ACKNOWLEDGEMENTS

ABOUT THE AMERICAN BRAIN TUMOR ASSOCIATION

Founded in 1973, the American Brain Tumor Association (ABTA) was the first national nonprofit organization dedicated solely to brain tumor research. The ABTA has since expanded our mission and now provides comprehensive resources to support the complex needs of brain tumor patients and caregivers, across all ages and tumor types, as well as the critical funding of research in the pursuit of breakthroughs in brain tumor diagnoses, treatments and care.

To learn more, visit abta.org.

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INTRODUCTION

Conventional external beam radiation therapy is the most common form of radiation treatment for brain tumors. The goal of radiation is to destroy or stop a brain tumor. Radiation success depends on several factors: the type of tumor being treated (some are more sensitive to radiation than others) and the size of the tumor (smaller tumors are usually more treatable than larger ones).

Some tumors are so sensitive to radiation that radiation therapy may be the only necessary treatment. Radiation can be used after a biopsy, or following partial or complete removal of a brain tumor. When a tumor is surgically removed, some microscopic tumor cells may remain. Radiation attempts to destroy these remaining cells.

Radiation is also used to treat inoperable tumors and tumors that have spread to the brain from another part of the body (metastatic brain tumors). Radiation may also be used to prevent metastatic brain tumors from developing. This type of preventative therapy is called prophylactic radiation, and is most often used for people with small-cell lung cancer. Sometimes the purpose of radiation therapy is to relieve symptoms rather than to eliminate the tumor. This is called palliative radiation.
Before you or your family member begins radiation treatments, you will meet a doctor – a radiation oncologist – to plan your therapy. A radiation oncologist is a physician with advanced, specialized training in the use of radiation as a treatment for disease in any part of the body, including the brain. When you meet with the radiation oncologist, ask what the goals are for your treatment plan. It is also common to inquire as to the duration, in weeks, of the treatment course. This is also your opportunity to ask questions about the treatment itself so you understand the recommendations made by your radiation oncologist.

**HOW DOES RADIATION WORK?**

Radiation (also called X-rays, gamma rays, protons or photons) either kills tumor cells directly or interferes with their ability to grow. Radiation affects both normal cells and tumor cells. However, following standard doses of radiation, healthy cells repair themselves more quickly and completely than tumor cells. As the radiation treatments continue, an increasing number of tumor cells die. The tumor shrinks as the dead cells are broken down and disposed of by the immune system.

Like any organ in the body, normal brain tissue can tolerate only a certain amount of radiation. Different brain tumors require different amounts of radiation to cure or control them. Sometimes a form of local radiation may be used in addition to, or following, conventional radiation. That is called a radiation “boost.”

Radiation therapy may be given before or after chemotherapy, or with drugs that make tumor cells more sensitive to the radiation (radio sensitizers). This is becoming more common in the treatment of more aggressive brain tumors. In infants and young children, chemotherapy may be used to delay radiation therapy until the developing brain is more mature.
WHAT HAPPENS BEFORE TREATMENT BEGINS?
First, the radiation oncologist will review your medical records, including the operative reports, pathology reports and imaging studies such as CT or MRI scans. The type and location of the tumor is determined from your records. Of course, the radiation oncologist will meet with you and discuss the treatment plan and expectations in detail. The radiation oncologist then decides on the radiation target area and the amount of radiation that area should receive.

The area to be radiated usually includes the tumor and an area surrounding the tumor. This is because some brain tumors have “roots” that extend out into surrounding normal brain tissue. For those with a metastatic tumor, radiation may be given to the entire brain. If the tumor has spread to the spinal cord, or if there is a high risk of this type of spread, the spine might be radiated as well.

To maximize the amount of radiation the tumor receives, and to avoid as much healthy tissue as possible, the radiation frequently will be directed from several different angles. Computers are used to help shape and direct the radiation beams. The radiation oncologist will usually require a CT or MRI to assist with the treatment planning process and to confirm the target area.

Once the decision to proceed with radiation has been made, one or two planning sessions (called simulations) are required. Each session will last approximately 30 minutes. You likely will be fitted for a face mask designed to help hold your head still, and specialized marks will be placed on the mask to ensure accurate treatment delivery. On some occasions, a mask is not used, and marks will be placed on the skin. The marks and face mask help insure the accurate position of your head for the radiation treatment.
You also will have another opportunity to meet with the radiation oncologist before your treatments begin. Use that time to ask any questions you still have. You might want to discuss the benefits and risks of the treatment. Managing potential side effects during or after treatment is another common area of concern. Make sure you have a clear idea of who to call, the phone number and when that call should be made if something unusual occurs between treatment sessions.

Before starting your treatments, be sure to let the radiation oncologist know about all the medications you are taking. Also, if you are using antioxidant vitamins or herbal supplements, bring the bottle(s) with you so the doctor can see the products and the amounts you are taking. He or she will give you instructions about using them during radiation therapy.

Once your radiation oncologist has planned the treatment, certified radiation technologists called radiation therapists will actually operate the treatment equipment. They are specially trained and licensed to administer the prescribed treatments under the doctor’s supervision.
WHAT HAPPENS DURING TREATMENT?
Radiation therapy is usually given on an outpatient basis. Unless radiation is to be delivered to the spine, you won’t have to remove or change your clothes for treatment.

The total procedure – checking into the radiation department, waiting your turn, and receiving treatment – should take between 10 and 20 minutes. The treatment itself takes just a few minutes.

The session takes place in a specially designed room which houses the treatment machinery (a linear accelerator or “linac”). The radiation equipment is very large. The therapist will help you onto the table used for the treatment and position you. The radiation machine will then be directed to rest above, below or to the side of you. The table may move slowly from side to side while you are in the treatment room, but only under the expert guidance of the radiation therapists.

Your therapist will leave the room prior to the actual treatment (just as the dentist does when X-ray ing your teeth). Don’t worry – you’ll be seen and heard on a closed-circuit television monitor. Even though you seem to be alone, you’re still in close contact. If you need help, just speak up.
Radiation treatments are painless and feel no different than getting a chest X-ray. During the treatment, a few people notice an unusual smell or see flashes of light even when their eyes are closed. That is normal. You will need to remain perfectly still until the session is over. Special equipment or medication can help infants and young children stay still.

During the treatment you may hear a gentle humming noise which is made by the treatment machine. Sometimes, the therapist will come in and out of the treatment room, usually to reposition you or the treatment equipment.

A typical schedule for radiation therapy consists of one treatment per day, five days a week for two to seven weeks. However, treatment schedules may vary. Your doctor will explain your individualized schedule to you.

You are NOT radioactive during or after this type of radiation therapy. The radiation is active only while the machine is on. There is no need to take any special precautions for the safety of others.

You may hear various personnel in the radiation oncology department use a variety of letters as a short hand to describe a portion of the treatment. The most common would be IMRT, which stands for intensity modulated radiation treatment. This is a sophisticated method of treatment delivery that allows for precise placement of the radiation dose. It is most frequently used when the tumor is close to critical parts of the brain, such as the eyes or visual apparatus. Another short hand expression you might hear is IGRT, which stands for image guided radiation therapy. It simply means that images are taken each day prior to the treatment to make sure that everything is lined up just as prescribed by your physician.
WHEN WILL I SEE THE RESULTS OF RADIATION THERAPY?

Tumor cells damaged by radiation cannot reproduce normally. Tumor cells that are unable to reproduce die over a period of weeks to months. During that time, the brain works to clear away those dead or dying tumor cells. This may cause swelling in the area of the tumor.

The best way to measure the effects of radiation is by a CT or MRI scan. An initial follow-up scan is usually planned for one to three months following treatment unless there is some reason to perform one sooner. Scans taken during this time can be confusing because the dying or dead cells are often accompanied by brain swelling, resulting in the mass appearing larger than the original tumor when scanned. That mass may also cause symptoms similar to the original tumor.

If your post-treatment scans do not show shrinkage immediately, don’t be disappointed. It often takes several months or more before your scans show the real results of treatment, and sometimes the scan does not look improved because the tumor is replaced by scar tissue.

Your symptoms may fade as your tumor shrinks. Sometimes they disappear completely. Some effects may continue even if your brain tumor is cured. Some symptoms, whether related to the tumor or its treatments, may not resolve. Your doctor can discuss this possibility with you.

WHAT ARE SOME OF THE COMMON SIDE EFFECTS?

Most people have some side effects from radiation therapy. The immediate or short-term effects tend to be manageable discomforts rather than pain or serious problems. Knowing about these in advance can help you plan for some temporary, but necessary, flexibility in your schedule.
FATIGUE
The most common side effect of radiation therapy is fatigue (tiredness). Fatigue is temporary. You may begin to feel unusually tired a few weeks into treatment, and this may last weeks or even several months after treatment has ended. Most patients feel run down or tired, but some become very fatigued.

Make a plan to conserve your energy, but don’t become inactive. Do what you must at the time of day you feel best. Ask family and neighbors to help with routine jobs such as laundry, grocery shopping, or car pools. Can you work shorter hours while you are in treatment? Can you do some of your work at home? Plan easy meals using prepared foods or rely on frequent, nutritious snacks.

Also, a small amount of exercise (if approved by your doctor) may actually increase your energy level. Once you finish treatment, you’ll probably begin feeling better, but be patient. You will generally feel much less tired a few weeks after the treatment is complete, but it can be a long time (as long as six months or more) before you feel “normal” again.

HAIR LOSS
About two weeks into treatment you may start to lose the hair in the path of radiation beams. Hair loss is related to the amount of radiation, the area radiated and the use of other treatments such as chemotherapy. Your doctor can advise you whether you will experience this effect, and if it is likely to be permanent or temporary.

If the loss is temporary, hair regrowth usually begins about two to three months following treatment, but may take six months to a year for maximum regrowth. A change of texture and/or change in the color of the re-growth may occur.

SKIN CHANGES
You may notice changes in your skin over the area being treated. It may be reddened, darkened, itchy or appear
“sunburned.” It’s important not to scratch or rub these spots. If your ears are in the path of the radiation beams, they may become sore and reddened inside and out. You may have difficulty with your hearing, due to fluid collecting in your middle ear. **Do not treat any of these symptoms by yourself.** Ask your doctor or radiation therapist for advice. Over the counter lotions can make the situation worse; use only products your doctors or nurses suggest.

Avoid anything that causes irritation to the area being radiated. Do not use heating pads or ice packs during this time. Stay out of the direct sun, and keep your head covered if you have any skin problems or if you are taking a radiosensitizing drug.

**SWELLING/EDEMA**

Edema (brain swelling) is another common, usually temporary, side effect of radiation therapy. The edema can cause an increase in your brain tumor symptoms. Steroids are medications used to help reduce that swelling. The medications may be given to you during, and for a while after, your treatments.

Be sure to follow your doctor’s exact instructions for taking the steroids. **Never abruptly discontinue steroid medications.** When they are no longer needed, your doctor will give you instructions for “tapering,” or slowly reducing, the steroids. This process allows your body time to slowly begin making its own natural steroids again.

Often, your doctor will prescribe a medicine to prevent the stomach irritation which may occur with steroid use. Taking the steroids with meals can also help reduce this side effect. Some people who take steroids experience a markedly increased appetite, along with weight gain which often is most apparent in the face and abdomen. Your facial appearance and body shape will return to baseline once the steroids are discontinued, but it will take several months.
Nervousness or difficulty sleeping can be a side effect of steroids. Your doctor may prescribe a medication to calm you or help you sleep. Some people who take steroids develop a yeast infection in their mouth. If this occurs, you’ll notice a sore mouth or throat, possibly with “fruity” smelling breath. Yeast infections are easily treated with medication. People with (or prone toward) diabetes might experience an increase in their blood sugar level. If you begin to have excessive thirst with frequent urination – common symptoms of diabetes – let your doctor know immediately. Also, people who take steroids for more than a month may notice a weakness in their legs. This may be noticed when they try to stand from a sitting position, or when they get up from the bed or the toilet. This symptom will disappear once the steroids are discontinued, although it may take several weeks to months for one’s strength to completely return.

**NAUSEA**

Sometimes people feel sick to their stomach following their radiation treatment, especially if they are receiving chemotherapy at the same time. There are medications, called anti-emetics, which help control nausea. These medicines are generally taken prior to, and sometimes after, your treatments. It’s important to let your doctor or nurse know if you feel nauseated so they can help you manage this symptom. If for any reason the first anti-emetic medication does not work, call your nurses to let them know. Other medications or medication combinations can be tried until a treatment is found that works best for you.

Constipation can be a side effect of some of the common nausea medications, so be alert for changes in your bowel habits. If you develop constipation, it is generally easy to control as long as it is not present for too long before starting treatment.

While you are going through treatment, your body needs extra protein and calories to keep your immune system
healthy and to heal the effects of radiation. Ask your doctor for a referral to the dietician or nutritionist at the hospital. He or she can determine your personal nutrition needs, and help you with personalized dietary counseling. If you choose to look for nutrition services outside of the hospital, be sure to seek a licensed and registered professional.

**SEXUAL EFFECTS**

Your desire for sexual activity may be lowered now. Again, this is a normal – and temporary – side effect of therapy. The fatigue of treatment, as well as the conscious and unconscious stress associated with having a brain tumor, can cause this effect in both men and women. For now, try non-sexual closeness. Sexual desires often return to normal after treatment. (Also, don’t be surprised if one of the side effects of steroid treatments is an increase in sexual interests). If you are sexually active, it is best to use effective birth control as you do not want to conceive a baby during radiation treatment.

**BLOOD CLOTS**

For reasons that are not well understood, as many as one in three people with a brain tumor may develop a blood clot. Most often, the clot develops in one leg, causing swelling of the foot, ankle and/or calf, usually with pain in the calf or behind the knee. If you develop these symptoms, call your doctor immediately. A special test called a Doppler study can be performed. If a clot is seen, blood thinners can be prescribed to dissolve the clot and prevent it from traveling into the lungs.

Because people who have a brain tumor tend to have blood clots more often than people who do not have a brain tumor, it is important that your doctor be aware of all the medications you are using. This includes over the counter drugs, herbs, vitamin supplements and complementary or alternative therapies. Filling your prescriptions at one pharmacy can also help avoid drug interactions that can make clotting problems worse.
EFFECTS ON MEMORY
It is not uncommon to have some change in memory, short-term in particular, related to the treatment. If patients have some issues with memory, it is often short term items such as what they had for lunch yesterday, or remembering the few items to buy at the grocery store. Memory changes can be related to the tumor, surgery, chemotherapy, or radiation. Fatigue also can play a role in decreasing memory and attention. Adding a little bit of light exercise to the daily routine can be helpful in maintaining memory. Although the treatments themselves, including radiation, can have an impact on memory, tumor growth has the greatest risk to memory and other neurologic decline. Generally patients feel that their potential memory issues are less bothersome over time, but can be persistent.

OTHER EFFECTS
Radiation therapy may have intermediate and long-term effects. Information about those effects should be obtained from your doctor who can help you weigh the benefits of the treatment against the risks involved. If you have any questions, or notice any changes you think are important or worrisome, call your doctor or the radiation department at the hospital.

THE ABTA IS HERE FOR YOU
You don’t have to go through this journey alone. The American Brain Tumor Association is here to help.

Visit us at www.abta.org to find additional brochures, read about research and treatment updates, connect with a support community, join a local event and more.

We can help you better understand brain tumors, treatment options, and support resources. Our team of caring professionals are available via email at abtacares@abta.org or via our toll-free CareLine at 800-886-ABTA (2282).
AMERICAN BRAIN TUMOR ASSOCIATION
INFORMATION, RESOURCES AND SUPPORT

BROCHURES
Educational brochures are available on our website or can be requested in hard copy format for free by calling the ABTA. Most brochures are available in Spanish, with exceptions marked with an asterisk.

GENERAL INFORMATION
About Brain Tumors: A Primer for Patients and Caregivers
Brain Tumors Handbook for the Newly Diagnosed*
Caregiver Handbook*

TUMOR TYPES
Ependymoma
Glioblastoma and Anaplastic Astrocytoma
Medulloblastoma
Meningioma
Metastatic Brain Tumors
Oligodendroglioma and Oligoastrocytoma
Pituitary Tumors

TREATMENT
Chemotherapy
Clinical Trials
Conventional Radiation Therapy
Proton Therapy
Stereotactic Radiosurgery*
Steroids
Surgery

Information
American Brain Tumor Association
1900 Eye Street, N.W.
Suite 800
Washington, DC 20006
202-479-0450
www.abta.org

General Information
About Brain Tumors: A Primer for Patients and Caregivers
Brain Tumors Handbook for the Newly Diagnosed*
Caregiver Handbook*

Tumor Types
Ependymoma
Glioblastoma and Anaplastic Astrocytoma
Medulloblastoma
Meningioma
Metastatic Brain Tumors
Oligodendroglioma and Oligoastrocytoma
Pituitary Tumors

Treatment
Chemotherapy
Clinical Trials
Conventional Radiation Therapy
Proton Therapy
Stereotactic Radiosurgery*
Steroids
Surgery

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INFORMATION

ABTA WEBSITE | ABTA.ORG
Offers more than 200 pages of information, programs, support services and resources, including: brain tumor treatment center and support group locators, caregiver resources, research updates and tumor type and treatment information across all ages and tumor types.

EDUCATION & SUPPORT

- ABTA Educational Meetings & Webinars
  In-person and virtual educational meetings led by nationally-recognized medical professionals.

- ABTA Peer-to-Peer Mentor Program
  Connect with a trained patient or caregiver mentor to help navigate a brain tumor diagnosis.

- ABTA Connections Community
  An online support and discussion community of more than 25,000 members.

- ABTA CareLine
  For personalized information and resources, call 800-886-ABTA (2282) or email abtacares@abta.org to connect with a CareLine staff member.

GET INVOLVED

- Join an ABTA fundraising event.
- Donate by visiting abta.org/donate.

CONTACT THE ABTA

CareLine: 800-886-ABTA (2282)
Email: abtacares@abta.org
Website: abta.org