

# Telling Your Story & Talking About Proton Therapy

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The first step in advocacy – whether talking to lawmakers, the media, or your community – is to think about what you want to say and prepare to say it in the most powerful way. This guide will help. It includes tips for how to tell your personal story and talking points about proton therapy and access issues.

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## TELLING YOUR STORY

Your personal story as a patient, survivor or family member will distinguish your interaction from the dozens of other meetings and conversations a reporter, lawmaker, or member of the public will engage in that day. Your story will have an impact because it puts a “face” on the issue. It’s not just a recitation of facts and figures. It’s memorable.

Your story will help people understand the unique value of proton therapy. Depending on your experience, your story might also shed light on the heavy emotional and financial burden cancer patients endure trying to get their insurer’s approval for the treatment their physician recommended. Regardless of who you are sharing your story with or how long you speak, your story will connect the dots for a reader or decisionmaker. It will have a huge impact.

## TIPS

- Take the time to develop how you want to share your experience. It is likely you won’t have a lot of time in your meeting to lay out your full story: symptoms to diagnosis to physician recommendations to appeals to treatment. Think about how you would share your story if you only had five minutes.
- Write it down. Practice it. If your goal is to convey how critical proton therapy is to your livelihood, explain how it has allowed you to continue to do the work (or hobbies) you love. If your main goal is to explain how stressful the appeals process was, emphasize that. You might want to have short, medium and long versions.
- Remember, this is YOUR story and YOU are the expert on it.



## WE CAN HELP GUIDE YOU

These tips and talking points will help you communicate effectively with the media, lawmakers, and your community.

Read our other guides:

- Talking to Lawmakers
- Talking to the Media
- Talking to Your Social Media Networks

## Share Your Story

### Contact

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## PROTON THERAPY TALKING POINTS

When you meet with a lawmaker or reporter or have a chance to talk about your experience at a public forum, these talking points will help you share some basic information about proton therapy and the access issues that are keeping too many cancer patients from receiving the treatment.

**PROTON THERAPY.** Having these tidbits about proton therapy treatment will help you answer the question “What is proton therapy” before someone even asks you. It’s a fascinating treatment that may be new to the person you are speaking to.

- Proton therapy is an FDA-cleared treatment and is routinely approved for pediatric patients and by Medicare to treat certain types of cancer.
- It is a precise form of radiation therapy treatment. It targets cancer cells without exposing large parts of surrounding healthy tissue to radiation, thereby reducing the risk of harmful side effects.
- Patients who receive proton therapy are at a lower risk for secondary cancers and other related diagnoses because of the reduced exposure to radiation on healthy organs and tissues.
- Patients who receive proton therapy generally experience a higher quality of life during treatment due to the limited side effects.

**THE PROBLEM.** You may want to identify the problem that patients and caregivers face when trying to access proton therapy. [This helps explain why you are talking about the treatment and sharing your story.](#)

- **Nearly two-thirds (63 percent)** of cancer patients aged 18 to 64 receive denials from their insurers when their doctors recommend proton therapy.
- Far too many patients are suffering undue health risks, anxiety, and financial hardship as they confront broken insurance review and appeal processes that drastically delay or make it impossible to receive proton therapy treatment.

- Patients and their physicians are sometimes successful in reversing the initial denial, but time spent waiting – and delaying treatment – averages nearly **three weeks (13 working days)**.
- In the end, proton therapy is denied more than **four times out of ten (42 percent)** and it takes an average of more than **five weeks (27 working days)** to receive that final denial.
- Cancer patients should not have to fight insurance companies for access to the doctor-recommended treatment they deserve. Instead, they should be spending their energy on fighting cancer.

**THE SOLUTION.** Telling your story is important, and so is presenting a solution. Tell your audience that we need lawmakers to adopt these principles of the Cancer Patients’ Timely Treatment Bill of Rights that hold insurers accountable for providing what all cancer patients deserve:

**Fair, appropriate access to doctor-recommended treatment**, with approval/denial decisions made:

- In a transparent process.
- Based on accurate and up-to-date clinical criteria.
- Appeals handled by a medically qualified expert in the type of cancer the patient is facing, and the specific type of treatment recommended.

**Timely access to treatment** with initial approval/denial decisions made within **1 day** – and appeals settled no later than 5 days – from the initial request. State insurance commissioners review final denials and hand down a decision within **15 days**

**Enforcement mechanisms executed by insurance commissioners**, including:

- Automatic approval if insurer fails to meet 5-day timeline for expedited appeal.
- Meaningful and substantial fines for repeated failure to provide fair, appropriate approvals.

### ABOUT THE ALLIANCE FOR PROTON THERAPY ACCESS

The Alliance for Proton Therapy Access is working to make sure all cancer patients seeking proton therapy receive fair and timely payment decisions from their health insurers. Patients, families, caregivers, and physicians are speaking out. Our mission is to attain a fast, fair, and transparent insurance review process for cancer patients in need of proton therapy.