

The OHSU Pituitary Unit

I Have Been Diagnosed with a Pituitary Tumor - What Should I Do Next?

To discover that one has a pituitary tumor can be extremely frightening. About 40% of pituitary tumors secrete prolactin and can be medically treated (i.e., shrunk with medicines) -- see Diseases of the Pituitary--Prolactinomas. Large non-functioning pituitary tumors or any tumor (large or small) that secretes GH (acromegaly) or ACTH (Cushing's disease) will likely need to be removed surgically. Fortunately, the large majority of pituitary tumors are benign (don't metastasize) and can be resected fairly easily by a neurosurgeon expert in this task. Regardless of the nature of the tumor (large or small, functional or non-functional), patients should undergo preoperative and postoperative endocrine testing and have their care coordinated with a neuroendocrinologist (an endocrinologist that specializes in pituitary disease.) If a pituitary tumor needs to be removed, the most pressing issue for the patient becomes finding the right neurosurgeon. The following sections are intended to aid the patient in search of quality care for managing a pituitary tumor.

How to find a good neurosurgeon

Because pituitary tumors are relatively uncommon, only a handful of specialty centers around the country have surgeons with sufficient experience to consistently perform pituitary surgery well. Inexperienced or technically sub-optimal surgeons can do a lot of damage. Because of the small number of expert specialty pituitary centers around the country, a patient may need to travel to get optimal care. Fortunately, expert pituitary neurosurgeons and their endocrinologist colleagues are accustomed to managing patients who live long distances away and this should not be an issue. The patient has the right to direct their health care including picking their surgeon. Reasonable questions to ask a surgeon include: 1) How many pituitary surgeries has the surgeon performed (most people consider 200 surgeries in a surgeon's career a minimum requirement although high volume centers perform 50 to 100 or more per year). 2) What is the surgeon's rate of success and complications? Measures of pituitary surgery success include rate of cure for Cushing's disease and acromegaly as well as rate of vision improvement after debulking large tumors. Measures of postoperative complications include the rate of postoperative pituitary damage, diabetes insipidus, vision loss, hypothalamic damage, CSF leaks, infections, etc. Experienced surgeons will be able to answer these questions and compare their surgical outcomes to the standards of excellence. The section Pituitary Support Resources -- Pituitary Disease Specialty Centers may give the interested patient a good starting list to review.

How to find a good neuroendocrinologist

Most endocrinologists who are qualified to manage pituitary tumors are closely associated with good neurosurgeons. Many general endocrinologists see very few pituitary tumors in their careers. A good question to ask them is how many pituitary tumor patient's do they manage a year. Most qualified pituitary specialists (neuroendocrinologists) see enough pituitary patients that they have specialty neuroendocrine or pituitary disease clinics. Endocrinology is a very academic field and there is a good correlation between the experience and expertise of a neuroendocrinologist and their academic contributions to the field (publications, lectures, etc.)

Pituitary Surgery - What to expect

There are different surgical approaches to resecting pituitary tumors. The most common approach is under the upper lip and through the sphenoid sinus (sublabial transsphenoidal approach). The endonasal (through the nose) transsphenoidal approach is the method of choice of some surgeons. Complicated tumors such as meningiomas are often removed through the top of the skull (transcranial approach). The pamphlet "Understanding Transsphenoidal Surgery" from the National Institutes of Health can be downloaded at:

http://www.cc.nih.gov/ccc/patient_education/pepubs/transsphenoidal.pdf.

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