

## BRAIN TUMOUR – EMOTIONS YOU CAN EXPERIENCE

**A brain tumour diagnosis will turn your life upside down. Denial, anger, and then acceptance are normal emotions that you can expect to feel.**

Hearing the words, "It's a **brain tumour**," may send you spiraling out of control. At first, nothing can be of comfort. Not the fact that doctors continue to improve survival odds for those with brain cancer. Not the fact that many of the side effects of brain tumours, including **seizures**, can be controlled with medicines. All you know is that you have a very serious illness and you are in shock.

These feelings are perfectly normal. Emotional ups and downs after receiving a diagnosis of a serious condition, like a spinal cord or brain tumour, should be expected. But, at some point, you must find a way to accept your diagnosis so that you can focus all your energy on doing what it takes to get well.

### **Accepting Your Diagnosis**

While there is no "right" way to emotionally digest something like a **spinal cord or brain tumour diagnosis**, below is a list of five emotions people typically experience:

1. **Shock**. Most people are not prepared for a spinal cord or brain tumour diagnosis, so it is common to feel confused and numb when you first hear your diagnosis. Don't be surprised if your first reaction is more of a blank stare than an emotional outburst. This may be your mind's way of protecting itself from getting overwhelmed.
2. **Denial**. You may not believe what is happening to you. Your friends and family may be surprised at how unconcerned you seem about the whole thing. But denial can't last forever, and you must eventually accept and face your diagnosis.
3. **Guilt**. Many people who are diagnosed with spinal cord and brain tumours eventually feel guilty. Though it is not rational, you may blame yourself for getting the tumour. Remember, you didn't do anything to cause your tumour. In fact, doctors do not know much about the cause of brain tumours.
4. **Anger**. It is common to feel angry about your diagnosis. Your anger can be directed at a variety of people, including your doctors, friends, family, strangers, or God. When you feel angry, talk about your feelings, which helps you deal with them in a healthy way.
5. **Acceptance**. To move forward and meet the challenges of your diagnosis and treatment, you will have to eventually learn to accept your diagnosis. Joining a support group of other spinal cord or brain tumour survivors can help you accept your condition and learn how other people are dealing with it.

## **Other Emotions**

You will most likely experience a rollercoaster of other feelings, including helplessness, fear, panic, loss of control, sadness, and anxiety, throughout your journey.

It is not uncommon for people battling a brain tumour to experience anxiety and depression. However, if you let these emotions linger, they can make it difficult for you to take care of yourself, which is crucial in your fight against the illness. If you are experiencing symptoms of anxiety or depression, call your doctor immediately.

These symptoms may include:

- Fast heartbeat
- Shortness of breath
- Nausea
- Loss of appetite
- Sleep disturbances
- Persistent feelings of hopelessness or sadness
- Thoughts of suicide

Talk with your treatment team about your emotions. They can point you in the direction of resources that can help.

## **Symptoms of Fear**

It is common for people who are experiencing fear related to their brain tumour to deny that emotion, even to themselves. And, while it is normal to feel some fear, it is not healthy to let fear get the best of you. If you have ongoing symptoms of fear, such as the following, talk to your doctors. They can recommend a counsellor or therapist to help you better cope with your feelings.

- Worry that won't go away
- Trouble focusing
- Tense muscles
- Restlessness
- Anger and irritability

## **Brain Tumour: Managing Fear**

Tips for managing your fear include:

- **Lean on your loved ones.** Talking with your loved ones about your fear can help ease your anxiety. "What helped me with my fear is my family and my friends just being there for me," says a brain tumour patient.
- **Find a support group.** Make an effort to hear experiences and tips from other people who have been through what you are going through.
- **Get help if you need it.** Talk with your doctor about your fear. Uncontrollable fear and anxiety can be treated with psychotherapy and anti-anxiety medications.
- **Stay positive.** Even though it can be difficult, smiling, appreciating your friends and family, and finding humor in life can really help to alleviate fear. Joking around just kind of helps to ease the tension with everybody.

## **Brain Tumour: Coping With Fear**

**Along with cancer comes fear. Lean on your loved ones, try to laugh, and get help if you feel the fear is getting the best of you.**

For many people, fear is at its worst right after they're diagnosed with a **brain tumour**. "Once your doctor tells you what's wrong and what needs to be done in order for things to get better — hearing that is the biggest blow.

Treatment can be scary, too. Brain **surgery** and other treatments for a brain tumour are complicated procedures with many risks. Sometimes thinking about the future can trigger fear, as well. You may worry about pain, dying, what will happen to you after death, and what your loved ones would do if you were no longer there. If your tumour has been successfully treated, you probably will feel some ongoing fear about the possibility that your tumour might return or get worse. These are all normal **emotions**.

## **Tips for Telling Your Employer**

Here are some tips to keep in mind when telling your employer about your illness:

- **Do your homework.** Before you meet with your employer, figure out exactly what accommodations you will need. Talk to your doctors and ask their advice. They will be able to tell you how much time you should take off and what you can and can't do during your **treatment** and afterward. Provide your boss with brochures and pamphlets about your illness so that he or she can better understand what you are dealing with. This conversation will not be easy; but, it is important, nevertheless.
- **Get a doctor's note.** Your doctor can write a simple note explaining that you will be under medical care, out of work for some time, and eventually be able to return to work (if applicable). Your doctor can also explain your limitations and what accommodations you may need.
- **Practice your speech.** Rehearse what you are going to say in advance so that your message will be fairly scripted by the time you talk with your employer. Stay calm and remember there are laws to protect your rights.
- **Take notes.** After your meeting, write down everything that was said so that you have a written record of the conversation in case you need it.

## **Brain Tumour: Work After Treatment**

Telling your boss about your **diagnosis** can lift a tremendous weight off your shoulders. It is important that your focus be on your health, not on how much work you are missing, while you are being treated for a brain tumour. And remember that just because your treatment ends doesn't mean everything will go back to "normal." It is common to experience emotional ups and downs and have fatigue, pain, and other symptoms after treatment for a brain tumour. If you are having trouble adjusting back at work, talk with your employer about special accommodations. See if you can work from home, or have more time off so that you can take care of what matters most — your health.

## **10 Important Questions to Ask Your Doctor**

If you have been diagnosed with a brain tumour, you most likely have a lot of questions and concerns about your treatment and **prognosis**. Don't rely on memory alone to get you through the initial doctor visits. Instead, make a list of questions beforehand and bring them to your appointments.

Taking a friend or family member with you will also help. And ask your doctor for brochures and other publications to take home.

1. **What type of tumour do I have?** Knowing exactly what type of tumour you have guides all other steps in your journey. Find out whether you have a primary or metastatic spinal cord tumour or brain tumour. Primary means the tumour is located in the place it first developed and is not a result of cancer that has spread from another part of the body; metastatic means the cancer has spread to the brain or spinal cord from another part of the body. It's also important to find out the grade of your tumour. In general, the higher the number, the more aggressive the cancer.
2. **What is my prognosis?** Your doctor may not be able to definitively answer this question so early on, but he or she should be able to provide a general idea of your long-term outlook based on past experiences with other patients.
3. **What are my treatment options?** Your treatment is determined by several factors, the most important being the type and location of the tumour and your overall health. Standard treatments include surgery, radiation, and chemotherapy.
4. **How complex will my treatment be?** Your doctor may recommend a single type of treatment, or a combination based on your particular spinal cord or brain tumour. If you need chemotherapy, ask if you will be hospitalized or if it can be done on an outpatient basis. Discuss your family support and work circumstances to help your doctor make the best decisions for you.
5. **What type of treatment would you choose if you had my type of tumour?** Your doctor has daily experience with brain tumours. Ask what he or she would do in your case.
6. **What are the side effects of treatments?** Side effects vary from treatment to treatment and person to person. Your doctor can tell you what side effects you can expect based on your treatment plan and how to manage them.
7. **Should I get a second opinion concerning my tumour?** Yes. "There is never anything wrong with getting a second opinion. "If your doctor objects, that's probably a good sign that you should."
8. **Can I get treated in my hometown or do I need to find a specialty hospital?** Location and insurance requirements may put limitations on your care, but asking this question will help you determine the quality of care and the experience of those who will be providing that care for you. If you are not comfortable with the quality of care you will be receiving in your hometown, ask your doctor about what options you have for getting treated in a hospital that specialises in brain tumour treatment.
9. **Could I have prevented this?** It is important to ask this question because so many people feel guilty, especially parents with children who have been diagnosed with a brain tumour.
10. **Can I go on with my life?** Ask your doctor how your diagnosis and treatment will affect your everyday life.

If, after your appointment, you think of something else you would like to know, don't hesitate to call your doctor. You and those supporting you have every right to be fully informed about your diagnosis and what lies ahead.

Everyday Health. (n.d.). *Brain Tumor: Boarding an Emotional Rollercoaster*

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