CONDITION

Craniopharyngioma

Craniopharyngioma is a noncancerous brain tumor that can affect vision, hormones, growth, and weight.

WHAT IT IS
Noncancerous tumor near the pituitary gland

BODY SYSTEM
Nervous and hormone systems

MAIN SYMPTOMS
Headaches, vision changes, hormone problems, growth changes

WHAT CAUSES IT
Acquired cell changes, not usually inherited

HOW IT IS DIAGNOSED
MRI scans and tumor tissue analysis

MAIN TREATMENT
Surgery, radiotherapy, hormone replacement, sometimes targeted therapy

CAN IT BE CURED?
Sometimes - treatment achieves lasting tumor control

IS IT AN EMERGENCY?
Sometimes - sudden vision loss, confusion, seizure, or collapse

LONG-TERM OUTLOOK
Often manageable with lifelong monitoring and hormone care

Overview

A craniopharyngioma is a rare tumor that grows near the pituitary gland at the base of the brain. It is noncancerous, meaning it does not usually spread to distant parts of the body. However, its position can make it a serious condition.

The pituitary is a small gland that helps control growth, puberty, fertility, metabolism, stress responses, and the body's water balance. A craniopharyngioma may also press on the optic nerves, which carry visual information from the eyes, or the hypothalamus, an area involved in appetite, sleep, temperature, and hormone control.

Craniopharyngiomas can occur at any age. One main type, called adamantinomatous craniopharyngioma, is more common in children but also affects adults. The papillary type occurs almost entirely in adults. The types look different under a microscope and have

different cell changes.

Although treatment can control or remove the tumor, its effects may continue after treatment. Hormone problems, vision loss, changes in weight, and difficulties with memory or energy may require long-term care.

Symptoms

Symptoms usually develop because the tumor presses on nearby structures or interferes with hormone production. They may appear slowly, and they are not the same for everyone.

Possible symptoms include:

A large tumor may block the normal flow of fluid around the brain. This can cause hydrocephalus, a buildup of fluid that raises pressure inside the skull. Symptoms may include worsening headache, vomiting, confusion, or difficulty staying awake.

Many of these symptoms have more common causes. Having one does not mean that you have a craniopharyngioma, but persistent or progressive symptoms should be assessed.

- Persistent or worsening headaches
- Blurred vision, double vision, or loss of side vision
- Nausea, vomiting, or unusual sleepiness
- Excessive thirst and frequent urination
- Unexplained tiredness, weakness, or sensitivity to cold
- Changes in appetite, weight, sleep, or mood
- Reduced sexual interest or problems with fertility
- Irregular or absent menstrual periods
- Delayed puberty or slow growth in children
- Reduced school or work performance, memory, or concentration

Causes and risk factors

A craniopharyngioma develops when cells left from early development begin to grow abnormally. Researchers have identified changes in cell-growth pathways that help explain this growth.

Most adamantinomatous tumors have changes involving the CTNNB1 gene and a cell signal

called beta-catenin. Most papillary tumors have a BRAF V600E change. These changes are usually acquired within the tumor cells. They are not generally inherited from a parent or passed to children.

No everyday behavior, food, injury, or environmental exposure has been established as a cause. There are also no well-defined lifestyle risk factors. A craniopharyngioma is not caused by something you or your family did.

Diagnosis

Diagnosis usually begins with a medical history, physical examination, vision assessment, and hormone tests. Blood tests can show whether the pituitary is producing enough hormones or properly directing other glands.

An MRI scan provides detailed images of the tumor and its relationship to the pituitary, optic nerves, blood vessels, and hypothalamus. A CT scan may also be used because it shows calcium deposits, which are common in adamantinomatous tumors.

Formal visual-field testing checks central and side vision. This creates a baseline for comparing vision before and after treatment.

Imaging may strongly suggest a craniopharyngioma, but examination of tumor tissue usually confirms the diagnosis and identifies the type. Tissue is commonly obtained during surgery or a biopsy. Molecular testing can look for a BRAF V600E change in a papillary tumor because this may affect treatment options.

Other tests may assess growth, puberty, fertility, memory, sleep, or body composition. These do not confirm the tumor, but they help show how it is affecting you.

Treatment and management

Care is usually planned by a team with expertise in brain tumors, pituitary conditions, vision, and radiotherapy. The best approach is influenced by the tumor's size, type, location, symptoms, previous treatment, and effect on nearby structures.

Surgery may remove all or part of the tumor, relieve pressure, drain a cyst, and provide tissue for diagnosis. Some tumors can be reached through the nose using an endoscope, which is a thin instrument with a camera. Others require an opening in the skull.

Complete removal may offer long-term control, but aggressive surgery can damage the hypothalamus, optic nerves, pituitary, or nearby blood vessels. For this reason, a planned

partial removal followed by radiotherapy may sometimes offer a better balance between tumor control and long-term function.

Radiotherapy uses focused radiation to control remaining or recurrent tumor cells. It may follow limited surgery or be used when another operation would carry substantial risk. Techniques include highly focused photon radiation and proton therapy. Treatment is planned carefully to limit radiation reaching healthy tissue.

A fluid-filled tumor cyst may sometimes be drained through a small tube or reservoir. Certain treatments can also be placed directly into a cyst at specialist centers.

Targeted therapy may be considered for papillary craniopharyngiomas with a BRAF V600E change. Medicines that block BRAF and a related signal called MEK can shrink some of these tumors. This may be used before surgery or for persistent or recurrent disease, usually through a specialist team.

Hormone deficiencies are treated separately from the tumor. Depending on which hormones are affected, treatment may replace cortisol, thyroid hormone, sex hormones, growth hormone, or vasopressin, the hormone controlling water balance. Some people need these replacements for life.

Rehabilitation and supportive care may include help with vision, mobility, learning, memory, fatigue, weight management, mental health, school, or work. Regular MRI scans, eye examinations, and hormone reviews remain important after initial treatment.

Complications

Complications can result from the tumor, treatment, or both. They may include permanent pituitary hormone deficiencies, reduced vision, recurrent cysts, and hydrocephalus.

Damage to the hypothalamus can disrupt appetite and energy use. This may cause rapid or difficult-to-control weight gain, sometimes called hypothalamic obesity. It is not simply due to a lack of willpower and may need specialist support.

Problems with sleep, temperature control, memory, attention, mood, or impulse control can also occur. Children may experience effects on growth, puberty, learning, and future independence.

Craniopharyngiomas can return after treatment, even after apparently complete removal and many years without growth. Follow-up is therefore long term.

Prevention

There is no known way to prevent a craniopharyngioma. Its tumor-cell changes are not linked to established lifestyle choices or avoidable exposures.

Screening is not recommended for people without symptoms, and relatives do not usually need testing. Follow-up imaging after diagnosis is intended to detect regrowth early, not to prevent the original tumor.

Living with it and what to expect

The course over months and years is different for each person. Some tumors are controlled after one period of treatment. Others need additional surgery, radiotherapy, cyst drainage, or targeted treatment because of residual growth or recurrence.

Hormone problems often continue even when the tumor is no longer growing. Taking replacement hormones correctly and knowing what to do during illness are important parts of daily care. People who need cortisol replacement should receive written advice about sick-day management and emergency treatment from their endocrine team.

Vision may improve after pressure on the optic nerves is relieved, but established vision loss may be permanent. Low-vision services and workplace or school adjustments can help with independence.

Weight and energy changes can be among the most difficult long-term effects, especially when the hypothalamus has been affected. Care may involve nutrition, physical activity adapted to your abilities, sleep treatment, psychological support, and specialist weight services. These measures support health even when weight loss is difficult.

Many people return to school, work, family life, and usual activities, although some need lasting adjustments. Follow-up commonly includes MRI scans, hormone blood tests, eye examinations, and reviews of memory, mood, sleep, growth, and weight. The timing is usually closer together after treatment and may become less frequent when the condition is stable, but monitoring is generally lifelong.

When to get medical help

Arrange a routine appointment if you develop persistent headaches, gradual vision changes, unexplained thirst or urination, menstrual changes, sexual difficulties, unusual fatigue, or concerns about a child's growth or puberty. These symptoms have many possible causes, but

they deserve assessment if they continue.

If you have already been treated, contact your specialist team promptly about new vision changes, increasing headaches, rapid weight change, worsening thirst and urination, or difficulty taking prescribed hormone replacement.

Seek urgent or emergency care for:

If you have an emergency steroid like prednisone or hydrocortisone card or medical alert information, take it with you and show it to the emergency team.

- Sudden loss or major worsening of vision
- A severe or rapidly worsening headache with repeated vomiting
- New confusion, extreme drowsiness, fainting, or a seizure
- Collapse, severe weakness, or confusion when cortisol may be low
- Inability to keep down essential hormone medicines during illness
- Extreme thirst and urination followed by weakness, dizziness, or reduced alertness

Common questions

Is a craniopharyngioma cancer?

No. It is usually classified as a noncancerous tumor because it does not spread through the body like cancer. It can still cause major health problems because it grows beside structures that control vision, hormones, appetite, sleep, and fluid balance.

Can a craniopharyngioma be completely cured?

Some people have lasting tumor control after surgery, radiotherapy, or both. However, recurrence can occur even after complete removal. Doctors may therefore use terms such as "controlled" or "no evidence of growth" rather than promise a permanent cure.

Can a craniopharyngioma grow back?

Yes. Regrowth can occur from a small amount of tumor left behind, and it can occasionally happen after apparently complete removal. It may occur years later, which is why long-term MRI follow-up is important.

Will I need hormone treatment for life?

Many people do, particularly after surgery or radiotherapy near the pituitary. The hormones required are different for each person. Needs may also change during illness, pregnancy, growth, or aging, so regular endocrine reviews remain important.

Why can craniopharyngioma cause weight gain?

The tumor or its treatment can affect the hypothalamus, which helps regulate hunger, fullness, activity, and energy use. Weight gain related to hypothalamic injury can be rapid and difficult to reverse. It is a medical effect of the condition, not simply a matter of motivation.

Can craniopharyngioma affect fertility or pregnancy?

Yes. Reduced pituitary hormones can affect puberty, menstrual periods, sperm production, and fertility. Treatment may make pregnancy possible for some people. Pregnancy planning should include specialist hormone review because replacement needs and monitoring may change.

Sources

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