chordoma is a rare cancer that most often develops at the base of the skull, along the spine, or in the sacrum. Because chordomas often grow close to important structures, such as the brainstem, spinal cord, optic nerves, and major blood vessels, treatment needs careful planning by a team with experience in chordoma.

Radiation therapy is often an important part of chordoma care. It may be used after surgery, when surgery is not possible, if the tumour comes back, or to help control symptoms from metastatic disease.

Chordoma usually needs a high dose of radiation to control the tumour. The challenge is giving enough radiation to treat the chordoma while protecting nearby healthy tissues. The best radiation approach depends on your individual situation, including where the tumour is, whether you have had radiation before, and what structures are nearby.

Because chordoma is rare and often needs highly specialized radiation planning, it is important to have a radiation oncologist with chordoma experience involved in your care. This does not necessarily mean changing your whole care team; in many cases, a chordoma-experienced radiation oncologist can review your case, provide input on treatment options, and help your local team think through questions about dose, nearby critical structures, and whether photon or particle therapy should be considered. The Chordoma Foundation's Doctor Directory can help patients and families identify doctors with experience treating chordoma.

RADIATION OPTIONS

Photon & Particle Therapy

Radiation therapy uses carefully targeted beams to treat cancer cells. For chordoma, radiation planning is especially important because the tumour may be close to sensitive parts of the body.

Most chordoma radiation is given from outside the body using a machine. This is called external beam radiation therapy. The two main types discussed for chordoma are:

PHOTON THERAPY

Photon therapy uses high-energy X-rays. Modern photon treatments can be very precise. These include:

- **IG-IMRT and IG-VMAT**
  Image-guided intensity-modulated radiation therapy and image-guided volumetric modulated arc therapy are highly shaped precise forms of radiation
- **SRS/SBRT**
  Stereotactic radiosurgery and stereotactic body radiotherapy are very focused radiation sometimes used for small tumours, recurrences, or selected metastatic sites both in spine and skull

These forms of photon therapy are available in Canada. Experienced radiation centers are able to safely deliver the dose needed in chordoma cases with these technologies.

PARTICLE THERAPY

Proton therapy and Carbon Ion therapy are types of particle therapy. Proton therapy is more widely available and Carbon ion is considered emerging. It can reduce radiation exposure to nearby healthy tissues because of how proton beams deposit dose. This may be helpful when a chordoma is close to critical structures.

However, proton therapy is not necessarily better for every patient. Its value depends on the tumour's size, shape, location, prior treatment, and the nearby organs at risk. Proton therapy is not currently delivered in Canada, so Canadian patients who are approved for proton therapy usually need out-of-country treatment. Similarly, Carbon Ion therapy is not available in Canada.

THE KEY QUESTION

The most important question is not simply "proton or photon?" There are different risks associated with each technology and the key question for your radiation oncologist is: ***Which plan can safely deliver the dose needed to treat the chordoma while protecting nearby critical structures?***

Why Dose Matters

Chordoma often requires a higher radiation dose than many other cancers. When visible tumour remains after surgical resection, treatment often involves a total dose of about 74 Gy or higher, depending on the situation. If the tumour has been completely removed, the recommended dose may be different.

Because these doses are high, planning must be done carefully. Once an area has received a full course of radiation, it may be difficult or sometimes impossible to safely treat the same area with radiation again. If chordoma comes back, your team will consider where it returned, how much radiation was given before, how much time has passed, and whether focused radiation can be used safely.

In some recurrent or metastatic situations, lower doses may be used to slow tumour growth, relieve symptoms, or improve quality of life.

Ask your radiation oncologist

- What dose do you recommend for me?
- Is the goal cure, long-term control, symptom relief, or another goal?
- Can this dose be delivered safely with photon therapy?
- What nearby structures are most important to protect?
- Do you recommend a consultation with a proton facility?
- What are the potential short, medium and long term side effects associated with my radiation treatment?

WHAT DOES GY MEAN?

Gy is a unit doctors use to describe radiation dose. You can think of it like a dosage number, similar to milligrams for medication.

ACCESS IN CANADA:

Province & Territory Pathways

Photon radiation therapy is available in Canada at major cancer centres. If your care team thinks proton therapy might be helpful, treatment requires a referral to a centre outside Canada. This process is handled through your province or territory, and the steps can be different depending on where you live.

In most cases, the process starts with your radiation oncologist. Typically, all cases are reviewed in a tumour board or provincial review group. They may review whether proton therapy should be considered and whether a proton vs. photon comparison plan would help. If proton therapy is recommended, a separate funding approval process is needed before out-of-country treatment can happen, as the cost can reach hundreds of thousands of dollars.

Even when medical treatment is covered, other expenses, such as flights, accommodation, meals, local transportation, travel insurance, caregiver travel, childcare, or time away from work, may not be covered. Coverage varies across Canada, so patients should confirm details with their care team and provincial or territorial health plan before making treatment or travel plans.

PROVINCE & TERRITORY PATHWAYS AT A GLANCE

WHERE YOU LIVE	WHO USUALLY STARTS THE PROCESS?	MAIN REVIEW / APPROVAL PATHWAY	COST & TRAVEL NOTE
British Columbia	A radiation oncologist within BC Cancer	Reviewed through BC Cancer/provincial process; out-of-country approval through the British Columbia Ministry of Health	Medical costs may be covered if approved; travel, accommodation, and other indirect costs are generally not covered

WHERE YOU LIVE	WHO USUALLY STARTS THE PROCESS?	MAIN REVIEW / APPROVAL PATHWAY	COST & TRAVEL NOTE
Alberta	The consultant radiation oncologist who has assessed the patient	Reviewed through Proton Therapy Referral Rounds, then by the Senior Medical Director of Cancer Care Alberta; final funding approval through the Alberta Health Special Program Unit	Medical costs are covered if approved; some transportation support may be available, especially for children
Saskatchewan	A radiation oncologist through the Saskatchewan Cancer Agency	Reviewed through the Saskatchewan Cancer Agency and provincial out-of-country prior approval process	Medical costs may be covered if approved; indirect cost support varies
Manitoba	A radiation oncologist within CancerCare Manitoba	Reviewed through disease site group rounds; out-of-country approval through Manitoba Health	Medical costs may be covered if approved; some transportation reimbursement may be available, but many indirect costs are not covered
Ontario	An Ontario radiation oncologist	Reviewed through physicians selected by the program; out-of-country approval through Ontario Health	Medical costs may be covered if approved; indirect costs are generally not covered
Quebec	A radiation oncologist within Quebec's oncology network	Reviewed by the Comité provincial de protonthérapie; funding approval through RAMQ	Medical costs and some travel-related costs may be covered if approved
Nova Scotia, New Brunswick, and PEI	Usually a radiation oncologist through the Nova Scotia Health pathway	Reviewed by tumour board/Department of Radiation Oncology; applications handled case by case through provincial departments of health	Medical costs may be covered if approved; indirect costs are generally not covered

WHERE YOU LIVE	WHO USUALLY STARTS THE PROCESS?	MAIN REVIEW / APPROVAL PATHWAY	COST & TRAVEL NOTE
Newfoundland and Labrador	A radiation oncologist within the provincial cancer program	Likely reviewed through internal cancer program or tumour board process; out-of-country approval through the MCP Out-of-Province / Out-of-Country Prior Approval Program	Public details are limited; ask specifically about travel, accommodation, meals, and caregiver support
Yukon, Northwest Territories, and Nunavut	Usually an oncologist in the partner province after referral south	Reviewed through the receiving provincial cancer system; approval coordinated by the territorial health department and partner province	Patients already travel for specialized radiation care; ask early about medical travel benefits, companion travel, lodging, and meals

This table is a starting point. Processes and funding rules can change, and public information is limited in some areas. Patients should confirm the current process with their radiation oncologist, provincial or territorial health plan, and cancer agency before making treatment or travel plans.

QUESTIONS TO ASK BEFORE AN OUT-OF-COUNTRY REFERRAL

Before an out-of-country proton therapy referral is submitted, you may want to ask:

- Is proton therapy worth considering in my case, and why?
- Can radiation available in Canada safely deliver the dose I need?
- Would a proton vs. photon comparison plan be helpful?
- Has my case been reviewed by a chordoma-experienced radiation oncologist or tumour board?
- Who submits the referral and funding request?
- Which proton therapy centre would I be referred to?
- How long would I need to be away from home?
- What costs are covered, and what costs might I need to pay myself?
- Who can help me understand the practical and financial steps before travel is planned?

DETAILED PROVINCE & TERRITORY PATHWAY NOTES

British Columbia

Who starts the process?
Usually a radiation oncologist within BC Cancer, after assessing whether proton therapy may provide benefit. BC Cancer oversees radiation services across the province.

Who reviews or approves the request?
Cases are reviewed through BC Cancer's multidisciplinary process. Out-of-country treatment approval is through the British Columbia Ministry of Health.

What criteria are commonly considered?
Proton beam therapy generally needs to be for curative intent and is available only for a subset of paediatric and adult cancers.

Use of comparative planning
Public details are not clearly available. A proton vs. photon dosimetry comparison may be handled internally through the provincial cancer agency review process.

Common referral destinations
Public details are not clearly available. Referral destinations are likely determined through BC Cancer and provincial review.

What should I ask about?
Ask whether a proton vs. photon comparison plan is recommended in your case. Also ask whether travel, accommodation, meals, caregiver costs, or other indirect costs are covered. Current information suggests medical costs may be covered if approved, but indirect costs such as travel and accommodation are not covered.

Alberta

Who starts the process?

The referral must come from the consultant radiation oncologist who has seen and assessed the patient. Radiation services are delivered through Cancer Care Alberta, within Alberta Health Services.

Who reviews or approves the request?

Cases are reviewed at Proton Therapy Referral Rounds, a multidisciplinary review process that considers eligibility, alternative treatments, travel issues, and follow-up care. A referral can move forward only if Proton Therapy Referral Rounds recommends proton beam therapy and the recommendation is approved by the Senior Medical Director of Cancer Care Alberta. Final funding approval is determined by the Alberta Health Special Program Unit.

What criteria are commonly considered?

Required criteria include curative intent, being well enough for outpatient treatment and out-of-country travel, expected survival greater than five years, and being able and willing to travel.

Adult diagnoses that may be considered include ocular tumours, central nervous system diagnoses, skull-base tumours, primary spinal tumours, advanced or unresectable head and neck cancers, paranasal sinus/nasal cavity/salivary gland tumours, mediastinal lymphomas, hepatocellular carcinoma, sarcomas, certain genetic syndromes such as NF-1 and retinoblastoma, and selected re-irradiation cases where photon therapy cannot safely meet critical structure dose limits.

Use of comparative planning

Comparative proton–photon dosimetric analysis may be used when the clinical benefit is unclear and may be required for non-routine diagnoses. If a case is considered borderline, the referring radiation oncologist may contact the Florida Proton Beam Program to request a comparative proton-photon plan. Once the plan is received, the case is discussed at Proton Therapy Referral Rounds.

Common referral destinations

Referrals are commonly directed to the University of Florida Proton Beam Institute, with capacity confirmed before referral submission. If that centre does not have capacity, referral to a non-contracted vendor may be required through the Out-of-Country Health Services Committee.

What should I ask about?

Ask whether your case needs a formal Request for Approval form, what documents are required, and whether a comparison plan is needed before referral. Also ask what costs are covered. Medical treatment is covered if approved. Flights may be covered for the patient and one parent or guardian for children, but accommodation and other special costs may not be covered. Applications may take about 30 days once complete. All the information for Alberta can be found in the following document: Cancer Care Alberta Proton Beam Radiation Therapy.

Saskatchewan

Who starts the process?

Referrals are made by radiation oncologists through the Saskatchewan Cancer Agency referral centres. The Saskatchewan Cancer Agency oversees radiation services.

Who reviews or approves the request?

Cases are reviewed and recommended by the site-specific radiation oncologist or by an institutional multidisciplinary tumour board. Out-of-country prior approval is handled through the Ministry of Health, through the Saskatchewan Cancer Agency.

What criteria are commonly considered?

General eligibility includes curative intent, a subset of paediatric and adult cancers, expected survival of at least five years, and ECOG performance status 0–2.

Use of comparative planning

Public details are not clearly available. A proton vs. photon comparison may be handled internally through the Saskatchewan Cancer Agency or provincial review process.

Common referral destinations

Public details are not clearly available. Referral destinations are likely determined through the provincial review and approval process.

What should I ask about?

Ask whether a proton vs. photon comparison plan is recommended and who would request it. Also ask what indirect costs are covered. Medical costs may be covered if approved. Adult patients may need separate insurance. For paediatric patients, coverage may depend on whether the referring facility provides a global package that includes stay and food paid directly by the health ministry.

Manitoba

Who starts the process?

Usually a radiation oncologist within CancerCare Manitoba, after assessing whether proton therapy may provide benefit. CancerCare Manitoba is the provincial cancer agency responsible for cancer treatment, including radiation therapy.

Who reviews or approves the request?

Cases are reviewed through multidisciplinary disease site group rounds involving oncologists from the patient's circle of care. Out-of-country approval is through the Manitoba Health Out of Country Prior Approval Program.

What criteria are commonly considered?

General eligibility includes curative intent, a subset of paediatric and adult cancers, and discussion through dedicated disease site group rounds.

Use of comparative planning

Public details are not clearly available. A proton vs. photon comparison may be handled internally through CancerCare Manitoba or the provincial review process.

Common referral destinations

Public details are not clearly available. Referral destinations are likely determined through CancerCare Manitoba and provincial approval.

What should I ask about?

Ask whether a formal application is needed, whether your case will be reviewed in disease site group rounds, and whether a proton vs. photon comparison plan is recommended. Also ask carefully about cost coverage. Medical costs may be covered if approved. Physician fees may be covered at the same rate a Manitoba doctor would receive, and hospital bills may be covered up to 75% of insured hospital services. Reasonable transportation costs may be reimbursed, but accommodations, meals, taxis, ambulance, and other expenses may not be covered.

Ontario

Who starts the process?
Usually an Ontario radiation oncologist who determines that proton therapy may provide clinical benefit. Radiation oncology services are overseen by Cancer Care Ontario, which operates as part of Ontario Health.

Who reviews or approves the request?
Cases are reviewed by physicians selected by the program. Out-of-country approval is through the Out-of-Country Prior Approval Program at Ontario Health.

What criteria are commonly considered?
General eligibility includes curative intent and a subset of paediatric and adult cancers.

Use of comparative planning
Public details are not clearly available. A proton vs. photon comparison may be requested through the Canadian proton consultation service or handled as part of the provincial review process, depending on the case.

Common referral destinations
Public details are not clearly available. Referral destinations are likely determined through Ontario Health and the out-of-country approval process.

What should I ask about?
Ask whether a proton vs. photon comparison plan is recommended and whether it should be requested before an out-of-country funding application. Also ask what costs are covered. Medical costs may be covered if approved, but indirect costs are generally not covered. Transportation may sometimes be covered by philanthropic agencies for children.

Quebec

Who starts the process?
Usually a radiation oncologist within Quebec's oncology network after assessing the patient. Radiation oncology services are coordinated through the provincial health system under the Ministère de la Santé et des Services sociaux, with cancer care delivered

through designated oncology centres and guided in part by the Direction québécoise de cancérologie.

Who reviews or approves the request?

Cases are reviewed by the Comité provincial de protonthérapie. Funding approval is through the Régie de l'assurance maladie du Québec.

What criteria are commonly considered?

General eligibility includes curative intent, selected paediatric and adult cancers, possible second-line treatment, expected survival greater than five years, ECOG performance status 0–2, and evidence that proton beam therapy would provide significant benefit over available radiation options.

Use of comparative planning

Public details are not clearly available. Because Quebec criteria include whether proton therapy offers significant benefit over available radiation options, patients may wish to ask whether a proton vs. photon comparison plan would help support this assessment.

Common referral destinations

Public details are not clearly available. Referral destinations are likely determined through the Comité provincial de protonthérapie and RAMQ approval process.

What should I ask about?

Ask whether a proton vs. photon comparison plan is recommended and whether it would help show that proton therapy offers a meaningful advantage. Also ask what travel-related costs are covered. Current information suggests medical costs are covered if approved, and travel costs including accommodation and transportation are also covered.

Nova Scotia, New Brunswick & Prince Edward Island

Who starts the process?

Usually a radiation oncologist within Nova Scotia Health, after assessing whether proton therapy may provide benefit. Because of shared care pathways and limited province-specific public information, Nova Scotia, New Brunswick, and Prince Edward Island are often discussed together. Specialized radiation oncology services are primarily delivered through Nova Scotia Health and coordinated by the Nova Scotia Cancer Care

Program. Patients from New Brunswick and Prince Edward Island may be referred to Nova Scotia for specialized radiation oncology care.

Who reviews or approves the request?

Cases are reviewed and approved by a tumour board and the Department of Radiation Oncology. Out-of-country treatment applications are handled case by case through the provincial departments of health.

What criteria are commonly considered?

Published details are limited. General eligibility appears to focus on selected curative-intent paediatric cases.

Use of comparative planning

Public details are not clearly available. A proton vs. photon comparison may be handled internally through Nova Scotia Health, the Department of Radiation Oncology, or the relevant provincial review process.

Common referral destinations

Public details are not clearly available. Referral destinations are likely determined case by case through the provincial departments of health.

What should I ask about?

Ask whether adults with chordoma can be considered, whether a proton vs. photon comparison plan is recommended, and which provincial department handles the application. Also ask about travel and accommodation costs. Medical costs may be covered if approved, but indirect costs are generally not covered.

Newfoundland & Labrador

Who starts the process?

Usually a radiation oncologist within the provincial cancer program after assessing the patient. Radiation oncology services are delivered through Newfoundland and Labrador Health Services, with cancer care coordinated through the Cancer Care Program of Newfoundland and Labrador.

Who reviews or approves the request?

Cases are likely reviewed through multidisciplinary tumour boards or internal cancer program processes before referral, but public details are not clearly available.

Out-of-country approval is through the Department of Health and Community Services, through the Medical Care Plan Out-of-Province/Out-of-Country Prior Approval Program.

What criteria are commonly considered?

Public details are not clearly available and are likely handled internally through the provincial cancer agency review process.

Use of comparative planning

Public details are not clearly available. A proton vs. photon comparison may be handled internally through the provincial cancer program or prior approval process.

Common referral destinations

Public details are not clearly available. Referral destinations are likely determined through the provincial cancer program and MCP out-of-province/out-of-country approval process.

What should I ask about?

Ask who reviews proton therapy requests, whether there is a formal application, whether a proton vs. photon comparison plan is recommended, and what criteria are used for chordoma. Also ask specifically about financial support for travel, accommodation, meals, caregiver costs, and other indirect expenses, since public details are limited.

TERRITORIES

Yukon, Northwest Territories & Nunavut

Who starts the process?

The territories do not have in-territory radiation oncology facilities. Patients are usually referred to a southern provincial cancer centre first, and proton therapy discussions are typically initiated by oncologists in the partner province after the patient has entered that care pathway.

Typical pathways are:

- Yukon → BC Cancer
- Northwest Territories → Alberta Health Services / Cancer Care Alberta
- Nunavut → Cancer Care Ontario / Ontario Health

Who reviews or approves the request?

Clinical review usually happens through the receiving provincial cancer system, including multidisciplinary tumour board review when required. Approval is coordinated through

the territorial government health department, usually in collaboration with the partner province and based on the clinical recommendation.

What criteria are commonly considered?

Public territorial criteria are not clearly available. Criteria from the partner province may be used or may strongly influence the process.

Use of comparative planning

Public details are not clearly available. A proton vs. photon comparison may be requested through the partner provincial cancer system, depending on where the patient is referred for care.

Common referral destinations

Public details about U.S. proton centres are not clearly available. Referral destinations are likely determined through the partner provincial system: BC Cancer for Yukon, Cancer Care Alberta for Northwest Territories, and Ontario Health/Cancer Care Ontario for Nunavut.

What should I ask about?

Ask which provincial pathway applies to you, who is responsible for submitting the request, whether the partner province's proton therapy criteria will be used, and whether a comparison plan can be requested. Also ask early about medical travel benefits, companion or caregiver travel, lodging, meals, and local transportation. Patients in the territories already need to travel long distances for specialized radiation care, not only proton therapy, and decision-making may be less transparent because the process is embedded within partner provincial systems.

Evidence & Uncertainty

It is normal to hear different opinions about proton and photon radiation for chordoma. Chordoma is rare, so there are not many large studies directly comparing every radiation option. In many cases, decisions are based on expert experience, treatment guidelines, smaller studies, and detailed treatment planning.

For an individual patient, the most important question is often not which technology sounds best. The most important question is:

WHICH TREATMENT PLAN CAN SAFELY DELIVER THE DOSE NEEDED WHILE PROTECTING NEARBY CRITICAL STRUCTURES?

That answer may be different for each person. It depends on the tumour's location, size, shape, whether radiation was given before, and which organs or nerves are nearby. Your radiation oncologist can help you understand the benefits, risks, and uncertainties for your situation and there are experienced Canadian chordoma radiation oncologists you can reach out to.

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Support

Navigating chordoma treatment decisions can feel overwhelming, especially when those decisions involve complex radiation planning, cross-country referrals, and out-of-country travel. You don't have to figure it out alone.

Reach out to the Chordoma Foundation with questions about your diagnosis, treatment options, and how to connect with chordoma-experienced specialists.

Email our support team at support@chordoma.org