Early Detection, Diagnosis, and Staging

Detection and Diagnosis

Catching a tumor early might allow for more treatment options. Some early tumors may have signs and symptoms that can be noticed, but that is not always the case.

- Can Pituitary Tumors Be Found Early?
- Signs and Symptoms of Pituitary Tumors
- How Are Pituitary Tumors Diagnosed?

Staging

For most types of cancer, the stage (extent) of the cancer is an important part of determining treatment options. But for pituitary tumors, other factors, such as if the tumor is releasing hormones or causing symptoms, are often more important.

- How Are Pituitary Tumors Staged?

Questions to Ask About Pituitary Tumors

Here are some questions you can ask your health care team to help you better understand your diagnosis and treatment options.

- What Should You Ask Your Doctor About Pituitary Tumors?

Can Pituitary Tumors Be Found Early?

No imaging tests or blood tests are recommended to screen for pituitary tumors in people who are not at increased risk. (Screening is testing for tumors in people without any symptoms.)
For members of families known to be at increased risk because of a genetic syndrome such as multiple endocrine neoplasia, type I (MEN1), doctors often recommend regular blood testing of pituitary hormone levels. These tests increase the odds of finding a tumor early so that it can be removed completely, increasing the chance for a cure.

Rarely, a pituitary tumor is found early because a person has a CT or MRI scan of the brain for an unrelated problem. These tumors are sometimes referred to as incidentalomas, meaning they are found incidentally (by accident).

Functional pituitary adenomas (tumors that make excess hormones like prolactin or ACTH) are often found when they are still small because the excess hormones cause symptoms.

Non-functional pituitary tumors are less likely to be found early because they don’t cause symptoms until they’ve grown large enough to press on normal pituitary cells, nerves, or parts of the brain near the pituitary.

- References
See all references for Pituitary Tumors

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Signs and Symptoms of Pituitary Tumors

Not all pituitary tumors cause symptoms. But when they do, they can cause many different types of symptoms. The first symptoms often depend on whether the tumor is functional (releasing excess hormones) or non-functional (not releasing excess hormones).

Functional adenomas can cause problems because of the hormones they release. Typically, a functional adenoma makes too much of a single pituitary hormone. These tumors are often found while they are still fairly small (microadenomas). Symptoms from functional adenomas are described below, based on which hormone they secrete.
Tumors that aren’t making excess hormones often become large (macroadenomas) before they are noticed. These tumors cause symptoms when they press on nearby nerves, parts of the brain, or other parts of the pituitary.

Non-functional adenomas that cause no symptoms are sometimes found because of an MRI or CT scan done for other reasons. These tumors are now being found more often as more MRI and CT scans of the brain are done. These may be the most common pituitary tumors. As long as they aren’t causing problems, they are typically just watched closely without needing treatment.

Large tumors (macroadenomas) and pituitary carcinomas

Pituitary macroadenomas (benign tumors larger than 1 cm) and carcinomas (cancers), whether functional or not, can be large enough to press on nearby nerves or parts of the brain. This can lead to symptoms such as:

- Blurred or double vision
- Loss of peripheral vision
- Sudden blindness
- Headaches
- Facial numbness or pain
- Dizziness
- Loss of consciousness (passing out)

Vision problems occur when the tumor “pinches” the nerves that run between the eyes and the brain. Sudden loss of vision, loss of consciousness, and even death can result from sudden bleeding into the tumor.

Macroadenomas and pituitary carcinomas can also press on and destroy the normal parts of the pituitary gland, causing a shortage of one or more pituitary hormones. This can lead to low levels of some body hormones such as cortisol, thyroid hormone, and sex hormones. Depending on which hormones are affected, the symptoms might include:

- Nausea
- Weakness
- Unexplained weight loss or weight gain
- Feeling cold
- Feeling tired or weak
- Menstrual changes or loss of menstrual periods in women
- Erectile dysfunction (trouble with erections) in men
• Decreased interest in sex, mainly in men

**Diabetes insipidus:** Large tumors can sometimes press on the posterior pituitary, causing a shortage of the hormone vasopressin (also called *anti-diuretic hormone* or ADH). This can lead to diabetes insipidus. In this condition, too much water is lost in the urine, so the person urinates often and becomes very thirsty as the body tries to keep up with the loss of water. If left untreated, this can cause dehydration and abnormal blood mineral levels, which can lead to coma and even death. Fortunately, this condition is easily treated with a drug called desmopressin, which replaces the vasopressin. (Diabetes insipidus is not related to diabetes mellitus, in which people have high blood sugar levels.)

**Growth hormone-secreting adenomas**

The major symptoms from these tumors are caused by having too much growth hormone (GH). These effects are quite different in children and adults.

In children, high GH levels can stimulate the growth of nearly all bones in the body. The medical term for this condition is *gigantism*. Its features typically include:

- Being very tall
- Very rapid growth
- Joint pain
- Increased sweating

In adults, the long bones (especially in the arms and legs) can’t grow any more, even when GH levels are very high. But bones of the hands, feet, and skull can grow throughout life. Adults with GH-secreting adenomas don’t grow taller and develop gigantism. Instead, they develop a different condition called *acromegaly*. The signs and symptoms are:

- Growth of the skull, hands, and feet, leading to increase in hat, shoe, glove, and ring size
- Deepening of the voice
- Change in how the face looks (due to growth of facial bones)
- Wider spacing of the teeth and protruding jaw (due to jawbone growth)
- Joint pain
- Increased sweating
- High blood sugar or even diabetes mellitus
- Kidney stones
- Heart disease
- Headaches
- Thickening of tongue and roof of mouth, leading to sleep disturbances such as snoring and sleep apnea (pauses in breathing)
- Thickened skin
- Increased growth of body hair

Many of these changes can occur very slowly, and people might not notice them until they look at an old picture of themselves (or try to put on a hat or ring they haven’t worn in many years).

**Corticotropin (ACTH)-secreting adenomas**

High ACTH levels cause the adrenal glands to make steroid hormones such as cortisol. Having too much of these hormones causes symptoms that doctors group together as Cushing’s syndrome. When the cause is too much ACTH production from the pituitary it is termed Cushing’s disease. In adults, the symptoms can include:

- Unexplained weight gain (mostly in the chest and abdomen)
- Purple stretch marks on the abdomen
- New or increased hair growth (on the face, chest, and/or abdomen)
- Swelling and redness of the face
- Acne
- Fat areas near the base of the neck
- Moodiness or depression
- Easy bruising
- High blood sugar levels or even diabetes mellitus
- High blood pressure
- Decreased interest in sex
- Changes in menstrual periods in women
- Weakening of the bones, which can lead to osteoporosis or even fractures

Most of these symptoms can also occur in children. Children with Cushing’s disease may also stop growing and have problems with school performance.

**Prolactin-secreting adenomas (prolactinomas)**

Prolactinomas are most common in young women and older men. In women before menopause, high prolactin levels cause menstrual periods to become less frequent or to stop. High prolactin levels can also cause abnormal breast milk production, called galactorrhea. In men, high prolactin levels can cause breast growth, erectile dysfunction (trouble with erections), and loss of interest in sex.
If the tumor continues to grow, it can press on nearby nerves and parts of the brain, which can cause headaches and vision problems. In females who don’t have periods (such as girls before puberty and women after menopause), prolactinomas might not be noticed until they cause these symptoms.

**Thyrotropin (TSH)-secreting adenomas**

These rare tumors make too much thyroid-stimulating hormone (TSH), which then causes the thyroid gland to make too much thyroid hormone. This can cause symptoms of hyperthyroidism (overactive thyroid), such as:

- Rapid heartbeat
- Tremors (shaking)
- Weight loss
- Increased appetite
- Feeling warm or hot
- Sweating
- Trouble falling asleep
- Anxiety
- Frequent bowel movements
- A lump (enlarged thyroid) in the front of the neck

**Gonadotropin-secreting adenomas**

These uncommon tumors make luteinizing hormone (LH) and/or follicle-stimulating hormone (FSH). This can cause irregular menstrual periods in women or low testosterone levels and decreased interest in sex in men.

Many gonadotropin-secreting adenomas actually don’t make enough hormones to cause symptoms, so they are basically non-functional adenomas. These tumors may grow large enough to cause symptoms such as headaches and problems with vision before they are detected (see the symptoms for large tumors above).

- References

See all references for Pituitary Tumors

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How Are Pituitary Tumors Diagnosed?

Pituitary tumors are usually found when a person goes to the doctor because of symptoms they are having. But sometimes these tumors don't cause symptoms, and they are found by medical tests done for other health problems.

If there’s a reason to suspect you might have a pituitary tumor, your doctor will use one or more tests to find out. Signs and symptoms might suggest that you could have a pituitary tumor, but tests are needed to confirm the diagnosis.

Medical history and physical exam

If your symptoms lead your doctor to believe that you might have a pituitary tumor, the first step is to take a complete medical history to check for risk factors and to learn more about your symptoms. Your doctor may ask about your family history of tumors or other problems to see if you might have an inherited genetic syndrome, such as multiple endocrine neoplasia, type I (MEN1).

Your doctor will also examine you to look for possible signs of a pituitary tumor or other health problems. This may include exams to look for vision or nervous system problems that could be caused by a tumor.

If a pituitary tumor is strongly suspected, your doctor may refer you to an eye doctor to check your vision, as pituitary tumors can damage nerves leading to the eyes. The most common test is to measure how well you can see. The doctor may also test your field of vision (or visual fields). At first, pituitary tumors only press on part of the optic nerves. This often leads to the loss of peripheral vision, meaning things that you can see off to the side without actually looking directly at them. Eye doctors have special instruments that can test for this.

You might also be referred to other doctors, such as an endocrinologist (a doctor who treats diseases in glands that secrete hormones) or a neurosurgeon (a doctor who uses surgery to treat brain and pituitary tumors), who might order other tests.

Blood and urine tests of hormone levels
If your doctor suspects you might have a hormone-producing pituitary tumor, hormone levels in your blood and/or urine will be measured.

**Growth hormone-secreting adenoma**

A physical exam may alert the doctor to look for this tumor because the signs and symptoms are often very distinctive.

The next step is to check the levels of growth hormone and insulin-like growth factor-1 (IGF-1) in your blood samples, which are taken the morning after an overnight fast. When growth hormone levels are high, they cause the liver to make more IGF-1. Testing the IGF-1 level can be more helpful than checking the level of growth hormone, because the IGF-1 level doesn’t change much during the day, while the level of growth hormone can go up and down.

If both levels are very high, the diagnosis is clearly a pituitary tumor. If the levels are slightly increased, another test called a glucose suppression test is often done to be sure. You will be asked to drink a sugary liquid, and the levels of growth hormone and blood sugar will be measured at intervals afterward. The normal response to suddenly taking in so much sugar is a drop in growth hormone levels. If the growth hormone levels remain high, a pituitary adenoma is probably the cause.

**Corticotropin (ACTH)-secreting adenoma**

Most of the signs and symptoms of ACTH-secreting tumors come from having too much cortisol (an adrenal steroid hormone). Quite a few diseases can cause Cushing’s syndrome, in which the body makes too much cortisol. If you have symptoms suggesting this condition, you will need tests to determine if it’s caused by a pituitary tumor or something else.

These tests may include measuring levels of cortisol and ACTH in blood samples taken at different times of the day. You may be asked to collect all of your urine over a 24-hour period, which is then tested to measure daily production of cortisol and other steroid hormones. Blood or urine cortisol levels may be checked again after taking a dose of a powerful, cortisone-like drug called dexamethasone. Levels of cortisol in the saliva late at night can also be checked. These tests help to distinguish ACTH-secreting pituitary tumors from other diseases, such as adrenal gland tumors, that can cause similar symptoms.

**Prolactin-secreting adenoma (prolactinoma)**
Blood prolactin levels can be measured to check for a prolactinoma.

**Gonadotropin-secreting adenoma**

Luteinizing hormone (LH) and follicle-stimulating hormone (FSH) blood levels can be checked to see if you have a gonadotropin-secreting tumor. Levels of related hormones, such as estrogen, progesterone, and testosterone, are often checked as well.

**Thyrotropin-secreting adenoma**

Tests to measure blood levels of thyrotropin (TSH) and thyroid hormones can usually identify people with a thyrotropin-secreting adenoma.

**Non-functional (null cell) adenoma**

A pituitary adenoma is considered non-functional if it doesn’t make too much of a pituitary hormone. Pituitary hormone levels are not high in people with non-functional tumors. Sometimes, though, blood levels of some pituitary hormones may actually be low because the adenoma crowds out the cells that normally make these hormones.

**Testing for diabetes insipidus**

Diabetes insipidus can occur if the part of the pituitary that stores the hormone vasopressin (ADH) is damaged, which leads to too much water being lost in the urine. This condition can be caused by pituitary macroadenomas (or carcinomas in rare cases), or by tumors starting in parts of the brain or nerves next to the pituitary gland. It can also be a side effect of surgery to treat pituitary tumors or tumors next to the pituitary gland.

In many cases, this diagnosis is made with tests that measure the amount of urine made over a 24-hour period, sodium and glucose levels in the blood, and osmolality (total salt concentration) of the blood and urine. If these tests are inconclusive, then a water deprivation study may be done. In this test, you are not allowed to drink fluids for several hours. The test is often done overnight. If your body is not making enough vasopressin, you will continue to make urine even though you are not taking in any fluid. You may also be given an injection of vasopressin to see if this corrects the problem.

**Venous blood sampling**
Corticotropin (ACTH)-secreting adenomas may be too small to be seen on imaging tests such as MRI scans (see the next section). When the ACTH level is high, but a person’s MRI scan is normal, a venous sampling test may be useful to find the tumor.

For this test, catheters (small tubes) are placed into veins on each inner thigh through small nicks in the skin and are guided all the way up into the petrosal sinuses near the base of the brain. The sinuses hold 2 small veins that drain the blood from each side of the pituitary gland. After an injection of corticotropin-releasing hormone (CRH, a hormone from the hypothalamus that normally causes the pituitary to secrete ACTH), blood samples are taken from both sides and compared to see if the ACTH level is higher on one side than the other. If it is, the source of the high ACTH level is a pituitary tumor.

**Imaging tests**

Imaging tests use x-rays, magnetic fields, or other means to create pictures of the inside of your body. They may be done to look for pituitary tumors or to see if they have grown into nearby structures. In some cases, an imaging test of the head done for another reason may detect a pituitary tumor.

**Magnetic resonance imaging (MRI) scan**

MRI scans use radio waves and strong magnets to create detailed pictures of the inside of the body. The energy from the radio waves is absorbed and then released in a pattern formed by the type of tissue and by certain diseases. A computer translates the pattern into a very detailed image of parts of the body. A contrast material called gadolinium is sometimes injected into a vein to improve the quality of the image.

MRI scans are very helpful in looking at the brain and spinal cord and are considered to be the best way to identify pituitary tumors of all types. MRI images are usually more detailed than those from CT scans (see below). They can show macroadenomas of the pituitary gland, as well as most microadenomas. But MRI might not detect microadenomas that are smaller than 3 mm (about 1/8 inch) across. Sometimes the MRI scan will show a small abnormality in the pituitary that has nothing to do with the patient’s symptoms. Between 5% and 25% of healthy people have some minor abnormality of the pituitary gland that shows up on an MRI scan.

MRI scans can take a long time – often up to an hour. You have to lie inside a narrow tube, sometimes with a small frame around your head, which can be confining and may upset people with a fear of enclosed spaces. Newer, open MRI machines may help with
this, but the images might not be as detailed, so they can’t be used in all cases. The MRI machine also makes buzzing and clicking noises that may be disturbing. Some people may need medicine to help them relax for the test.

**Computed tomography (CT) scan**

The CT scan uses x-rays to create detailed cross-sectional images of part of your body. CT scans can find a pituitary adenoma if it is large enough, but MRI scans are used much more often to look at the brain and pituitary gland.

A CT scanner has been described as a large donut, with a narrow table that slides in and out of the middle opening. You will need to lie still on the table while the scan is being done. CT scans take longer than regular x-rays, and you might feel a bit confined by the ring while the pictures are being taken. Instead of taking one picture, like a standard x-ray, a CT scanner takes many pictures as the camera rotates around you. A computer then combines these pictures into an image of a slice of your body.

Before the test, you may get an injection of a contrast dye through an IV (intravenous) line. This helps better outline any tumors that are present. The injection can cause some flushing (redness and warm feeling). A few people are allergic to the dye and get hives or, rarely, have more serious reactions like trouble breathing and low blood pressure. Be sure to tell the doctor if you have any allergies or have ever had a reaction to any contrast material used for x-rays.

**Tests of pituitary tissue samples**

In diagnosing tumors of most parts of the body, imaging tests and blood tests may strongly suggest a particular type of tumor, but a biopsy (removing a sample of the tumor to examine under a microscope) is usually the only way to be certain of the diagnosis. In many situations, doctors will not treat the tumor until a biopsy has been done.

But a biopsy is not usually needed before treating a pituitary tumor. One reason is that the hormone tests for some types of adenomas are very accurate, so a biopsy isn’t likely to provide much more information. Biopsies in this part of the body can also pose a very small risk of serious side effects. On top of this, some types of adenomas can be treated without surgery, using medicines or radiation therapy.

When pituitary tumors are removed by surgery, they are examined under a microscope to determine their exact type. Special stains may be used on the tumor to color the
areas making hormones, which helps classify the tumor.

- References
  See all references for Pituitary Tumors

How Are Pituitary Tumors Staged?

Staging is the process of determining how far a cancer has spread. This is done to guide treatment and to help determine the most likely outcome for the patient. But pituitary tumors are nearly always benign (not cancer), so there is no staging system for them. Pituitary carcinoma (cancer) is too rare for a staging system to have been developed.

The most useful information for guiding the treatment of a pituitary adenoma is:

- Whether it is a microadenoma (smaller than 1 centimeter across) or macroadenoma (1 centimeter across or larger)
- Whether it has grown into nearby structures (such as bones of the skull)
- Whether it is causing symptoms such as vision changes
- Whether it is functional (making excess hormones) or non-functional
- Which hormone it releases

- References
  See all references for Pituitary Tumors

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What Should You Ask Your Doctor About Pituitary Tumors?

As you deal with your tumor and its treatment, you need to have honest, open discussions with your health care team. Feel free to ask any question, no matter how small it might seem. Here are some questions you might want to ask. Be sure to add your own questions as you think of them. Nurses, social workers, and other members of the treatment team may also be able to answer many of your questions.

- Is my tumor benign or malignant? How certain is the diagnosis?
- Has my tumor spread into the nearby brain tissue or other structures?
- Is my tumor secreting excess amounts of hormone? If so, which one?
- Do I need other tests before we can decide on treatment?
- Do I need to see other doctors?
- How much experience do you have treating this type of tumor?
- Should I get a second opinion? Can you recommend a doctor or hospital?
- What are my treatment choices? What do you recommend? Why?
- What is the goal of treatment (cure, keeping the tumor in check, etc.)?
- Is treatment needed right away?
- What are the possible risks or side effects of treatment?
- Will this treatment affect my ability to have children?
- What should I do to be ready for treatment?
- How long will treatment take? What will it be like? Where will it be given?
- What is my expected prognosis (outlook), based on my tumor as you view it?
- What would we do if the treatment doesn’t work or if the tumor comes back?
- What type of follow-up will I need after treatment?

Along with these sample questions, be sure to write down any others you want to ask. For instance, you might want information about recovery times so that you can plan your work and activity schedule. Or you may want to ask about clinical trials for which you may qualify.

- References
  See all references for Pituitary Tumors

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