After Pituitary Tumor Treatment

Living Well After Treatment

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

- Living as a Pituitary Tumor Survivor

Living as a Pituitary Tumor Survivor

For most people with pituitary tumors\(^1\), treatment can remove or control the tumor. The end of treatment can be both stressful and exciting. You may be relieved to finish treatment, but it’s hard not to worry about the tumor growing or coming back. 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.

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 doesn't go away can be difficult and very stressful. It has its own type of uncertainty.

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 returned 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 level tests can often be done within days or weeks after surgery to see if treatment worked. Blood tests will also be done to see how well the remaining normal pituitary gland is working. If the results show that the tumor was removed completely and that pituitary function is normal, you’ll still need regular visits with your doctor. Your hormone levels may need to be checked again in the future to check to see if the adenoma comes back. 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 check-ups for several years. The response of the tumor to radiation therapy is hard to predict, and while the benefits and side effects of treatment can be seen within months, some might take years to know how well it worked. 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 have low pituitary hormone levels 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. But it may be possible with hormone therapy.

If you're 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 stays 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 watched 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 check-ups for these conditions are recommended.

Diabetes insipidus (see Signs and Symptoms of Pituitary Tumors) can be a short-term result of surgery, but in some cases it might last longer. It can usually be treated. If the problem is mild, simply taking in enough fluids might treat this problem. For more severe problems, the drug called desmopressin is given either by nasal spray or by tablet. It's 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. Some people with pituitary tumors might be able to have genetic tests done 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.

Sometimes 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.

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

Talk with your doctor about developing a survivorship care plan for you. 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 early detection (screening) tests for cancer, or tests to look for long-term health effects from your tumor or its treatment
- 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
- Reminders to keep your appointments with your primary care provider (PCP), who will monitor your general health care
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 about 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 pituitary adenoma progressing or coming back?

If you have (or have had) a pituitary tumor, you probably want to know if there are things you can do that might lower your risk of it growing or coming back, such as exercising, eating a certain type of diet, or taking nutritional supplements. Unfortunately, it’s not yet clear 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. But we do know that these types of changes can have positive effects on your health.

About dietary supplements

So far, no dietary supplements (including vitamins, minerals, and herbal products) have been shown to help lower the risk of a pituitary tumor growing 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 don’t have to be proven effective (or even safe) before being sold, but there are limits on what they’re allowed to claim they can do. If you’re thinking about taking any type of nutritional supplement, talk to your health care team. They can help you decide which ones you can use safely while avoiding those that might be harmful.

Hyperlinks


References

See all references for Pituitary Tumors
(https://www.cancer.org/content/cancer/en/cancer/pituitary-tumors/references.html)

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