

Chapter 8

Comfort & Coping

Whether you are the person with the tumor, a caregiver, or a family member, you might still be trying to make sense out of the words “brain tumor.” You may be frightened or feeling isolated. Comfort and control probably seem like a dream.

This chapter offers suggestions and advice from professionals who specialize in helping people cope, and from other patients and those close to them who have had experiences similar to yours. We hope some of their ideas work for you.

What Are Seizures?

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.

Normally, your body's nerve cells communicate with each other via carefully controlled electric signals. If something interferes with those signals and they become more intense, a seizure results. While seizures are usually brief, their effects may linger for several hours.

There are different types of seizures. The type you experience depends on which area of the brain has the abnormal electrical signals.

Most seizures occur randomly, at any time and without any particular cause. However, you might have some advance notice. Headache, mood changes and/or muscle jerking might signal a coming seizure. Those warning signals are called "auras." An aura may precede a seizure by a few seconds or even minutes. Use that time to safeguard yourself. For example, if you are chewing, remove the food from your mouth. If you are walking, sit or lie down.

If you have recurrent seizures, you might notice that some events "trigger" them. Bright lights, flashing lights, specific odors, lack of sleep, missed meals, menses, increased stress or emotional difficulties, alcohol, new medications, or changed dosages of existing medications can all be triggers. Keeping track of what you were doing immediately prior to each seizure can help you identify your personal triggers. Having a seizure does not necessarily mean your tumor is growing.

Types of Seizures

There are two primary types of seizures — partial (also called focal) seizures and generalized seizures.

PARTIAL (FOCAL) SEIZURES

There are two types of partial seizures: Simple partial seizures, which don't cause unconsciousness and complex partial seizures, which do cause loss of consciousness.

Simple partial seizures

Simple partial seizures commonly cause convulsive jerking or twitching (if the frontal lobe is involved), tingling or numbness (if the parietal lobe is involved) or other unusual sensations. These symptoms can begin in one part of the body and then spread to other areas. Chewing movements or lip smacking (if the anterior temporal lobe is involved), buzzing in the ears, flashes of lights, sweating, flushing and pupil dilation are other common symptoms. Psychic symptoms include a sense of déjà vu, imaginary sights (if the occipital lobe is involved), smells (if the temporal lobe is involved) or tastes, or imaginary sounds.

Complex partial seizures

Complex partial seizures cause some loss of consciousness and usually indicate temporal lobe involvement. Purposeless, automatic movements might occur. The seizure may be preceded, accompanied by, or followed by psychic symptoms. A state of confusion may last for a time after the attack. In patients with low-grade gliomas, this is the most common type of seizure.

GENERALIZED SEIZURES

These seizures may begin as partial seizures and abruptly change into generalized seizures. There are several different types of generalized seizures.

Absence (petit mal) seizures

Absence seizures cause an impairment of consciousness and may be accompanied by a feeling of limpness. The person having the seizure may miss a few words or stop speaking for a few seconds during a conversation. You may think he or she has been daydreaming. The beginning and end of the episode is usually sudden. This type of seizure most commonly begins in childhood and often stops by age 20.

Atypical absence seizures

Atypical absence seizures may cause more extensive changes in muscle tone, or they may have a more gradual beginning and ending than typical absence seizures.

Atonic seizures (epileptic drop attacks)

Atonic seizures, also called "epileptic drop attacks," are characterized by sudden limpness. Generally, all muscle tone and consciousness are lost.

There are many books available that can help parents explain their illness to children. Although most of these books are about cancer, the advice they contain is useful for many illnesses. Read these books with your children; offer them the opportunity to ask questions and to express their fears and concerns.

Most importantly, remember that children of all ages need to be reassured that you have planned for their needs. Explain those plans and arrangements to your children, making sure they know you are still very much involved, even if from a distance.

If friends offer to help, accept their offers. You will benefit from the assistance, and your friends will feel needed. Groceries, laundry, a meal on the day of your doctor visit, transportation to the clinic for therapy — there are many possibilities. Keep a “Wish List” of things you “wish” you had the time to do. When someone offers to help, reach for that list. Don’t be shy!

Although most people will be supportive, some will be unable to deal with or even acknowledge your illness. Also, be prepared for well-meaning neighbors who insist upon telling you stories about “miraculous” cures. Don’t let their second and third-hand news make you feel obligated to start yet another information search. Thank them for their concern, but remember to put their tales in perspective. There are many different types of brain tumors, and many different treatments. What works for one person may not be appropriate for another. Ask your doctor.

Your Feelings

When you first heard your diagnosis, you were probably shocked. Chances are you understood or remember little of what you were told at that time. That is a perfectly normal reaction. Most people experience some or all of the following coping mechanisms following the diagnosis of a brain tumor.

DENIAL

Denial — disbelief or lack of concern over the diagnosis — is normal for some. It may take time to accept the news. Some may initially

pretend it hasn’t happened. Others may be in a state of shock. “How could I have a brain tumor?” or “Why me?” are common questions. Some people may refuse to discuss or even acknowledge their diagnosis.

GUILT

When something overwhelming happens, people try to blame someone. When you blame yourself, you feel guilt. People ask: Is this a punishment? Did I do something to deserve this? The cause of most brain tumors is unknown. Nothing you did, said or thought made this happen.

ANGER

Anger at your husband, wife, children, neighbor, boss, doctor or anyone and everyone — is not unusual. You may say hurting, bitter things you don’t really mean and later regret. Small children may kick or bite to show their anger. Hidden anger sometimes causes irritability, sleeplessness, fatigue, over-eating, or over-drinking.

DEPRESSION

Depression or grief at the loss of your previous lifestyle may occur. While physical activity may be the last thing you feel you have the energy for at this time, it often helps the most.

Later, or when you complete treatment and your life becomes less hectic, the enormity of all that is happening becomes vivid. Now, you need to cope with your fears and anxiety.

It is normal for people to experience anxiety when going through stressful times. Many people feel “anxious” while waiting for test results or when returning to the doctor for follow-up visits. Symptoms of anxiety include a sense of fear, a feeling that “something bad” is going to happen, a rapid heart rate, perspiration, nausea, shortness of breath, dizziness, or a feeling of unreality.

It is important to talk to your doctor about your physical symptoms even though they may be psychologically based. Sometimes, just the reassurance that your doctor provides will be enough to relieve your anxiety. If your doctor determines that the symptoms warrant treatment, he may suggest medication or an appointment with a psychiatrist, psychologist or social worker.

While many of the feelings people experience are normal and can be worked through, there are some for whom these changes are overwhelming. Those people may become very depressed, and need help in dealing with those feelings. Some of the symptoms of major depression are: persistent depression or no feelings whatsoever; irritability; loss of enjoyment and pleasure in people or activities that are normally enjoyable; difficulty sleeping — such as trouble falling asleep or waking too early and being unable to fall asleep again; loss of appetite; or wanting to give up or to inflict self-harm. When these feelings persist for more than two weeks, or when they are severe, it is important to bring the symptoms to the attention of a doctor. The doctor will determine whether these are signs of major depression, and if so, will provide direction. The doctor may prescribe medication or suggest a psychiatric consultation. Depression is treatable, but first must be diagnosed.

There is no magic pattern for dealing with your emotions. One day you may feel better, and the next day feel upset again. Not everyone shows their emotions, nor does everyone have the same kinds of feelings. If this is your first experience with crisis, you will learn which coping methods work best for you. Hopefully, those who deal with their emotions in an unpressured way will begin to accept the reshaping of their lives, facing it with a realistic amount of hope and a determined attitude.

Living Your Life

Part of our identity is how we present ourselves to others. An undesired change in the way we look can understandably be upsetting.

Hair lost during surgery, radiation, or chemotherapy often grows back, but may take months. Wigs are available for both men and women. If you find a wig uncomfortable, consider a scarf or a loose hat.

Look through your closet for the clothes you look best in. Or, treat yourself to a new blouse or tie. When you look good, you feel better. Many hospitals offer make-up and hair sessions for those who have gone through cancer treatments. The workshops give you tips about your appearance, and are great for your self-confidence.

Many people with a brain tumor have questions about sex. Can I still have sex? How soon after surgery can I have sex? Will my treatments affect my desire for sex? Talk to a member of your healthcare team — they can answer your questions and provide suggestions.

Your desire for sex may decrease temporarily because you're tired, you feel unattractive, or you fear hurting yourself. Or, your partner may be afraid of hurting you. For the time being consider replacing sexual activity with non-sexual physical closeness such as holding hands, kissing or hugging. Find activities you can comfortably share and special times to be alone.

You may feel tired due to medications, treatments, and traveling to and from your treatments. Be realistic — keeping up with your usual responsibilities may be difficult. Set priorities. Do only what has to be done, and if you still have the energy or inclination, then consider other chores or errands. Call upon friends and neighbors to help. Plan frequent rest periods during the day. Save your energy for special events or unavoidable chores.

Make time to be good to yourself. Take up a hobby or learn a new craft. Visit your hair dresser. Go to the library and check out those books you always wanted to read. Keep a journal, take a walk, pray or laugh. Look for ways to enjoy yourself.

Coping With Stress

For most people, a fear of the unknown and an uncertain future cause great stress. This is normal. Give yourself permission to be temporarily overwhelmed. Then, take a deep breath and begin to think about the things you can control.

Ask family and friends to help with household responsibilities. Find someone to assist you in completing medical forms and claims. Participate in planning your treatment. Help determine your medication or treatment schedules. Decide which chores are important, and which can be temporarily ignored. Choose to share your experience with others, or not. The choice is yours.

Reducing stress means being kind to yourself. Soft music, attending a ball game, a mid-afternoon nap — all are relaxing activities that also pamper you.

If you are a family member or a caregiver, permit yourself some “time off” to take care of your own needs, despite the confusion of the situation. Call upon other relatives or friends to serve as relief workers so you can take much needed breaks.

Communication is an important part of reducing stress. Talk to your family about your needs, feelings, and responsibilities. Listen to their concerns as well. Sometimes one person will take on too many responsibilities. Or, in trying to protect others, a family member may not express her/his own needs. Taking the time to talk — about what needs to be done and who can reasonably do it — allows everyone to feel useful and avoids feelings of resentment. Relaxation, meditation or imagery techniques can also help reduce stress for you and your family. Consider taking a class together.

Birthdays, holidays, or anniversaries can be a difficult time for your family. Anxiousness or irritability around these days is normal. Plan ahead and make activities simple and memorable.

Close friends, religious leaders, or your health professional can be a source of emotional and physical strength. Friends may be able to search for community and medical resources of value to you. Contact your library, local civic organizations, village hall, or religious institutions. Many community programs are available — learn what they are and take advantage of their services. Each resource you find makes it easier for you and your family to cope with your new situation.

Finding a Support Group

Most of us don't want to be alone when facing a crisis. Emotional support from family, friends, and loved ones gives us comfort and strength, but may not be enough. There is often a need to connect with someone in the same situation.

Patients and families often find help through brain tumor support groups. A support group is a gathering of people seeking to share their experiences with a professional. They come for emotional, and possibly, spiritual support. Within the safety of a support group, many people are able to share their fears and concerns about day-to-day problems and the future.

There are different types of support groups for adults, for parents of children with brain tumors, for children and siblings. Most of these groups also welcome concerned friends. If you are not comfortable with a particular group or it doesn't meet your needs, try another one.

SOCIAL WORK SERVICES

Our social workers can help you or your family explore other support options as well. There are many sources of online support, community-based wellness programs, and opportunities to contact others living with this diagnosis. Our Social Work office can be reached at 800-886-2282.