The National Association for Proton Therapy

A PATIENT'S GUIDE TO

NAVIGATING THE INSURANCE APPEALS PROCESS

Partnering with your Healthcare Provider to Access Proton Therapy

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Dealing with cancer is a stressful time for any patient and their family members.

A cancer diagnosis can be overwhelming, and if your insurance company denies your treatment, it can only add to the uncertainty you feel.

However, there are options to consider after a denial, and opportunities for a positive outcome. It is crucial to understand that there are several steps that you and your healthcare provider can take to reverse or appeal the decision, enabling you or your loved one to access timely treatment.

It is essential to realize that navigating the appeals process can be intricate, and winning an appeal requires patience, persistence, and a good understanding of why your physician recommended proton therapy.

We provide guidance and a roadmap that you can use to help bolster your chances of success in overturning a denial and obtaining approval for proton therapy.

Proton therapy providers **partner** with cancer patients to face this challenge by taking a proactive approach to appealing these denials. Cancer patients should work in collaboration with their proton therapy provider to advocate on their own behalf to overturn these denials.

NOTE: This resource was prepared by the National Association for Proton Therapy to serve as a general educational resource for patients seeking an understanding of the process involved in appealing decisions made by third party payors. You should always refer to the third-party payors' coverage guidance and documentation governing your specific situation. You are solely responsible for your appeal and the outcomes thereof, and NAPT is not responsible or liable for your use of the toolkit or reliance on its contents. You are encouraged to seek independent legal counsel for any legal concerns or questions regarding your specific insurance denial and any applicable appeal.

Understanding Your Insurance Plan

Before you begin the appeals process, it is important for you to be familiar with the type of insurance you have and how it is administered. Depending on the structure and funding of your plan, you may have additional options during and following the appeal process beyond the options outlined in your plan language.

Types of insurance plans:

- **Health Maintenance Organization (HMO)**
- **Exclusive Provider Organization (EPO) Preferred**
- **Provider Network (PPO)**
- **High Deductible Health Plan (HDHP)**
- **Employer-based Self-Funded Plan**
- **Catastrophic Health Insurance Plan**
- **Medicare**
- **Medicare Part C / Medicare Advantage Plans**
- **Medicaid**
- **TRICARE Military Plan**

If your plan is sponsored by a large corporation, or one that has alerted you that they "self- fund" their health insurance benefits, this means that the employer may maintain influence in the ultimate decisions made on payment of medical claims and healthcare decisions related to the plan language.

For **self-funded plans**, it is beneficial to keep the human resources or internal insurance personnel at the company aware of your intention to appeal.

You should also inform them about any insurance barriers that you are experiencing and explain how this is affecting your healthcare. By doing so, the human resources staff may be able to reach out to key decision makers and advocate for a favorable outcome in certain situations.

Find additional Insurance information in the Glossary

Understanding the Types of Appeals

Internal Review: Internal review is the initial step in the appeals process for healthcare denials. First Level Appeals involve submitting a formal appeal or request for reconsideration to the insurance company or payer that issued the denial. The internal review process typically requires the healthcare provider or patient to provide additional documentation, such as medical records, supporting the medical necessity or appropriateness of the denied service or treatment.

The insurance company or payer will review the appeal and reconsider the denial based on the additional information provided. Internal reviews are usually conducted by the insurance company's internal staff or a designated review team.

Second Level Appeals are typically reviewed by a medical director of your insurance plan who was not involved in the claim decision. The goal of this appeal is to prove that the request should be accepted within the coverage guidelines. There may be an additional level of appeals to determine if the medical care or service is experimental or investigational or medically necessary.

The decision of an external reviewer is typically **binding** and must be accepted by the insurance company or payer.

External Review: If the denial is not resolved through the internal review process, the healthcare provider or patient may have the option to pursue an external review.

External review involves an independent third-party review of the denial by a qualified external reviewer who is not affiliated with the insurance company or payer that issued the denial. External reviewers are typically independent medical professionals with expertise in the relevant field of medicine. The external reviewer will evaluate the denial based on the medical evidence and documentation provided, as well as applicable medical guidelines and standards of care. The decision of the external reviewer is typically binding and must be accepted by the insurance company or payer.

Expedited appeals: Both internal and external appeals are made in urgent or emergency situations where a denial of coverage could result in serious harm or adverse health outcomes. You may request an expedited review and decision from the insurance provider to address the immediate need for care.

Beginning Your Appeal: Collaboration is Key

After you receive a denial for proton therapy, talk to your provider's Patient Services team before proceeding.

Proton therapy providers have Patient Services or Insurance Billing Teams who work behind the scenes to coordinate prior authorizations and manage appeals. These experts are an invaluable resource for you and have expertise in managing denials. Along with your doctors, the billing team is there to collaborate with you and to advocate for access to the treatment that your doctor has prescribed.

To ensure your healthcare team can effectively argue or work on your behalf to give you the best opportunity to have your care authorized, it's important to be cautious and not initiate an appeal on your own as there are only a limited number of appeals available. It's recommended that you always contact your billing team before responding to any insurance denial that you receive via mail or email.

Managing your appeal is a team effort.

Normally, when your insurance company denies proton therapy, a member of your healthcare center's patient services team is likely already aware. The first step is to speak with the billing team as soon as you receive a denial. Often, they will begin the appeal process for you or have very specific personalized guidance for your unique case. They will work through any steps required by your insurance company to submit the documents for an appeal.

The appeal process may include one or multiple appeals and may last one to four weeks. Your healthcare center's billing and clinical providers will keep you informed and explain options during the entire appeals process. Again, successfully appealing a denial requires assistance from experts at your treatment center.

Preparing Your Appeal: Where to Start

How to Start

When your healthcare center receives an initial denial for proton therapy and requests an internal appeal for your denial, your insurance company may ask your healthcare provider for more information. Make sure to check your phone, voicemail, email, or other form of communication to ensure your team has the documents they need to file your appeal in a timely manner. Your insurance company should inform you and your healthcare center about any deadlines and required information to make a decision. Remember, you should also receive the denial and the reason for the denial of treatment in writing. Make sure to share any communication from your insurance provider with your healthcare provider.

Before initiating the appeals process, it is advisable to speak with a financial counselor or billing office representative at your healthcare center. This will enable you to gain a better understanding of the appeals process and receive necessary support. You should also ensure that your healthcare team or doctor contacts your insurer's medical management department or medical director to request a peer-to-peer review to discuss the specific reason proton therapy was recommended. This may help to resolve your issue without having to undergo a more formal internal appeal or exceptions request process. However, it is important to keep in mind that your provider may sometimes skip certain authorization steps, such as peer-to-peer review, to optimize your chances of success. If a peer-to-peer review is not required or recommended, you can inquire about the reasoning behind this decision and ask for alternatives.

Remember:

- To receive the denial and the reason for the denial of treatment **in writing**.
- Share any communication **from your insurance company** with your healthcare provider.

Documentation

Once you start communicating with your health insurer, it's important to document every interaction. Be sure to:

- Keep a record of every phone call made and received. Document the date, time, phone number, department, and full name and position of the health insurer representative with whom you spoke.
- Document the conversation, including the questions you asked and the answers you received. This information may be important later in the appeals process.
- Maintain copies of any written communication that you send to the health insurer, healthcare provider, or physician, as well as any written documentation that you receive.

- During conversations with your health insurer, remain calm and respectful, even if frustrated with the representative on the call. If representative believes someone is abusive, they have the right to terminate the call. If the representative is not helpful or responsive on the call, request to speak to a supervisor or manager.

Your health insurance company uses written documentation as their way to communicate the decision to deny coverage. You can request this information from the insurance company – they are legally obligated to provide it.

It is important to maintain close communication with your healthcare provider to ensure that your actions are aligned with those of their staff. **Consider yourself and the proton center staff as a team, working collaboratively to overturn the denial.**

At times, patients may make the mistake of taking actions that their healthcare provider is already taking, which can inadvertently undermine the appeal process. Therefore, it is crucial to always consult with your healthcare provider before taking any action on your own.

Important Information for Your Appeal

- A **letter of medical necessity** from your treating provider indicating the clinical reasons that proton therapy should be approved
- **Notes** from your treating physician that provide information on the medical care provided to you including how you responded to treatment
- The **results** of any relevant tests or procedures related to the requested service

Identify Why Proton Therapy Was Denied

Your health insurance plan must notify you in writing of the reason they did not authorize proton therapy, as well as how to appeal their decision. Some of these reasons include:

- Services are deemed **not medically necessary**
- Services are considered **experimental or investigational** for this condition The **effectiveness** of proton therapy has **not been proven**
- You are **not eligible** for the benefit requested under your health plan

If you have received a letter of denial, ensure that the information provided clearly addresses the reasons for the denial. If the reason is related to medical necessity, your doctor's support in the form of a letter, including any relevant research studies that support the benefits of the proton therapy in question, could be highly useful in your appeal.

It is helpful to include the following:

- Any **current medical literature such as peer reviewed studies** from professional journals documenting the medical effectiveness of proton therapy
- If you are **enrolled in clinical study**, especially a nationally recognized, federally supported clinical trials, be sure to include this information. Your provider may include a letter from the National Cancer Institute (NCI) supporting insurance coverage for evidence development
- Your own **personal narrative** or the narrative of an authorized representative describing the need for the requested service.

Tips to Remember

- Avoid verbal appeals – they are not usually effective and will count against one of your three allotted appeal steps.
- Cancer patients have the right to ask for the rationale used by the health insurer to determine a denial of coverage.
- Ask for your insurer's policy on proton beam therapy coverage and their definition of medical necessity. Some policies have a provision regarding the cost effectiveness of the requested treatment.
- Continue to follow up with the health insurer through all levels of appeal, even if continued denials are received.
- Don't skip any part of the process unless advised to do so by your doctor or healthcare provider.
- It is very important that you understand exactly why your physician recommended proton therapy as the preferred treatment for you.

A useful online resource is www.pubmed.gov

Advocating for Coverage of Treatment

Personal Letter to Your Insurance provider

To enhance the appeal of your healthcare center, inform them of your desire to submit a **personal letter to the insurance company**. It would be advisable to have the center review your letter to provide input, submit it on your behalf, or suggest the appropriate timing to include it. To strengthen your case for proton therapy approval, your letter should contain the following details:

- The reason why you and your doctor have determined that proton therapy is the most appropriate treatment for your condition.
- Pertinent clinical information regarding your health and medication history, including any medical records documenting your health history. For example, any history of heart disease, cancers, previous radiation, or other medical factors that would substantiate better outcomes with proton therapy -- specifically for you. (Your doctor should also have copies of your medical notes and records to help with this.) Problems, challenges, and hardships – medical, emotional, financial and others – that may develop from receiving other types of treatment than proton therapy.
- This may include the ways in which traditional radiation could affect your quality of life due to professional or personal responsibilities. For example, if you are a coach, singer or teacher, traditional radiation to the head, neck or throat could diminish your ability to use your voice.
- The increased costs related to treating the side effects from other types of treatment, including those such as long-term medical supplies, medical devices and medications, hospitalizations, and in-home nursing care.

Doctor's Letter to Your Insurance provider

Request that your physician write a **letter of medical necessity**. Your insurance company may have its own definition of medical necessity, but a treatment such as proton therapy may be considered medically necessary if it meets any one of these standards. It is important to know if your policy includes a provision that includes cost effectiveness when defining medically necessary care. Talk to your doctor about including reasons why proton therapy is medically necessary for your treatment and may be superior to other types of radiation.

- The service or benefit will, or is reasonably expected to, prevent the onset of an illness, condition, or disability.
- The service or benefit will, or is reasonably expected to, reduce, or ameliorate the physical, mental, or developmental effects of an illness, condition or disability.
- The service or benefit will assist the individual to achieve or maintain maximum functional capacity in performing daily activities, considering both the functional capacity of the individual and those functional capacities that are appropriate for individuals of the same age.

If Your Appeal is Denied

Follow Up

If your appeal is denied, discuss with your healthcare provider about proceeding to the next level of appeal. Do not assume that this will happen automatically as it usually does not. Ensure that you communicate your desire for a second-level or independent external review, also known as an IRO Appeal, with your provider and then with your insurance company who denied the claim.

It is important to remember that your healthcare provider's insurance billing department may be taking steps on your behalf as your guardian representative. If you take any actions that interfere with their advocacy, it could lead to delays or impair your ability to receive a successful approval.

What is an IRO?

An **Independent Review Organization (IRO) appeal** refers to a process in which an individual or a third party appeals a decision made by a health insurance plan or managed care organization. An IRO is an external, independent entity that reviews disputes or denials related to health insurance coverage, treatment decisions, or payment. It is usually the last step taken once all internal appeals have been exhausted.

An IRO is an **external, independent** entity that reviews disputes or denials related to health insurance coverage, treatment decisions, or payment.

If the independent reviewers decide that your request for treatment should be authorized, your health plan must abide by this decision. Here is what you need to know about this type of appeal:

- The independent review of an insurance company's decision to approve your proton therapy typically involves a thorough analysis of several factors.
- These include medical necessity, clinical appropriateness, the level of care required, the effectiveness of a covered benefit, any experimental or investigational elements of the care, and any other matters that involve medical judgment. The purpose of the review is to determine whether proton therapy is suitable for your specific case.
- A patient can bypass an internal appeal and go straight to an independent review if the condition is deemed life-threatening or if state law allows, or the insurance company has made missteps or delays in processing your submission or appeal for approval (documentation is critical).

- An independent review requires a formal request to be made to the insurance carrier, who then forwards the request to the insurance department for assignment to an IRO. In some cases, your healthcare center may coordinate this process on your behalf. It is important to provide your healthcare provider with any necessary signed documents or materials so that they can facilitate the process on your behalf. Some healthcare centers act as your representative for IROs and may require you to sign documents promptly to proceed.

An IRO is conducted by a third-party organization that is completely independent of your health insurance plan. If an IRO fails to overturn an insurer's decision, you still have the option to take the case to district court. On the other hand, the health plan does not have the same option if the IRO rules against it.

Nonetheless, it's worth noting that many courts are reluctant to overturn IRO decisions, unless there was a critical clinical detail missing, or an unusual event occurred during the IRO process. Such instances are rare, and it's best to consider the IRO decision as final.

Insurers are legally obligated to follow an IRO's decision. The insurer or its utilization review agent must pay the cost for an independent review.

LOOK FOR IT!

Did you know that every claim document sent from your insurance company must outline your appeal rights and the appeal process?

The Exceptions Process: Medical Necessity

The Exceptions Process for Medical Necessity allows you to request coverage for proton therapy, a cancer treatment, even if it is not included in your current insurance plan's guidelines. You can appeal the denial of proton therapy by citing that proton therapy is medically necessary. This process differs from a regular appeal, but follows a similar insurance approval approach.

Your plan documents will inform you whether to use an exceptions process or the standard internal appeal and external review process to request coverage for treatment, depending on your eligibility for this approach.

If you are unsure which route to take, you should consult your healthcare provider or contact your state's insurance department to learn more about your rights under state law. It's crucial to keep in mind that, for many plans, federal law mandates exceptions processes to:

- Provide a decision within 72 hours of the request, and within 24 hours in urgent cases.
- Provide access to an independent external review if your exceptions request is denied by your insurance company.

After speaking to your healthcare center about the denial, take the time to know your rights.

The Affordable Care Act (ACA) often specifies how your insurance company should handle your appeal, which is typically referred to as an "internal appeal." During an internal appeal, experts who work within the insurance company review your case and determine whether the denial was justified.

If the internal department denies your appeal (you may be allowed to submit up to two appeals), the ACA typically allows an independent review organization to review your case and decide whether to overturn the insurance company's decision.

Pursuing an independent external review is your right, and your insurance company cannot prevent you from doing so. Importantly, an independent review organization (IRO) is a state or federally accredited group that is entirely separate from the insurance company.

This outside review is conducted to ensure that your case's final decision is unbiased, and typically involves 1-3 impartial external medical experts who review your case. The ACA requires this final check, known as the "external review," to ensure that all the merits of your reasons for appropriate proton therapy are justly reviewed.

Although these ACA rules apply only to newer plans enacted since the law was passed, insurance companies must still comply with separate state and federal laws that offer similar rights.

For example, the Employee Retirement Income Security Act of 1974 regulates many plans predating the ACA.

Therefore, it is crucial to speak with your health care center's billing team, who can help you navigate the best approach and exercise your rights when it comes to appeals. They can inform you about the plan you have, which law or rules apply, and provide constructive guidance.

KNOW YOUR RIGHTS!

Know your right to appeal a decision made by your insurance company to ask for reconsideration without backlash is guaranteed.

Under the ACA, many insurance companies must follow this process and grant you the following rights if they deny proton therapy:

- If English is not your first language, you may be entitled to request information in your preferred language, upon request.
- You have up to 6 months from the date of your denial to request an internal appeal

If your insurance company denies proton therapy, they must notify you of the following:

- **Why proton therapy was denied**
- **The right to request an internal appeal**
- **The right to an external review if your internal appeal was unsuccessful**

- **Information about the availability of a Consumer Assistance Program (CAP) that can help you file an appeal or request a review.**

If the insurance company still denies your appeal, you can ask for an independent external review as discussed above. Your insurance company must include information on your denial notice about how to request the external review. You may be able to get help with this request from your state insurance department, or, in some states, a Consumer Assistance Program (CAP). However, you should first contact your healthcare provider as they are likely in a position to help you with arranging an external review. If the external reviewer overturns your insurer's denial, your insurer will be obligated to authorize the treatment requested. It is important to know that when an external review is pursued, they are legally binding. Unless an important fact was missing or a mistake was made during the external review, there are very few options for this decision to be overturned.

QUICK TIP:

Think of an appeal as a contract dispute over interpretation of the plan coverage details. Your plan language defines your contract.

Keep in mind that the appeal rights available to you may differ based on the state you reside in and the type of insurance plan you have. Certain group plans may mandate multiple levels of internal appeals prior to your ability to file a request for an external review. However, there are instances where you can bypass internal reviews entirely to expedite the process. To determine your rights and the most effective approach, it would be beneficial to contact your healthcare provider to discuss the best strategy for your appeal.

When to Consult an Attorney

Cancer patients may occasionally require the assistance of an attorney, particularly those who specialize in handling insurance coverage denial appeals. This can provide significant benefits to both the patients and their families.

A competent attorney will possess knowledge of the applicable state laws regarding health insurance and denial appeals, which can ensure that the health insurer adheres to their own rules as well as the law. Retaining an attorney often results in health insurers taking the denial appeal more seriously. Nonetheless, it is crucial to discuss the legal fees beforehand to ensure that the cost of legal representation does not outweigh the benefits for the individual case.

Other Options & Beginning Your Cancer Treatment

If all levels of your appeal have been denied, you should speak with your healthcare center's financial counselor or billing representative about the following options:

- Request an independent board to review the case by filing a complaint with the State Insurance Commissioner.
- Determine if paying for the treatment from your personal funds (also known as self-pay option) is a feasible option and discuss the cost of receiving proton therapy.
- If paying for your treatment is not financially viable or is not recommended by your doctor, discuss alternative ways to effectively treat your tumor. Remember, it is essential to start therapy for your cancer. Even if proton therapy is recommended, your doctor may have other effective ways to treat you, and you should not delay treatment if your doctor advises it despite the insurance denial.
- Contact your state's Representatives or Senators, who may have useful contacts or inroads at the insurance company. You can find your representative's contact information at www.house.gov/representatives/find-your-representative.

Laws & Departments that May Influence the Appeals Process

ERISA

The **Employee Retirement Income Security Act of 1974** (ERISA) is a federal law that sets minimum standards for most non-governmental health plans to provide protection for individuals in these plans.

ERISA requires that participants insured by most group health plans are informed of the processing of benefit claims, your rights when a claim is denied, and the timeline for a decision when you file an appeal.

Consumer Assistance Programs

Numerous states have implemented **consumer assistance programs** to aid individuals with appeals and to facilitate comprehension of their health insurance entitlements. Your insurance plan's correspondence should furnish you with contact information for the consumer assistance program in your state.

Alternatively, you can contact your state's insurance department as they can provide you with the necessary contact details for the consumer assistance program in your state.

You may also visit the Center for Consumer Information and Insurance Oversight at www.cms.gov/CCIIO, they work closely with state regulators and consumers to ensure the needs of the American people are being served.

Contact your state department of insurance if:

- You have a grievance against a licensed health insurer.
- You wish to learn more about the external review process.
- You would like to know more about the availability of a Consumer Assistance Program.

You can find contact information for your State Department at www.naic.org/state_web_map

Glossary

Know your type of healthcare coverage

Health care insurance can generally be categorized into two types: funded plans and self-funded plans.

Funded Plans: Funded plans are also known as fully-insured plans. In funded plans, the employer or individual pays a premium to an insurance company, and in return, the insurance company assumes the financial risk of covering health care expenses. The insurance company is responsible for paying the claims of the insured individuals, and the premiums are determined based on various factors such as the level of coverage, age, location, and other risk factors. There are different types of funded plans, including:

- Employer-Sponsored Health Insurance: Many employers offer health insurance benefits to their employees as part of their compensation package. The employer selects an insurance plan and negotiates the premiums with the insurance company. The employer usually pays a portion of the premium, and the remaining portion is deducted from the employee's paycheck.
- Individual Health Insurance: Individual health insurance plans are purchased by individuals directly from an insurance company or through the health insurance marketplace. Individuals who are self-employed, not eligible for employer-sponsored coverage, or do not have access to other forms of coverage may opt for individual health insurance.

Self-Funded Plans: Self-funded plans, also known as self-insured plans, are health insurance plans in which the employer assumes the financial risk of providing health care coverage for its employees. Rather than paying premiums to an insurance company, the employer establishes and manages a fund to pay for health care expenses. The employer is responsible for paying the claims directly and assumes the financial risk of high claim costs. Self-funded plans are subject to federal regulations under the Employee Retirement Income Security Act (ERISA) and are typically used by larger employers who have the financial resources to assume the risk of health care expenses for their employees. To protect against high claim costs, employers may purchase stop-loss insurance, which provides coverage for claims that exceed a certain threshold.

Medicare, Medicare Advantage, and Medicaid are three different government-sponsored health insurance programs in the United States that provide coverage to different populations.

Medicare: Medicare is a federal health insurance program for individuals aged 65 and older, as well as certain younger individuals with disabilities or specific medical conditions. It is divided into four parts:

- **Part A (Hospital Insurance)**: Provides coverage for inpatient hospital stays, skilled nursing facility care, hospice care, and some home health care.
- **Part B (Medical Insurance)**: Provides coverage for outpatient medical services such as doctor visits, preventive care, and medical supplies.
- **Part C (Medicare Advantage)**: Allows beneficiaries to receive Medicare benefits through private insurance companies approved by Medicare. Medicare Advantage plans often include Part D prescription drug coverage and may offer additional benefits such as dental, vision, and fitness programs.
- **Part D (Prescription Drug Coverage)**: Provides coverage for prescription medications through private insurance plans approved by Medicare.

Medicare Advantage: Also known as Medicare Part C, Medicare Advantage plans are offered by private insurance companies approved by Medicare. These plans provide an alternative way to receive Medicare benefits, as an alternative to Original Medicare (Part A and Part B). Medicare Advantage plans often include prescription drug coverage (Part D) and may offer additional benefits beyond what is covered by Original Medicare, such as dental, vision, and hearing services.

Medicaid: Medicaid is a state and federal program that provides health coverage for low- income individuals and families. Eligibility and benefits vary by state, but Medicaid generally covers a wide range of medical services, including hospitalization, prescription drugs, prenatal care, and preventive care. Medicaid is jointly funded by the federal government and state governments and administered by states within broad federal guidelines.