

## Chapter 8

# *Comfort & Coping*

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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.

## Understanding Your Disease

For many people, understanding is the foundation for coping. Arming yourself with information, understanding as much as you can about the options open to you, and making an informed decision can greatly increase your comfort level.

Begin by listening carefully to your doctors and nurses when they explain your illness and treatment options. They are the best source of information about *your* brain tumor. Don't be afraid to ask questions. Most healthcare professionals want patients to be knowledgeable so they can be active members of their treatment team.

You probably have lots of questions. List them in a notebook, placing the most important questions at the top of the list. Bring your questions to your doctor and jot down the answers. It can be helpful to have someone with you. A relative or friend can provide moral support and also help you remember what was said. If it's okay with your doctor, bring a tape recorder with you. You will then be able to listen to the doctor again in the comfort of your own home.

During your doctors' visits, ask for written information about your brain tumor, your symptoms, suggested treatments, and your medications. Before you leave the doctor's office, make sure you understand any instructions you were given. For example, do you have another appointment? If so, when is it? If you are scheduled to have additional tests, do you know when and where to go? Ask the nurse to write important dates and instructions in your notebook.

## Telling Family and Friends

Many people find that it helps to share their news with others.

Telling your family and friends you have a brain tumor isn't easy. If you are uncomfortable telling them, consider having a care conference with your doctor and invite the primary members of your family. When you speak

with your family, remember that written information about brain tumors is available and can help explain your situation more easily. Like you, your family needs time to understand the diagnosis. A family that understands your illness and the options available to you has the opportunity to be supportive and helpful unlike an uninformed, or misinformed, family.

Social workers can help you find ways to share your feelings with your family, and help you and your family cope. Most hospitals have social work departments. You can also find social workers at community centers, government health agencies and schools.

If you are a parent with young children and you have a brain tumor, try to anticipate your children's concerns. Children use their imaginations to fill in the gaps; their fantasies can cause undue fears and anxieties. Give children information in words they understand. Use their questions as a guide to the amount of information they want. Be prepared for questions that aren't easily answered; reply honestly and simply. Young people often have remarkable insight and can be a source of great comfort.

### TALKING WITH CHILDREN

These sample explanations can be adapted for conversations with your children. Change the phrases to match your situation.

"The doctor wants to do some tests to find out why you are getting sick to your stomach and having headaches..."

"An MRI scan takes picture of your brain, but it cannot see what you are thinking."

"A brain tumor is a lump in the brain that doesn't belong there. The doctor is going to operate and take it out."

"No one knows for sure what causes a brain tumor. They just happen. But we do know that nothing you did, or thought, or said caused the tumor. We also know that you don't 'catch' brain tumors from other people."

"Would you like to talk about this? Is there anything you would like to ask?"

Above all, reassure your children they are loved and will be taken care of.

For additional suggestions and explanations children can understand, please visit our children's web site — ABTA Kids — at [www.abta.org/kids/home.htm](http://www.abta.org/kids/home.htm).

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.