



Brain Tumors

This booklet provides information and resources that University of Washington Medical Center (UWMC) and Harborview Medical Center patients and family members have told us have been helpful.

There are also excellent materials from the American Brain Tumor Association that we have in our center. We are happy to provide copies of these materials at no charge.

Introduction

The diagnosis of a brain tumor can be very frightening for patients and their families. The neuro-oncology health care team is here to help you understand more about your condition and its treatment. We can also suggest resources, help you deal with stress, and assist you in obtaining the best possible care.

You may find it easier to cope with your illness if you:

- Understand the reasons for the doctor's recommendations.
- Know in advance what to expect.
- Know the symptoms to look for and what to do if they should occur.
- Feel reassured you are receiving state-of-the-art treatment.

You may want to read more about your illness, to:

- Know that no possible option has been overlooked.
- Explore investigational treatments.

As you read through this booklet, please keep in mind that while you may share some traits with others who have the same type of tumor, your symptoms and response to treatment are unique to you.

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Neuro-Oncology Team Members

Your neuro-oncology team includes doctors, nurses, social workers, and patient care coordinators from University of Washington Medical Center and Harborview Medical Center.

The doctors include:

- **Neurosurgeons**, who perform an operation to biopsy or remove the tumor from your brain.
- **Neuro-oncologists**, who prescribe chemotherapy drugs for the treatment of brain tumors. They are specialists in the medical treatment of brain tumors.
- **Radiation oncologists**, who plan and prescribe the radiation treatment for brain tumors. They are specialists in radiation therapy for brain tumors.
- **Neuroradiologists**, who review your scans and any X-rays.
- **Neuropathologists**, who look at the tumor tissues and identify what kind of tumor cell you have. This information is important in knowing how to manage your illness.

Other members of your health care team include:

- **The Nurse Practitioner (ARNP) and Physician Assistant Certified (PAC)**, who work as part of the neuro-oncology health care team. They diagnose, monitor symptoms, and prescribe tests and medications. You may see one of these providers during your treatment and follow-up visits.
- **Nurses**, who provide patient care in areas such as the Radiation Oncology Clinic, Neuro-Surgery/Neuro-Oncology Clinic and the Infusion Center. Call the nurse when you have questions or concerns about your diagnosis, surgery, radiation treatment, chemotherapy, or any symptoms or problems. Nurses are your advocates. They can help you reach the doctor, interpret information that has been given to you by doctors and other health care staff, and help connect you to other people who can assist you, such as the social worker, dietitian, rehabilitation therapists, neuropsychologists, and visiting nurse services.

- **Social Workers**, who provide counseling to patients and family members who face a serious illness. They can help you deal with the emotional and psychological impact of your illness and find coping strategies for managing stressful changes you may experience. They can provide support and reassurance as you deal with the unfamiliar systems and procedures of a large medical center. They can also direct you to resources you may need. Sometimes, social workers lead support groups. Ask your nurse if you would like to meet with a social worker.
- **Front Desk Staff of the Cancer Center**, who facilitate your care at University of Washington Medical Center and Harborview Medical Center by assisting you with visits for CT or MRI scans and other diagnostic tests, and contacting other medical services (such as the eye clinic, dermatology, etc.) to arrange for consultations that your doctor requests.
- **The Neuro-Oncology Patient Care Coordinator**, who schedules initial visits with the neurosurgeon or neuro-oncologist and works with their staff to schedule any surgical procedures needed.
- **Other Staff**, who include medical assistants in the clinic, radiation-treatment therapists who are experts in administering your radiation treatment as prescribed by the radiation oncologist, and nurses on the inpatient units who provide your care during hospital stays.
- **The Neuro-Oncology Tumor Board**, a group of specialized doctors who meet weekly to review each patient's case and make treatment recommendations, which are shared with the patient or the patient's doctor.

About Brain Tumors

Primary brain tumors are tumors (abnormal growth of cells) that arise from the brain and brain structures. These are not tumors that have spread, or *metastasized*, to the brain from other parts of the body or from the brain to other parts of the body.

If you have a brain tumor that came from a different primary cancer, please ask for our handout on that topic.

In the United States, *primary intracranial tumors*, those occurring within the cranial vault, occur in about 15,000 people per year, a rate of 3.7 per 100,000 people. About 50% of these tumors are *gliomas*.

Types of Brain Tumors

Brain tumors are grouped into two main categories:

1. Gliomas

A *glioma* is a tumor involving the supportive cells (or glial cells), found in the white matter of the brain. There are three main types of glial cells: the *astrocytes*, the *oligodendrocytes*, and the *ependymal* cells. Tumors starting from these cells are called *astrocytomas*, *glioblastomas multiforme*, *brain stem gliomas*, *oligodendrogliomas*, and *ependymomas*.

2. Non-gliomas

Non-gliomas also can occur in other brain structures. Some of the more common areas involved include the *meninges* (tissue coverings of the brain) and nerve sheath. Tumors that start from the meninges are called *meningiomas*, and those that start from the nerve sheath are called *acoustic neuromas*, *vestibular schwannomas*, and *neurilemmomas*.

Term Definitions

***Glioma* = a tumor involving the *glial* (supportive) cells found in the white matter of the brain**

***Metastasized* = spread**

***Non-glioma* = a tumor occurring in brain structures other than the white matter**

Anaplastic = malignant

Low-grade or High-grade Tumors

Tumors of the nervous system can be low-grade or high-grade, depending on how the tumor cells look under the microscope, their potential for growth, and their potential rate of growth. In most cases, low-grade tumors are tumors that, if removed completely, may not recur, or recur slowly. Grade I tumors are the least malignant and associated with long-term survival. Examples of Grade I tumors are *gangliocytoma* and *ganglioglioma*.

High-grade tumors tend to recur. Any tumor that is not completely removed will recur or continue to grow. If the tumor is high-grade, it has the potential to recur at a more rapid rate than a low-grade tumor.

Oligodendroglioma and Oligoastrocytoma

- *Oligodendrogliomas* are gliomas that arise from *oligodendrocytes* – fried-egg-shaped cells within the brain. These cells normally form the covering layer of nerve fibers in the brain.
- *Astrocytomas* are gliomas that arise from *astrocytes* – star-shaped cells within the brain. Astrocytes store information and nutrients for nerve cells in the brain.
- *Oligoastrocytomas* are “mixed gliomas” containing both oligodendroglioma and astrocytoma cells.

Using the World Health Organization classification system, oligodendrogliomas and oligoastrocytomas can be either Grade II or Grade III tumors. The cells of Grade II tumors are referred to as “well-differentiated” – they appear slightly abnormal when compared to normal cells. These cells reproduce slowly.

Grade III tumors are *anaplastic*, or *malignant* tumors. The cells of these tumors are clearly abnormal in appearance. Anaplastic tumors tend to contain many blood vessels and cells capable of quickly reproducing. Some anaplastic oligoastrocytomas contain Grade IV glioblastoma cells, which are aggressive cells that reproduce quickly.

Glioblastoma Multiforme and Anaplastic Astrocytoma

Astrocytomas are named after astrocytes, the star-shaped cells from which they grow. Astrocytomas often contain a mix of cell grades. An anaplastic astrocytoma is a Grade III, or mid-grade malignant tumor. An anaplastic astrocytoma that contains dead tumor cells (necrosis) is called glioblastoma multiforme. This is a Grade IV tumor.

“Glioblastoma,” “glioblastoma multiforme,” “grade IV astrocytoma,” and GBM are all names for the same tumor.

Incidence

About 4% of primary brain tumors are oligodendrogliomas, representing about 10 to 15% of the gliomas. Most occur in adults ages 50 to 60, and are found in men more often than women.

About 50% of gliomas are glioblastomas. They are most common in adults ages 45 to 55, and affect more men than women. Anaplastic astrocytomas occur more often in younger adults. About 9% of childhood brain tumors are glioblastomas.

Cause

The cause of these tumors, as well as other types of brain tumors, is unknown. Many studies have examined a wide spectrum of environmental factors as a cause for brain tumors. Of the long list of factors studied, only exposure to *ionizing radiation* has consistently been shown to put one at increased risk for developing a brain tumor.

Concerns about heredity and brain tumors are common, and if you have concerns about your family history, we suggest that you share your family’s medical history with your primary doctor.

He or she will want to know the type of brain tumor and your relation to the person with the tumor. Although routine screening for brain tumors is not available, unusual headaches or short-term memory loss can be investigated with your family history in mind.

Term Definitions

**Mass = another name
for a tumor**

Symptoms

General

Brain tumors cause symptoms in several ways. A tumor, also called a *mass*, takes up space within the skull as the tumor grows. Because the skull is a rigid container, it does not “give” to allow for expansion as the tumor grows. This can cause an increase in pressure within the brain that may cause some general symptoms. These symptoms occur no matter where the tumor is and may include headache, blurred vision, vomiting, confusion, and/or drowsiness. General symptoms may improve when the increased pressure within the brain is relieved by surgery and other treatments.

Focal

Other symptoms are *focal* symptoms. The types of focal symptoms a person may have depend on the location of the tumor. A tumor causes focal symptoms by putting pressure on brain structures and interfering with the transmission of information (nerve impulses) to and from the involved area of the brain.

Examples of focal symptoms include language comprehension or speech difficulties associated with the *dominant temporal lobe*, usually the left temporal lobe (especially in right-handed persons), or a weakness in a limb opposite the side of the tumor if the tumor is in the *motor cortex* or its pathways (nerve fibers). Focal symptoms can improve if brain cells have not been permanently damaged by the tumor and its effects.

Seizures in patients who have a brain tumor are focal symptoms. The type of seizure depends on the area of the brain involved and to what brain areas the seizure activity spreads. For more information on seizures, see page 23.

Tumors of the frontal lobe may cause weakness on one side of the body, personality or behavior changes, and difficulty with short-term memory. Temporal lobe tumors are usually “silent,” causing few symptoms.

For a summary of the functions associated with areas of the brain and for illustrations showing the brain areas, see *A Primer of Brain Tumors*, published by the American Brain Tumor Association.

Brain Edema

When a mass or tumor is present in the brain, it can interfere with the blood supply to and drainage from the brain. When this happens, fluid collects in the tissues or cavities around the mass, resulting in swelling. This fluid, together with the original mass, acts as an even larger mass, called *mass-effect*. The fluid around the mass is called *edema*.

A steroid medicine, most often Decadron (also called Dexamethasone), is used to reduce swelling that may be caused by the tumor or its treatment. Steroids can temporarily relieve the effects of edema in the brain, improve neurological symptoms, and promote a feeling of well-being.

Swelling in the brain can cause increased neurological symptoms. Symptoms may include:

- Increased weakness, especially on one side of the body.
- Visual abnormalities.
- Severe headaches.

Headaches that are “bad” or severe, that don’t go away with over-the-counter Tylenol/acetaminophen or ibuprofen medicines, or that are different than headaches you had in the past may be helped by steroid medication. **DO NOT WAIT** to tell your doctor or nurse about severe headaches, or suddenly increased neurological symptoms. The steroid dose may need to be adjusted.

Steroids are usually given on a temporary basis. They have some temporary and expected side effects, including:

- Increased appetite.
- Increased volume of urination.
- Fluid retention (swelling).
- Difficulty sleeping.
- Mood changes.
- Leg cramps (rarely).

Term Definitions

***Edema* = swelling caused by excess fluid in body tissues**

Term Definitions

Intravenous = injected into a vein, also called an IV

When You Take Steroids (Decadron):

<p>Do:</p> <ul style="list-style-type: none">• Take steroids with food, milk, crackers, or a prescribed antacid medication. Usually, a medicine is given to decrease stomach acid and overall stomach irritation while on Decadron.	<p>Do Not:</p> <ul style="list-style-type: none">• Take steroids on an empty stomach.• Decrease or stop taking this medicine without being told to do so by your doctor.
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Doses of Decadron can be increased or decreased during radiation treatment based on your symptoms. Eventually, the medicine doses will be tapered over a period of time, and then discontinued. When Decadron is stopped, the medicine given to decrease stomach acid can also be stopped.

Diagnosis of Brain Tumors

Brain tumors can be detected by using special diagnostic tests. Two common tests are:

- A **CAT** (computed axial tomography) scan, which uses X-rays and a computer to reconstruct images of the brain.
- An **MRI** (magnetic resonance imaging) scan, which uses magnetic fields, radio waves, and a computer to reconstruct images of the brain. An MRI is not an X-ray.

Both scans provide detailed pictures of the brain. An MRI provides clearer and more detailed pictures of the brain, but in some cases a CAT scan is preferred.

Both the CAT scan and the MRI may be done using a contrast agent. A contrast agent, when *intravenous* (injected into a vein, also known as an IV), will make some types of tumors appear brighter than the surrounding brain structures on the scan. Your doctor or nurse will tell you what to expect during these procedures. Patient education handouts about the procedures are also available from the Radiology Department.

Treatment of Brain Tumors

Surgery

Resection, the surgical removal of brain tumors, is recommended to relieve the pressure from the tumor and to provide tumor tissue for biopsy so a diagnosis can be made. The tumor tissue can be analyzed under a microscope by a pathologist to find out what type of tumor it is. Other treatment recommendations will depend upon the type of tumor it is and whether the tumor was completely removed or if any tumor cells remain after surgery. It is best to remove as much tumor as is safely possible. This minimizes the number of remaining tumor cells and maximizes the effectiveness of other treatments.

In some cases, tumors may be “inoperable” because of their location. A small biopsy of these tumors may be done using special X-ray guidance called *stereotactic biopsy*. This procedure enables the doctor to obtain a sample of the tumor tissue so that a diagnosis of the type of tumor and recommendation for further treatment can be made. In some cases, even a biopsy of the tumor may be dangerous. Treatment is then prescribed based on the appearance of the tumor on the scan and the most likely tumor type found in that area of the brain.

Brain mapping is a technique that can be used during surgery to identify precisely where functions such as speech, comprehension, sensation, or movement are located in the brain. Brain mapping has shown that the body areas for different functions of the brain are not located in the same place. By knowing exactly what areas of the brain are responsible for important functions in each person, the surgeon can remove as much tumor as is safely possible.

Methods also have been developed that assist the surgeon to more accurately locate the tumor and its boundaries during surgery. These techniques include *direct cortical stimulation*, *somatosensory-evoked potentials*, *functional MRI*, *intraoperative ultrasound imaging*, and *intraoperative MRI*.

Term Definitions

***Brain mapping* = a technique to identify precise locations of brain functions**

***Resection* = surgical removal of a brain tumor**

Term Definitions

***Craniotomy* = surgical opening of the skull**

Your doctor or nurse can describe these procedures in more detail and answer any questions you may have. Be sure to ask your nurse for a copy of the surgery brochure from the American Brain Tumor Association.

What to Expect

Most patients who have a *craniotomy* (surgical opening of the skull) for tumor removal can expect a hospital stay of about 5 to 7 days. Before your surgery, you will meet with doctors who will talk with you and examine you. You will need to have lab work done and might need a new scan. You may need to receive high doses of anticonvulsant or steroid medications, and these may be given through an IV.

After your surgery, you can expect to spend about 1 to 3 days in the intensive care unit (ICU), where the nurses will watch you closely. When you can be safely transferred, you will go to another unit to continue to recover from your surgery.

The time you spend in the hospital will vary based on your situation. If the symptoms you had before surgery remain after surgery or if post-surgical brain swelling (edema) has caused some temporary symptoms, you can expect a longer stay in the rehabilitation unit. Many patients are surprised at how little discomfort they have from surgery and how quickly they recover.

Recovery Time

Any type of surgery causes trauma to your body. Your recovery time will vary based on factors such as:

- Procedure used to remove your brain tumor.
- Location of the portion of your brain that was resected.
- Areas of your brain affected by the surgery.
- Your age and overall general health.

Talk to your neurosurgeon about your expected recovery time. Then you can set a realistic goal based on the estimate.

Next Step After Surgery

Once the pathology report comes back, the care team will talk with you about the next part of your treatment plan. If you need chemotherapy, a neuro-oncologist will talk with you. If you need radiation therapy, a radiation oncologist will meet with you. Surgery may be the only treatment you needed, and your healing process now begins.

No matter where you are in your treatment, your task now is becoming well again. Organize yourself with a calendar and notebook to list all your appointments, scans, blood draws, and “to do” items. It will be useful to have a notebook at hand at all times, to make or add to lists of questions and errands. A notebook also helps with memory, which is often a problem after any surgery.

Radiation Therapy

Radiation therapy is usually prescribed for low-grade (benign) tumors that are incompletely removed and for all high-grade (malignant) tumors. Radiation therapy works mainly by damaging the genetic information in cells, and preventing those cells from dividing (growing).

Since tumor cells are capable of dividing, radiation therapy is given to prevent growth in any tumor cells that may remain after surgery. Normal brain cells do not divide as rapidly as tumor cells and are not affected as strongly by radiation. Normal brain cells also have the capacity to repair radiation damage, while tumor cells are less able to repair themselves.

Standard external beam (outside the body) radiation therapy is usually given 5 times a week for about 6 weeks, or for 28 to 33 treatments, depending upon the grade and location of the tumor. The radiation oncologist will decide what dose of radiation to use, the areas of the brain that are to be treated, and how the radiation will be given. A *dosimetrist* works with the radiation oncologist and a computer to figure out how the radiation treatment can deliver the highest amount of radiation to the tumor with the least amount of exposure to normal cells.

Term Definitions

***Dosimetrist* = a member of the care team who helps plan the radiation treatment**

Term Definitions

Radiation oncologist = a member of the care team who decides on the radiation target area and the amount of radiation that area should receive

Radiation therapist = a member of the care team who gives the actual treatment

Simulation = a planning session to ensure accurate positioning of your head for the radiation treatment

What to Expect

You will meet with the radiation oncologist before your treatments begin. Use this time to ask questions. Benefits, risks, side effects, and follow-up care will be reviewed. Let clinic staff know what medications you are taking, including over-the-counter medications, antioxidant vitamins, and/or herbal supplements.

Your radiation oncologist reviews your records and decides on the radiation target area and the amount of radiation that area should receive. Computers are used to help shape and direct the radiation beams. You will need to come to the Cancer Center to go to a planning session called *simulation*. It may last from 30 minutes to 2 hours. Special marks will be placed on your skin, and/or you will be fitted for a mask to help hold your head still. These devices will ensure accurate positioning of your head for the radiation treatment.

Radiation therapists give you your prescribed treatments. You will spend about 1 hour in the Cancer Center when you come for treatment.

You will enter the room with the large radiation machine. Your radiation therapist will help get you into the right position. When you are ready, the radiation therapist will leave the room – before the actual treatment. There is a camera and intercom system inside the room. If you want to ask a question or if you have a concern, just speak and you will be heard.

The radiation treatment is painless. You will probably not see, hear, or feel anything. Some people may have the sensation that they are smelling something burning, tasting something metallic, or seeing flashes of light, even with closed eyes. These sensations are normal. **DO NOT** move during treatment.

What to Avoid During Radiation Treatment

Patients often ask about taking **vitamins** during their treatments. A regular multivitamin is safe for you to take. However, you must not take “mega” doses of vitamins A, beta

carotene, C, or E during radiation therapy or during and within a few days before and after receiving chemotherapy drugs. These vitamins may reverse the effects of radiation or chemotherapy on the tumor cells. With the **exception** of vitamin A, which can be toxic in high doses, these vitamins may safely be taken after your radiation treatment is done.

Most Common Side Effects of Radiation

Many people receiving brain radiation have no side effects other than *alopecia* (hair loss). Others may have some minor side effects. When side effects do occur, they most often include:

- Skin irritation or redness in the area being treated.
- Hair loss.
- Fatigue.
- Nausea.
- Headaches.
- Rare side effects include a small amount of fluid collection in the middle ear (behind the ear drum), and irritation of the ear canal (if radiation is being given in this area).

Skin Irritation or Redness

Do not treat skin irritation yourself. Putting cream on the affected scalp area can cause a radiation burn. Your doctor or nurse will give you a special solution or medication that you can safely apply to irritated areas.

You can shampoo your scalp and hair as often as you wish with a mild, fragrance-free soap such as Ivory or Basis, or with Neutrogena shampoo. Do not scrub your scalp.

Protect your scalp and other radiation treatment areas from the sun. **DO NOT** use sunscreen on affected areas during the 6-week period of your radiation therapy. Instead, cover your head with a hat or scarf.

Term Definitions

***Alopecia* = hair loss**

Hair Loss

Hair loss in the treatment area begins 2 to 3 weeks after your first treatment. Hair loss occurs because radiation affects cells that are dividing, which includes hair follicles.

Hair regrowth patterns vary. Hair may begin to regrow anywhere from 3 to 12 months after radiation therapy. Your hair may come back thinner than your normal hair; it may even return a different color or texture.

In some cases, depending on the radiation dose, hair regrowth does not occur. There are a variety of resources for headwraps, turbans, and wigs offered through UWMC Service League's "The Beauty and Cancer Program" for women and "For Men With Cancer" for men. Their telephone number is 206-598-3604. At Harborview Medical Center, these needs are met by the oncology and neurosurgery social workers, who can be reached at 206-731-8030.

If you want information about wigs, wraps, or hats, please tell your nurse or social worker. The American Cancer Society offers a list of resources for patients with hair loss, which may also be helpful.

Fatigue

If fatigue occurs, it tends to increase as the treatment progresses. For example, it may be more noticeable on Fridays (the fifth day of radiation treatment each week) and toward the end of the radiation treatment (during the fourth or fifth week). Why this fatigue occurs is not clearly understood.

If you develop fatigue, take a nap each day to help relieve it. In some cases, patients experience fatigue after radiation treatment is completed. Delayed fatigue may occur from 1 to 3 months after treatment and may last from 4 to 6 weeks.

Nausea and Appetite Changes

Sometimes, based on what brain areas are being treated, you may feel nauseated an hour or two after your daily radiation treatment. Most times, this can be managed with anti-nausea medication. You may also have a decrease in appetite.

Be sure to eat healthy, well-balanced meals during your radiation treatment. A clinical dietitian is available to advise you on nutrition concerns. If you lose weight, you may need to add a dietary supplement to your daily food intake.

Headaches

Some patients may have headaches that may be treated with steroid medication.

Middle Ear Fluid Build-up

Fluid build-up in your middle ear may cause a feeling of having “plugged” ears and decrease hearing in the ear that is in the radiation treatment field. This is usually temporary and results from inflammation of the middle ear.

If you develop this problem, your radiation oncologist may prescribe medication to help “dry up” this fluid. Also, your ears will be looked at for any signs of infection which may occur with the irritation and fluid build-up in the ear. If you have an infection, an antibiotic will be prescribed.

Treatment Results

How well your tumor responds to the radiation treatment may not be known for several months. This is because tumor cells may remain for a time after radiation therapy, since the brain is not as efficient as other organs of the body in “cleaning up” dead tissue.

Most times, an MRI or CAT scan will be done a few weeks after your radiation therapy is done. This scan may still show the presence of tumor cells, but cannot verify whether these tumor cells are dead or active. The scan is used to find out if there has been tumor growth, and to provide a baseline for future scans.

Long-term injury from radiation is much less common than the side effects noted above. Your radiation oncologist will talk to you about these less common side effects.

Other Types of Radiation Treatment

Other methods of delivering radiation therapy include radiation seed implants or radiosurgery.

Radiation Seed Implants (Brachytherapy)

Radiation seed implants involve placing small radioactive seeds directly around the tumor bed after the brain tumor has been removed. This allows the doctor to deliver a high dose of radiation to the tumor bed.

Radiosurgery

Radiosurgery, also known as “gamma knife surgery,” is a method of delivering radiation treatment to tumors of a certain size and location. With this type of radiation treatment, a precisely focused high-dose beam of radiation can be delivered to a small tumor. Because gliomas tend to be widespread, this treatment is often not an option for these tumors. However, it may be useful if the tumor is very small.

If you are wondering if these treatments might be useful in your situation, talk with your doctor. Pamphlets on radiation therapy for brain tumors are available free of charge from the American Brain Tumor Association.

Chemotherapy

Chemotherapy drugs are given to kill cancer cells. They are usually recommended for the treatment of higher grade or recurrent brain tumors. It may be given before, during, or after radiation therapy. The chemotherapy may be given orally, intravenously (IV) or, rarely, into the spaces surrounding the brain or directly into the tumor. The goals of chemotherapy are to keep the tumor stable and to stop it from growing any further.

Chemotherapy affects both tumor cells and normal cells. It works on cells that are dividing, so cells that divide the fastest are most affected. For this reason, a person’s bone marrow (where blood cells are made) and hair follicles (which cause hair growth) may also be affected by the chemotherapy. How

much the blood cells and hair follicles are affected differs with each person and with the type of chemotherapy given.

There are different kinds of chemotherapy for treating brain tumors:

- *Temodar* is a pill form of chemotherapy used to treat certain types of brain tumors. It may be taken during and/or after radiation, depending on what is recommended by your doctor.
- Another type of chemotherapy is the *Gliadel wafer*. These wafers are placed around the resection cavity while in surgery and deliver chemotherapy to the tumor.

There are also other types of chemotherapy given by IV that can be used to treat brain tumors. Your doctor will talk with you about the chemotherapy that is best for you and your specific tumor.

What to Expect

Chemotherapy is generally given in cycles. Each type of chemotherapy may have a different cycle. Some chemotherapy is given continuously for many cycles as long as the tumor shows a response, does not grow, or decreases in size. Other chemotherapy drugs are “dose limited,” meaning the total amount of the drug which can be given safely, is limited. This could mean that one course of chemotherapy could take 4 to 6 months or up to 2 years or more to complete.

After each cycle you will usually see your neuro-oncologist. You may also get an MRI or CAT scan to see if the chemotherapy is working. Your neuro-oncologist will let you know what the schedule of the chemotherapy will be and how often you will need to get scans.

It is also very important to have your blood tested weekly while on chemotherapy. This is because it is possible for the chemotherapy to lower your blood counts. The *white blood cells* are needed to fight infection. The *platelets* help the blood to clot and prevent bleeding, and the *red blood cells* carry oxygen to body tissues.

Term Definitions

***Platelets* = help blood to clot, prevent bleeding**

***Red blood cells* = carry oxygen to body tissues**

***White blood cells* = help your body fight infection**

If these blood cell counts become decreased in number, you may be more prone to infection, increased bleeding, or fatigue. These conditions can be dangerous and may require IV antibiotics or blood transfusions. By having your blood tested weekly, your health care team can monitor for these conditions. Your chemotherapy dose may be reduced or delayed if your blood cells are affected.

Frequent blood draws and intravenous (IV) medications can sometimes affect your veins, making blood draws and IV placement difficult. If this happens, a temporary device, called a Porta-Cath, can be implanted into the large vein in your upper chest. To learn more about Porta-Caths, please talk with your doctor.

What to Avoid During Chemotherapy

Patients often ask about taking **vitamins** during their treatments. A regular multivitamin is safe for you to take. However, you must not take “mega” doses of vitamins A, beta carotene, C, or E during radiation therapy or during and within a few days before and after receiving chemotherapy drugs. These vitamins may reverse the effects of radiation or chemotherapy on the tumor cells. With the **exception** of vitamin A, which can be toxic in high doses, these vitamins may safely be taken after your radiation treatment is done.

Most Common Side Effects of Chemotherapy

Some of the more common side effects of chemotherapy include:

- Bone marrow toxicity (which causes your blood counts to fall).
- Nausea and vomiting.
- Fatigue.
- Constipation or diarrhea.
- Hair loss.

There may be other side effects that are specific to your chemotherapy medication. Your doctor will give you information on all potential side effects.

Bone Marrow Toxicity

Your white blood cell count may decrease to a level that can place you at increased risk for infection. Call your nurse or doctor to report any signs of infection, such as:

- Fever greater than 100.5°F.
- Coughing or sore throat.
- Burning with urination.

If your white count decreases to a very low level, you will be asked to take your temperature every 4 hours and to report to the emergency room right away if you develop a fever. A fever could indicate that you have an infection and you will need to have IV antibiotics. Changes in diet will not affect your white blood cells, either positively or negatively. Sometimes, a medication that stimulates the bone marrow to manufacture white blood cells will be prescribed during a chemotherapy cycle. This medication is called G-CSF, *granulocyte colony stimulating factor* (Neulasta).

If your platelets decrease in number, you will be at increased risk for bleeding. If this occurs, you will be notified and asked to take care to avoid situations that could cause bleeding – from being extra cautious about falls to brushing your teeth very gently. If your platelets drop to a very low level (this happens rarely), you may need to have a platelet transfusion.

Your red blood cells also may be affected by chemotherapy. When red blood cells decrease in number, you will be *anemic*. This may cause you to feel fatigued or even short of breath. Taking iron supplements, or eating iron-rich foods such as red meat and green leafy vegetables, can help to correct this. If your counts remain low, you may need to get a medication called *darbopoetin* (Aranesp). This medication helps to increase the number of red blood cells.

Rarely, your red blood cells could decrease to a very low level. If this happens, you will need to have a blood transfusion.

Term Definitions

Antiemetics = anti-nausea drugs

Nausea and Vomiting

Nausea and vomiting can occur with some of the chemotherapeutic medications. Many people have heard “horror” stories about chemotherapy. However, with newer *antiemetics* (anti-nausea drugs) and combinations of anti-nausea drugs, nausea and vomiting are often eliminated or kept to a minimum. Be sure to inform your nurse or doctor any time you have nausea, so that your anti-nausea medication can be adjusted to find what works best for you. Your nurse can give you more information on chemotherapy and tips on diet while you are taking chemotherapy. A dietitian is also available to talk with you about dietary problems or concerns.

Fatigue

Fatigue is the most common side effect of cancer treatments including chemotherapy, radiation, and surgery. Fatigue often increases and decreases as other things such as pain control changes. Stay flexible with your plans, and make plans for rest breaks. Avoid overdoing it. Mild exercise like walking or riding a bike at least every other day for 20 minutes will also help with fatigue. It may be helpful if you keep a diary of your symptoms and activities. To learn more about dealing with fatigue, talk with your nurse.

Diarrhea and Constipation

Diarrhea is defined as more than 2 loose or watery stools a day. It may be caused by some chemotherapy. If left untreated, it can cause dehydration, weakness, weight loss, and electrolyte imbalance. It is recommended that you increase your fluids, avoid eating high fiber or fatty foods, and avoid caffeine and alcohol, as they may increase your diarrhea. If you have diarrhea, let your nurse or doctor know.

Constipation is when you are not able to move your bowels as you normally would. It can be caused by some chemotherapies, including Temodar. You can help prevent constipation by increasing fluids and fiber in your diet,

exercising daily, and, if needed, taking medication to help prevent or manage constipation. Talk with your nurse or doctor about medications and other ideas to help with constipation.

Hair Loss

Some chemotherapy drugs can cause temporary hair loss, also known as *alopecia*. With most of the chemotherapy used to treat brain tumors, hair loss is rare. Even when it does occur, in most cases hair grows back a couple of months after the chemotherapy is stopped.

Clinical Trials

In addition to standard chemotherapeutic drugs, new treatments for brain tumors are being developed all the time. There are studies going on at University of Washington Medical Center and at other centers across the country. Talk with your neuro-oncology team about clinical trials that you might qualify for. There is also a resource list on finding clinical trials on page 33 of this booklet.

Living with a Brain Tumor

Some brain tumor patients find their illness particularly difficult because the part of their body affected – the brain – is so closely associated with their identity, their sense of who they are. Changes or injuries to the brain, especially those that affect cognitive functioning, can be very threatening. However, there is wide variability in how brain tumors and treatments impact patients.

The impact of your tumor or your treatments depends on the type of tumor you have, its size, and its location. Some brain tumor patients sail through treatment with few side effects. After recovering from surgery or receiving other treatments, they return to their lives with little change. Other patients do notice changes in their physical or mental functioning. These changes can be quite subtle or more noticeable. Discuss any potential risks with your doctor before agreeing to any treatment.

If, after surgery, you do notice changes, it is important to know that, for many patients, recovery happens most rapidly in the months right after surgery. However, improvements in functioning can continue as long as a year or more after surgery. If you experience either physical or mental changes, rehabilitation services may be needed or desired.

The Rehabilitation Medicine Department (Rehab) at University of Washington Medical Center offers many useful services to patients after surgery. This help may be given on an inpatient basis right after surgery or on an outpatient basis. Outpatient services are useful as patients may notice new problems when they return home that had not been apparent to them when they were in the hospital. To learn more about the services of the Rehabilitation Medicine Department, ask your nurse or doctor.

How might my tumor or treatments affect me?

Your doctor is the best source of information on how your treatment will most likely affect you, but he or she may not be able to predict exactly what you will experience. Keep in mind that there are differences from patient to patient.

Problems Affecting Mobility

Some people have symptoms caused by their brain tumors that remain after surgery. Others may develop temporary symptoms right after surgery. Some develop new symptoms that may be from tumor growth or edema (swelling) in the area around the tumor. These symptoms, based on which area of the brain is affected, may include:

- Weakness or numbness in a limb, the face, or on one side of the body.
- A loss of awareness of where an arm or leg is located in space.
- Problems with speaking or understanding speech.
- Problems with memory.

Fatigue

Many patients feel fatigued after their surgery and sometimes during radiation treatment or chemotherapy. Some may continue to have a loss of energy for years after treatment.

Those who have these side effects may find that they need to slow down and do less. They may even need to change their schedule to include a 30-minute nap during the day (longer naps can interfere with sleep at night). Others may only have fatigue while receiving chemotherapy or radiation and find this side effect gradually disappears after treatment is finished.

In managing fatigue, many patients find that light exercise (short walks or light workouts) for 20 minutes or more at least every other day, gives them more energy than being inactive.

Depression

Everyone feels depressed at some time in his or her life. It is normal to feel sad or depressed after losing a loved one or when facing health problems. The depressed feeling gradually lessens and goes away over a period of weeks.

When depression does not improve over time, is not related to a specific event, or is out of proportion to the problem, this could indicate the presence of clinical depression. This type of depression usually does not get better without help. If you are feeling this way, talk to your doctor or nurse. Treatments are available.

Cognitive Deficits

Changes in thinking processes, known as *cognitive deficits*, can be very frustrating for patients who have brain injury caused by their tumor or surgery.

- Some patients notice problems with **short-term memory**: “I find I can’t remember names or where I parked the car. It’s very frustrating.” “By the time I read to the bottom of the page, I can’t remember what I read at the top.”
- Others experience problems with **concentration**: “I don’t like to read anymore because I can’t seem to finish a page.”

- Still others find it is more **difficult to organize tasks**: “I can’t seem to manage to get my shopping list together.” “I’m getting stuck making simple decisions like what socks to wear.”
- Some patients have trouble with **multi-tasking**: “I used to be able to manage 10 things at once and I can no longer do that.”

It may become difficult to manage several things at once. If too many people are talking at the same time, for example, patients may feel overloaded and confused. This can be quite an unpleasant experience.

Some patients who have noticed some or all of the above changes have found they improve over time as they recover from surgery or other treatments. For other patients, these changes develop into conditions that they must continue to live with.

Patients have found creative ways to adapt. Some find they can no longer rely on their memory and must develop the habit of writing everything down. Carrying a calendar and notebook with “to do” lists for the day are aids many have found useful in keeping themselves on track. It is helpful for patients to let family members and employers know what problems they are having so that others can help to manage memory-related tasks.

A problem that some patients experience is **difficulty with word-finding**. It can be a struggle to come up with the right word, even when it is one they know well. Working on re-learning vocabulary may help speed recovery in this area. It can be both useful and fun to work crossword puzzles or play word-finding games.

Another difficulty that patients may experience is a **lack of motivation**. This may be due to fatigue, difficulty with organizing tasks, or it can be a sign of depression.

You may also notice that you feel more emotional than usual, and your **emotions are harder to control**. You may be more likely to lose your temper or cry more easily than before your diagnosis and treatment. If you notice any of these changes, talk with your doctor or nurse about them.

All of these symptoms can be very stressful for the patients who experience them and for their partners, spouses, and other family members and friends. It is not only important to know that these problems can occur, but also that if they do occur, they often improve with time. It is also helpful to know that problems with memory, concentration, organizing, and word finding are often made worse by stress.

What seems to be most important is that patients and their families learn to identify and describe what has changed so they can work with these changes effectively to avoid frustration and further stress. Help is available for patients who have these problems through the Brain Tumor Support Group and through the Brain Injury Program in the Rehabilitation Medicine Department.

Help with Deficits That May Occur

The **Brain Injury Program** is a special program within UWMC's Rehabilitation Medicine Department. The staff on this team (doctors, nurses, speech therapists, physical therapists, occupational therapists, neuropsychologists, social workers, and vocational rehabilitation specialists) have expertise in helping patients who are having physical, cognitive, communication, emotional, and social problems as a result of neurological injury, such as a brain tumor.

The team works with patients to assist them in maximizing their abilities. This helps them live as independent and productive a life as possible. Each program is designed to address specific needs and concerns.

If you are referred to the Brain Injury Program, you will typically first meet with the **physiatrist**, the Rehabilitation Medicine doctor, and the **neuropsychologist**, who will talk with you about your goals and what treatments (such as physical therapy, speech therapy, psychotherapy, vocational assistance) are likely to be most helpful to you.

Term Definitions

Physiatrist = a doctor who specializes in the diagnosis and treatment of musculoskeletal injuries and pain syndromes, electrodiagnostic medicine, and the rehabilitation of patients with severe impairments. Physiatrists help restore optimal function to people with injuries to the muscles, bones, tissues, and nervous system.

Neuropsychologist = a doctor who has special training in the causes of brain disorders. Neuropsychologists specialize in diagnosing and treating these disorders.

What about family and friends?

It is very difficult for others to watch someone they love go through the experience of being diagnosed and treated for a brain tumor. Even if everything goes very well, it is still upsetting and scary. If the loved one is left with some deficits, it can be even more difficult.

Learning as much as possible about what changes have occurred and what should be expected can help. The doctor, nurse, and staff in the Rehabilitation Clinic are your best resources for information. Sometimes people hesitate to ask questions because they don't want to bother the staff, or feel their question may be silly. But, it is important for you and your loved ones to ask questions until you feel you fully understand your situation and what options exist.

There are many special challenges for a patient's family members and friends. They may feel helpless when they see their loved one in trouble and they are unable to make the problem go away. Family members and friends are sometimes unsure how best to support the patient. How much should they do for the patient? When should they forget the tumor and just act normally toward him or her? What does the patient need and want?

Good communication is key. Patients need to be able to share how they are feeling with those close to them and let them know what kind of support they want. They need family and friends to be patient and understanding listeners. Let loved ones know that you want to be with them, that you want them to understand how you feel to the extent possible for you, and that you want to know how they feel. Let loved ones know when you just need them to listen to you share your concerns and experiences.

How can we cope with everything that is happening?

Sometimes the challenges of dealing with a brain tumor can be overwhelming. If you are feeling this way, it is important

to know that you are not alone. Most patients and families hit some rough spots and feel overwhelmed along the way. This may happen at diagnosis, in response to treatment side effects or symptoms, or when difficult choices must be made. Many patients and families have struggled in dealing with a brain tumor, and have found ways to manage. You can, too!

The staff are here to support you. Let clinic staff know how you are feeling and the concerns that you have. Brain tumor support groups and online support groups are helpful in talking with others who are dealing with some of the same difficulties that you are dealing with.

Seizures

What is a seizure?

A seizure is an attack caused by abnormal electrical activity in the brain. It lasts only a short period of time and may cause unusual movements, a change in the level or loss of consciousness, and/or sensory distortions. Epilepsy is defined as recurrent seizures.

People who have brain tumors may be at an increased risk for seizures. This is thought to occur because the normal functioning of brain cells is disrupted due to pressure caused by the tumor itself, edema (brain swelling), or associated “scar tissue.” Seizures occur when brain cells discharge uncontrolled electrical signals. These abnormal discharges may then spread to other brain cells. As more brain cells become involved, seizures result.

The type of symptom, or seizure, depends upon which area of the brain is involved in this abnormal electrical activity. If the motor areas of the brain are affected, muscle groups in the limbs or face may develop involuntary movements, such as jerking or posturing. If just the motor area of the brain that represents the leg is involved, the seizure will only affect the leg. The same is true for the arm and face.

If the sensory area of the brain is involved, the seizure may be experienced as tingling, numbness, buzzing, or other

strange sensations in the body part. Seizures in the temporal lobe or in some areas of the frontal lobe can result in a change in consciousness during which a person may continue to do a meaningful activity, but in an inappropriate manner, such as walking about, shuffling papers, looking around, and so on. The person appears to be aware of his or her surroundings, but is usually unable to respond when spoken to. During some types of seizures, the person may appear to be in a daze or stare blankly.

When seizure activity in the brain spreads to involve the other side of the brain, consciousness is lost and the person may have what is referred to as a *generalized tonic clonic* or *grand mal* seizure, which is involuntary jerking of all the limbs.

What does a generalized tonic clonic (grand mal) seizure look like?

A *grand mal* seizure often starts with a hoarse cry caused by air being suddenly forced out of the lungs. The person falls to the ground unconscious. The body stiffens briefly, and then begins jerking movements. Bladder or bowel control is sometimes lost. The tongue may be bitten. A frothy saliva may appear around the mouth. Breathing may get very shallow and even stop for a few moments. Sometimes the skin turns a bluish color because the lower rate of breathing is supplying less oxygen than usual. The jerking movements then slow down, and the seizure ends naturally after a minute or two. When conscious again, the person may feel confused and sleepy. In some cases, only a very short recovery period is needed. Most people can go back to their normal activities after a while.

What do other seizures look like?

Absence (petit mal) seizures look like daydreaming, or blank staring. They begin and end abruptly, last only a few seconds, and are most often seen in children. A child having this kind of seizure is unaware of people and things around him for a few seconds, but quickly returns to full awareness.

These little seizures happen so quickly that the child (and sometimes other people around him) may not notice them. Parents and teachers may think the child is just daydreaming. Sometimes these seizures also produce blinking or chewing movements, turning of the head, or waving of the arms.

Complex partial seizures (also called *psychomotor* or *temporal lobe* seizures) are a type of seizure in which the extra brain activity does not affect the whole brain. Although they are sometimes called “temporal lobe seizures,” they can actually occur in several areas of the brain.

During a complex partial seizure, the person looks as if he is in a trance and goes through a series of movements over which he has no control. While the kind of movements may vary from person to person, there is usually a set of actions that each person follows every time a seizure happens.

A seizure of this type may start with a strange sensation such as a feeling of fear, a sudden sick feeling in the stomach, or seeing or hearing something that is not really there. The person stares blankly, and may make chewing movements. He may move an arm, pull at clothing, get up and walk around, all the time looking as if he is in a daze. Although not aware of things and people around him in the usual sense, a person having this kind of seizure may be able to follow simple directions if they are given in a calm, friendly voice.

Although this type of seizure lasts for just a minute or two, full awareness may not return for some time afterwards. Confusion and irritability may follow, and the person will not remember what happened or what he did while the seizure was going on.

During *simple partial* seizures, the person remains conscious. This type of seizure may consist of sensations, such as tingling or numbness of an arm or leg, or uncontrollable limb movements, such as trembling or jerking. Another type of simple partial seizure produces unusual feelings. Things may look strange, or the person may “see” people or things that are not there. He may “hear” strange sounds or have a feeling

that what is happening around him has somehow happened before (*déjà vu*). He may feel strange sensations on one side of his body. The reason for these sensations, which may be frightening and upsetting to someone who doesn't know their cause, is seizure activity taking place in parts of the brain that control seeing, hearing, memory, or feeling.

Any of these partial seizures may affect enough brain cells to spread and become a generalized tonic clonic (grand mal) seizure.

What is an aura?

An *aura* is an unusual sensation that warns the person who has it that a major seizure is about to begin. It might be a feeling of fear or sickness, or an odd smell or taste. The aura is, in fact, the start of seizure activity in the brain before it spreads to other areas. People who have this warning often have time to move away from possible hazards before a major seizure starts. Sometimes the seizure does not spread, and all that happens is the special sensation.

Seizure Medications

Anticonvulsant medication is prescribed for patients to decrease the risk of having a seizure. It is important to take anticonvulsants as prescribed and to have the blood level of these medications checked on a regular basis.

Some of the more common anticonvulsant medications prescribed include:

- Phenytoin (Dilantin)
- Phenobarbital (Luminal)
- Carbamazepine (Tegretol)
- Divalproex sodium (Depakote)
- Felbamate (Felbatol)
- Lamotrigine (Lamictal)
- Levetracetam (Keppra)

- Oxcarbazepine (Trileptal)
- Tiagabine (Gabitril, Topiramate)
- Zonisamide (Zonegran)
- Gabapentin (Neurontin)

Tell your nurse if you are having any new symptoms or side effects from the seizure medication(s).

Seizures and First Aid

What should you do if someone has a generalized tonic clonic (grand mal) seizure?

First aid for epilepsy, or tumor-related grand mal seizures, is very simple. The goal is to keep the person safe until the seizure stops by itself.

These are the key things to keep in mind:

- Keep calm and reassure other people who may be nearby.
- Clear the area around the person of anything hard or sharp.
- Loosen ties or anything around the neck that may make breathing difficult.
- Put something flat and soft, like a folded jacket, under the head.
- Turn the person gently onto his side. This will help keep the airway clear. Do not try to force his mouth open with any hard implement or with fingers. It is not true that a person having a seizure can swallow his tongue. Efforts to hold the tongue down can injure teeth or the jaw.
- Don't hold the person down or try to stop his movements.
- Don't attempt artificial respiration (CPR) except in the unlikely event that he does not start breathing again after the seizure has stopped.
- Stay with the person until the seizure ends naturally.
- Be friendly and reassuring as consciousness returns.

- Offer to call a taxi, friend, or relative to help the person get home if he seems confused or unable to get home by himself.

Should an ambulance be called?

If you know the person has epilepsy, or tumor-related seizures, it is usually not necessary to call an ambulance unless the seizure lasts longer than five minutes, unless another seizure begins soon after the first, or unless the person cannot be awakened after the jerking movements have stopped. If the person having the seizure seems ill, injured, is diabetic or pregnant, an ambulance should be called.

What should you do if someone has one of the other types of seizure?

You don't have to do anything if a person has brief periods of staring or shaking of the limbs. If someone has the kind of seizure that involves a dazed state and automatic behavior, the best thing to do is:

- Watch the person carefully and explain to others what is happening. Often people who don't recognize this kind of behavior as a seizure will think that the dazed person is drunk or on drugs.
- Speak quietly and calmly in a friendly way.
- Guide the person gently away from any danger, such as a steep flight of steps, a busy highway, or a hot stove. Don't grab hold, however, unless some immediate danger threatens. People having this kind of seizure are on "automatic pilot," so far as their movements are concerned, and instinct may make them struggle or lash out at another person who is trying to hold them.
- Stay with the person until full consciousness returns, and offer help in returning home.

For more information on first aid during a seizure, see the table *Seizure Recognition and First Aid* on page 36.

Information adapted from: *Epilepsy: Questions and Answers, About Seizure Disorders*, Epilepsy Foundation of America, 1994. (Used with permission.)

Seizure Recognition and First Aid				
SEIZURE TYPE	WHAT IT LOOKS LIKE	WHAT IT IS NOT	WHAT TO DO	WHAT NOT TO DO
GENERALIZED TONIC-CLONIC (Also called Grand Mal)	Sudden cry, fall, rigidity, followed by muscle jerks, shallow breathing or temporarily suspended breathing, bluish skin, possible loss of bladder or bowel control, usually lasts a couple of minutes. Normal breathing then starts again. There may be some confusion and/or fatigue, followed by return to full consciousness.	Heart attack. Stroke.	Look for medical identification. Protect from nearby hazards. Loosen ties or shirt collars. Protect head from injury. Turn on side to keep airway clear. Reassure when consciousness returns. If single seizure lasted less than 5 minutes, ask if hospital evaluation wanted. If multiple seizures, or if one seizure lasts longer than 5 minutes, call an ambulance. If person is pregnant, injured or diabetic, call for aid at once.	Don't put any hard implement in the mouth. Don't try to hold tongue, it can't be swallowed. Don't try to give liquids during or just after seizure. Don't use artificial respiration unless breathing is absent after muscle jerks subside, or unless water has been inhaled. Don't restrain.
ABSENCE (Also called Petit Mal)	A blank stare, beginning and ending abruptly, lasting only a few seconds, most common in children. May be accompanied by rapid blinking, some chewing movements of the mouth. Child is unaware of what's going on during the seizure, but quickly returns to full awareness once it has stopped. May result in learning difficulties if not recognized and treated.	Daydreaming. Lack of attention. Deliberate ignoring of adult instructions.	No first aid necessary, but if this is the first observation of the seizure(s), medical evaluation should be recommended.	
SIMPLE PARTIAL	Jerking may begin in one area of body, arm, leg, or face. Can't be stopped, but patient stays awake and aware. Jerking may proceed from one area of the body to another, and sometimes spreads to become a convulsive seizure. Partial sensory seizures may not be obvious to an onlooker. Patient experiences a distorted environment. May see or hear things that aren't there, may feel unexplained fear, sadness, anger or joy. May have nausea, experience odd smells, and have a generally "funny" feeling in the stomach.	Acting out, bizarre behavior. Hysteria. Mental illness. Psychosomatic illness. Parapsychological or mystical experience.	No first aid necessary unless seizure becomes convulsive, then first aid as above. No immediate action needed other than reassurance and emotional support. Medical evaluation should be recommended.	
COMPLEX PARTIAL (Also called Psychomotor or Temporal Lobe)	Usually starts with blank stare, followed by chewing, followed by random activity. Person appears unaware of surroundings, may seem dazed, and mumble. Unresponsive. Actions clumsy, not directed. May pick at clothing, pick up objects, try to take clothes off. May run, appear afraid. May struggle or fall at restraining. Once pattern established, a set of actions usually occurs with each seizure. Lasts a few minutes, but post-seizure confusion can last substantially longer. No memory of what happened during seizure period.	Drunkenness. Intoxication on drugs. Mental illness. Disorderly conduct.	Speak calmly and reassuringly to patient and others. Guide gently away from obvious hazards. Stay with person until completely aware of environment. Offer to help getting home.	Don't grab hold unless sudden danger (such as a cliff edge or an approaching car) threatens. Don't try to restrain. Don't shout. Don't expect verbal instruction to be obeyed.

Resources

Social Work Services

Social workers can help you with the emotional and psychological impact of your illness. They can also connect patients and families with community resources and support.

- **UWMC Social Work and Coordinated Care (inpatients)**
206-598-4370
- **UWMC Cancer Center Social Worker (outpatients)**
206-598-4108
- **Harborview Neurosurgery Social Worker**
206-731-4051
- **Harborview Oncology Social Worker**
206-731-4051

Centers and Libraries

UWMC Cancer Library **206-598-7880**

*Oncology Inpatient Unit, UWMC
7-Southeast, Room 7322*

This library is for cancer patients and their families. It is always open and has books, tapes, and videos about cancer, treatments, coping, talking with children about cancer, relaxation, imagery, and many other subjects. It also has a computer with Internet access.

UWMC Health Information Resource Center

206-598-7960

UWMC main lobby, next to the gift shop

The Health Information Resource Center at UWMC provides high-quality, individualized health information to patients, families, and community members. The center houses four computer stations equipped with Internet access for users to browse bookmarked Web sites, on-line journals and newsletters, and patient education databases. Pamphlets, books, and articles are also available for use.

Harborview Patient Education Resource Center

206-731-2000

Ground floor, East Hospital, Harborview Medical Center

This library is for patients and their families and includes materials on cancer and brain tumors.

Rehabilitation Programs

UWMC Neuro-Rehabilitation Program, Department of Rehabilitation Medicine **206-598-5903**

If you and your doctor feel your illness has limited your ability to work, counselors in UWMC's Rehabilitation Medicine Department can assess your needs and options for returning to work. They offer a wide range of services to help patients 18 years of age and older cope with the complex and long term consequences of brain injury/tumor. If interested, ask your doctor for a referral.

**Harborview Medical Center CORP
(Comprehensive Rehabilitation
Program)
206-731-2140**

If you and your doctor feel your illness has limited your ability to work, staff in the Rehabilitation Medicine Department can assess your needs and options for returning to work. They offer a team approach.

**Washington State Division of
Vocational Rehabilitation (DVR)**

A state agency that offers employment counseling and training for people with disabilities related to illness or injury. They have local offices in many cities throughout the state. In Seattle, their phone numbers are listed in the Blue pages under Washington State, Social and Health Services Department, Vocational Rehabilitation Division.

Protection Against Job Discrimination

Under federal law and many state laws, it is illegal for an employer to discriminate against a worker because he or she has cancer. Some protections are offered through the Americans with Disabilities Act and the Federal Rehabilitation Act.

The ability to take additional medical leave without risking job loss is provided in many circumstances to workers under the Family and Medical Leave Act. For related publications and more information on these laws, contact the NCCS or the American Cancer Society.

- **American Cancer Society (ACS)**
800-729-1151 (toll-free in Washington state)
206-217-9525, Patient Services
Web site: www.cancer.org
 - **National Coalition for Cancer Survivorship (NCCS)**
888-650-9127
Web site: www.canceradvocacy.org
E-mail: info@canceradvocacy.org
-

Brain Tumor Organizations

Acoustic Neuroma Association
600 Peachtree Parkway, Suite 108
Cummings, Georgia 30041
770-205-8211
Web site: www.ANAUSA.org
E-mail: ANAUSA@aol.com

American Brain Tumor Association
2720 River Rd., Suite 146
Des Plaines, IL 60018
Patient line: 800-886-2282/ 847-827-9910
Fax: 847-827-9918
Web site:
<http://hope.abta.org/site/pageserver>
E-mail: info@abta.org

**Brain Tumor Foundation for Children,
Inc.**
6065 Roswell Rd. N.E., Suite 505
Atlanta, Georgia 30328
404-252-4107
Web site: www.braintumorkids.org
E-mail: btfc@bellsouth.net

Brain Tumor Foundation of Canada
111 Waterloo St., Suite 201
London, Ontario N6B 2M4
CANADA
800-265-5106
Web site: www.btfc.org

The Brain Tumor Society

124 Watertown St., Suite 3H
Watertown, MA 02472
617-924-9997
800-770-8287 (toll-free in the United States)
Fax: 617-924-9998
Web site: www.tbts.org
E-mail: info@tbts.org

The Children's Brain Tumor Foundation, Inc.

274 Madison Ave., Suite 1004
New York, NY 10016
Web site: www.cbtf.org
E-mail: info@cbtf.org

National Brain Tumor Foundation

22 Battery St., Suite 612
San Francisco, CA 94111-3520
800-934-CURE (800-934-2873)
Web site: www.braintumor.org
E-mail: nbtf@braintumor.org

Pediatric Brain Tumor Foundation of the U.S.

302 Ridgefield Ct.
Asheville, NC 28806
800-253-6530
Fax: 828-665-6894
Web site: www.pbtfus.org

The Preuss Foundation

2223 Avenida de la Playa, Suite 220
La Jolla, CA 92037
858-454-0200
Fax: 858-454-4449

Other Brain-Related Organizations**The Central Brain Tumor Registry of the U.S.**

244 East Ogden Ave., Suite 116
Hinsdale, IL 60521

630-655-4786

Web site: www.cbtrus.org

E-mail: cbtrus@aol.com

Epilepsy Foundation of America

4351 Garden City Dr.
Landover, MD 20785-7223
800-332-1000
Web site: www.epilepsyfoundation.org

Hydrocephalus Association

870 Market St., Suite 705
San Francisco, CA 94102
888-859-3789 (toll-free)
415-732-7044
Fax: 415-732-7044
Web site: www.hydroassoc.org

National Aphasia Association

7 Dey St. Suite 600
New York, NY 10007
800-922-4622
E-mail: naa@aphasia.org

Cushing's Support and Research Foundation

65 East India Row, Suite 22B
Boston, MA 02110-3389
617-723-3674 (phone and fax)
Web site: <http://csrf.net>

National Neurofibromatosis Foundation, Inc.

95 Pine St., 16th Floor
New York, NY 10005
800-323-7938 (toll-free)
212-344-6633
Fax: 212-747-0004
Web site: www.nf.org
Or: www.neurofibromatosis.org

National Tuberous Sclerosis Association

8000 Corporate Dr., Suite 120
Landover, MD 20785
800-225-6872 (toll-free in the U.S. and
Canada)
301-459-9888
Web site: www.nts.org

Neurofibromatosis, Inc.

P.O. Box 18246
Minneapolis, MN 55418
800-942-6825 (toll-free)
301-918-4600

Southeastern Brain Tumor Foundation

P.O. Box 422471
Atlanta, GA 30342
404-843-3700
E-mail: sbtfatlanta@aol.com

South Florida Brain Tumor Association

P.O. Box 770182
Coral Springs, FL 33067-0182
305-755-4307
Web site:
<http://members.aol.com/Btldiva/SFBTA.html>

Trigeminal Neuralgia Association

925 Northwest 56th Terrace, Suite C
Gainesville, FL 32605-6402
800-923-3608 (toll-free)
352-331-7009
Fax: 352-331-7078
Web site: www.tna.support.org
E-mail: tnational@tna-support.org

Pituitary Network Association

P.O. Box 1958
Thousand Oaks, CA 91358
805-499-9973
Fax: 805-480-0633
Web site: www.pituitary.org
E-mail: PNA@pituitary.org

Von Hippel-Lindau Family Alliance

171 Clinton Rd.
Brookline, MA 02146
Patient Support: 800-767-4VHL (toll-free)
617-232-5946
Fax: 617-734-8233
Web site: www.vhl.org/
E-mail: info@vhl.org

Internet Resources

The Healing Exchange Brain Trust

www.braintrust.org
Provides information on communication opportunities and tools for those affected by intracranial tumors and space-occupying lesions and those who treat or study these disorders.

International Radiosurgery Support Association

www.irsa.org
Provides information about radiosurgical methods, emotional support, and links to member institution radiosurgery sites.

Massachusetts General Hospital

<http://neurosurgery.mgh.harvard.edu/nonc-hp.htm>
Information on the treatment of malignant brain, spine, and peripheral nerve tumors and links to other nervous-system tumor resources.

National Center for Complementary and Alternative Medicine, National Institutes of Health

<http://nccam.nih.gov>

Offers information on complementary and alternative treatments, research and training, and links to resources for more information.

New York University Department of Neurosurgery

<http://mcns10.med.nyu.edu>

Offers information about several neurologic disorders, including brain tumors.

National Institute of Neurologic Disorders and Stroke

www.ninds.nih.gov

Provides neuroscience research updates, general information about selected neurological diseases, NINDS-sponsored clinical trials, and NINDS-NIH clinical studies.

Oncolink

<http://cancer.med.upenn.edu>

An extensive cancer resource site that offers information on disease (brain tumors included), screening and prevention, support resources, and financial assistance.

Radiation Therapy Oncology Group

www.rtog.org

Provides an extensive, searchable database of RTOG clinical trials including protocol summaries, and links to member institutions.

St. Jude Children's Research Hospital

www.stjude.org/patient/cancers.htm

Includes specifics on different types of brain tumors.

University of Minnesota Hospital Department of Neurosurgery

www.neuro.umn.edu

Describes clinical trials available at the University of Minnesota.

University of Texas MD Anderson Cancer Center's Brain and Spinal Tumor Center

www.mdanderson.org/centers/neuro

Provides a list of clinical trials offered at MD Anderson, basic information about the design of clinical trials, and how to find one that is right for you, as well as support information.

Chat Rooms**AN-Info@ANUSA.org**

Unmoderated e-mail list-serve group for those interested in acoustic neuromas. To subscribe, send an e-mail to LISTSERV@ANUSA.org with SUBSCRIBE AN-INFO YourFirstName YourLastName in the body of the e-mail.

AN-Support@ANUSA.org

Private, moderated e-mail list. See guidelines at the ANA Web site (<http://anausa.org/list.htm>). To subscribe, send an e-mail to ANAmo@aol.com with SUBSCRIBE AN-Support YourFirstName YourLastName in the body of the e-mail.

Braintmr

Moderated list open to anyone interested in brain tumors. To subscribe, send an e-mail to LISTSERV@mitvma.mit.edu. In the body of the e-mail, type SUBSCRIBE BRAINTMR followed by your real name. Leave the subject empty or type "none."

America Online Brain Tumor Chat Room

Moderated list on America Online. From the main AOL menu: go to "People Connections," click "Find a Chat Room," click "Enter a Private Chat," and type in the full word, "braintumor."

Hyceph-L Mailing List

For hydrocephalus patients and their families. To subscribe, send an e-mail to: listserv@vm.utoronto.ca. In the body of the e-mail, type: subscribe HYCEPH-L Firstname Lastname.

Medulloblastoma Tumor List

For anyone interested in medulloblastoma and PNET. To subscribe, send an e-mail to medulloblastoma-subscribe@onelist.com. Leave the subject and the body of the e-mail empty.

Meningioma Tumor List

For meningioma patients and their caregivers. To subscribe, send an e-mail to requests@hydra.welch.jhu.edu. In the body of the e-mail, type SUBSCRIBE MENINGIOMA.

Skull Base Tumors Public Guestbook

<http://neurosurgery.mgh.harvard.edu/GB>
For patients with cranial base tumors to post an entry where others are able to read and respond to it.

The Status.Com

www.theStatus.com

Free, easy, secure, private Internet site where patients and their families can create and update their own Web pages to share patient-status information with family and friends.

Seattle Cancer Care Alliance (SCCA) and Care Pages

A private and fully secure service that is password-protected and complies with all patient privacy regulations. SCCA and Care Pages have teamed up to help patients and caregivers use the Web to communicate with loved ones while going through treatment. Log on to www.seattlecca.org, click on Care Pages logo.

Medical Search Engines

- **HealthAtoZ**
<http://Healthatoz.com>
 - **Healthfinder**
www.healthfinder.gov
-

Finding Clinical Trials

- **National Cancer Institute and Cancer Information Service**
800-422-6237
- **Resource Listing of Physicians Participating in Clinical Trials for Brain Tumors**
800-886-2282
- **National Institute of Health Clinical Trials**
www.clinicaltrials.gov
- **National Cancer Institute Clinical Trials Web Site**
www.cancer.gov/clinicaltrials
- **Coalition of Cancer Cooperative Groups**
www.cancertrialshelp.org

