

NATIONAL BRAIN TUMOR FOUNDATION

Fact Sheet



Health Insurance Coverage and Brain Tumors: Frequently Asked Questions

1. What are the different kinds of insurance?

There are various kinds of insurance available, including private insurance, federal and state insurance, and COBRA. Many insurance plans have managed care. Managed care plans have a defined system of providers and apply systems and techniques to control the use of health care services. These controls include a review of medical necessity, incentives to use certain providers, and case management.

A. Private Insurance

Private insurers are companies (i.e. Blue Cross and Blue Shield, Aetna, Cigna) that contract with employers to provide insurance benefits. Individuals can also buy insurance plans from private insurers if they are not insured through an employer. Private insurers provide a number of different types of plans (i.e. HMO, PPO, and Fee-for-Service plans).

- Health Maintenance Organization (HMO) plans deliver medical services through physicians and other providers that contract with or are employed by the insurer. Patients can only see networked providers — individuals that are contracted with the insurer.
- Preferred Provider Organizations (PPO) are set up so that the insurer contracts with a group of medical care providers who furnish services at lower-than-usual fees in exchange for prompt payment and a certain volume of patients. Enrollees have the option of using medical providers that are not contracted with the insurer. However, the co-payment will be higher in those cases.
- Point of Service (POS) plans (often called open-ended HMOs or PPOs) allow enrollees to choose providers outside of the plan, yet encourage the use of network providers through financial incentives.
- Fee-for-Service health insurance plans allow the insured to make almost all health care decisions independently. The plan holder pays for a service, submits a claim to the insurance company, and, if the service is covered in the policy, receives reimbursement. Fee-for-service plans often have higher deductibles or co-payments than managed care plans.

B. Federal and State Insurance

The federal government funds Medicare (health insurance for the elderly), and partners with each of the 50 states to fund Medicaid (health insurance for low-income individuals and the disabled).

Medicare

Medicare is a federal health insurance program for people age 65 or older, people with certain disabilities, and people with End-Stage Renal Disease (ESRD).

The federal government funds the program and the Center for Medicare and Medicaid Services (CMS) administers it. CMS contracts with local insurers (i.e. BCBS, Aetna, Cigna) to administer Medicare benefits at the local level. The Medicare Program has two components: Part A and Part B. Part A benefits include coverage and payment for inpatient hospital care, inpatient care at a skilled nursing facility, home health care, and hospice care. There is no premium for Part A. Part B benefits include coverage and payment for physician services, outpatient services and supplies, durable medical equipment, and outpatient surgical services and supplies. Part B has a premium of \$54 per month. Patients are required to pay certain deductibles and co-payments for both Parts A and B.

Additional information is available on the Internet at www.medicare.gov.

Medicaid

Medicaid is a jointly-funded, federal-state health insurance program for certain low-income and disabled people. It covers approximately 36 million individuals including children, the aged, blind, and/or disabled, and people who are eligible to receive federally-assisted income maintenance payments. Medicaid is a state-administered program and each state sets its own guidelines. Additional information is available at www.cms.gov/medicaid.

C. Consolidated Omnibus Budget Reconciliation Act (COBRA)

A federal law known as the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) provides continuation of coverage between health plans. It provides a vital bridge for qualified workers, their spouses, and dependent children when their health insurance might otherwise be cut off. Because of that security, COBRA has been hailed as a much-needed safety net for families in the midst of crisis, such as unemployment, divorce, or death of a family member.

Under COBRA, persons who voluntarily resign from a job or are terminated for any reason other than “gross misconduct” are guaranteed the right to continue their former employer’s group plan for individual or family health insurance for up to 18 months at their own expense. In many cases, spouses and dependent children are also eligible for COBRA coverage, sometimes for as long as three years. However, individual plans — that is, plans purchased by individuals and not provided by an employer — are not subject to the COBRA law. If a person is covered under a self-insured plan, once that coverage ends, it is not possible to get an extension under COBRA. However, many states have developed “mini-COBRA” plans that will assist self-insured individuals whose health insurance has been terminated.

2. What should I look for when choosing insurance?

There are many things to look for when purchasing an insurance policy. Most people do not pay much attention to the details of their policies until they are facing a health care crisis. One should understand some basic provisions of the plan before signing up:

- **Co-payment** – the amount the enrollee will have to pay for each office or hospital visit
- **Deductible** – a fixed amount that the enrollee is responsible for, before the insurance plan will provide any payment
- **Annual and Lifetime Caps** – the maximum amount of out-of-pocket expenses for which the enrollee will be responsible
- **Type of Plan** – Be sure you understand the difference between an HMO plan, a PPO plan, or whatever marketing term used to define the plan’s benefit design. Be sure to read your policy. The HMO policy for one insurance company can be very different from the HMO policy for another.
- **Controls** – Health plans use a variety of controls to limit the cost of care. Be sure you understand those restrictions. For example, many HMOs require enrollees to obtain a referral from a primary care physician before seeing a specialist.
- **Services Covered** – Brain tumor patients often need neuropsychological testing, cognitive rehabilitation, and long-term care. Be sure to look at the coverage for these services. Insurance companies sometimes cover clinical trials, so be sure to look at these policies as well.

3. I have PPO or indemnity insurance. Is there anything specific I should be aware of regarding my co-payments?

Yes! Patients with PPO or indemnity insurance have more freedom to pick their doctors. However, PPO enrollees have to pay a higher percentage of the bill than HMO enrollees. For most healthy people, this is fine. However, there are details that people may overlook until they have a large medical bill. Insurance companies often agree to pay a percentage of what they consider “usual, customary and reasonable” (UCR) charges, but this may be significantly less than the doctor’s fee. For example, a doctor charges \$1,000 for treatment. One would assume if the insurance company is responsible for 80% then it will pay \$800. However, the insurance company decides what the UCR charge is for that service in that geographic area. If the insurance company decides that the UCR charge is \$500, it will pay 80% of \$500. The patient will be responsible for the remainder: \$600 instead of \$200.

If you are scheduled for a procedure or treatment, find out from your insurance company what its “usual, customary and reasonable” charges are and compare that with your doctor’s fee. You can ask your doctor to reduce his or her fees if they are out of line with what the insurance company says other doctors in the area charge for the same service.

4. I am no longer ill, but I’m afraid I’ll be denied new health insurance because of my pre-existing condition. What should I do?

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 imposes limits on the extent to which group health plans can exclude coverage for pre-existing conditions. As long as you have “credible” health insurance for 12 straight months, with no lapse in coverage for 63 days or more, coverage of medical conditions must occur as soon as you enroll in a new plan. Unfortunately,

HIPAA does not eliminate the common practice of requiring a new employee to go through a waiting period (generally one to three months) before becoming eligible to join a new group health plan at a new job. Additionally, HIPAA provides no protection if you switch from one individual health plan to another individual health plan. You may want to visit the Centers for Medicare and Medicaid Services website, www.cms.hhs.gov/riskpool/ to research high risk pool insurance offered in your state.

5a. How do I avoid having a claim denied?

You (the patient) should take a proactive role in preventing denials of your medical claims.

Verify that products, services, and/or providers are covered under your plan. Before you receive any treatment from a provider, ask the provider (or someone who works in his/her office) if the products and services you are seeking are covered under your insurance plan. If your provider does not know the answer to that question, request that the provider contact your insurer to verify that the services are in fact covered under your plan.

Determine if the products or services require prior authorization. Many insurers require that you obtain authorization for certain procedures and products before receiving them. Ask your provider beforehand to confirm whether or not services require prior authorization. If prior authorization is required, ensure that your provider has obtained the necessary permission on your behalf.

Consult the individual within your company responsible for health benefits. If the explanation you receive from your provider or insurer is not consistent with your understanding of your health benefits, do not hesitate to contact the person in your company who is responsible for benefits administration. That person is usually in the Human Resources department.

5b. How do I fight a denied claim?

Below are important guidelines to follow when you have a dispute with your health insurer. Bear in mind that every insurer has its own set of procedures for handling complaints or appeals, which must be followed.

Document Everything

It is critical to organize and maintain accurate records throughout this process. Always note the dates, times, and names (first and last) of any health plan employees you speak with about your situation. Keep copies of all correspondence related to your dispute.

Contact Your Health Plan Immediately

Many health plans offer a toll-free customer service number for enrollees to use in the case of a question, complaint, or grievance. If you find yourself in a dispute with your plan, call this number immediately. Many of these customer service numbers employ call-tracking systems to record customer complaints. By calling them, you will initiate a traceable record of concerns, complaints, and grievances.

Clearly Explain the Problem

When communicating with a representative from your health plan, be direct and to the point in explaining your problem. If the representative is not able to solve your problem immediately, ask how long you should expect to wait for a response to your complaint. The response period should be no longer than 31 days.

Put It In Writing

It is always better to have a paper trail. Following your phone conversation, send a written letter stating your complaint again. Be sure your problem is stated in a clear, concise manner and include copies of all appropriate documentation with the letter. Include your full name, the insurance company's name, your policy number and policy ID, and any test results, doctor's statements etc., that back up your complaint.

Get It In Writing

If you are denied coverage, ask the insurer to provide a letter explaining the basis for the denial. If you have it in writing, you'll be better equipped to fight back. In addition, ask for the passage from your benefits handbook that explains the basis for denial.

State What Actions You Want the Insurer to Take

While it is important to outline your grievances, you also need to say how you want this situation addressed. Clearly state what action you want your health insurer to take to solve the problem.

If Your Initial Appeal is Denied, Appeal Again

If your initial call and letter do not solve your problem, appeal your grievance to a higher level within the company. Most grievance procedures unfortunately have several levels of appeals. The process can take an excessive amount of time. When you or a family member is ill, time is of the essence. Therefore, do not hesitate to fight for your rights outside the plan's appeals system as well.

Enlist Your Doctor and Other Health Care Professionals

Do not be afraid to ask your physician to contact the insurer on your behalf. Your doctor can prove to be a powerful ally! Many doctors and health care professionals will act as advocates when patients experience problems with their insurers. The assistance of health professionals is invaluable, particularly in cases where denial of coverage hinges on the medical necessity of the service or treatment.

Seek the Assistance of Your State Insurance Commissioner

Contact your state insurance commission (or other state agency that regulates insurance) in writing about your complaint, and send them copies of correspondence between you and your insurer. Let your insurer know that you are contacting the state insurance commission by sending copies of your letters to them as well. Many states not only allow you to file complaints against your insurer, but will assist you in resolving the problem. Insurance commissions can also provide you with additional information about your rights and your insurance.

Contact Your Employer's Human Resources Department

If you receive your insurance through your employer, inform the human resources department about your dissatisfaction with the plan. If you are a federal employee, contact the Federal Employee Health Benefit Program (FEHBP) at the Office of Personnel Management (OPM).

Contact Your State and Federal Elected Officials

Your representatives in the state government and in Washington, DC may be able to assist you in the appeals process and provide other help in resolving your problem. In addition, by contacting elected officials, you are giving them a first-hand look at the problems patients commonly face within the managed care system. It may encourage them to take action to address those problems.

Be Persistent

Working through a dispute with your insurer can be an overwhelming experience. In the face of such difficulty, it is very easy to become frustrated or discouraged, but do not give up! The harder you fight back, the better the chances that your dispute will receive the attention it deserves and hopefully be resolved in your favor.

6. How do I find out if clinical trials are covered under my insurance?

The best source of information on coverage for a particular clinical trial is from the investigator conducting the trial. In many cases, the cost of therapy administered during a trial is covered by a grant provided to the investigators. The federal government recently passed legislation requiring Medicare to cover services provided to its beneficiaries during a clinical trial.

Additional information about specific state laws requiring insurance coverage for services received during a clinical trial can be found at www.insure.com/health/lawtool.cfm.

7. Will my health insurance cover drugs used off-label for treatment of my brain tumor?

The term off-label refers to the use of a prescribed medication for conditions or indications other than those stated in the FDA-approved labeling. In order for an anti-cancer drug to be covered for an off-label indication, the following criteria must be met:

1. The usage is supported by one or more citations in at least one of the three drug compendia (official pharmaceutical drug lists).
2. The usage is supported by clinical research that appears in peer-reviewed medical literature.

Currently, 31 states have developed specific state laws regarding coverage of off-label drug use. In these states, private insurance companies must cover a drug for an off-label indication if the above-mentioned requirements are met. Additionally, the U.S. Congress passed a law requiring Medicare to cover off-label use of FDA-approved anti-cancer products.

8. Who should I contact if I have more questions about insurance?

There are a number of different sources that you can turn to for additional assistance with your insurance.

Your Employer

If you, or the insurance holder, are still employed, then the first place to go for assistance would be your company's health benefits administrator. This individual should be able to help you understand the details of your insurance policy and answer any questions that you may have. If he or she does not know the answers to your questions, he or she should be able to help you obtain the information or put you in touch with someone who can.

Your Insurance Company

Most insurance companies have websites that contain basic insurance information, including information about your plan. Additionally, the website should list different numbers that beneficiaries can call, depending on their inquiry.

For general insurance questions, contact the Member Services department within the company. If you have specific questions about what is covered and not covered under your individual plan, you can contact the Eligibility or Benefits departments. For questions about a specific claim, contact the Claims Administration department.

Manufacturer-Sponsored Programs

A large number of pharmaceutical and biotechnology manufacturers have developed reimbursement support programs, which assist individuals with payment and insurance issues related to their product. These programs are available free-of-charge. In addition, most reimbursement support programs will provide assistance with any insurance issue related to the illness for which their product is being used. A listing of manufacturer-sponsored reimbursement support programs can be found on the website of the Association of Community Cancer Centers at www.accc-cancer.org/publications/hotlines.asp. The website lists a description of the types of services provided. Your physician may also be able to provide you with information about specific programs.

Internet Resources

There is a significant amount of information available on the Internet. Be aware that not all information online is reliable. Below are some useful websites for dealing with insurance problems:

Center for Patient Advocacy (www.patientadvocacy.org): Provides helpful consumer information about health care. The site contains guidelines for handling a dispute with your health plan, a glossary of insurance and medical terms, an explanation of the role of the state insurance commissioner, a directory of state insurance departments, advice and information about choosing the right physician, and contact information for regional Medicare offices and Medicare-approved HMOs.

Patient Advocate Foundation (www.patientadvocate.org): Provides information about services and resources available to assist patients in dealing with financial and insurance problems. Case managers and lawyers will work with patients on an individual basis to identify local, state, and federal programs that can provide assistance for their individual needs. They will also assist patients with issues related to access to care (i.e. preauthorization, insurance appeals processes, access to necessary drugs and devices, etc.). A number of informative publications can be downloaded free-of-charge from their website.

State Departments of Insurance and/or Managed Care: Provide information about specific insurance laws in each state and the procedures for appealing a denied claim. Additionally, many states have insurance advocates that will work with patients to help resolve insurance problems. Each of these agencies has its own website. The National Association of Insurance Commissioners website provides a list of state insurance departments. Visit www.naic.org/state_contacts/sid_websites.htm

9. What options do I have if my insurance company only pays for part of my medication?

Assistance is available for patients of all ages through manufacturer-sponsored programs (*see question 8*). In the case of children, assistance is also available through joint state and federally funded Children with Special Health Care Needs programs. Additionally, many states have now developed programs to assist the elderly with high drug costs.

Children with Special Health Care Needs Programs (CSHCN)

CSHCN programs provide services to ill or disabled children. While federal and state governments jointly fund CSHCN programs, each state has complete jurisdiction over the design, implementation, and administration of its own programs. Eligibility varies by state, based on the child's condition and the family's economic status. Nationally, these programs are administered through the U.S. Department of Health and Human Services' Maternal and Child Health Bureau (www.mchb.hrsa.gov). Information about the program in your state is available on the web or through your county health department.

State Pharmaceutical Assistance Programs for the Elderly

At least 34 states have established or authorized programs to provide pharmaceutical coverage, or assistance, primarily to low-income elderly persons or persons with disabilities who do not qualify for Medicaid. Every state covers the cost of pharmaceuticals for most Medicaid beneficiaries. If you qualify for Medicaid, check with your state Medicaid agency to see if it will cover the cost of your medications. Most of the state pharmaceutical assistance programs are limited to people with incomes below certain levels, but those levels vary widely by state. Additionally, the majority of the programs are tied to Federal Poverty Guidelines and, as a result, change each year. A few states have "drug discount" programs which are available to state residents regardless of income. A listing of states that have implemented these types of programs can be found at www.ncsl.org/programs/health/drugaid.htm.

10. What options do I have regarding payment for follow-up MRIs?

Prior to receiving your follow-up MRI, you or your provider can contact your insurer to determine if this procedure is going to be covered. If yes, ask for a specific prior authorization number, and make note of it. Your provider will need to include that prior authorization number on the claim form that he or she submits to your insurer for the MRI. If no, your physician may have to submit a *Letter of Medical Necessity* (a letter that provides a short medical history and why this specific procedure is necessary) to the insurer.

Additional assistance may be available through a manufacturer-sponsored reimbursement program. If you are currently taking a drug covered by a manufacturer-sponsored reimbursement support program, you may be able to obtain assistance through that program (see question 8). Contact the specific program for the drug to determine if assistance coverage and payment for your follow-up MRI is available.

11. What role does my doctor play in getting my treatments and checkups approved?

Your physician can play a very important role. Prior to administering any treatment or performing a check-up, the physicians or physician's office can contact your insurer to obtain prior authorization for the procedure or service. If, for some reason, your provider is not willing to obtain the prior authorization on your behalf, you can contact your insurance company directly. However, you will likely need specific diagnosis, procedure, and billing codes that your physician must provide to you.

12. Is there a non-profit agency or government body that handles insurance complaints?

All states have departments of insurance that assist patients with insurance complaints. Within those organizations there are specific departments that handle health insurance issues. Each of the state organizations has a website that provides information about the specific processes for filing insurance complaints. The websites also contain important contact information so that you can speak with someone in the department directly. The National Association of Insurance Commissioners website, www.naic.org/state_contacts/sid_websites.htm, provides a list of State Insurance Departments.

The following web resources may also be helpful:

- U.S. Department of Labor (DOL) Office of Disability Employment Policy (ODEP)
www.dol.gov/odep/
Provides fact sheets regarding disability issues, discrimination and legal rights.
- National Coalition for Cancer Survivorship (NCCS)
www.canceradvocacy.org
Publication available: "What Cancer Survivors Need to Know About Health Insurance"
- Pharmaceutical Research & Manufacturers of America (PhRMA)
www.phrma.org
Directory of Prescription Drug Patient Assistance Programs.
- Indigent Patient Programs Needy Meds
www.needymeds.com
Lists medicine assistance programs available from drug companies.

This fact sheet was prepared by Guilford Pharmaceuticals and was reviewed by brain tumor patients and health care professionals.

The National Brain Tumor Foundation (NBTF) was founded in 1981 as a non-profit organization by people whose lives were affected by brain tumor disease. NBTF provides support services for patients and their families and raises funds for research to treat and cure brain tumors. For more information call 800.934.2873.

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