



Del Mar Caregiver Resource Center  
*A program of Health Projects Center*

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## **Fact Sheet**

# **Brain Tumors**

### **Definitions**

A brain tumor is a collection of damaged cells that multiply out of control within the brain. Also called a neoplasm, growth, mass or lesion, a brain tumor is classified as either primary or secondary (metastatic), and can be benign or malignant.

- *Primary brain tumors* develop and generally remain in the brain.
- *Secondary brain tumors*, or metastatic brain tumors, are cancers that develop elsewhere in the body and spread to the brain. The most common cancers that spread to the brain are lung and breast cancers.
- *Malignant brain tumors* grow rapidly and invade other cells.
- *Benign brain tumors* generally do not grow rapidly. However, even benign tumors can be life-threatening.

While diagnosis of a brain tumor is difficult for families, there are also many reasons to be hopeful. Substantial progress had been made in the medical understanding of cancers and more effective treatment of brain tumors. Many of these treatment options are discussed below.

### **Facts**

According to the North American Brain Tumor Coalition, an estimated 40,000 new cases of primary brain tumors are diagnosed in the U.S. each year. Some research indicates that the number of primary brain tumors is rising, particularly in the elderly. Primary malignant brain tumors represent 2.4 percent of all deaths due to cancer in the U.S. However, nearly half of all primary brain tumors are benign and can be treated successfully.

An additional 150,000 individuals are diagnosed with metastatic brain tumors each year. The frequency of metastatic brain tumors appears to be increasing: improvements in treating primary cancers elsewhere in the body allow people to live longer, but stray cancer cells can find their way to the brain.

There are more than 100 types of brain tumors. Certain types of primary brain tumors most commonly occur in children, while others occur more frequently in adults. Adult brain tumors typically appear between the ages of 40 and 60 years, and occur slightly more often in men.

### **Symptoms**

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**Health Projects Center's  
Del Mar Caregiver Resource Center**  
Serving Monterey, San Benito and Santa Cruz Counties

(831) 459-6639  
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[www.delmarcaregiver.org](http://www.delmarcaregiver.org)

As tumor cells multiply within the brain, they can press against, irritate and/or destroy normal brain tissue. As a result, brain tumors may cause symptoms such as:

- headaches
- seizures
- speech problems
- weakness
- bad vision
- pain or numbness
- movement problems
- paralysis
- nausea or vomiting

Brain tumors may cause feelings of tiredness or fatigue. In addition, brain tumors can cause problems with memory, reading and talking. However, not everyone gets every symptom. About one-third of people with brain tumors have no symptoms at all.

## Diagnosing Brain Tumors

Brain tumors may be diagnosed and evaluated using one or more of several different types of procedures:

- MRI - Magnetic Resonance Imaging
- CT - Computerized Tomography
- PET - Positron Emission Tomography
- Biopsy

MRI, CT, and PET scanning are all ways to take pictures of the inside of the body. They are all painless, and do not require surgery. These procedures are discussed in more detail below.

### MRI - Magnetic Resonance Imaging

MRIs use an extremely strong magnet to produce images. With contrast-enhanced MRI, the patient is first injected with a dye that makes normal and tumor tissue display differently. If your loved one requires an MRI, be sure to tell your doctor of any history of allergies or drug reactions.

Because the MRI uses a magnet, no metal can be brought into the room while the MRI is taking place. Patients who have pacemakers and/or metal implants cannot have an MRI. People who suffer from claustrophobia (the fear of being in tight spaces) may have difficulty dealing with the enclosed space of the MRI tube. There are a few possible solutions to this problem. If the imaging site allows it, a friend or relative can be there during the MRI. Another option, if the doctor agrees that it is appropriate, would be to take a tranquilizing medication before the scan. A third option would be to have the scan in a newer “open” MRI, which does not use a tube.

### CT - Computerized Tomography

A CT scan may be used for patients who cannot undergo MRI because they have pacemakers, metal implants, allergies or claustrophobia.

CT scan machines take multiple x-rays of small areas of the brain from different angles. The computer then combines the scans to make a detailed, three-dimensional image.

Because iodine may be used as a contrast agent to enhance the image, you should tell the healthcare provider if your loved one has any allergies, diabetes, asthma, a heart condition, kidney problems or thyroid conditions.

Side effects from iodine use are infrequent. Your loved one may experience a brief warm or hot “flushed” sensation during the actual injection of the iodine and a brief “metallic” taste in the mouth. If your loved one experiences itching over various parts of their body, tell the healthcare provider so that they can prescribe medication to treat this response. Serious reactions are rare, and may include breathing difficulty, swelling of the throat, or swelling of other parts of the body. Any of these reactions should be reported to the healthcare provider *immediately*.

### PET - Positron Emission Tomography Scan

PET scans are sometimes used in addition to MRI or CT to evaluate brain tumors. After receiving treatment for a brain tumor, PET scans can also be used to detect new tumor growth and

scar tissue or any necrosis (cells killed by radiation).

## Biopsy

Under certain circumstances, a doctor may need to take a biopsy. This means that a small piece of the tumor tissue may be surgically removed to be studied.

## Treating Brain Tumors

There is a range of options to be considered in the treatment of brain tumors. Your healthcare team will design a plan to help treat the tumor as well as to relieve any symptoms the brain tumor may be causing.

The following healthcare professionals may be part of the treatment team:

- **Neurologist:** a doctor who specializes in the management of patients with diseases of the brain and other parts of the nervous system.
- **Neurosurgeon** (or brain surgeon): a doctor who specializes in surgery of the brain and the rest of the nervous system.
- **Neurooncologist:** a doctor who specializes in the management of patients with brain tumors and other nervous system tumors.
- **Neuropsychologist:** a psychologist who specializes in how the brain works and the impact that damage to the brain has on the patient.
- **Radiation Oncologist:** a doctor who specializes in the management of cancer patients and treats them with radiation therapy.
- **Physical therapist:** a healthcare provider who teaches and guides the patient through various exercises to prevent pain and restore function or help the patient to adapt to new physical limits.
- **Speech-language pathologist or speech therapist:** a healthcare provider who specializes in the treatment of communication and swallowing problems.
- **Social worker:** a healthcare provider who provides a wide range of services directly to persons with cancer and their families including counseling, support and education.

## Surgery

The first treatment of choice, depending on the location and size of the tumor, is surgical removal of as much of the lesion as possible (also called resection). Surgery can also reduce symptoms caused by swelling in the skull, thus reducing the need for medication. Improvement in surgical techniques in recent years has made surgery much safer; however, surgery always has risks that you and your loved one should discuss with the oncologist and neurosurgeon. Surgery may be followed by radiotherapy (see below) to help prevent the formation of new tumors. In deciding whether surgery is right for your loved one, your doctor will consider the size, location and type of the tumor, overall health, and medical history.

## Radiation Therapy or Radiotherapy

Patients with more than one tumor, or with one tumor that is not readily accessible, are typically treated with radiation therapy. Radiation Therapy is the use of painless x-rays directed to damage or destroy tumor cells. Radiation may be used after surgery to prevent the tumor from coming back (recurrence), or to destroy tumor tissue that could not be completely removed. In cases where surgery is not an option, radiotherapy may be used instead of surgery to destroy tumor tissue or to relieve symptoms. Radiation is painless, and is typically given in 15-minute visits over several weeks. Radiation has the potential to cause various side effects, depending on your treatment plan. Ask the radiation oncologist about potential side effects of treatment.

Different types of radiotherapy are described below.

- **Whole Brain Radiation Therapy (WBRT)** delivers an even dose of radiation to the entire brain. Whole brain radiotherapy is the preferred treatment for brain tumors, because it can treat small, undetectable tumors that may be developing in different areas of the brain. The advantages of whole brain radiotherapy are that it can treat large and small tumors, many tumors at the same time, and tumors deep in the brain that cannot be removed through surgery. Whole brain radiotherapy is often used to reduce the risk of tumor recurrence after surgery. Side effects of whole brain radiotherapy may include nausea, vomiting, headache, fever, and temporary worsening of neurological symptoms such as

memory loss and difficulty thinking. Discuss any concerns you and your loved one might have about side effects with the radiation oncologist.

- **Stereotactic Radiosurgery** is a more targeted form of radiation therapy, and is not actually surgery at all. It is called “radiosurgery” because it is so precise and focused. Other names you may hear for stereotactic radiosurgery include Gamma Knife™, X-knife™ and Cyber-knife™. This form of therapy delivers a higher dose of radiation to a small tumor (usually 1.5 inches or less in diameter) in a single treatment session. Because this form of radiation targets the tumor more precisely, it is less likely to hurt healthy tissue. Stereotactic radiosurgery only treats tumors that can be detected on MRI or CT scans. Possible side effects of radiosurgery include swelling, neurological problems, and build up of dead tumor cells in the brain that may need to be removed by surgery. Ask the doctor about side effects.
- **Brachytherapy** also called interstitial radiation therapy, is another form of targeted radiation for patients with tumors that are not responsive to other types of treatment. In contrast to external radiation, brachytherapy delivers radiation from inside the body through implanted radioactive pellets or liquid radiation balloons. The implant may be removed after a few days or longer. Surgery may be needed after brachytherapy to remove dead tumor cells. Brachytherapy delivers radiation directly to the local tumor site (i.e., rather than whole brain radiation which is more global). Brachytherapy is rarely used anymore.

## Chemotherapy

Chemotherapy is the use of special drugs to kill tumor cells. Some chemotherapy drugs are given by mouth; others are given by injection. In some cases, chemotherapy may need to be given without stopping over a long period of time. In this case, a pump or catheter may be placed underneath the skin to deliver the drugs.

There is a chemically protective layer around the brain called the blood-brain barrier. This barrier can prevent the drugs or chemotherapy given by mouth or injection from reaching the brain. To solve this problem, new ways of giving chemotherapy are being developed to deliver the drug directly to the tumor. One example of this is chemotherapy wafer implants that are surgically implanted in the tumor site and deliver treatment over time.

Because chemotherapy affects both healthy cells and tumor cells, side effects can occur. These vary depending on the type of drug and the individual. Side effects of drugs used in chemotherapy may include nausea or vomiting, skin rash, and occasionally soreness of the mouth or mouth ulcers. These side effects are usually reversible and may vary with each individual.

For a listing of common chemotherapy drugs used to treat brain tumors and their specific side effects,

visit:

[www.brainumor.org/patient\\_info/surviving/treatment/chemotherapy\\_effects.html](http://www.brainumor.org/patient_info/surviving/treatment/chemotherapy_effects.html)

## Treating the Symptoms

The following treatments can help with the symptoms of a brain tumor, such as headaches and nausea, although they will not actually help to remove the tumor or cure your loved one:

### Steroids (Corticosteroids)

Brain tumors often produce swelling and inflammation inside the skull. This can cause headaches, sleepiness and other problems. Steroids (corticosteroids), usually dexamethasone, reduce the swelling quickly and can improve mental functioning. Most patients feel better with short-term steroid medications; however, some will need to take steroids for more than a few months to control symptoms. If your loved one takes steroids as part of the treatment plan, be sure to tell the doctor or nurse about any changes in their health that you may notice. Steroids can cause side effects such as weight gain, increased appetite, insomnia and irritability. Also, your loved one should speak with the doctor if they decide to stop taking steroids as stopping suddenly can be dangerous.

### Anti-seizure Medications (Anticonvulsants)

Medications may be given to help prevent seizures. These medications are called anti-seizure medications or anticonvulsants. There are several different anti-seizure medications available such as Tegretol, Depakote, Neurontin, and Phenobarbitol. If your loved one is taking an anti-seizure medication as part of the treatment

plan and either it does not work or causes unpleasant side effects, the doctor will be able to switch to a different medication.

## Complementary Therapies

Your loved one's medical treatment is carefully planned to control the disease and reduce the symptoms as much as possible. Many people seek out complementary therapies to help them feel better and cope with the stress of cancer. These therapies are not meant to replace the medical therapy, but may help your loved one to manage his or her symptoms. Complementary therapies for cancer may include stress management, relaxation and imagery training, meditation, group support, family counseling, nutrition, herbal medicine, massage, acupuncture and education. Some cancer centers and hospitals offer these services for people with cancer, their families, and their caregivers.

## Can Clinical Trials Help Your Loved One?

Clinical trials are research studies to test new treatments. For cancer research a clinical trial might focus on medication, surgery, radiotherapy, a new type of therapy, or some combination of these. Benefits of participating in clinical trials include:

- Being among the first to receive a promising new treatment
- High-quality medical care
- Helping doctors understand more about cancer treatment, thus helping future cancer patients

The possible risks of participating in clinical trials include:

- An experimental treatment may not be as good as standard care
- The new treatment may not work for your loved one; also, your loved one may be in the study group that does *not* receive the new treatment

Doctors are now investigating several treatments for brain tumors in clinical trials. Some new drugs are designed to increase the effectiveness of standard treatments, such as radiotherapy and chemotherapy. Other new treatments are

designed to change tumor cells, so that their growth is under control.

There are many ways to find trials that might be appropriate for your loved one. Start by asking the doctor about what trials are available. Various organizations also provide lists of trials along with information about what is being tested, and where the trial is occurring. See the section below entitled Resources for information on how to contact these organizations. Be sure to check with your loved one's health insurance provider to see whether the costs of participating in the clinical trial are covered.

## What Will Happen After Treatment?

After treatment, a patient's health is monitored closely. An MRI, CT, or other type of imaging scan may be done every so often to see if the treatment is working. Frequent physical exams will help the doctor find out if the cancer has returned or if side effects are a problem. Be sure to report any recurrence of symptoms or other changes in your loved one's health promptly to the doctor or nurse.

## Issues for Caregivers

*Q: What effects do brain tumors have on the mind, emotions or personality?*

Brain tumors can indeed affect the mind, emotions, and/or personality. Problems with memory, speech, and/or concentration may occur. Your loved one may face serious mental challenges with feelings of confusion. Moods may change, as may the way a person acts. Your loved one may have difficulty doing more than one task at a time. Various treatments may slow the progression of these symptoms, so check with the doctor about what treatments may help.

Be aware that a neuropsychologist can help with rehabilitation. In order to come up with an effective plan, the neuropsychologist will first do a series of tests to look at your loved one's emotions, behaviors, and mental abilities. Based on the results of the tests, one or more of the following may be recommended:

- Cognitive rehabilitation, which means treatment for mental difficulties
- Occupational rehabilitation, which is education and training about how to be able to continue working
- Counseling to deal with emotional changes

***Q: How can the home be safer for your loved one with brain tumors?***

Due to possible muscle weakness, changes in balance, and other considerations, the following may help make the home a safer place for your loved one:

- Put handrails in shower and bathtub
- Get a shower chair
- If the home is more than one story, consider putting the your loved one's bed on the ground floor
- Consider getting a hospital bed
- Consider getting a portable toilet

***Q: How can I cope emotionally?***

As a caregiver, you may choose to receive counseling either to (1) learn how to help your loved one deal with the mental changes they are having, or (2) learn to deal with your own reactions to changes in your loved one. This is a difficult time for everyone involved. While illness may bring people closer together, it may also cause tension, unhappiness and stress. Here are some suggestions for coping:

- Find family members and friends who are willing to commit to helping you take care of your loved one.
- Involve those people in a caring community that provides both practical and emotional support to you and your loved one.
- Identify your strengths and the strengths of the others in your caring community.
- Take time off regularly! Caregiver burnout is a major concern.
- Get involved with outside groups and organizations that provide support and information for people with cancer and their friends and caregivers.

## Credits

American Brain Tumor Association, 1994, *Coping With A Brain Tumor*, Des Plaines, IL.

American Brain Tumor Association, 1996, *A Primer of Brain Tumors*, Sixth Edition, Des Plaines, IL.

National Brain Tumor Foundation, 2002, *Coping with your Loved One's Brain Tumor*, Oakland, CA.

National Brain Tumor Foundation, 2004, *Understanding Brain Metastases: A Guide for Patient and Caregiver*, Oakland, CA.

## Recommended Readings/Links

*Navigating Through A Strange Land. A Book For Brain Tumor Patients and Their Families*, Patricia Ann Roloff (Ed), 1995, Indigo Press, 109 Walnut St., San Francisco, CA 94118.

*Coping With a Brain Tumor Part I: From Diagnosis to Treatment and Part II: During and After Treatment*, American Brain Tumor Association, 2720 River Road, Ste. 146, Des Plaines, IL 60018.

*Coping with Your Loved One's Brain Tumor*, National Brain Tumor Foundation 2002. Available online: [www.braintumor.org/pservices/pdfarchive/CopingBrochure.pdf](http://www.braintumor.org/pservices/pdfarchive/CopingBrochure.pdf)

*A Primer of Brain Tumors, Sixth Edition*, Gail Segal, 1996, available from the American Brain Tumor Association, 2720 River Road, Ste. 146, Des Plaines, IL 60018.

*Love, Medicine and Miracles*, Bernie Siegel, 1986, Harper Perennial, New York, NY, (800) 242-7737.

*Brain Tumors: A Guide*, the National Brain Tumor Foundation, 2003, 414 Thirteenth St, Suite 700, Oakland, CA 94612-2603 (800) 934 2873. [www.braintumor.org](http://www.braintumor.org). Also available:

*SEARCH* (Newsletter), National Brain Tumor Foundation

*Brain Tumor Resource Directory* (2003), National Brain Tumor Foundation. Available online.

*“How Brain Tumors Affect the Mind, Emotion, and Personality”*, National Brain Tumor Foundation, 2002. Available online: [www.braintumor.org/pservices/pdfarchive/Fact%20Sheet-NeuroPsych.pdf](http://www.braintumor.org/pservices/pdfarchive/Fact%20Sheet-NeuroPsych.pdf)

Family Caregiver Alliance Fact Sheets: Available by sending \$1.00 to FCA Publication Orders, 180 Montgomery St., Ste. 1100, San Francisco, CA 94104 or free online.

[Caregiving and Depression](#) or [Taking Care of YOU: Self-Care for Family Caregivers](#)

## Resources

### MONTEREY COUNTY

Health Projects Center's

Del Mar Caregiver Resource Center

(831) 424-4359

Web site: <http://www.delmarcaregiver.org>

### SANTA CRUZ COUNTY

Health Projects Center's

Del Mar Caregiver Resource Center

(831) 459-6639

Web site: <http://www.delmarcaregiver.org>

### SAN BENITO COUNTY

Health Projects Center's

Del Mar Caregiver Resource Center

(831) 459-6639

Web site: <http://www.delmarcaregiver.org>

Del Mar Caregiver Resource Center supports and assists caregivers of brain-impaired adults through education, research, services and advocacy.

For residents of Central California, Monterey, Santa Cruz and San Benito Counties, Del Mar CRC provides direct family support services for caregivers of those with Alzheimer's disease,

stroke, head injury, Parkinson's and other debilitating brain disorders that strike adults.

### **Brain Science Foundation**

266 Main Street, Building 1, Suite 6B

Medfield, MA 02052

(508) 242-9830

[www.brainsciencefoundation.org](http://www.brainsciencefoundation.org)

### **Central Brain Tumor Registry of the United States**

3333 West 47th Street

Chicago, IL 60632

(773) 579-0021

[www.cbtrus.org](http://www.cbtrus.org)

### **The Healing Exchange BRAIN TRUST**

186 Hampshire Street

Cambridge, MA 02139-1320

(877) 252-8480 (toll free)

(617) 876-2002

[www.braintrust.org](http://www.braintrust.org)

### **National Brain Tumor Foundation**

22 Battery St., Ste. 612

San Francisco, CA 94111

Patient Information Line: (800) 934 2873

Email: [nbtf@braintumor.org](mailto:nbtf@braintumor.org)

[www.braintumor.org](http://www.braintumor.org)

### **National Cancer Institute**

Suite 3036A

6116 Executive Boulevard, MSC8322

Bethesda, MD 20892-8322

Phone: (800) 4CANCER (800-422-6237)

[www.cancer.gov](http://www.cancer.gov)

### **North American Brain Tumor Coalition**

(includes all of the Brain Tumor organizations)

[www.nabraintumor.org](http://www.nabraintumor.org)

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