After Brain and Spinal Cord Tumor Treatment in Adults

Get information about life as a brain or spinal cord tumor survivor, next steps, and what you can do to help.

Living as a Brain or Spinal Cord Tumor Survivor

For many people, tumor treatment often raises questions about next steps as a survivor.

- Living as a Brain or Spinal Cord Tumor Survivor

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- Follow-up care
- Ask your doctor for a survivorship care plan
- Recovering from the effects of the brain or spinal cord tumor and its treatment
- Keeping health insurance and copies of your medical records
- Can I lower my risk of the tumor progressing or coming back?
- If the tumor comes back
- Getting emotional support

For some people with brain or spinal cord tumors, treatment can remove or destroy the
tumor. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about the tumor growing or coming back (recurring). This is a very common concern if you've had a brain or spinal cord tumor.

For other people with brain or spinal cord tumors, the tumor may never go away completely. Some people may get treated with radiation therapy, chemotherapy, or other treatments to try to keep the tumor in check and limit symptoms from it. Learning to live with a tumor that does not go away can be difficult and very stressful. It has its own type of uncertainty. Managing Cancer as a Chronic Illness talks more about this.

**Follow-up care**

Whether you have completed treatment or are still being treated, your doctors will still want to watch you closely. It’s very important to go to all of your follow-up appointments.

**Exams and tests**

During follow-up visits, your doctors will ask about symptoms, examine you, and might order lab tests or imaging tests such as MRI scans to look for progression (growing) or a recurrence of the tumor. Even tumors that have been treated successfully can sometimes come back.

Whether the tumor was removed completely or not, your health care team will want to follow up closely with you, especially in the first few months and years after treatment to make sure there is no progression or recurrence. Depending on the type and location of the tumor and the extent of the treatment, the team will decide which tests should be done and how often.

During this time, it’s important to report any new symptoms to your doctor right away, so the cause can be found and treated, if needed. Your doctor can give you an idea of what to look for. If you need further treatment at some point, the doctor will go over your options with you.

**Ask your doctor for a survivorship care plan**

Talk with your doctor about developing your survivorship care plan. This plan might include:

- A suggested schedule for follow-up exams and tests
- A schedule for other tests you might need in the future, such as tests to look for
long-term health effects from your tumor or its treatment, or early detection (screening) tests for other types of cancer

- A list of possible late- or long-term side effects from your treatment, including what to watch for and when you should contact your doctor
- Diet and physical activity suggestions

Recovering from the effects of the brain or spinal cord tumor and its treatment

You might have side effects from the tumor itself or from its treatment, which can range from very mild to fairly severe. Some side effects might last a long time or might not even show up until years after you have finished treatment. Your doctor visits are a good time to ask questions and talk about any changes or problems you notice or concerns you have.

Once you have recovered from treatment, your doctors will try to determine if damage was done to the brain or other areas. Careful physical exams and imaging tests (CT or MRI scans) might be done to determine the extent and location of any long-term changes in the brain.

Many types of doctors and other health professionals might help look for these changes and help you recover. For example:

- A neurologist (a doctor who specializes in medical treatment of the nervous system) may assess your physical coordination, muscle strength, and other aspects of nervous system function.
- If you have muscle weakness, paralysis, or numbness, you will likely be seen by physical and/or occupational therapists and perhaps a physiatrist (a doctor who specializes in rehabilitation) while in the hospital and/or as an outpatient for physical therapy.
- If your speech is affected, a speech therapist (speech-language pathologist) will help improve your communication skills.
- If needed, an ophthalmologist (a doctor who specializes in eye problems) will check your vision, and an audiologist may check your hearing.
- After surgery, you may also see a psychiatrist or psychologist to determine the extent of any changes caused by the tumor or surgery. If you get radiation therapy and/or chemotherapy, this process may be repeated again after treatment is finished.
• If you were treated with surgery or radiation therapy for a tumor near the base of the brain, pituitary hormone production may be affected. You might need to see an endocrinologist (a doctor who specializes in hormone disorders). If hormone levels are affected, you might need hormone treatments to restore normal levels for the rest of your life.

**Keeping health insurance and copies of your medical records**

Even after treatment, it’s very important to keep health insurance. Tests and doctor visits cost a lot, and even though no one wants to think of their tumor coming back, this could happen.

At some point after your treatment, you might find yourself seeing a new doctor who doesn’t know your medical history. It’s important to keep copies of your medical records to give your new doctor the details of your diagnosis and treatment. Learn more in Keeping Copies of Important Medical Records.

**Can I lower my risk of the tumor progressing or coming back?**

If you have (or had) a brain or spinal cord tumor, you probably want to know if there are things you can do to reduce your risk of the tumor progressing or coming back, such as exercising, eating a certain type of diet, or taking nutritional supplements. At this time, not enough is known about brain and spinal cord tumors to say for sure if there are things you can do that will help.

Adopting healthy behaviors such as not smoking, eating well, getting regular physical activity, and staying at a healthy weight might help, but no one knows for sure. However, we do know that these types of changes can have positive effects on your health that can extend beyond your risk of brain tumors or other cancers.

**About dietary supplements**

So far, no dietary supplements (including vitamins, minerals, and herbal products) have been shown to clearly help lower the risk of brain or spinal cord tumors progressing or coming back. This doesn’t mean that no supplements will help, but it’s important to know that none have been proven to do so.

Dietary supplements are not regulated like medicines in the United States – they do not have to be proven effective (or even safe) before being sold, although there are limits
on what the companies who make them are allowed to claim they can do. If you’re thinking about taking any type of nutritional supplement, talk with your health care team. They can help you decide which ones you can use safely while avoiding those that might be harmful.

If the tumor comes back

If the tumor does recur, your treatment options will depend on the type and location of the tumor, what treatments you’ve had before, and your current health and preferences. For more information on how brain and spinal cord tumors are treated, see Treatment of Adult Brain and Spinal Cord Tumors, by Type.

For more general information, see Understanding Recurrence.

Getting emotional support

Some amount of feeling depressed, anxious, or worried is normal when a brain or spinal cord tumor is a part of your life. Some people are affected more than others. But everyone can benefit from help and support from other people, whether friends and family, religious groups, support groups, professional counselors, or others. Learn more in Coping With Cancer.

Hyperlinks


References


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