After Brain and Spinal Cord Tumor Treatment in Adults

Living as a Cancer Survivor

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

- Recovering from the Effects of the Brain or Spinal Cord Tumor and Its Treatment
- Lifestyle Changes During and After an Adult Brain or Spinal Cord Tumor
- How Might Having an Adult Brain or Spinal Cord Tumor Affect Your Emotional Health?

Cancer Concerns After Treatment

Treatment may remove or destroy the cancer, but it is very common to worry about the cancer coming back or treatment no longer working.

- What Happens After Treatment for Adult Brain and Spinal Cord Tumors?
- If Treatment for an Adult Brain or Spinal Cord Tumor Stops Working

What Happens After Treatment for Adult Brain and Spinal Cord Tumors?

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 coming back. (When a tumor comes back after treatment, it is called recurrence.) This is a very common concern in people who have had a brain or spinal cord tumor.
It may take a while before your fears lessen. But it may help to know that many cancer survivors have learned to live with this uncertainty and are leading full lives. Understanding Recurrence, gives more detailed information on this.

For other people, the tumor may never go away completely. Some people may continue to be treated with radiation therapy, chemotherapy, or other treatments to try to keep the tumor in check. 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 covers more on this.

**Follow-up care**

If you have completed treatment, your doctors will still want to watch you closely. It's very important to keep all follow-up appointments. During these visits, your doctors will ask about symptoms, examine you, and may order lab tests or imaging tests such as MRI scans to look for a recurrence of the tumor. In some cases, some of the tumor may still be left behind after treatment. 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 is 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.

Should your tumor come back, Understanding Recurrence has information on how to manage and cope with this phase of your treatment.

- References

See all references for Brain and Spinal Cord Tumors in Adults

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Recovering from the Effects of the Brain or Spinal Cord Tumor and Its Treatment

The tumor and its treatment can have physical and mental effects, which can range from very mild to fairly severe.

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.

Several types of doctors and other health professionals might help look for these changes and help you recover.

- 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 or paralysis, you will 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 will help you improve 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 be seen by 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.

References

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Lifestyle Changes During and After an Adult Brain or Spinal Cord Tumor

You can’t change the fact that you have had a brain or spinal cord tumor. What you can change is how you live the rest of your life – making choices to help you stay healthy and feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during treatment.

Making healthier choices

For many people, a diagnosis of a brain or spinal cord tumor helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on alcohol, or give up tobacco. Even things like keeping your stress level under control may help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on the things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about quitting smoking and need help, call the American Cancer Society at 1-800-227-2345. A tobacco cessation and coaching service can help increase your chances of quitting for good.

Eating better

Eating right can be hard for anyone, but it can get even tougher during and after treatment. Treatment may change your sense of taste. Nausea can be a problem. You may not feel like eating and lose weight when you don’t want to. Or you may have gained weight that you can’t seem to lose. All of these things can be very frustrating.

If treatment causes weight changes or eating or taste problems, do the best you can
and keep in mind that these problems usually get better over time. You might find it helps to eat small portions every 2 to 3 hours until you feel better. You may also want to ask your health care team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after treatment is put healthy eating habits into place. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

There is more information in Nutrition and Physical Activity During and After Cancer Treatment: Answers to Common Questions.

**Rest, fatigue, and exercise**

Extreme tiredness, called fatigue, is very common during and after treatment. This is not a normal tiredness, but a bone-weary exhaustion that often doesn't get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to be active and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it’s normal for your fitness, endurance, and muscle strength to decline. Any plan for physical activity should be tailored to your situation. If you haven’t exercised in a few years, you will have to start slowly – maybe just by taking short walks.

Talk with your health care team before starting anything. Get their opinion about your exercise plans. Then, try to find an exercise buddy so you’re not doing it alone. Having family or friends involved when starting a new exercise program can give you that extra boost of support to keep you going when the push just isn’t there.

If you are very tired, you will need to balance activity with rest. It’s OK to rest when you need to. Sometimes it’s really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to.

Keep in mind exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.
- Along with a good diet, it will help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue and helps you have more energy.
- It can help lower anxiety and depression.
- It can make you feel happier.
- It helps you feel better about yourself.

And long term, we know that getting regular physical activity plays a role in helping lower the risk of some cancers, as well as having other health benefits.

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

Most people want to know if there are specific lifestyle changes they can make to reduce their risk of the tumor progressing or coming back. Unfortunately, for most tumors there isn’t much solid evidence to guide people. This doesn’t mean that nothing will help – it’s just that for the most part this is an area that hasn’t been well studied. Most studies have looked at lifestyle changes as ways of preventing cancer in the first place, not slowing it down or keeping it from coming back.

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 be helpful. Adopting healthy behaviors such as eating well, staying active, and maintaining a healthy weight may 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 cancer.

- **References**
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During and after treatment, you may find yourself overcome with many different emotions. This happens to a lot of people.

You may find yourself thinking about death and dying. Or maybe you're more aware of the effect the tumor has on your family, friends, and career. You may take a new look at your relationships with those around you. Unexpected issues may also cause concern. For instance, you might be stressed by financial concerns resulting from your treatment. You might also see your health care team less often after treatment and have more time on your hands. These changes can make some people anxious.

Almost everyone who is going through or has been through tumor treatment can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, church or spiritual groups, online support communities, or one-on-one counselors. What's best for you depends on your situation and personality. Some people feel safe in peer-support groups or education groups. Others would rather talk in an informal setting, such as church. Others may feel more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The journey can feel very lonely. It’s not necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you do not include them. Let them in, and let in anyone else who you feel may help. If you aren’t sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you.

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If a tumor keeps growing or comes back after one kind of treatment, it’s often possible to try another approach to treating the tumor. Clinical trials also might offer chances to try newer treatments that could be helpful. But when a person has tried many different treatments and the tumor is still growing, even newer treatments might no longer be helpful. If this happens, it’s important to weigh the possible limited benefits of trying a new treatment against the possible downsides, including treatment side effects. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with a tumor — when you have been through many treatments and nothing’s working anymore. Your doctor may offer you new options, but at some point you might need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and side effects. Your doctor can estimate how likely it is the tumor will respond to treatment you’re considering. For instance, the doctor may say that more treatment might have about a 1 in 100 chance of working. Some people are still tempted to try this. But it’s important have realistic expectations if you do choose this plan.

You can learn more about the changes that occur when treatment stops working, and about planning ahead for yourself and your family, in Advanced Cancer and Nearing the End of Life.

**Palliative care**

No matter what you decide to do, it’s important that you feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called palliative care.

Palliative care helps relieve symptoms, but is not expected to cure the disease. It can be given along with tumor treatment, or can even be treatment. The difference is its purpose — the main goal of palliative care is to improve the quality of your life, or help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like pain or nausea. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat the tumor. But this is not the same as treatment to try to cure the tumor.

**Hospice care**

At some point, you may benefit from hospice care. This is special care that treats the
person rather than the disease; it focuses on quality rather than length of life. Most of the time, it’s given at home. Your tumor may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn’t mean you can’t have treatment for the problems caused by the tumor or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more about hospice in Hospice Care.

Staying hopeful is important, too. Your hope for a cure may not be as bright, but there’s still hope for good times with family and friends — times that are filled with happiness and meaning. Pausing at this time in your treatment gives you a chance to refocus on the most important things in your life. Now is the time to do some things you’ve always wanted to do and to stop doing the things you no longer want to do. Though the tumor may be beyond your control, there are still choices you can make

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