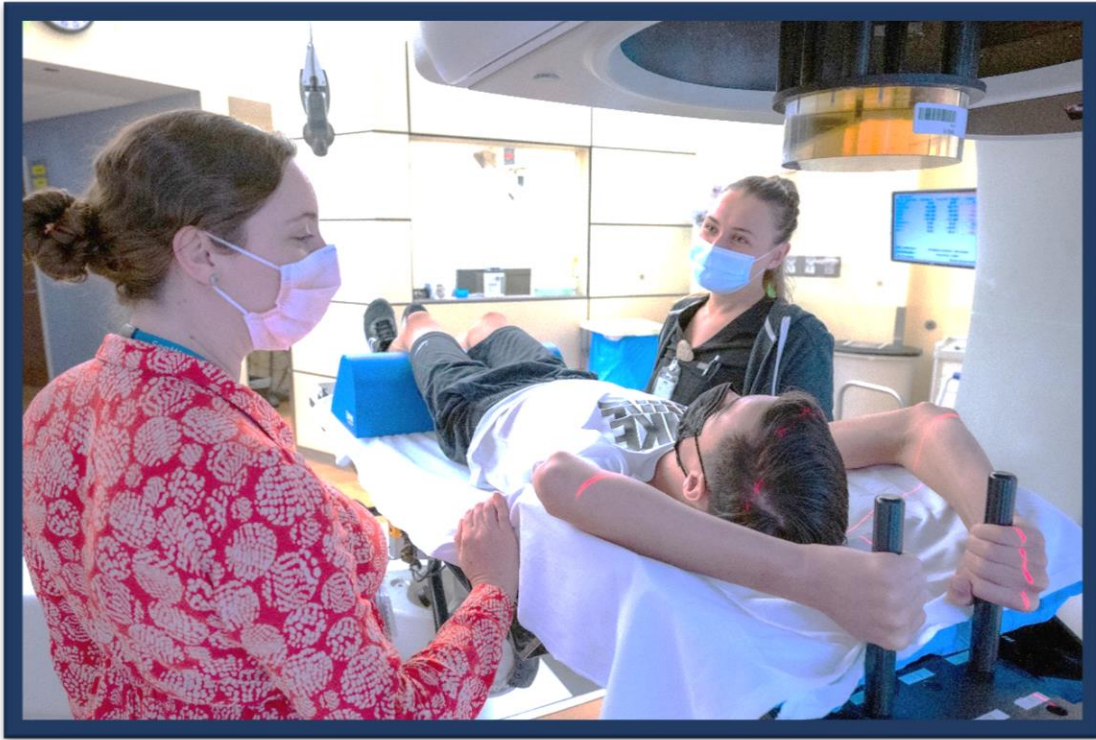


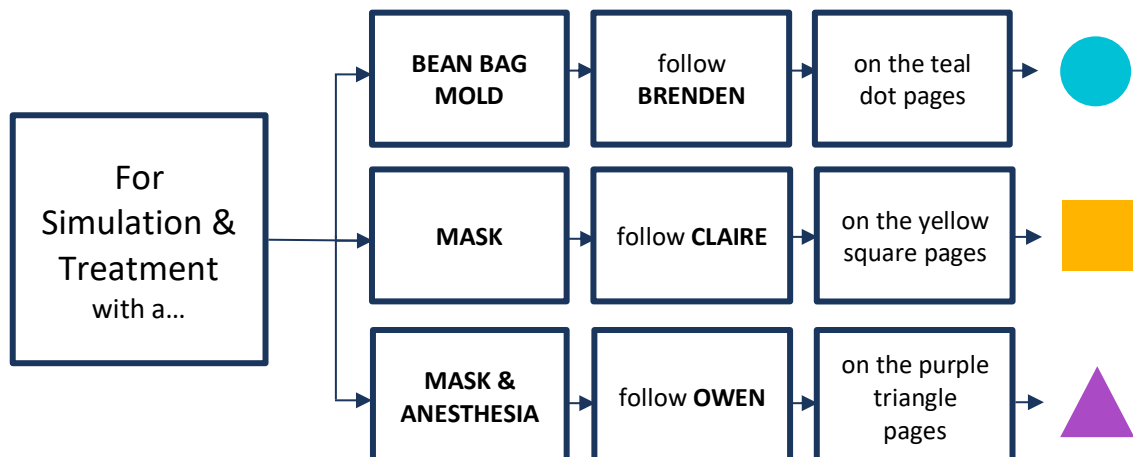
Proton Therapy



This preparation book was designed to help introduce you to proton therapy at Fred Hutchinson Cancer Center and what to expect throughout treatment. Our goal is to help you feel more comfortable with the experience and encourage questions.

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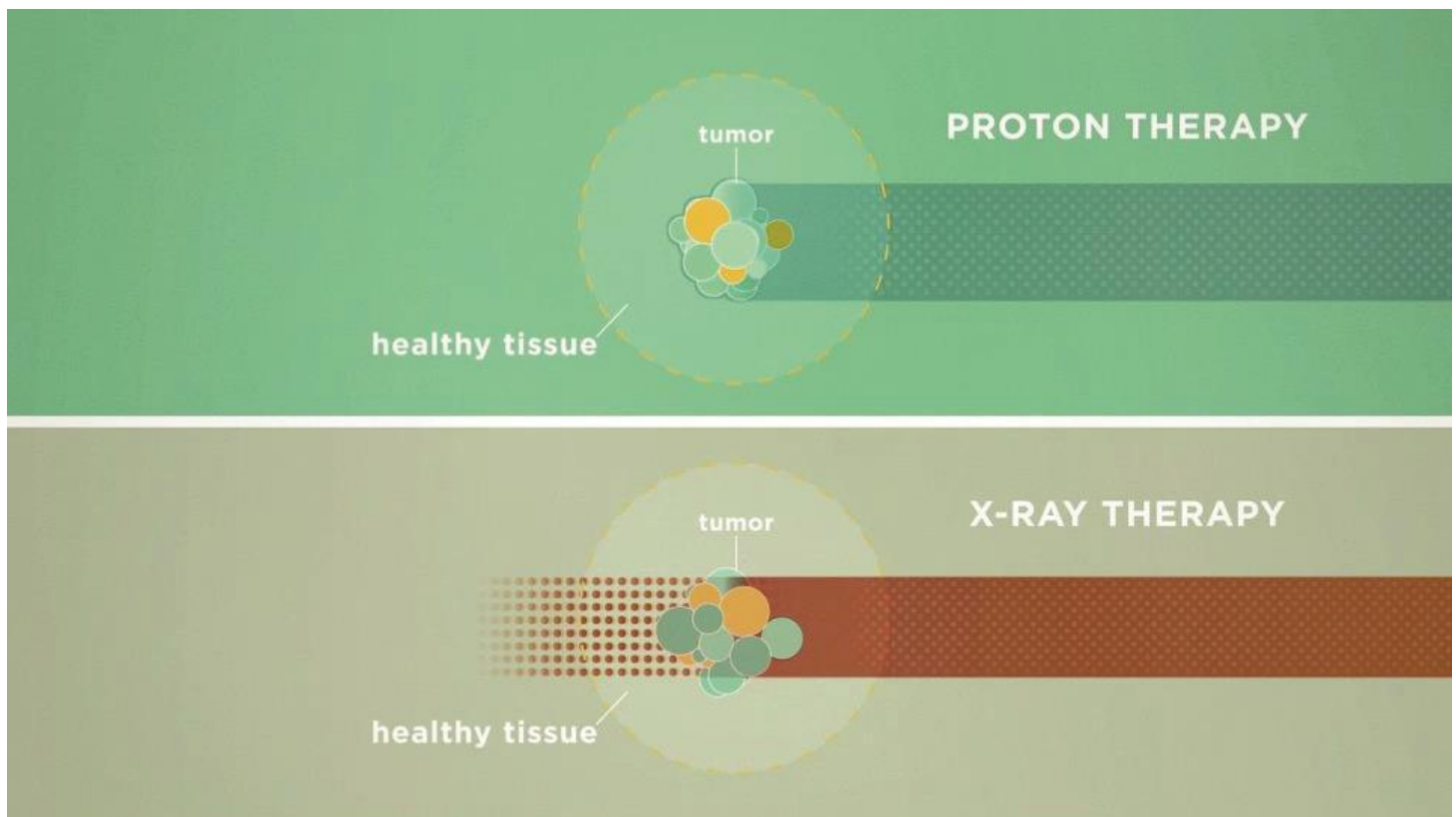
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Introduction to proton therapy

Proton therapy is a kind of radiation that is made up of beams of energy. It's different from X-rays in that the beams are made up of subatomic (tiny) particles called protons. The protons go into the body as far as the doctors want them to go, and then stop.

Here you can see how protons and X-rays are different. Proton therapy can help better protect the healthy areas of your body from radiation while targeting the treatment area.



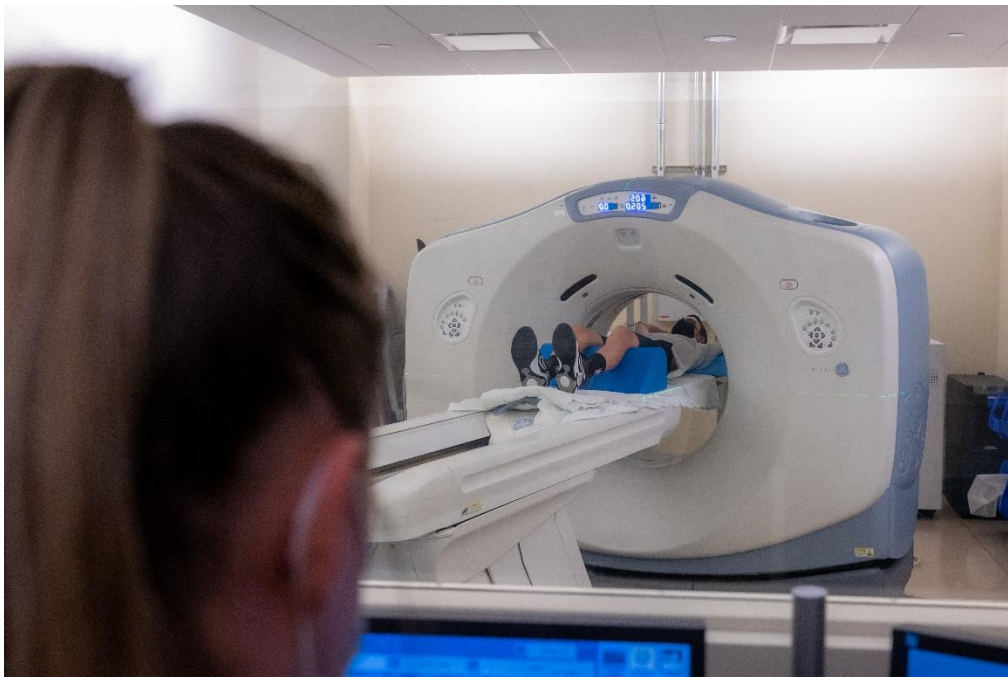
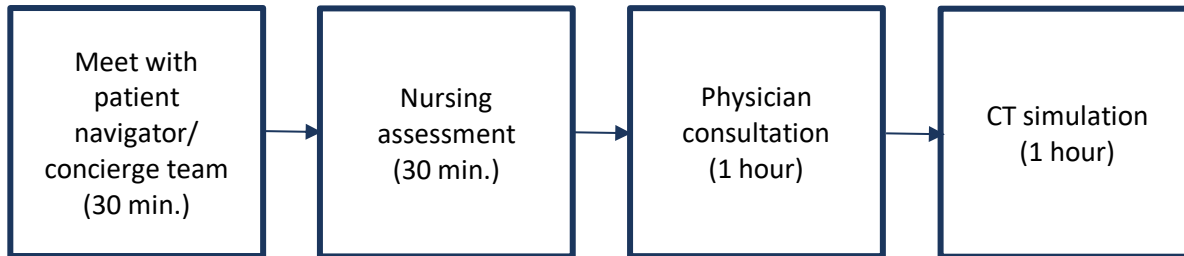
What does proton therapy feel like?

You don't feel or hear the proton radiation, although you may hear the machine. If you are being treated somewhere other than the head, you probably won't sense the radiation. It's kind of like the rays of the sun; we draw them in pictures because we know they are there, but when you look up at the sun, you can't see the individual beams. If you are being treated in your head, you may notice some strange smells or flashing lights; if you do, that is normal.

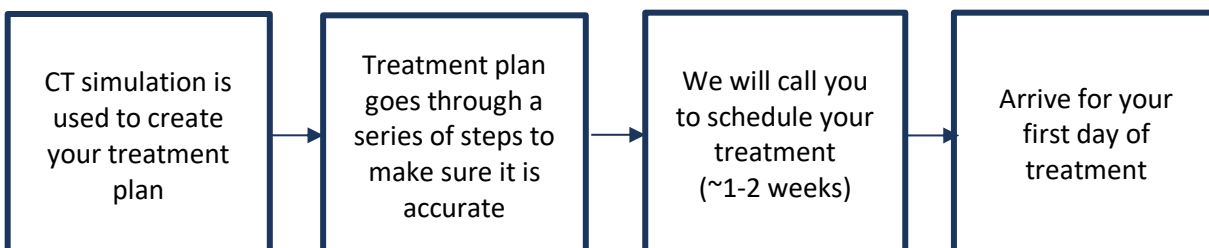
Timeline

Simulation day (Sim): On this day your team prepares everything they need for your treatment, which includes a CT scan. During the CT simulation, radiation therapists will make the mask and/or other positioning device if you need it. Sim day typically takes 3 to 4 hours.

Here's what to expect:

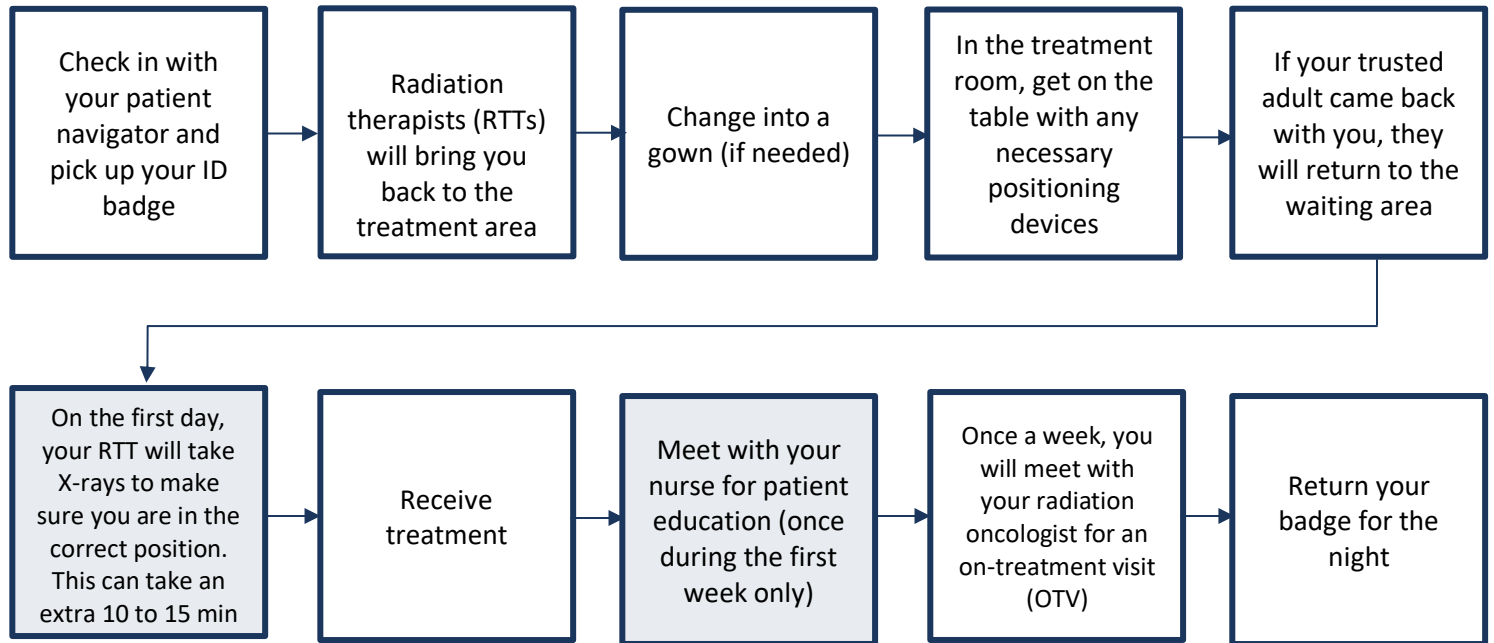


Between now and your first treatment: You will typically start treatment between one and two weeks later. During this time your care team will create your proton therapy plan by looking at and drawing on all the images they took today.



Treatment: Once your treatment plan is finished, you return here to begin your course of treatment. Most often, treatment will occur Monday through Friday for five to six weeks. Start to finish it may take about an hour.

Here's what to expect:



Pictured above is the gantry, one of our most common treatment rooms.

Meet the care team

During your time here, you may meet...



Ralph Ermoian, MD



Stephanie Schaub, MD



Layne Chapple, ARNP

Radiation Oncology Team:

These are the doctors and nurse practitioners that specialize in treating children with cancer.



Trang Nguyen



Ivana Juncaj



Alissa Wasson



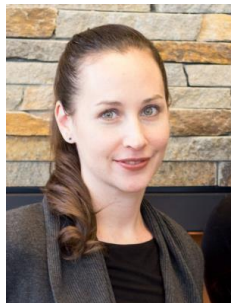
Kulani Chopra

Radiation Therapists (RTTs):

RTTs are the care team members who are responsible for your daily treatment.



Sita Bhattarai
Medical Assistant



Erin Behen
Child Life Specialist



Brooke Wolford
Child Life Specialist



Corrie Anderson, MD
Anesthesiologist

Here are some of the additional care team members you may see during your time while you are here.

Meet the patients

Let's follow Brenden, Claire and Owen as they guide you through their experience.



Name: **Brenden**

Age: **14**

Treatment area: **chest**

Positioning device: **bean bag mold**



Name: **Claire**

Age: **11**

Treatment area: **brain**

Positioning device: **mask**



Name: **Owen**

Age: **5**

Treatment area: **brain and spine**

Positioning device: **mask and anesthesia**

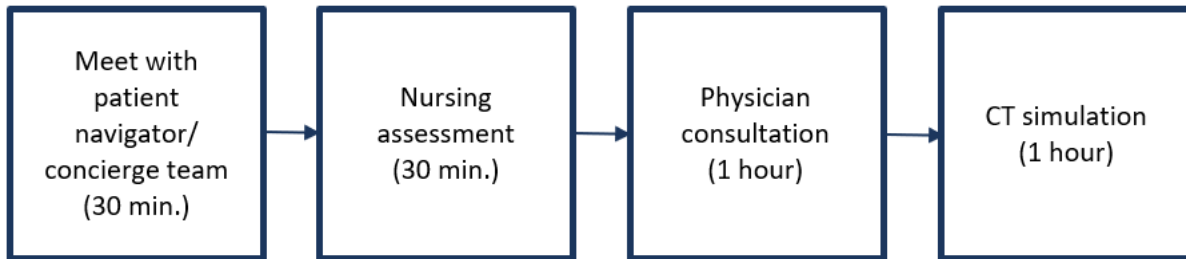


CT Simulation Day



Proton therapy is very precise and focuses directly onto the treatment area while avoiding your healthy areas as much as possible. To prepare for treatment our team will take images of the area being treated. Then, your team will also create any masks or molds needed for positioning your body so that you're in the same position every day.

Here's what to expect:



Sometimes the radiation oncologist, a radiation therapist (RTT) or the child life specialist will talk to you before the CT sim and explain each of the steps.

Here is Owen on his CT sim day:





After you talk with your care team, the RTT will have you lie down on the CT table and may send you through the machine for a quick image. If your plan requires any mask or mold for positioning your body, they will be made now. The RTT will have to leave the room while taking the images but can still see and hear you.

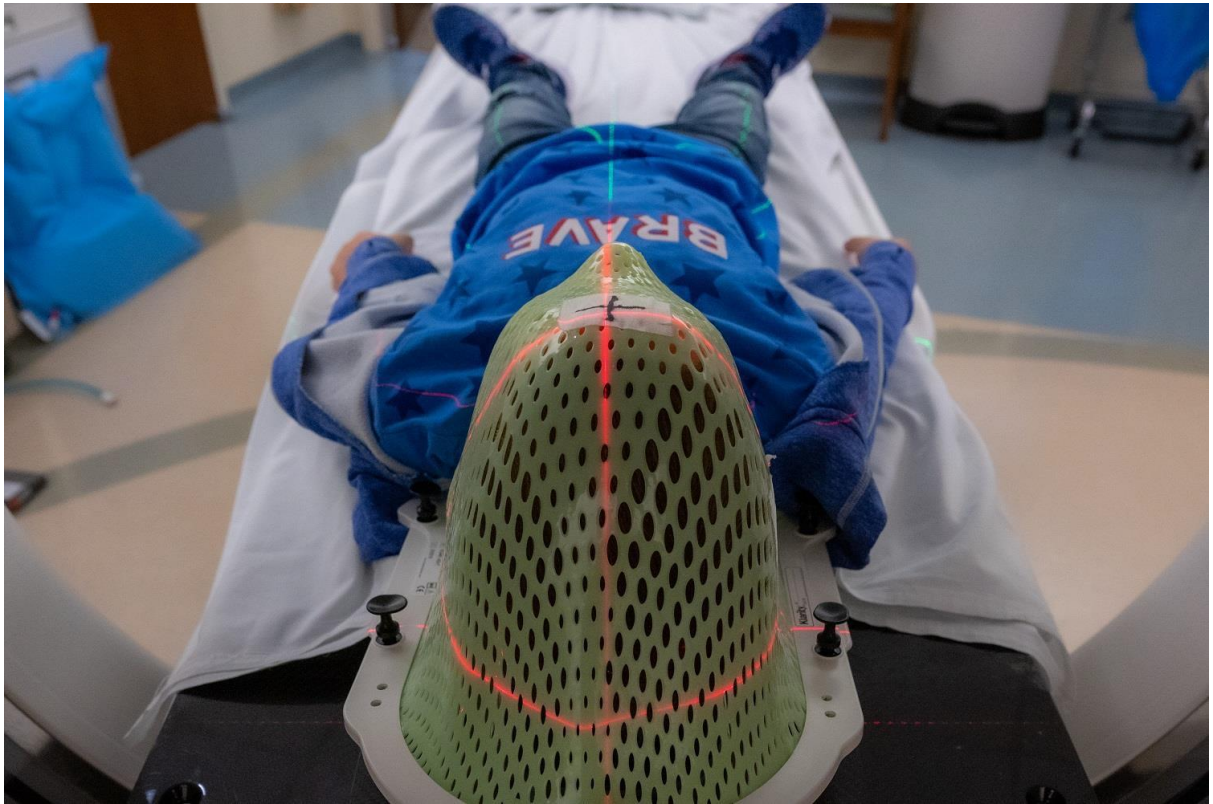
Here is Claire going through the CT machine before and after she had her mask made.



Here is Brenden going through the CT machine with a bean bag mold and other positioning items.



Owen had anesthesia and is sleeping through the whole process.



Here you can see Ivana in the other room while Brenden goes through the CT machine. She can communicate with him using the intercom.





Simulation day plan for:

_____ (name)

Before your simulation day, make a plan for your visit that will help you to relax. Share this with your medical team.

On my simulation day, I can:

- Bring a book
- Bring some music to listen to
- Bring a warm blanket
- Something else: _____

While I wait for simulation, I will:

- Talk to my family
- Play a game
- Draw or read
- Something else: _____

During simulation or while I fall asleep, I would like to:

- Listen to music
- Use a warm blanket
- Something else: _____

Afterwards, or when I wake up, I would like:

- My loved ones to hug me
- My favorite toy
- Something else: _____

My favorite songs are:

- _____
- _____
- _____
- _____

If you would like to listen to your own music, we can play your Spotify list in the simulation room.

- Create a free Spotify account and share your username with your radiation therapist (RTT).
- Create a specific playlist that is set for “public” and share that name with your RTT, too.
- User name: _____ Playlist name: _____

Having a mask made



You may have a mask made at the same time you are doing the CT simulation. The mask will make sure your head stays in exactly the right position for all your treatments. You only wear the mask during your proton therapy. It will stay here between treatments, but you can take it home after you are done with proton therapy.

This is RTT Trang, who is showing Claire what the mask looks like. It's made of a special material that can stretch when it's warm.



Trang is heating up the mask in a warmer. It will feel warm to touch but not hot.





Next, he pulls the mask over Claire’s face. It might feel weird – similar to cooked noodles – but it shouldn’t hurt. It cools in a couple of minutes. It will hold your head in position on the table. You don’t need to hold your breath. You can still breathe, talk, and open and close your eyes.



Here is RTT Alissa doing the same thing for Owen.

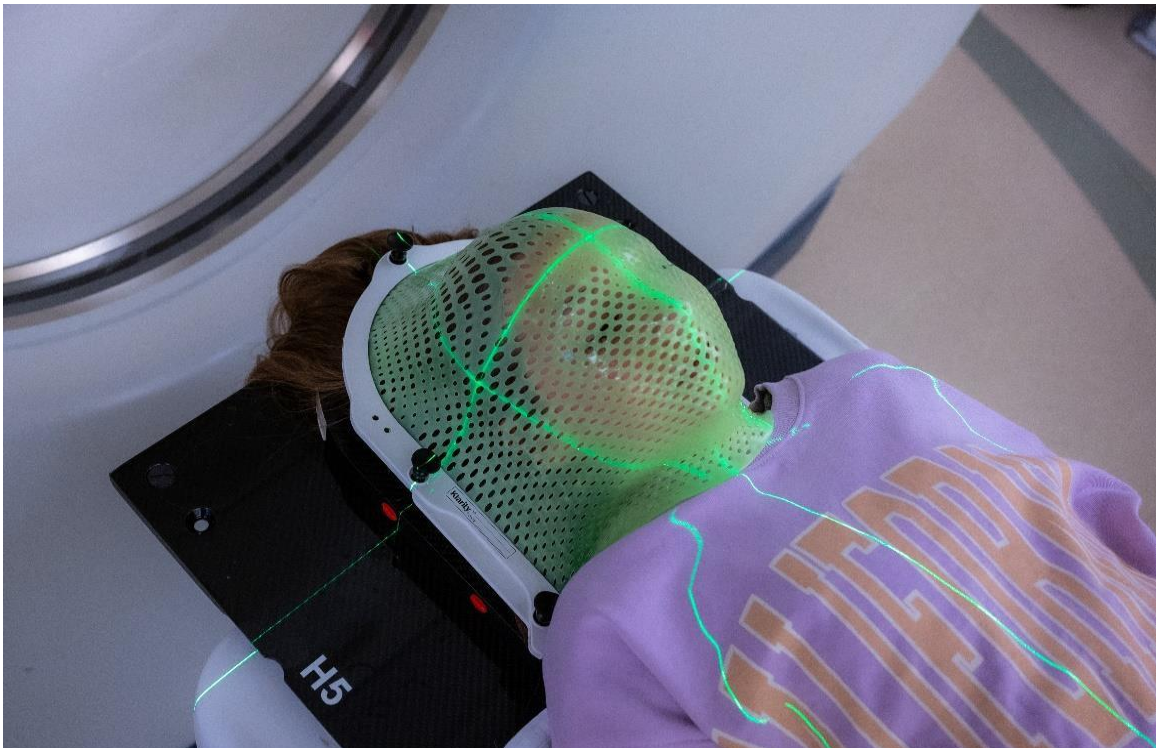




Next, Trang makes marks on the mask using tape, stickers or a pen. The marks show the RTTs where to line up the laser lights to make sure the area is treated in just the right place.



This is what it looks like when the laser lights are on. You can't feel them. Trang will move Claire through the CT machine to take the images of the area the radiation oncologists need to treat.



Having a bean bag mold made



You may have a bean bag mold made at the same time you are doing the CT simulation. The bean bag mold conforms to your body and will make sure you stay in exactly the right position for all your treatments.



This is RTT Ivana. She has positioned Brenden with a bean bag mold under his body. She will suck the air out of that bean bag mold and it will conform to his body. Brenden is also using a positioning item for his hands, so they will always be in the same position.

Ivana shows Brenden what the finished bean bag mold feels and looks like.



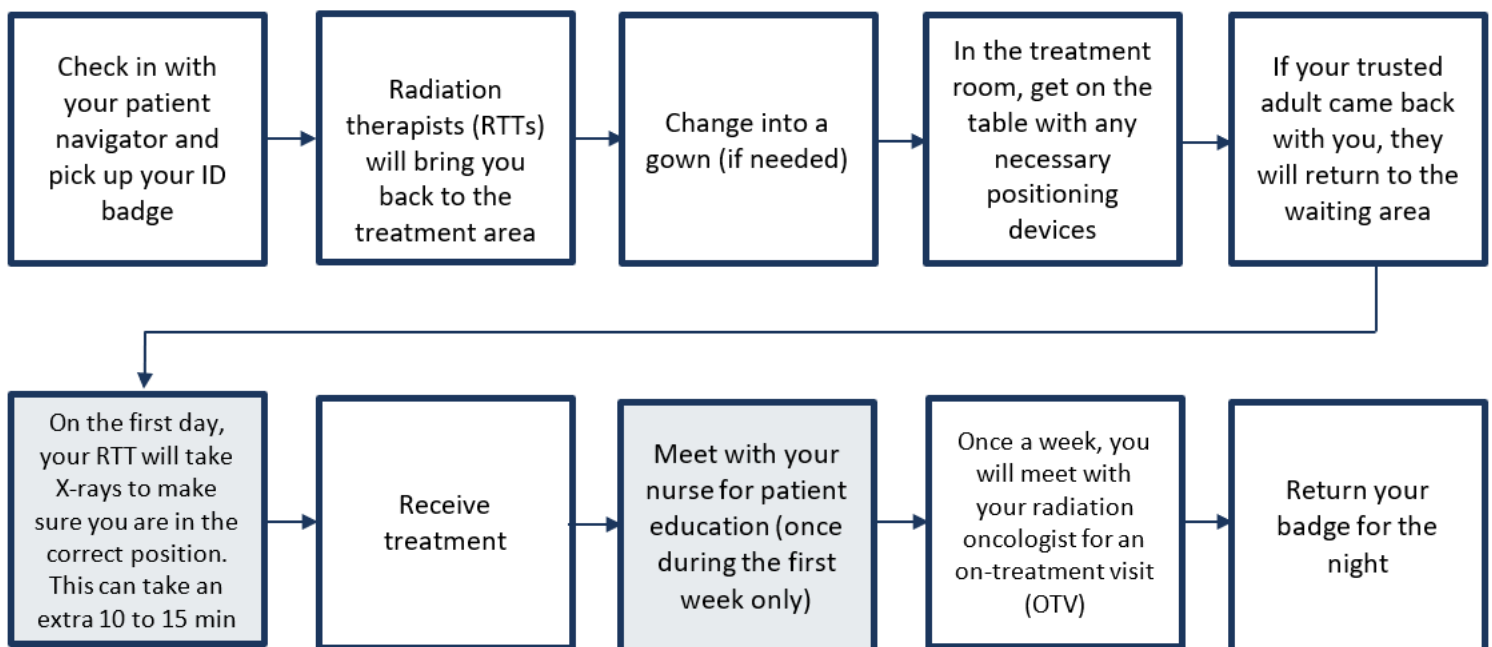
Treatment



Typically, five days a week for several weeks, you will go to one of our treatment rooms and receive proton therapy. If a mask or bean bag mold are part of your treatment plan, you will be positioned in them.

One of the treatment rooms is called the gantry. In this room, the table moves you into position and the treatment machine can move all the way around you. Depending on where you are being treated, the length of time this takes can vary but usually takes about an hour.

Here's what to expect.



Follow along with the patients as they start actual treatment.



Brenden's doctor, Dr. Schaub, is talking to him before treatment, making sure he understands everything and answering any last-minute questions.

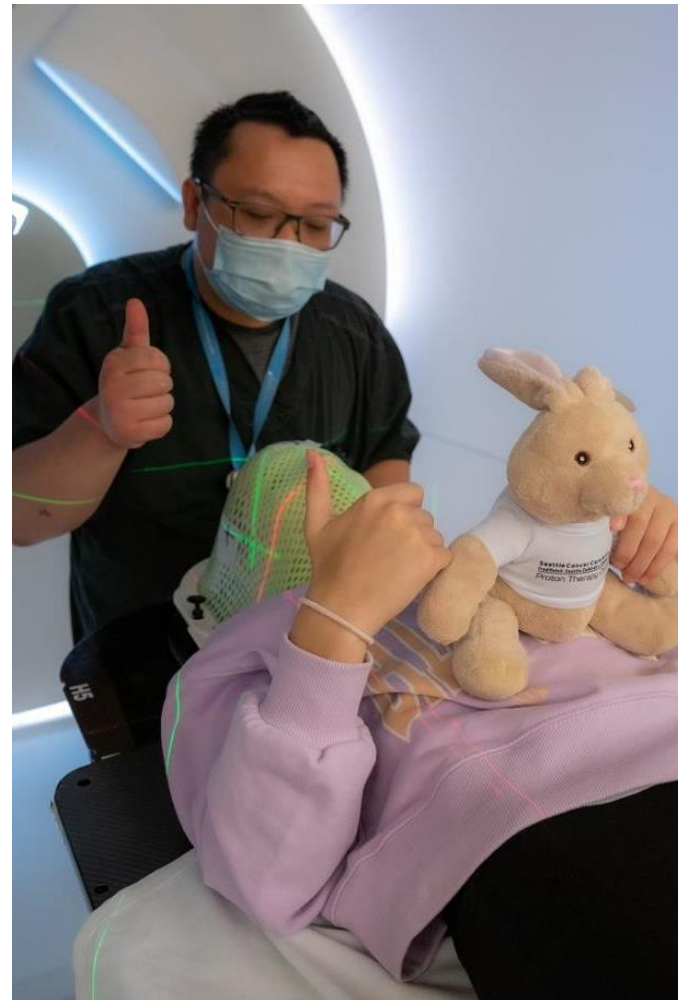
Claire's nurse practitioner is doing the same while she's being positioned.



The RTTs will teach you to use hand signals. You can do a thumbs up, down or sideways. When your therapist steps out of the room, you can also talk to them and they can hear you and talk to you, too.

Claire is telling Trang that she is not quite ready.

Now she's ready.





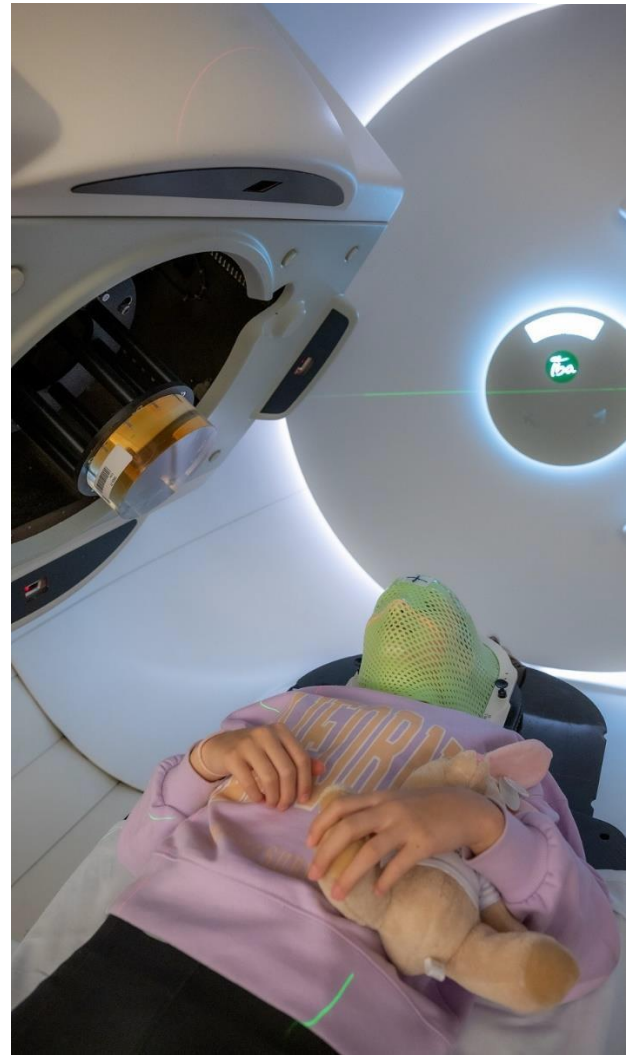
On your first day, it can take the radiation therapists a little extra time to get you in the correct position for treatment. They use X-rays to make sure you are exactly where they need you to be, so the protons only go into the exact area we want to treat. Set up for the following treatments should not take as much time.

X-ray arm



X-ray arm





Looks like everyone is ready. You won't be able to feel, see or hear the radiation during your treatment. Sometimes people will see a blue light or occasionally smell something. If this is your experience, please share with us so we can help if you are bothered by this.



After you're in position, the therapists leave the room for a short while, but they can see and hear you the whole time, and they can talk with you using the intercom.

On Treatment Visit (OTV)



Once a week, or every five treatments, you will have an appointment with your doctor. You can discuss how you are feeling.



You and your trusted adult can ask any questions you have. Rest assured, you will not be radioactive and won't hurt others. Depending on your case, you will be able to do many of the things you usually do. Side effects – if any – will be gradual, and your care team will help.



Your doctor may ask questions to make sure you are doing as well as you can be.

Finishing Treatment



When you are all finished with proton therapy, we will celebrate this milestone with you. You will get a challenge coin that has your own unique number on it. We'll also give you a graduation certificate. Then it's time to say goodbye.



Appendix: Getting a Badge



When you first come to the Fred Hutch, our team will make a badge for you. It will have your name and picture as well as a barcode on the back. This badge is an important piece of your treatment as the barcode is what your radiation therapists use to pull up your specific treatment plan.



When you are done with treatment, you can place your badge in our wooden box at the concierge desk before you prepare to leave for the day.

Appendix: The Child Life Specialist



A child life specialist can help you understand what is going to happen and find ways to make you as comfortable as possible. You can ask them any questions you have and make a plan to help you during treatment. Here are Owen and Claire meeting our child life specialist.

Owen can put the mask on the doll to help it get ready for a CT scan. He gets to feel the mask and play with it to get him familiar with the process.



Claire pushes the doll through the CT machine just as she will go through it later.



Appendix: Anesthesia



Some patients – like Owen – will have anesthesia to make sure they lie absolutely still for their treatments. Anesthesia means you go to sleep for treatment. Your trusted adult can be with you when you fall asleep and as you wake up.

This is the anesthesia bay where you will meet the anesthesiologist (and wake up after treatment).

Dr. Anderson is talking to Owen and his mom.



Your anesthesiologist and your nurse will also check your vitals before treatment.

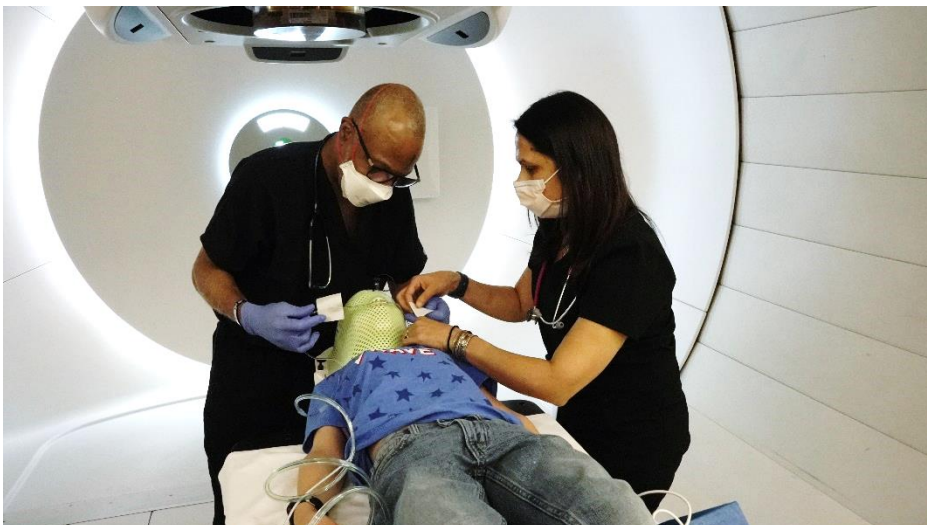




Then, Owen is brought into the treatment room and his mom holds him while the anesthesiologist gives him medicine. Once he's asleep, he's gently placed in position for treatment.



Owen's mask is put in place.



The RTT, nurse and anesthesiologist make sure everything is just right before treatment begins.

Appendix: Having your Vitals Taken



Before you have your CT scan, anesthesia, begin treatment, or see your doctor, a nurse or medical assistant will take your vitals and your weight.

Here are the patients meeting with our medical assistant, Sita.



Some of the vitals she may take are blood pressure, oxygen levels in your blood (it's a gentle clip on your finger)...



.... temperature, and weight.

Appendix: Proton Therapy Contacts



Fred Hutch
Cancer Center

Fred Hutchinson Cancer Center – Proton Therapy
1570 N 115th St.
Seattle, WA 98133
206-306-2800

| Contacts: | Contact when: |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Child Life Specialist: Brooke Wolford, CCLS childlife.proton@fredhutch.org 206-306-2812 (M & Th)</p> | <p>You or your child have questions about treatment and what to expect</p> |
| <p>Social Worker: Elizabeth Darlington, MSW, LICSW edarlington@seattlecca.org 206-306-2815 (Tu, Th, Fri)</p> <p>Patient Navigators/Concierge: concierge.proton@fredhutch.org 206-306-2028</p> <p>Patient Services Manager: April Clements april.clements@fredhutch.org 206-306-2038</p> | <p>You or your child have questions about lodging, transportation, or other local services, grants or emotional support</p> |
| <p>Patient Care Coordinators: Phone: 206-306-2800 option 1 Fax: 206-374-2645 Email: intake.proton@fredhutch.org</p> | <p>You or your child are exploring protons as a treatment option, have financial and/or insurance coverage questions or are interested in scheduling a consultation</p> |

Appendix: Connecting with Seattle Children's



Almost all pediatric patients will establish care at Seattle Children's Hospital (SCH). Generally, appointments at SCH will include:

- Weekly provider visits
- Labs
- Medication, nutrition or physical therapy needs
- COVID-19 testing (as needed)

Prior to or around your treatment start date you should hear from SCH for an appointment to establish care.

Contact information:

If you have any questions about scheduling or care at SCH, please call: 206-987-2106.

SCH is approximately a 15-minute drive away from the Proton Therapy Center.

Seattle Children's Hospital
4800 Sand Point Way NE
Seattle, WA 98105
Main entrance at Forest B.

All parking at SCH is free.

