

NORTH AMERICAN BRAIN TUMOR COALITION PRINCIPLES OF QUALITY CARE FOR BRAIN TUMOR PATIENTS

Brain tumors are actually 120 different diseases. As a result of the diversity of brain tumors, diagnosis with a brain tumor effectively means diagnosis with a rare or ultra rare-disease. Many primary care physicians have limited experience with brain tumor patients and may have no experience related to a specific kind of brain tumor. Improving the treatment outcomes for those with brain tumors requires that they receive prompt access to diagnostic services and quality brain tumor care, often at health care centers that treat a significant number of brain tumor patients.

Efforts by health plans to manage access to health services may represent an unreasonable barrier to care for brain tumor patients if those efforts slow access to care or prevent access to care at a major brain tumor center. Coordination of care by a primary care physician or requirements for pre-authorization of care may adversely affect the quality of brain tumor treatment.

The North American Brain Tumor Coalition recommends establishment of principles that health plans should observe in treating people with brain tumors.

1. Easy access to diagnostic tests -- Because early diagnosis of brain tumors is critical to improved outcome, patients with symptoms consistent with such tumors should not be denied access to state-of-the-art diagnostic tests if the diagnosis of a brain tumor cannot be definitively ruled out by the primary care physician. Health plans should develop guidelines identifying symptoms that are to be considered potential indicators of brain tumors.
2. Immediate referral upon diagnosis -- Upon suspicion of a diagnosis or recurrence of a brain tumor, a patient must immediately be referred to physicians specializing in brain tumors for evaluation and treatment. If necessary, health plans should make prompt referrals to physicians outside the plan network.
3. Pediatric patients -- Children who are diagnosed with brain tumors must be referred to physicians specializing in pediatric brain tumors. Young adult patients who were diagnosed with brain tumors as children should be given the option to be monitored and treated by pediatric neuro-specialists, even if those physicians are considered outside the plan network. This practice will help ensure continuity of care for young adults.

4. Multi-disciplinary approach -- The successful management of people with brain tumors often requires the involvement of more than one specialty. Decisions on when to involve particular specialties in the care of a brain tumor patient should not be made by a primary care physician but instead by a physician specializing in the treatment of brain tumors. The primary care physician can serve as a source of referrals, be part of the management team, and be kept informed of a patient's treatment and progress.
5. Monitoring and follow-up care -- Because of the strong possibility of long-term and late effects and/or recurrence of brain tumors, careful monitoring and follow-up care are critical. Brain tumor patients should be monitored by appropriate specialists in concert with primary care physicians. Patients with brain tumors should be guaranteed ready access to diagnostic tests that will allow detection of late effects and/or recurrence.
6. Gatekeeper function -- During the period of active treatment of a brain tumor patient, the patient's primary care physician should not have responsibility for approving particular tests, procedures, and treatment. In such circumstances, any gatekeeper function should be performed by the specialist physician principally responsible for the patient's care, who will also be responsible for communicating with the primary care physician.
7. Rehabilitation services -- In the frequent cases where patients need rehabilitative care to overcome physical, cognitive, and emotional problems resulting from brain tumors and their treatment, health plans must make available the full range of rehabilitation services, including physical therapy, occupational therapy, speech and language therapy, and neuro-psychological services.
8. Access to specialized facilities -- Brain tumor patients must have access to specialized facilities for diagnosis, treatment, and follow-up care.
9. Access to care outside of plan without cost to beneficiary -- In those circumstances where services must be provided outside the plan network, those services must be provided without extra cost to the beneficiary.
10. Coverage of off- label drug uses -- Brain tumor patients should have access to drugs used off-label, according to the standards of coverage that are followed in the Medicare program.
11. Clinical trials -- Brain tumor patients must be guaranteed access to high quality, peer-reviewed clinical trials. Such trials may represent the best possible treatment option, and the routine patient care costs of trial enrollees should be covered by health plans.

12. Psychosocial Services -- Brain tumor patients and their families must have access to psychological counseling including symptom management, psychosocial services, hospice care, and end-of-life services.
13. Protection Against Catastrophic Expenses – Initial treatment for a brain tumor may require an intensive utilization of health care services, and management of side effects of brain tumors and their treatment and possible recurrences may require significant use of health care services over a lifetime. Brain tumor patients must enjoy protection from annual and lifetime spending caps that would block their access to health services.