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, treatment can remove or control the tumor. For some, treatment might make the tumor go away completely, and they won't need any more treatment. For others, the tumor might never go away completely, or they might need to keep getting medicines or other treatments to help keep the tumor in check.

It can be 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 full lives while coping with this uncertainty.

Follow-up care

Follow-up care is very important after treatment for a pituitary tumor. Even if you've finished treatment, your doctors will still want to watch you closely. Be sure to go to all
of your visits with your health care team and follow their instructions carefully. Report any new or returning symptoms to your doctor right away. Ask questions if you don’t understand what your doctor says.

After surgery

Surgery is often the first treatment for many types of pituitary adenomas. If you had a functional (hormone-making) pituitary adenoma, tests of blood hormone levels 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. Even if the results show that the tumor was removed completely and that pituitary function is normal, you’ll still need regular visits with your doctors. Your hormone levels may need to be checked in the future 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 need to see other doctors, such as:

• A neurologist to check your brain and nerve function
• An ophthalmologist (eye doctor) to assess your vision

Some people might develop diabetes insipidus (see Signs and Symptoms of Pituitary Tumors) after surgery. This usually goes away on its own, but in some people it might last longer. It can usually be treated. If the problem is mild, simply taking in enough fluids might be enough to treat it. For more severe problems, a drug called desmopressin can be taken either by nasal spray or by tablet.

After radiation therapy

If radiation therapy was your main treatment (or was part of your treatment), you will need check-ups for several years afterward. The response of the tumor to radiation therapy can be hard to predict. The benefits and side effects of treatment can be seen within months in some people, while in others it might take years to know how well it worked. Your pituitary function will be checked at regular intervals. MRI scans are typically the main follow-up tests, along with blood tests of hormone levels (if your tumor made hormones).

Replacing hormones after surgery or radiation
It’s common for people to have low pituitary hormone levels after surgery or radiation therapy. If this happens to you, you’ll probably 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 injected monthly or implanted as a pellet under the skin every few months. In young women, estrogen can be 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 still be possible with hormone therapy.

**Follow-up while on medicines**

If you’re taking medicine to treat a prolactinoma (prolactin-making tumor), your hormone levels will be 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 whether the response to treatment is partial or complete. If you have a prolactin-producing microadenoma (smaller tumor), after a couple of years 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.

People getting drug therapy for corticotropin (ACTH)-producing or growth hormone (GH)-producing adenomas may have more frequent follow-up visits. Your hormone levels and symptoms will be watched carefully. People with GH-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.

**Genetic counseling and testing**

It’s important to consider whether your pituitary tumor might be a sign of a genetic syndrome in your family. Some people with pituitary tumors might want to talk to a genetic counselor about whether genetic testing to look for certain gene changes might be right for them. If a change is found, family members might want to be tested as well to see if they are at increased risk.

**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 summary of your diagnosis, the tests that were done, and the treatment you
received

- 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\(^9\) 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

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\(^10\).

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\(^11\), eating well\(^12\), getting regular physical activity\(^13\), and staying at a healthy weight\(^14\) might help, but no one knows for sure. We do know, however, that these types of changes can have positive effects on your health in many other ways.

About dietary supplements

So far, no dietary supplements\(^15\) (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, although 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


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