After Pituitary Tumor Treatment

Living Well After Treatment

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

- What Happens After Treatment for Pituitary Tumors?
- Lifestyle Changes After Having a Pituitary Tumor
- How Might Having a Pituitary Tumor Affect Your Emotional Health?

Other Concerns After Treatment

Treatment may remove or destroy the tumor, but you might have other questions or concerns come up after treatment.

- Keeping Medical Insurance and Copies of Your Medical Records

What Happens After Treatment for Pituitary Tumors?

For most people with pituitary 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 tumor growing or 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 pituitary tumor.

It may take a while before your fears lessen. But it may help to know that many pituitary tumor survivors have learned to live with this uncertainty and are living full lives. See Understanding Recurrence gives more detailed information on this.
For other people, the tumor might never go away completely. Some people may continue to get medicines or other treatments to help 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. See Managing Cancer as a Chronic Illness, talks more about this.

Follow-up care

Follow-up care is very important after treatment for pituitary tumors. Even if you have completed treatment, your doctors will still want to watch you closely. Keep all of your appointments with your health care team and follow their instructions carefully. Report any new or recurring symptoms to your doctor right away. Ask questions if you don’t understand what your doctor says.

Surgery is often the first treatment for many types of pituitary adenomas. If you had a functional (hormone-making) pituitary adenoma, hormone measurements can often be done within days or weeks after surgery to see if the treatment was successful. Blood tests will also be done to see how well the remaining normal pituitary gland is functioning. If the results show that the tumor was removed completely and that pituitary function is normal, you will still need periodic visits with your doctor. Your hormone levels may need to be checked again in the future to check for recurrence of the adenoma. Regardless of whether or not the tumor made hormones, MRI scans are often done as a part of follow-up. Depending on the size of the tumor and the extent of surgery, you may also be seen by a neurologist to check your brain and nerve function and an ophthalmologist (eye doctor) to assess your vision.

After radiation treatment, you will need checkups for several years. The response of the tumor to radiation therapy is hard to predict, and although the benefits and side effects of treatment can occur within months, some might take years to appear. Your pituitary function will be checked at regular intervals. MRI scans will be the main follow-up tests, along with testing hormone levels if your tumor made hormones.

It’s common for people to develop pituitary hormone deficiencies after surgery or radiation therapy. These people will need hormone replacement. Thyroid hormone and adrenal steroids can be taken as pills. In men, testosterone can be given to restore sex drive and help prevent osteoporosis (weak bones). Testosterone is available as a gel, liquid, or patch applied to the skin. It can also be given as a monthly injection or implanted as a pellet under the skin every few months. In young women, estrogen is given either by pills or a skin patch to avoid early menopause. Often, progesterone is given along with estrogen. Pituitary hormone deficiency can affect a woman’s ability to have children. However, if she wishes to become pregnant, it may be possible to restore
fertility with hormone therapy.

If you are taking medicine for a prolactinoma, you will have your hormone levels checked at least once or twice a year. If an MRI shows that the tumor has shrunk after treatment, the MRI might not need to be repeated, depending on the size of the tumor and whether the response is partial or complete. If you have a prolactin-producing microadenoma, you may be able to stop drug treatment after several years of therapy. Your doctor might recommend stopping the drug and then checking your prolactin level. If it remains normal, you may be able to stay off the drug.

For patients getting drug therapy for corticotropin (ACTH)-producing or growth hormone-producing adenomas, follow-up may be more frequent. Your hormone levels and symptoms will be monitored carefully. People with growth hormone-producing adenomas have an increased risk of developing high blood pressure and heart failure. They also have a higher risk of getting colon cancer. Periodic checkups for these conditions are recommended.

Diabetes insipidus (see Signs and Symptoms of Pituitary Tumors) can be a short-term result of surgery, although in some cases it might last longer. It can usually be treated effectively. If the problem is mild, simply taking in enough fluids might treat this problem. For more severe problems, the drug desmopressin is given either by nasal spray or by tablet. It is always important to drink enough fluids to avoid dehydration.

It’s also important to consider whether your pituitary tumor might be a clue to a genetic syndrome in your family. In the near future, people with pituitary tumors might be able to have genetic tests done on a sample of the tumor and blood tests to look for certain gene changes. If a change is found, family members might want to be tested as well to see if they are at increased risk.

Occasionally, people with large or fast-growing pituitary adenomas may be disabled or have their lives shortened because the tumor or its treatment destroys vital brain tissue near the pituitary gland, but this is rare. In general, when a pituitary tumor is not cured, people live out their lives but may have to deal with problems caused by the tumor or its treatment, such as vision problems or hormone levels that are too high or too low.

- References
  See all references for Pituitary Tumors

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Keeping Medical Insurance and Copies of Your Medical Records

At some point after your treatment, you may find yourself seeing a new doctor who doesn’t know about your medical history. It’s important to be able to give your new doctor the details of your diagnosis and treatment. Gathering these details during and soon after treatment may be easier than trying to get them at some point in the future. Make sure you have this information handy and always keep copies for yourself:

- A copy of the pathology report(s) from any biopsies or surgeries
- Copies of imaging tests (CT or MRI scans, etc.), which can usually be stored digitally (on a DVD, etc.)
- Copies of lab tests showing hormone levels both before and after treatment
- If you had surgery, a copy of the operative report(s)
- If you stayed in the hospital, copies of the discharge summaries that the doctor prepared when you were sent home
- If you were or are taking medicines to treat your tumor, a list of the drugs and drug doses
- If you had radiation therapy, a summary of the type and dose of radiation and when and where it was given
- The names and contact information of the doctors who treated your tumor

It’s also 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. For more about costs and health insurance, see Understanding Health Insurance.

References

See all references for Pituitary Tumors

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Lifestyle Changes After Having a Pituitary Tumor

You can’t change the fact that you have had a pituitary 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.

Make healthier choices

For many people, a diagnosis of a pituitary 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. Some treatments might 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 problems, do the best you can and keep in mind that these problems usually get better over time. You may 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.

Some drug treatments for pituitary tumors, such as octreotide and lanreotide, can affect
how the body absorbs fats, which might cause changes in bowel movements. Eating a low-fat diet may help with this.

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.

**Rest, fatigue, and exercise**

Extreme tiredness, called fatigue, is common 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 the 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 fit your own situation. A person who has never exercised won’t be able to take on the same amount of exercise as someone who plays tennis twice a week. If you haven’t been active 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 activity can give you that extra boost of support to keep you going when the push just isn’t there. You can read more about healthy eating and exercise in Nutrition and Physical Activity During and After Cancer Treatment.

If you are very tired, you will need to learn 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’re 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. (For more information on dealing with fatigue, see Fatigue in People With Cancer and Anemia in People With Cancer.)

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 to 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.

At this time, not enough is known about pituitary tumors to say for sure if there are things you can do that will help. Adopting healthy behaviors such as eating well and staying at 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 tumor recurrence.

• References

See all references for Pituitary Tumors

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How Might Having a Pituitary Tumor Affect Your Emotional Health?

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 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 don’t 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. See Coping With Cancer for more information.

- References
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