



FOCUSING ON TREATMENT

Sharing knowledge. Sharing hope.

Radiation Therapy

A BASIC GUIDE



American Brain Tumor Association

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American Brain Tumor Association

A Word About ABTA

Founded in 1973, the not-for-profit **American Brain Tumor Association** has a proud history of funding research, providing patient services, and educating people about brain tumors. Our mission is to eliminate brain tumors through research and meet the needs of brain tumor patients and their families.

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Introduction

This pamphlet is about conventional external beam radiation therapy, the most common form of radiation treatment for brain tumors. Other forms of radiation therapy and other methods of treatment are also used to treat brain tumors. For information about those other therapies, please contact us.

Why Do I Need Radiation Treatments?

The goal of radiation therapy is to cure brain tumors, or, when brain tumors can't be cured, to slow their growth or shrink them. The ability of radiation to cure a tumor depends on several factors, primarily, 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 treatment needed. Radiation is most often used after biopsy, partial, or complete removal of a brain tumor. When a tumor is surgically removed, some microscopic tumor cells may remain. Radiation attempts to destroy those 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). Or, radiation may be used to prevent metastatic brain tumors from developing. That 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 cure. This is called palliative radiation.

How Does Radiation Work?

Radiation (also called x-rays, gamma rays, 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.

Like any organ in the body, normal brain tissue can tolerate only a limited amount of radiation. And 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. 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, a specially trained doctor (a radiation oncologist) reviews 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 established from that information. 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 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 avoid as much healthy tissue as possible, the radiation may be directed from several angles. Computers often are used to help shape and direct the radiation beams. The radiation oncologist may require more scans or x-rays to assist with the treatment planning process and to verify the target area.

Once the decision to proceed with radiation has been made, a planning session (called simulation) is required. This session will last between 30 minutes and 2 hours. Special marks will be placed on your skin, or you may be fitted for a device designed to help hold your head still. The marks and head-holding device help insure the accurate position of your head for the radiation treatment.

HEAD HOLDING DEVICE



Courtesy of Dr. Shaw

You will have the 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 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 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.

By the time you check into the radiation department, wait your turn and have a treatment, somewhere between 10 and 20 minutes will have elapsed. The treatment itself, however, takes only a few minutes.

LINEAR ACCELERATOR USED TO DELIVER RADIATION THERAPY



Courtesy of Siemens Medical Systems, Inc. Oncology Care Systems

The session takes place in a specially designed room which houses the treatment machinery. The radiation equipment is very large and impressive. The therapist will help you onto the table used for the treatment and position you. The radiation machine will then be positioned above, below, or to the side of you. Your therapist will leave the room prior to the actual treatment (just as the dentist does when x-raying 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 contact. If you need help, just speak up.

Radiation treatments are painless and feel no different than getting a chest x-ray. You will not feel, see, or hear anything. 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 machine.

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

You are NOT radioactive during or after 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.

When Will I See the Results of Therapy?

Tumor cells damaged by radiation cannot reproduce normally. Gradually, the damaged cells die. Radiated tumor cells die about as quickly as they grow — which is generally over a period of weeks to months. The brain then struggles to clear away those dead tumor cells. Because of this lengthy process, it can be several months or longer before the full effects of the therapy can be evaluated.

The best way to measure the effects of radiation is by 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 dying or dead cells, often accompanied by swelling, may appear on the scan to be a mass larger than the original tumor. And, that mass may cause symptoms similar to the original tumor. If your post-treatment scans do not show tumor 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. But 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 extreme 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. 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. It can be a long time (as long as six months) before your energy level achieves a new "normal."

HAIR LOSS

About two weeks into treatment you may start to lose the hair in the path of the 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 2-3 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 regrowth may occur. Attractive scarves (some even have bangs sewn onto them) or caps can help. Plan ahead – contact us before you begin treatment. We'll be happy to provide resources for hair loss accessories.

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, or you may have difficulty with your hearing. **Do not treat any of these symptoms by yourself.** Ask your doctor or radiation therapist for advice. 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, or keep your head covered if you have any skin problems or if you are taking a radiosensitizing drug.

EDEMA/STEROID EFFECTS

Edema (brain swelling) is another common, 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.

Other steroid side-effects include nervousness or difficulty sleeping. 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

Less commonly, some people might feel sick to their stomach following their radiation treatment. If you experience this effect, tell your doctor or technologist. There are medications, called anti-emetics, which help control nausea.

Your body now needs extra protein and calories to keep your immune system healthy and to heal the effects of radiation. Eating frequent, small amounts might be helpful. Consider egg nog or milk shakes for snacks. Add yogurt, honey, powdered milk, or powdered supplements to your liquids. The dietician or nutritionist at the hospital can help you with meal-planning tips to spark your interest in food and keep your diet balanced.

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.)

OTHER EFFECTS

Radiation therapy may also 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.

When the Treatments Are Over...

Most people feel an unexpected sense of depression when their treatments end. The frequent appointments for therapy stop, and appointments for follow-up care become further apart. The pace slows, and another period of adjustment begins. It is a time when it becomes difficult to do nothing after having done so much.

Your task now is becoming well again. Make appointments for your follow-up doctor visits or scans and mark them on your calendar. Begin to rebuild your life. Within the guidelines set by your healthcare team, exercise and eat well. Get out — go to the movies, visit museums. Find a support group if you'd like to meet others with brain tumors. See friends. Be very good to yourself! You deserve it. But be patient — getting well takes time.

A Next Step

“Becoming Well Again Through...” is an ABTA quality of life series exploring rehabilitative medicine, memory retraining, caregiver stress management, and managing fatigue. Please call us at 800-886-2282 for a copy of the series.

Our web site — www.abta.org — offers extensive brain tumor information, treatment and research updates, and patient/family stories. The thread that runs through each of our services and programs is hope. Become involved — join us in some way, to make sure there is a cure, and ultimately, a way to prevent brain tumors.

We hope that the information in this pamphlet helps you communicate better with the people who are caring for you. Our purpose is not to provide answers; rather, we encourage you to ask questions.

Questions I Want to Ask

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Publications & Services

BUILDING KNOWLEDGE

A Brain Tumor — Sharing Hope
Tumor del Cerebro — Compartiendo la Esperanza
Dictionary for Brain Tumor Patients
Living with a Brain Tumor
A Primer of Brain Tumors

FOCUSING ON TUMORS

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

FOCUSING ON TREATMENT

Gene Therapy
Radiation Therapy of Brain Tumors: A Basic Guide
Stereotactic Radiosurgery

FOR & ABOUT CHILDREN

Alex's Journey: The Story of a Child with a Brain Tumor
(for ages 9-13, video and booklet formats)
When Your Child Returns to School

SUPPORT RESOURCES

A Bibliography of Books & Resources
Brain Tumor Survivor's Guide to the Internet
Care Options
Emergency Alert Wallet Cards
Financial Aid Resources
Housing During Treatment Resources
Organizing a Self Help Group
Scholarship & Educational Financial Resources
Support Group Listings
Transportation Resources
Wig and Head Covering Resources
Wish Granting Resources



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