It is important to explore what a patient hopes for. Is it: freedom from pain or other physical symptoms, independence for as long as possible, participating in a family event or gathering, making peace in a troubled relationship, dying with dignity? What people hope for frequently changes throughout life, but rarely does anyone stop hoping.

— Deanna Glass-Macenka, RN
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Managing Common Side Effects

Not everyone experiences the same side effects, but this information is here to help if you experience any of these more common problems. You can keep notes about how you feel and work closely with your doctors and nurses to find the best ways to feel better.

THINGS TO REMEMBER

-> Your symptoms are linked to the location of the tumor in your brain, and result from your treatments.

-> There are ways to relieve symptoms and side effects, but this process is not perfect and it requires time and patience.

-> Rehabilitation specialists (physical, speech and occupational therapists) can be terrific help. Try to find a team that is experienced in working with brain tumor patients.

-> Keep track of how you feel (or ask someone to keep notes for you.) Aim to bring your notes to appointments to help you remember what you’d like to discuss.

-> Many cognitive symptoms (memory loss, anger, anxiety or depression) not only affect you, but also people close to you.

-> Try to be patient with yourself and with others as you strive for a higher quality of life.

-> Licensed social workers and support groups can help as you cope with depression, anxiety, or other changes in your life. (See Chapter 5 for more.)

-> Complementary or alternative medical techniques, such as diet changes, exercise, or relaxation techniques, may also help you feel better.
LOCATION MATTERS

As a brain tumor grows, it presses on the surrounding brain tissue, which affects the function controlled by that part of the brain. This chart shows symptoms that can be caused by tumors in different parts of the brain and the spinal cord.

<table>
<thead>
<tr>
<th>LOCATION OF THE TUMOR</th>
<th>SYMPTOMS</th>
</tr>
</thead>
</table>
| Frontal lobe           | Changes in personality  
                          | Loss of inhibitions, behaving aggressively  
                          | Losing interest in life (apathy)  
                          | Difficulty with planning and organizing  
                          | Being irritable  
                          | Weakness in part of the face, or on one side of the body  
                          | Difficulty walking  
                          | Loss of sense of smell  
                          | Problems with vision or speech |
| Temporal lobe          | Forgetting words  
                          | Short term memory loss  
                          | Seizures associated with strange feelings, smells |
| Parietal lobe          | Difficulty speaking or understanding what is said to you  
                          | Problems with reading or writing  
                          | Loss of feeling in part of the body |
| Occipital lobe         | Sight problems or loss of vision on one side |
| Hindbrain (cerebellum) | Poor coordination  
                          | Uncontrolled movement of the eyes  
                          | Nausea and vomiting  
                          | Neck stiffness  
<pre><code>                      | Dizziness |
</code></pre>
<table>
<thead>
<tr>
<th>LOCATION OF THE TUMOR</th>
<th>SYMPTOMS</th>
</tr>
</thead>
</table>
| **Brain stem**        | • Poor coordination  
                         | • Drooping eyelid or mouth on one side  
                         | • Difficulty swallowing  
                         | • Difficulty speaking  
                         | • Seeing double |
| **Spinal cord**        | • Pain  
                         | • Numbness in part of the body  
                         | • Weakness in the legs or arms  
                         | • Loss of control of the bladder or bowel  
                         | • Difficulty walking |
| **Pituitary gland**    | • Irregular or infrequent periods  
                         | • Infertility in men and women, impotence  
                         | • Lack of energy  
                         | • Weight gain  
                         | • Mood swings  
                         | • High blood pressure  
                         | • Diabetes  
                         | • Enlarged hands and feet |
| **Nerves controlling sight or hearing** | • Blurry vision  
                         | • Hearing loss |
| **Meninges**           | • Headache  
                         | • Nausea and vomiting  
                         | • Sight problems  
                         | • Neck pain |

QUESTIONS TO ASK ABOUT SIDE EFFECTS

1. What side effects should I expect?
2. When should I call you for immediate help? (With which side effects?)
3. What can I do to manage my side effects? Can you help me create a management plan?
4. How do you recommend I keep track of how I feel, and what do you need to know?
5. What can I do to feel better?

Adapted from Cancer Research UK. www.cancerresearchuk.org
After any surgery or cancer treatment, it is not unusual to feel worse than you did before. Though this is temporary, it can be depressing. Brain surgery is a lot for your body to cope with. Swelling in the brain after an operation means it will take some time before you feel the benefit from having your tumor removed.

You may experience dizzy spells or get confused about where you are and what’s happening. These episodes can come and go. This is normal and part of the recovery period.

For some people, recovery may be complete after a few weeks or months; for others, you may have to learn to adjust and manage permanent changes in your life including not being able to work or accomplish all of the tasks you did before. Your surgeon can give you some idea, but ask as many questions as you can about what to expect for your recovery.

It was hard to see Archie’s heart break when he couldn’t express himself. It was hard for me to receive text messages that made no sense. Practice is critical. Archie is a published author, but he had to relearn so much. I just wanted him to be patient with himself. So he would practice, and say words over and over again until he got it right.

— Sarah, caregiver
People who experience a variety of physical symptoms including weakness, difficulty speaking, stiffness, problems with movement, etc. can benefit from various forms of rehabilitative treatment. Every person with a brain tumor deserves to function as optimally as possible, so patients should be evaluated for successful rehabilitation treatment.

Physical, occupational, and speech therapists are experts in this area – and ideally, you can work with professionals who are experienced in working with brain tumor patients and/or neurological disorders (rather than sports injuries, for example):

- **Physical therapists** help patients improve their walking, balance and strength. Some people experience permanent mobility problems. Physical or occupational therapists will offer exercises to support your range of motion and make sure your body has proper positioning to help decrease pain and freezing of the limb(s) as much as possible.

- **Occupational therapists** teach patients how to manage their side effects so that they can go about their lives and perform daily activities, such as cooking, writing, and driving.

- **Speech therapists** help people overcome problems understanding and producing language. Speech therapists also help with eating and swallowing caused when there are oral motor problems. They teach patients how to improve their speech process and adjust how they verbalize or otherwise express themselves.

If you need them, there are assistive devices and exercises that can be prescribed by rehabilitation specialists. Handrails and grab bars, and bath or shower chairs are some. There are also tools and tips to help with eating and dressing, and to help a person maintain computer access and independence. Keeping track of issues and talking regularly with rehabilitation specialists can help you get the support you need.

It is also useful to know about the federal and state programs that link people with services, technology, and funding. For example, the Americans with Disabilities Act helps people who experience a disability due to illness, like a brain tumor, but want to go back to work with reasonable accommodations. (Chapter 6 offers more information, or visit [www.govbenefits.gov](http://www.govbenefits.gov), or [www.abledata.com](http://www.abledata.com).)

**QUESTIONS ABOUT REHABILITATION SERVICES**

1. How long do you estimate that I will need rehabilitation services?
2. Do I have insurance benefits for rehabilitation? If so, what will it cover?
3. If I haven’t met my rehabilitation goals before my insurance benefit runs out, how will that be handled?
**HEADACHES**

Headaches are most often caused by edema (swelling of the brain caused by the tumor or treatment). Steroids may be prescribed to reduce edema. Unfortunately, steroids can cause their own set of problems (difficulty sleeping, sweating, over eating, agitation). If you take steroids, be clear with your medical team and tell them if you experience sleeplessness or other new symptoms so they can adjust the dose.

Some headaches are connected with symptoms such as dizziness, nausea, or vomiting, often because of where the tumor is located in the brain. The surgical removal of the tumor will often relieve those headaches; and post-operative headaches often go away after a short period of time.

If headaches persist, you should be evaluated. If headaches return, it could be a sign of recurrent edema or a new tumor and should be addressed by your treatment team.

**SEIZURES**

A seizure is a sudden attack or convulsion caused by an abnormal burst of electrical activity in the brain. It can cause a range of reactions, from muscle contractions, to staring, to loss of consciousness.

Some people only experience one seizure while others suffer from reoccurring seizures, or epilepsy. Seizures are common with slow-growing gliomas, meningiomas, and metastatic brain tumors.

- **Simple Partial Seizures** can cause involuntary jerking, tingling or numbness in one part of the body, buzzing in the ears, lip smacking, and dilated pupils.

- **Complex Partial Seizures** cause altered consciousness. A patient may be aware of his or her surroundings but unable to speak, or may feel confused and hallucinate (imagining sights, odors, and sounds).

- **Generalized Seizures** are also called grand mal seizures. They begin with a sudden loss of physical control with flailing arms and legs, unconsciousness, twitching muscles, and incontinence, or shallow breathing. Afterward, the patient may be limp or confused.
Patients who suffer from multiple seizures can keep a journal of when and for how long the seizures occur. The doctor can then find a pattern and adjust antiepileptic drugs to help.

A patient may be put on an antiepileptic or antiseizure drug if he or she experiences a seizure or to prevent seizures. The type and amount of medication is based on the level of seizure control needed and how well you react to the medication.

Some AEDs react badly with certain chemotherapy drugs and should not be used together. If side effects are a serious problem, a doctor can change the medication.

If you are aware of AED medications, or other medications that you should not take or react badly to, it is helpful to consider wearing a medical alert bracelet with this information.

HELPING SOMEONE WHEN THEY HAVE A SEIZURE

If someone is experiencing a seizure, stay with them and allow the seizure to pass. This can take a few seconds to a few minutes. Loosen any tight clothing if possible, and make sure they are breathing. Try to remove or cushion harmful objects to prevent injury, and do not put anything in their mouth.

Call for emergency help if the seizure lasts longer than five minutes, if a second seizure immediately follows, or if the person has trouble breathing or is injured.
**BLOOD COUNTS**

**Anemia** is when red blood cell (RBCs) levels are unusually low. RBC's are important because they contain hemoglobin which allows the oxygen exchange to occur as blood circulates through our bodies. Low RBC levels lead to fatigue or symptoms like dizziness, or shortness of breath. If anemia becomes severe, it can be treated with medications or with a blood transfusion.

**Leukopenia** is when white blood cells (WBCs) are unusually low. WBCs are important because they help to fight infection. Chemotherapy can affect your ability to maintain adequate amounts of WBCs. Steroids can also lower certain WBCs, called lymphocytes. Your doctor may prescribe antibiotics to help protect you.

**Thrombocytopenia** is when the level of thrombocytes or platelets is unusually low. Platelets are important for our blood to clot. Chemotherapy can decrease the production of these cells, and when they fall too low we are at risk for spontaneous bleeding. If thrombocytopenia becomes too severe, platelet transfusions may be necessary.

**Thrombosis** is the formation of blood clots as a result of increased clotting factors in the blood. With deep vein thrombosis blood clots form in the legs, and disrupt the flow of blood, causing pain or swelling in the calf, behind the knee, or in the thigh. If blood clots break loose and block blood vessels in the lung, it is called pulmonary embolus (PE), which requires immediate medical attention. DVT and PE may occur at any time after brain tumor surgery, especially when a patient is not physically active. Patients and caregivers need to be aware of DVT symptoms and call the doctor immediately if they have concerns.

Staying active and walking as much as possible is the best way to prevent DVT. Compression stockings and medication to thin the blood are also used for prevention.

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**GASTRO-INTESTINAL (GI) PROBLEMS**

GI problems can include any difficulty with digestion or stomach discomfort. Chemotherapy is well known for causing GI problems.

**TIPS TO RELIEVE CONSTIPATION**

- Eat more fiber-rich foods (whole grains, fruits and vegetables)
- Increase physical activity
- Consider laxatives
- Drink more water
**TIPS TO RELIEVE NAUSEA AND VOMITING**

- Antinausea medications called antiemetics may help
- Diet changes are useful. For example, when you don’t feel like eating, try frequent healthy snacks rather than large meals
- Bland foods, crackers, and clear liquids between meals may be better tolerated
- Avoid foods with strong odors, heavy spice, alcohol, and greasy or fried foods
- Suck on a lemon drop candy to relieve nausea

**FATIGUE**

Feeling exhausted or extremely tired is the most common side effect reported by patients.

Fatigue is not relieved by a good night’s sleep; it can last for a short time or for many years. It is caused by many things, from tumor treatments to the tumor itself, to the healing process, to poor sleep, stress, or anemia. Fatigue is considered to be one of the most debilitating symptoms and side effects of a brain tumor because it limits a person’s ability to function.

No matter what the cause, fatigue can be managed. The goal is to conserve energy so you can focus on doing the things that are important to you.

**TIPS TO MANAGE FATIGUE**

- Try to establish a daily routine
- Listen to your body. Rest when you need to
- Mild exercise will help give you more energy
- Make lists of things you need to do and recruit help
- Make plans to get things done during the time of day when you have the most energy
- If one reason for your fatigue is anemia (a low level of red-blood cells), seek medication to increase the level of your red blood cells
- Ask if drugs, like Provigil, may help reduce fatigue
COGNITIVE AND BEHAVIORAL CHANGES

A brain tumor and its treatment(s) can cause changes in a person’s behavior and ability to think. Patients may experience difficulties with their communication, concentration, memory, and their personality may change.

These difficulties may affect a patient’s ability to work or go about his/her daily life, and they do not always go away. This can cause stress for both the patient and his or her family.

Medication may be prescribed to reduce problems with cognitive and behavioral changes, and counseling may help a patient recognize when they are experiencing cognitive problems.

More tools to cope with cognitive and behavioral changes include:

Cognitive Rehabilitation
Cognitive rehabilitation is designed to help people regain as much of their mental, physical and emotional abilities as possible.

• **Compensation techniques** are methods to develop alternate skills to make up for those that have been lost, such as exercises to strengthen sight, speech, and movement. When full recovery is not possible, treatment includes compensation techniques like learning to live with memory loss by keeping calendars, reminder systems, and organizers. Neuropsychologists are cognitive experts that can help identify compensation solutions or offer medications to enhance mental functioning (for example, Ritalin).

• **Anger management training, counseling or medication** can help a patient who experiences behavioral and personality changes such as impulsiveness, frustration, or moodiness.

Caregivers and/or family members also benefit from compensation techniques. Often, a caregiver feels frustrated (“Why can’t [the patient] do a simple task?”) and angry (“He/She’s driving me nuts!”). Mixed emotions towards a loved one are common. These feelings make home life very complicated – especially as people with brain tumors live longer in a cognitively impaired state. It is important that a caregiver has help or compensation strategies that he/she can use to maintain the high level of patience that is required. (See Chapter 7)
At first I didn’t realize how much self-esteem I’d lost. I’m in cognitive therapy now and it’s like psychotherapy. Three weeks in and I feel better mentally at work, and I’ve noticed a difference in myself.

— Darren, patient

**EXERCISE YOUR BRAIN**

**PLAY TO YOUR STRENGTHS.**
Use memory tools to help you remember. Sticky notes, lists, and always putting your keys in the same place help take the burden off your memory systems. Tools (notebooks, calendars) can also help you remember.

**CHALLENGE YOURSELF IF YOU CAN.**
Puzzles, games, playing an instrument, and reading all help to improve your memory and thinking abilities. Be patient with yourself.

**GET ENOUGH SLEEP.**
Your body needs 7-9 hours of sleep per day. When you’re recovering from brain surgery, you will want even more sleep. Take cat-naps during the day if you’re having trouble with sleep during the night.

**PRACTICE RELAXATION.**
Remember that stress plays a large role in memory. Relax using yoga, meditation, exercise, and other techniques.

**EXERCISE YOUR BODY.**
Even light exercise greatly improves mental performance by bringing oxygen and nutrients to your brain.

**EAT RIGHT.**
Focus on eating fruits and vegetables. Keeping your blood sugar normal improves mental performance. Adding essential fatty acids (Omega 3s from fish and flax seed), B-Vitamins, and Amino acids will also help.

**ADJUST MEDICATIONS.**
If you think that your memory problems may be worsened by something you’re taking, ask your doctor.
Anxiety is a normal response to new and stressful situations. Feeling anxious, from the diagnosis or from medications that increase agitation, may make every situation feel even more intense. Common symptoms of anxiety include: rapid heart-beat, fear, restlessness, nervousness, and sweaty palms.

If you are feeling anxious it is important to talk about your feelings and concerns, and to find ways to regain a sense of control in your life.

Often, depression and anxiety go together. Depression is common in people with brain tumors. People who feel depressed experience a sense of irritability, hopelessness, an inability to concentrate, apathy, withdrawal, and mood swings – sometimes a desire to harm themselves. While many of these symptoms can be attributed to a tumor, depression can and should be treated on its own.

Treatments include anti-depressant medication and counseling. Just talking about how you feel with someone skilled in relieving emotional problems can help make you feel better.

Most people note that their mood improves as the symptoms of a brain tumor or side effects from treatment are managed and go away.
Hormonal Changes
Changes in hormones and endocrine function may result from a tumor found in or near the hypothalamus, pituitary or pineal glands, or as a delayed effect of radiation therapy. If left untreated, hormone disruptions can become a disturbing, chronic problem that causes mood and personality changes, as well as sexual dysfunction. These conditions require specialized treatment and monitoring by an endocrinologist.

Fertility
Many of the treatments used for brain tumors can impact a person’s fertility either temporarily or permanently. Options are available for people who wish to get pregnant after treatment, but you must speak up before treatment begins to consider sperm or egg banking, or tissue freezing. Insurance coverage is not consistent for these things, so ask your insurance company about what’s covered before you begin.

Sexuality
Changes in sexuality from treatment or a tumor can result from a decreased libido, fatigue, changes in self-image (from the surgery and treatment). Many people don’t feel comfortable talking about this problem with their doctor, although it might be important to do so. Consider that your doctor or nurse may have helpful suggestions and advice.

HORMONAL CHANGES, FERTILITY AND SEXUALITY

TIPS TO RESTORE INTIMACY

- Communication is essential. To feel connected with your partner, consider how he/she “hears” what you want to say
- Find ways to feel more attractive to yourself, and in turn, to your partner
- Be open to discovering new ways that you and your partner can connect and feel close
- Remember to make small, intimate gestures, like a smile, a touch, or a hug
- Look online for the American Cancer Society’s booklet on sexuality and intimacy after cancer (www.cancer.org)
Complementary or Alternative Medicine (CAM)

The medical community is increasingly recommending complementary medical techniques to relieve symptoms for brain tumor patients. CAM is primarily used to relieve side effects and stress.

The most common CAM techniques are: eating a plant-based diet, relaxation, exercise, acupuncture, chiropractic, guided imagery or meditation, healing touch (such as Reiki), herbal medicine, and massage therapy. If you choose to use a CAM approach, then it is important to inform your medical team. In some cases, CAM practices could impact the way traditional cancer treatment is provided, so it’s a good idea to keep your medical team informed about your entire system of care.

**DIET AND NUTRITION**

The purpose of a nutritious diet is to provide energy and to improve immune functioning. Most often, people are asked to eat more plant-based foods (vegetables, fruits, beans and whole grains) – while avoiding or minimizing processed foods, refined sugars, meat and cheese. A plant-based diet has been shown to improve our body’s ability to fight disease, reduce blood pressure, reduce cholesterol, and improve overall health. Avoiding cured food (like deli meat or salted chips) and eating more whole foods high in antioxidant vitamins may lessen the risk of developing additional cancer – and over time – improve your body’s ability to fight the cancer you have.

There are some worthy diet recommendations available, such as in *Eat to Live* by Joel Fuhrman, MD, or *Eating Hints: Before, During, and After Cancer Treatment* by the National Cancer Institute. Under all circumstances, it is best to eat whatever food you can tolerate. Talk to a dietician educated in working with cancer patients, and ask your neurologist if a diet you’d like to use is safe for you.

**EXERCISE**

The goal of exercise is to enhance—rather than deplete—energy, strength, and vitality. It helps you breathe properly and increases your lung capacity, which in turn benefits the immune system. It also improves muscle strength and heart health. Patients who must take steroids for long periods of time minimize damage to muscle strength with exercise. Several studies have shown that exercise can help people have better treatment outcomes, as well as secondary psychological benefits.

Exercise can be simple, or more intense, depending on your ability. You can start with walking, light weight lifting, or practices such as Tai Chi, yoga, or Pilates. It is helpful to start slowly with a goal to build up your energy level and abilities.

To learn more about CAM, look for information on the National Center for Complementary and Alternative Medicine’s website: nccam.nih.gov.
**GREAT FOODS TO EAT**
- raw and cooked colorful vegetables: dark green, deep yellow, orange, red, or purple
- raw and cooked lightly colored vegetables: cauliflower, mushrooms, onions, cucumber, lettuce
- raw and cooked starchy vegetables: squash, potatoes, corn
- fresh and dried fruits, avocado
- nuts, seeds and oats
- tofu and beans

**STAY HYDRATED**
- water
- fruit juice
- coconut, almond, or rice milk
- decaffeinated tea
- fruit smoothies

**FOODS TO LIMIT**
- cured meats
- red meat
- alcohol
- sugary sweets
- processed foods with food coloring and saturated fats
- fried foods
- cheese

**30-60%**
Vegetables
1/2 Raw, 1/2 Cooked

**10-40%**
Fruits

**10-40%**
Beans/Legumes

**10-20%**
Seeds, Nuts, Whole Grains

**5-10%**
Fish, Eggs, Poultry, Dairy

**1-5%**
Beef, Sweets, Cheese, Processed Foods

**HEALTHY EATING TIPS**
Our dietician was so helpful. She gave Darren tips to feel more energy, tips to get more liquid into his diet when he was dehydrated, tips to address lots of side effects. And it works. ...It’s funny, we thought we ate healthy before, but the dietician showed us how we really ate! Now we do better.

— Carrmen and Darren, caregiver and patient
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CANCER SUPPORT COMMUNITY’S FRANKLY SPEAKING ABOUT CANCER SERIES
Cancer Support Community’s Frankly Speaking About Cancer: Brain Tumors program is part of a national education program that provides support, education, and hope to people affected by cancer and their loved ones.

Frankly Speaking About Cancer booklets feature information about treatment options, how to manage side effects, the social and emotional challenges of the diagnosis, and survivorship issues.

For more information about this program, the Frankly Speaking About Cancer series or Cancer Support Community, please visit our website at www.cancersupportcommunity.org or call us toll-free at 1-888-793-9355.
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