

PITUITARY TUMOURS

Information for Patients and Families

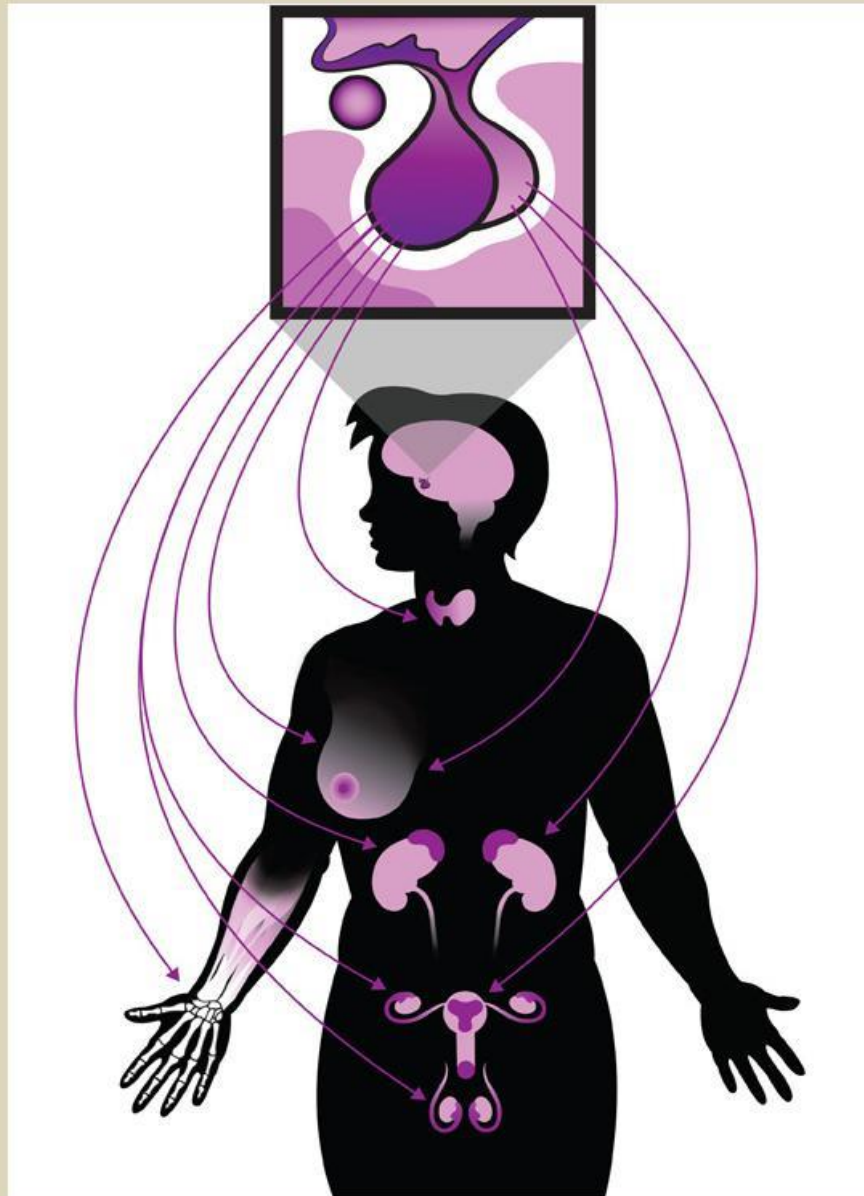


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WE SHOULD HAVE SECTIONS ON YOUR STAY IN HOSPITAL, DISCHARGE DAY AND WHAT TO EXPECT WHEN GOING HOME

Medical Disclaimer

This information is not intended as a substitute for professional medical care. Ask your healthcare provider about this information if you have any questions.

You can find more detailed information on our website: www.stmichaelshospital.com/pit

INTRODUCTION

Read this booklet to learn about:

- pituitary tumours
- symptoms you may experience
- tests
- specialists
- treatment options
- a checklist for a 1st appointment
- information for hospital stays and afterwards
- contact information

Write down any questions you have at the end of this document.

St. Michael's Hospital strives to provide the highest quality of care for all patients. Our Interdisciplinary Pituitary Disorders Centre of Excellence has designed this brochure for patients and family members.

WHAT IS THE PITUITARY GLAND?

The human body has many glands in it and these glands make hormones. Hormones help the body work. The pituitary gland is a small, pea-sized gland at the base of your brain. The pituitary gland is often called the “master” gland because it controls other glands in the body. The pituitary gland controls other glands including the thyroid gland, the adrenal glands, the ovaries, and the testes.

The hormones that the pituitary gland makes are involved in:

- how the body grows
- menstrual cycles
- how the body digests food (your metabolism)
- temperature and energy control
- making breast milk
- the balance of water in our bodies.

Pituitary tumours can affect these processes.

WHAT IS A PITUITARY TUMOUR?

A pituitary tumour (adenoma) occurs when the cells in the pituitary gland grow out of control and form a mass (see Figure 1).

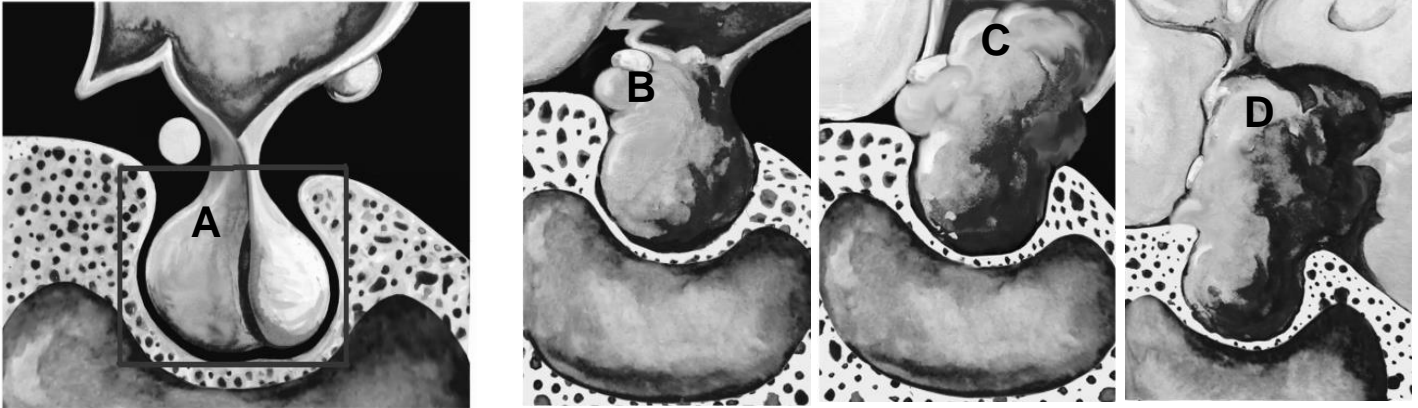


Figure 1: Normal pituitary gland (A) and three abnormal growth patterns of pituitary tumors (B, C, D)

Most pituitary tumours are not cancerous. The risk of the tumour spreading to other parts of the brain or your body is very low.

There are 2 types of pituitary tumours. One type is called a 'functioning adenoma', and the other is called a 'non-functioning adenoma'.

Functioning adenomas may cause the pituitary gland to make too much of one of the pituitary hormones. If the tumour makes too much prolactin, growth hormone or ACTH, the patient will have changes in their body, depending on which hormone it is. Non-functioning adenomas do not make hormones. Both types of tumours can cause the pituitary gland to stop one or more of its normal hormone functions.

Both types of tumours can press on the nerves that help a person to see and so can cause problems with vision.

How common is it?

1 out of every 3 people can have a pituitary tumour and never know it. This is because the tumour rarely grows large enough to cause any symptoms. Pituitary tumours usually grow very slowly. It may take years before people start to notice something is wrong.

How do I know if I have a pituitary tumour?

There are tests to see if you have a pituitary tumour. The tests measure hormone levels in your blood and urine. If your hormone levels are very high, this could mean that you have a pituitary tumour. Other tests are brain scans called MRIs or CT scans and vision tests to check eyesight.

TYPES OF TUMOURS AND SYMPTOMS

There are two types of pituitary tumours. Both types can press on the nerves of your eyes and cause problems.

Types of functioning tumours (make too much pituitary hormone):

1. Prolactin-producing tumours (Prolactinomas)
2. Growth hormone-producing tumours (Acromegaly)
3. ACTH-producing tumours (Cushing's disease)

Non-functioning tumours (do not make active hormones):

Non-functional pituitary adenoma
Craniopharyngioma

The following are other common pituitary diseases:

1. Rathke's cleft cyst
2. Pituitary apoplexy
3. Craniopharyngioma

The symptoms that are caused by a pituitary tumour depend on:

- the size of the tumour
- how it affects the way other hormones are made in your body
- how the tumour affects your eyesight and brain.



TYPES OF FUNCTIONING TUMOURS (ADENOMAS)

1. Prolactin-producing tumours (Prolactinomas)

Prolactin-producing tumours make too much of a hormone called "prolactin". These tumours are called "prolactinomas."

Women with a prolactinoma may:

- stop having their menstrual period
- produce some breast milk (a condition called "galactorrhea", see Figure 2)
- become infertile (unable to have babies)

Men with a prolactinoma may:

- get headaches
- have problems with sexual desire or function
- loose peripheral vision (off to the sides) and only see straight forward.

Medicine can reverse these effects. Prolactinomas respond to medicine and rarely need surgery.

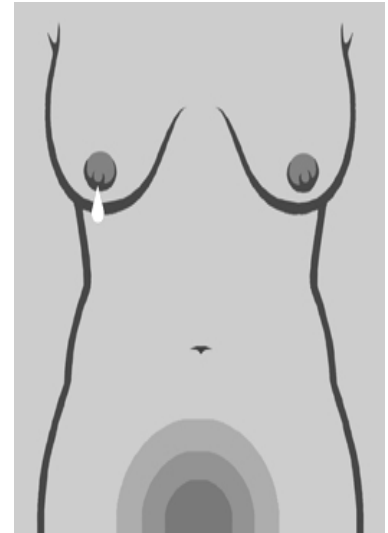


Figure 2: Abnormal secretion of breast milk (galactorrhea)

2. Growth hormone-producing tumours (Acromegaly)

Growth hormone-producing tumours make too much growth hormone. These tumours lead to a disease called 'acromegaly'. Acromegaly affects adults, children and teens in different ways.

Adults:

Acromegaly in adults causes the hands, feet, forehead, nose, lips, tongue, and internal organs (like the heart) to get bigger (see Figures 3 and 4).

In adults, acromegaly can lead to:

- high blood pressure
- high blood sugar
- heart disease
- snoring and breathing problems during sleep (known as sleep apnea)

- sweating
- skin tags (little growths on the skin; see Figure 4)
- premature heart attacks
- growths of lining of the intestine
- nerve pressure in the wrist (carpal tunnel syndrome)

Surgery is the most common method for treating acromegaly. Medicine and/or radiation can also help to decrease the amount of growth hormone. If all parts of the tumour are removed with surgery, some of the effects of acromegaly will start to reverse.

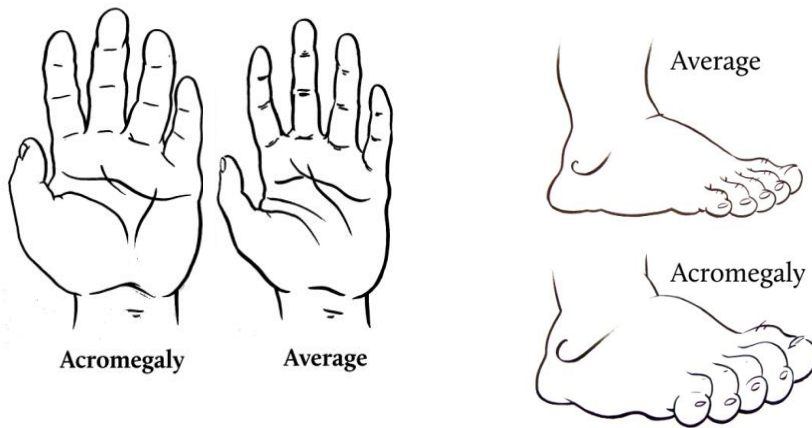


Figure 3: Enlarged hand and foot in a patient with acromegaly

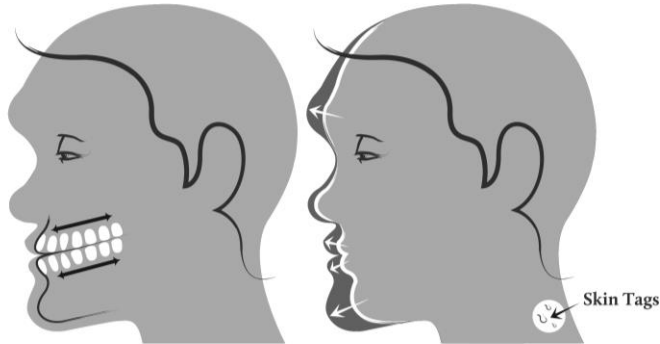


Figure 4: Acromegaly causes physical changes such as enlarged facial features and skin tags (little growths on the skin)

Children and teens (before puberty):

In children and teens, who have not started puberty yet, making extra growth hormone causes “gigantism”. Gigantism makes children and teens very tall. The reason why acromegaly results in gigantism in children and teens only (and not adults) is because children’s bones are still growing. Surgery is often the common method for treating acromegaly and gigantism. Medicine and/or radiation can also help to decrease the amount of growth hormone. Even if all parts of the tumour are removed with surgery, those who have grown very tall will remain tall.

3. ACTH-producing tumours (Cushing's disease)

ACTH-producing tumours produce too much of the hormone called "ACTH" (adrenocorticotrophic hormone) and causes what is called "Cushing's disease".

Cushing's disease is often hard to diagnose because it is very rare and often needs testing over a longer period of time to be detected. Too much of the hormone ACTH makes your body produce too much cortisol. Too much cortisol exposes your body to chronic stress and may cause the following:

Cushing's disease can cause:

- weight gain
- growth of hair on the face
- thinning of the skin
- stretch marks
- muscle weakness
- osteoporosis (bone weakness)
- easy bruising
- poor wound healing
- sadness or depression
- irritability (feeling angry)
- high blood pressure
- high blood sugar
- heart disease
- poor sleep

Cushing's disease is usually treated with surgery, which often has good results. After surgery, if your pituitary gland now makes too little ACTH, you will have low cortisol. You will then need to take cortisol replacement until your body can begin making its own cortisol again, a process that can take 6 to 12 months or longer.

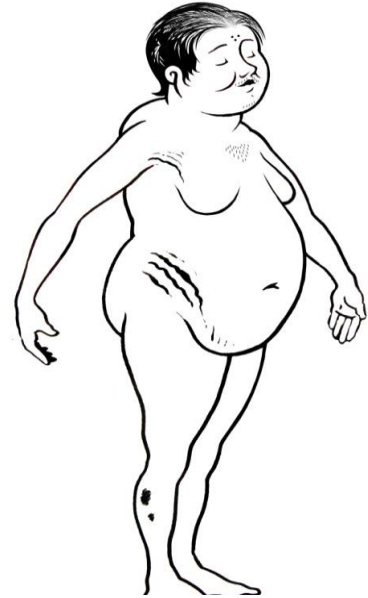


Figure 5: Patient with Cushing's disease

NON-FUNCTIONING TUMOURS (ADENOMAS)

Non-functioning tumours are different from the functioning tumours described above. Non-functioning tumours do not make hormones. They are usually found during tests for headaches or loss of vision. These tumours tend to be larger than functioning tumours. They may continue to grow, press on the normal gland and cause the pituitary gland to stop making some or all hormones. This is called hypopituitarism.

Hypopituitarism can cause:

- low energy levels; tiredness
- dizziness
- nausea and loss of appetite
- feeling very cold
- constipation
- weight gain or loss
- slowness of thought
- loss of menstrual periods in women; loss of sexual function in men

The treatment for hypopituitarism is to give the patient back the hormones they are lacking.

CRANIOPHARYNGIOMA

A **craniopharyngioma** is a rare non-cancerous tumour that develops above or in the pituitary gland. This type of tumour can cause headaches, vision problems, hypopituitarism, memory loss and reduced growth. Having a craniopharyngioma can also make the patient very thirsty and want to urinate more (this is called “diabetes insipidus”). Treatment for a craniopharyngioma is to remove the tumour with surgery and sometimes with radiation.

OTHER COMMON PITUITARY DISEASES

1. A **Rathke’s cleft cyst** is a pouch filled with fluid, and it sits inside or above the space where the pituitary gland is. If the pouch gets bigger, it can cause a loss of hormones, headaches or loss of vision. Surgery is usually the best way to take out the cyst and prevent further damage. You might need to have surgery if the cyst comes back.
2. **Pituitary apoplexy** happens when any type of pituitary tumour gets suddenly bigger or bleeds. When a tumour gets bigger or bleeds, you may feel a lot of pressure in your head, have a sudden, severe headache, loss of vision or double vision. In rare cases, you may have altered consciousness and shock. It is important to go to the doctor right away if you feel this way if you have a pituitary tumour.

WHAT ARE WAYS THAT A PITUITARY TUMOUR MAY AFFECT VISION?

How a tumour affects vision depends on the size of the tumour and how quickly it has grown. As the tumour grows, it presses on the nerves that allow one to see. The commonest symptoms are:

- dim or dark vision
- blurred vision
- changes in how you see colour
- problems with seeing objects on either side of you (see Figure 6)
- complete loss of vision in one or both eyes
- double vision or droopy eyelid(s)

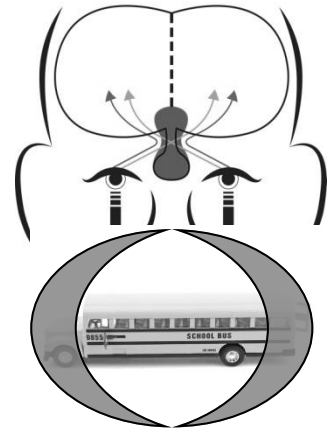


Figure 6: A pituitary tumour pressing against the nerves of the eyes may affect peripheral (side) vision

These symptoms usually happen slowly over time and often are not noticed until they are quite advanced. Sometimes, patients only notice problems with their vision if they happen to cover one eye and realize that they cannot see well out of the other eye. Rarely, the symptoms may happen all at once.

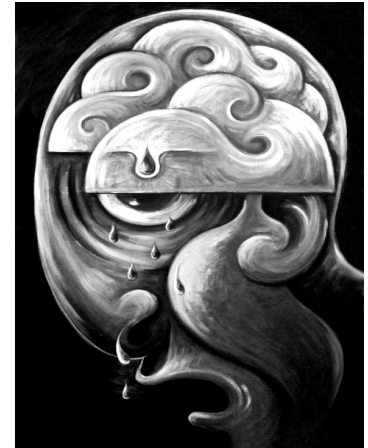
This is why people with pituitary tumours will see an eye specialist, called an ophthalmologist or neuro-ophthalmologist.

HOW CAN A PITUITARY TUMOUR AFFECT MY MOOD?



Because some of these tumours affect the hormones in your body, they can cause changes in your mood or emotions.

For example, some people with Cushing's disease can feel like crying all the time, sad, empty, anxious, grouchy, angry, worried, and scared.



The mood changes that may happen depend on:

- the type of tumour
- how the tumour is affecting your hormones
- its size

People with pituitary tumours may:

- have trouble focusing
- not be aware of things around them
- feel unsatisfied or hopeless
- feel restless and not be able to sit still
- not want to start or follow through with plans
- feel like nothing is important anymore
- have a lower interest in sex
- have very big changes in mood

People with small tumours that do not affect hormone levels may not notice any change in mood or it may be difficult to put down the mood changes to the tumour.. But some changes in your moods can be due to the stress of just knowing that you have a pituitary tumour. These feelings can affect your social life and how you relate to others.

WHAT KINDS OF HEALTH CARE PROVIDERS HELP MANAGE PATIENTS WITH PITUITARY TUMOUR?

More than one kind of doctors will be involved in your care since a pituitary tumour can affect your hormones, vision, and brain. These doctors include:

Neurosurgeon - Brain surgeon

Endocrinologist - Hormone specialist

Radiation oncologist - Cancer specialist (uses radiation therapy to treat tumours)

Otolaryngologist - Ear Nose & Throat (ENT) surgeon

Ophthalmologist or Optometrist or neuro-ophthalmologist- Eye specialist

Psychiatrist - Mental health specialist

Anesthetist - Doctor who gives anesthetic and pain killers for the surgery

Family doctor - Provides long-term care and general medical care to all family members

All of the doctors will ask for a history of symptoms and do a physical exam. Some of the doctors will focus more on certain areas, such as the eyes for the ophthalmologist and the nose for the ENT surgeon.

A number of other professionals, such as nurses, social workers, physiotherapists, and pharmacists may help with care as well. Several sorts of nurses are involved in care, each within a special area and a different role: the pre-admission clinic prior to surgery; in the surgery preparation area, the operating room, the recovery room, and in the various hospital wards.

TESTS

Blood tests

Blood tests are done to check hormone levels and other things like a person's blood type, blood chemistry or blood counts. They are done before visits with the neurosurgeon and endocrinologist, before surgery, right after surgery, and for follow-up visits.

Before surgery:

- If possible, come to St. Michael's Hospital's blood lab for blood tests. Come between 7:30 a.m. and 9:00 a.m. since hormone levels vary at different times of the day. An

appointment is not needed, but if you live too far away, you can do the blood tests at a location closer to where you live.

Blood tests will also be done during the pre-admission appointment, right after surgery and for follow-up visits with the doctor. These blood tests help doctors check hormone levels and how they might affect your body.

Since hormone levels vary over the day, for the best accuracy, the blood tests should be done at 8 a.m. If you are taking the hormone medicine Hydrocortisone (Cortef®), hydrocortisone, or prednisone, the blood tests should be done 24 hours after your last dose of medicine. This means, for instance, that if you are doing the blood test Monday morning, your last Hydrocortisone (Cortef®) pill should be Sunday morning, then you take the next pill right after you do the blood test. If you have questions about your blood tests, ask your doctor.

Vision tests

These tests are important to accurately measure vision and check the health of the nerves to the eyes.

Visual Field Test

Prior to coming to the appointment at St. Michael's, ask your eye doctor, family or referring doctor to arrange for a "visual field test" to check your peripheral (side) vision. The test, requires concentration, does not hurt, and requires that a button be pressed every time a flash of light appears in a screen.

After you have a visual field test, your neuro-ophthalmologist will decide if you will need more eye testing. The following are 2 other tests they may arrange for you.

Optical Coherence Tomography (OCT)

This is an ultrasound test to measure the thickness of the nerve in the back of the eye (i.e. optic nerves). This test can tell if the nerves of the eyes have ever been damaged.

The OCT may not be covered by provincial health insurance. Please ask your ophthalmologist for more information about the cost of an HRT.

Visual Evoked Potential

A Visual Evoked Potential test will help your doctors know if the nerves of your eyes have been damaged by the tumour. This test involves flashing a light in your eyes while a machine measures the amount of time it takes for your brain to record the visual signal caused by the flash of light. If the brain takes a long time to record the visual signal, this tells your doctor that there is damage to the nerves of your eyes.

Preparing for a visit with the neuro-ophthalmologist:

- Arrange for someone to drive you home from the appointment. The eye drops used during the visit will make it hard to focus.
- Bring eyeglasses
- Bring sunglasses to wear home after the test

Imaging

Magnetic Resonance Imaging Scan (MRI)

This test gives doctors pictures of the pituitary gland and surrounding brain. The test is often done in 2 steps. First one set of pictures is made and then right after, a second set is taken after injection of a dye into the vein through an IV (intravenous) line. This test is done before and after surgery and during the follow-up for years after surgery.

Computed Tomography Scan (“CT” or “CAT scan”)

Computed tomography (CT) is a test that combines X-rays and computer scans. The pictures provide very detailed pictures of the bones in the nose and the bottom of the skull to help provide accurate guidance during surgery. This CT scan should be done at St. Michael's. .

Note: If the MRI was done at a hospital other than St. Michael's, make sure to bring a copy of the MRI (loaded on to a CD-ROM or DVD) to the appointment with the neurosurgeon or endocrinologist.

Other tests

Hormones affect many internal organs and how your body functions. This means your doctors may need you to have tests to check your:

- heart (echocardiogram -ECG)
- intestines (colonoscopy)
- bones (bone mineral density for osteoporosis)
- prostate (for men only)
- sleep (sleep study).

TREATMENT

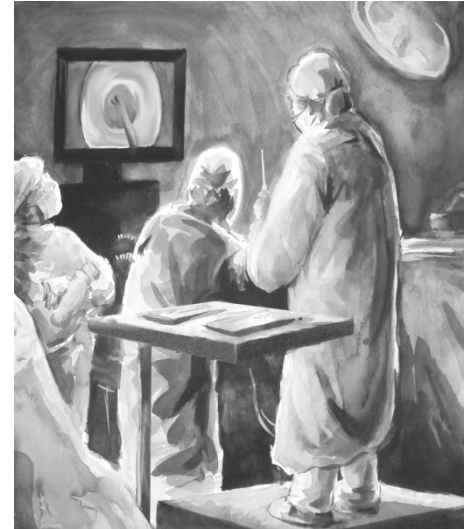
There are several types of treatment. These include:

- A) surgery
- B) radiation therapy
- C) medicine to replace hormones
- D) watching the tumour over time for future growth

A) SURGERY

Surgery is often the best treatment option for patients with a pituitary tumour who are healthy enough to have surgery and any of the following:

- whose tumour is putting pressure on or damaging the nerves of their eyes (optic nerves or chiasm)
- whose tumour is making too much hormone, such as growth hormone or ACTH
- whose prolactinoma is not responding to medicine
- whose tumour is growing
- whose diagnosis is not clear from other tests
- whose tumour has come back after surgery or is causing a leakage of brain fluid after surgery



Goals

The goals of surgery are to:

- 1) diagnose the type of tumour
- 2) reduce pressure on important structures like the nerves of the eyes
- 3) remove as much of the tumour as possible (this reduces the chance of the tumour coming back)
- 4) help reduce symptoms like headaches, visual loss, and high or low hormone levels

Types of surgery

There are two types of surgery for removing pituitary tumours: “**transphenoidal**” surgery or a “**craniotomy**”.

Transphenoidal surgery is done through the nose (see Figure 7). This method helps the surgeon access the base of the brain where pituitary tumours usually are.

A **craniotomy** is a type of surgery where the surgeon opens a window in the skull to access the tumour, instead of through the nose. This may be the best type of surgery if the tumour:

- is too large
- is of a certain type
- goes off to the sides
- lies deeper in the brain

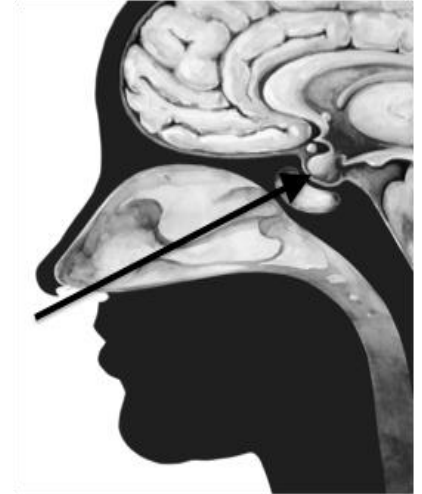


Figure 7:
Transphenoidal surgery

How does transphenoidal surgery work?

- 1) A general anesthetic to put the patient asleep is required.
- 2) During surgery, a small telescope with a tiny video camera at the end called an “**endoscope**” is guided through the nose and nostril passages to the tumour.
- 3) The surgeon will remove small pieces of bone to expose the pituitary gland and the tumour.
- 4) The surgeon will then remove the tumour. If the tumour is too large or if it is stuck to important structures in the brain, it may not be possible to remove the whole tumour.
- 5) The bones are usually replaced with a tiny amount of biological glue and can be covered with a layer of the nasal cavity lining called mucosa.
- 6) If there is a leakage of brain water called cerebrospinal fluid, some small pieces of fat or tissue that covers the thigh muscle will be taken from the side of the thigh or lower tummy to close the surgical area.

- 7) The surgeon will check for any leaking from your nose. Occasionally, if there is a large amount of cerebrospinal fluid (also called CSF) leakage there is a risk of developing a serious infection called meningitis. If this fluid is leaking a lot during or after surgery from your nose, the surgeon may place a drain in the lower back. This drain will allow the CSF to drain out into a bag for a few days. Draining the cerebrospinal fluid will relieve the pressure in your nose and allow your incision to heal.
- 8) Once the surgical area is sealed, two small plastic sheets are put in to the nose to prevent the growth of scar tissue. These sheets will be removed by the ENT surgeon 2 to 3 weeks after surgery.
- 9) At the end of the surgery, the nostrils are packed with Vaseline gauze or a sponge to prevent nose bleeding.
- 10) The surgery usually lasts a total of 3 to 6 hours but it depends on the tumour size, tumour extent, texture, and whether scar tissue exists.

What is the success rate?

The success rate of surgery for all kinds of tumours depends on the size and extent of the tumour, texture (firm or soft), and type of tumour. In most cases, if vision is impaired but still present before surgery, there is a good chance that the vision will be preserved and some chance of improvement, even if the tumour is large. If the tumour extends around the artery, tumour will usually remain after surgery. In the case of functioning tumours like Cushing's disease, the success rate is better if the tumour is visible on MRI and localized. Tumours that are invading structures around the pituitary gland, are growing rapidly or are regrowing have a lower chance of success.

What are the risks?

At St. Michael's Hospital, pituitary surgery is done often and is very safe. However, just as with any surgery, there are risks. Patients and families should ask questions and discuss the risks and benefits of surgery with their doctors before surgery. Some of the risks and the potential outcomes of these risks are listed below:

Risks	Potential Outcomes
Damage to pituitary gland	Loss of hormone functions. This might require taking hormone replacement medicine(s) (for replacing 1 to 6 hormone(s) either temporarily or permanently).
Damage to blood vessels (e.g., carotid arteries) that are around the pituitary gland	Stroke, a lot of blood loss, or death
Damage to lining of the brain	Leakage of brain fluid and may cause an infection called meningitis
Vision problems due to damage to the nerves of the eyes	Partial or complete blindness in one or both eyes
Scar tissue formation or crusting in the nose	This can lead to nasal obstruction or bad smells because the nose is not being cleaned properly
Sinus infection	Loss of smell and/or taste, need for antibiotics and nasal rinsing

What happens in hospital after surgery?

- Blood tests to check hormone levels or routine blood counts once or twice a day.
- Keeping track of how much is being drunk and how much pee (urine) is being produced is very important to make sure that the pituitary gland is making the right amount of the water hormone ADH. You will be asked to write down how much you are drinking. You will need to collect all your pee and give it to the nurse. The nurse will accurately measure how much urine you produce every day. If you get very thirsty and make too much urine, you may need to take a medicine called DDAVP (which acts like ADH). DDAVP will help your kidneys hold water in your body to prevent you from becoming dehydrated. Dehydration may cause low blood pressure.
- The same day or a day after surgery, the Vaseline gauze packing in the nostrils will be removed. It is common for some nose bleeding when it is removed but it usually stops within the first or second day. The nurses will show you how to gently wash your nose with salt water (saline) rinse once mild bleeding stops.

Checking for fever, blood pressure and pulse several times a day is routine.

How should I care for my nose after surgery?

It is important to take good care of your nose after surgery. You will need to rinse your nose 6-8 times every day after you leave the hospital, for several weeks after the operation.

Do not blow your nose until the Ear Nose and Throat (ENT) surgeon has told you that your nose has fully healed. The pressure from blowing your nose can prevent the incision from healing and push germs up into the brain. If the incision opens out, brain fluid can leak out and germs can enter the brain to cause an infection called meningitis.

A stuffy nose or blocked feeling can last a few weeks. Gentle nasal washes with a sterile saline solution to clear out any blockages. For the first few weeks after surgery, use a gentle saline mist spray 4-8 times per day. You can buy the spray at a local drugstore without a prescription.

Once the small plastic sheets in the nose are removed by the ENT Surgeon (usually 2-3 weeks after surgery), you can use a larger saline wash for your nose and sinus cavity. You can buy sterile saline packets and nasal rinse bottles at a local drugstore.

Instructions for Nose Saline Washes

1. Fill the nasal rinse bottle with 250mL (1 cup) of solution.
2. While in the shower or over a sink, bend your head over and aim the head of the bottle nozzle away from the centre of your nose. Open your mouth and pour the saline solution in your nose. The fluid will circulate in and out of your sinus cavities, coming back out of your nose. It is okay if some of the solution comes out through your mouth. Try not to swallow large quantities.
3. Repeat at least 2-8 times a day (as a minimum, once in the morning and once in the evening), until the stuffiness is gone.
4. After each use, rinse out the bottle and wash the tip with soap and water. Allow the bottle to air-dry completely. Once a week, sterilize the bottle by pouring 2/3 cup water and 1/3 cup of hydrogen peroxide into the irrigation bottle. Shake the solution and squirt it through the nozzle. Make sure the solution flows over the nozzle tip.

You can also make your own sterile saline solution by mixing **1 litre (1 quart) boiled or distilled water** with **1 teaspoon canning/pickling/kosher salt (non-iodized)** and **1 teaspoon baking soda**.

If you make your own sterile saline solution, it is important to keep the solution in the refrigerator. Before using the solution, make sure it is at room temperature. You can warm up the solution by using a microwave. After using the microwave, make sure the solution is cooled to room temperature before using.

To watch an online video of a nasal rinse, please visit www.stmichaelshospital.com/pit

What should I be careful about after my surgery?

Sneezing: If you need to sneeze, keep your mouth open to avoid pressure.

Avoid straining yourself:

- while lifting
- during a bowel movement
- during sex
- do not blow your nose for 3- to 4 weeks after surgery and given the OK by the nose specialist or neurosurgeon

Straining increases pressure in your head and may damage the delicate surgical area. If the surgical area is damaged, this may cause a leak of cerebrospinal fluid.

Driving: Do not drive until you are off painkillers and your doctor says it is safe. Be sure to talk to your doctor before you drive. If your vision was affected before surgery, you will have to have a special visual field test and permission by the ophthalmologist before you are legally allowed to drive again. In many cases, the law requires that doctors report patients who might have impairments like loss of vision to the Ministry of Transportation and the Ministry may elect to suspend the patient's driver's license..

Travelling: Do not travel by airplane or go out of the country unless your doctor has checked your health and said it is safe. Do not plan to travel for at least 4 weeks after surgery and only once the surgeons and eye doctors say it safe to travel. Make sure to take along all of your medicine, as well as some of your medical notes describing your condition. Family doctors usually receive this information if you include your family doctor's address and fax number when you register at the hospital.

Working: Most people are off work for about 6-8 weeks, but some are off for more or less time.

Being active after your surgery

It is important to be active after surgery and to continue this at home. Gentle exercising will prevent complications after the surgery (such as pneumonia or a blood clot in your legs).

Walking often is the best exercise. Walk frequently and gradually for as long as you can every day. Try to walk for longer periods of time until you can walk for 1 hour without stopping. If you can't walk for that long, try to do a little more each day.

Feeling tired is common and so short rests or even naps are OK.

Avoid heavy activities that may strain you.

Eating after your surgery

To prevent the result of straining (the need to strain during bowel movements):

- eat foods rich in fiber (such as whole grains, fruits such as prunes, leafy greens, and other vegetables),
- use stool softeners as needed (such as Colace).

Follow a normal balanced diet such as in Canada's Food Guide:

(<http://tinyurl.com/foodguide-canada>).

What changes can I expect in my symptoms?

You will know that your surgery has been a success if you have the following changes in your symptoms.

If your vision was affected before surgery:

- some vision often returns within days or weeks of the surgery

If you have acromegaly or Cushing's, your treatment is a success if:

- your hormone levels return to normal
- some of the changes that the tumour has caused go away

If you have a prolactinomas, your treatment is a success if:

- your menstrual periods return
- your fertility improves
- milk production stops
- you have improved sexual function or desire

If you have a large tumour and get headaches because of the tumour, your headaches will have a good chance of improving.

Follow-up appointments

After surgery, the staff in the hospital will arrange appointments for you to see:

- ENT surgeon in 2 to 3 weeks
- Endocrinologist in 2 to 4 weeks
- Ophthalmologist or optometrist for visual field testing and OCT in 4 weeks
- MRI in 4 weeks
- Neurosurgeon in 6 to 8 weeks (along with an MRI of the pituitary gland before you see your neurosurgeon)
- Family doctor every week for the next few weeks after your surgery

When should I contact my doctor or nurse?

Call 911 immediately or have someone take you to the nearest emergency hospital if you notice any of the following:

- Significant bleeding that does not stop with pressure or if there is a sudden gush of blood from your nose.
- Severe pain
- Fever (above 38.5°C or 100.5°F)
- Worsening headache
- Stiff or sore neck especially if fever is present
- You feel very weak, nausea (dizzy) or are vomiting
- Confusion
- Worsening vision

Call your neurosurgeon or nurse practitioner if you notice any of the following:

- Worsening pain or headache
- Stiff neck or headache
- Vision is worse

Call your ENT surgeon if you notice:

- Nasal discharge or bad smell
- Nose bleeding
- Clear or yellow nasal fluid leakage

Call your endocrinologist if you:

- Are very thirsty or if you produce a lot of urine (pee)
- Extreme weakness

If in doubt, please contact a health professional

OTHER TREATMENT OPTIONS

B) RADIATION THERAPY

Radiation therapy uses high-energy X-rays to control the growth of tumours. Radiation therapy can either be used after surgery or in cases where surgery is not an option. Radiation can also be very useful if the whole tumour cannot be removed during surgery and continues to grow, or if a tumour recurs after surgery.

There are a few ways to get radiation therapy. Your doctor will discuss which option is best for you:

- 1) Fractionated radiation
- 2) Stereotactic radiosurgery - Single dose radiation therapy

Fractionated radiation

In fractionated radiation therapy, patients get a small amount of radiation 5 times a week for 4 to 6 weeks. Because a small fraction of the total dose is given each weekday, it is called “fractionated”. Each treatment may last for 15 to 20 minutes per day. The radiation can be given in a variety of ways. In intensity modulated radiation therapy, the radiation is given precisely to an area slightly bigger than the tumour. This makes sure that the whole tumour gets radiation. The treatment is carefully planned using MRI images of the tumour and other methods. The radiation oncology doctor will decide on the length of the treatment and the radiation therapist works the machine that delivers the treatment.

Stereotactic Radiosurgery: Single dose radiation

In radiosurgery, you get all of the radiation you need in a single day. It is given in a very focused form. The most common way of having radiosurgery is with a tool called a “**gamma-knife**”. The gamma-knife focuses more than 200 tiny beams of radiation onto the tumour with the aid of a stereotactic frame which is like a box fixed to the patient with four little screws placed with local anaesthetic.

Since the gamma knife can target very tiny spaces, the tumours come under control faster than the fractionated way and there may be less radiation to brain tissue near the tumour. But, the highly focused beams from the gamma-knife could mean that tiny areas around the tumour could also be harmed by the radiation, so it can only be used if it is safe to do so, based on the nearby structures. Gamma-knife radiosurgery is usually a one-time therapy

completed in a single day although new techniques may allow a fractionated approach over a few days.

Side effects of radiation

All forms of radiation can damage normal pituitary and brain cells, which may lead to a loss of hormones over time. In rare cases, this damage may lead to memory loss or visual loss over several years. Radiation has a small risk of causing the growth of new tumours or cancers years after treatment.

C) MEDICINES

A third treatment option (to surgery and radiation) is medicine. Medicine can be used to:

- 1) block the tumour from making too much hormone and sometimes reduce the size of certain types of pituitary tumours (prolactinomas and acromegaly)
- 2) replace normal amounts of a hormone that has been lost due to pressure from the tumour or as a result of the effects of surgery or radiation.

Here are some medicines that patients with pituitary tumours might use. Ask your doctors and pharmacist for more information.

To treat prolactinoma

Cabergoline (or Dostinex®), Bromocriptine (or Parlodel®) and Quinagolide (Norprolac®) are three drugs that prevent the release of the prolactin hormone. They can be all that is needed to treat up to 90% of all patients with prolactinomas.

Bromocriptine (or Parlodel®) and Quinagolide (Norprolac®) are taken once or twice a day whereas cabergoline (or Dostinex®) is usually given one to three times a week. All can have side effects, including nausea, dizziness and stuffy nose. These side effects happen less often with Cabergoline.

Cabergoline is more expensive but all three are generally covered by most drug insurance plans. Bromocriptine is covered for patients on Trillium or Ontario Drug Benefits (ODB).

To treat acromegaly

Octreotide (or Sandostatin®) reduces the release of growth hormone in acromegaly and sometimes reduces the tumour size modestly. It is given as an injection every 3 or 4 weeks by a nurse. Most commonly, it is used in addition to surgery. In rare cases, it may be used alone when surgery is not possible.

This drug can cause gallstones, abdominal cramps and diarrhea. It is very expensive and can be used before surgery or as a lifelong treatment. It is covered for patients on Trillium or Ontario Drug Benefits (ODB) and by most insurance companies.

Hormone replacement

As the master hormone gland, the pituitary produces 7 different hormones, which control other important hormone-producing glands. The hormones from these other glands may need to be replaced when levels are low:

➤ Cortisol

Hydrocortisone (Cortef®) and prednisone are synthetic forms of the hormone cortisol. Either can be given to replace low amounts of the hormone in patients whose pituitary gland is not working properly. Too little hormone results in nausea, vomiting, dizziness, weakness and weight loss. Too much cortisol may cause symptoms similar to Cushing's disease.

➤ Thyroid Hormone

Levo-thyroxine is the synthetic replacement for thyroid hormone. It comes in different strengths and preparations. It is taken with water first thing in the morning on an empty stomach. If you have low levels of thyroid hormone, you will feel tired, cold, constipated and may gain weight. Too much will make you feel anxious, with shaking hands and a racing heart beat.

➤ Sex Hormones

Pre-menopausal women who stop having periods due to a loss of pituitary function will need estrogen and progesterone to protect their bone density. These hormones are often given in the form of the birth control pills, or as patches.

Men will need testosterone therapy to restore sex drive and sexual function if this hormone level is too low. They will get this therapy as an injection in a muscle every two weeks, or as gels, patches or pills.

For fertility, both men and women will need other injected medicine, to replace the missing pituitary hormones (LH and FSH) if they have low levels of the pituitary hormones that control the function of the testes or ovaries.

➤ **Antidiuretic Hormone (ADH)**

ADH is a hormone that is made by the pituitary gland and causes the kidney to make concentrated urine. If the pituitary gland does not produce enough ADH, the body will make too much urine (over 3 litres a day) and the person becomes very thirsty.

DDAVP is a synthetic form of the antidiuretic hormone (ADH). It is taken to increase the level of ADH in your body. DDAVP comes in different forms: as pills that are either melted under the tongue or swallowed, as a form that is sprayed into the nostril, or as an injection.

With more ADH in the body, the person will feel less thirsty and will not produce urine as frequently. The most common time for ADH to be low is right after surgery, but it usually comes back to normal levels after days to weeks.

➤ **Growth Hormone**

Finally, growth hormone levels can be low. This causes children to stop growing until they receive daily injections of growth hormone. Adults may feel very tired due to the lack of growth hormone, and may choose to take growth hormone therapy to improve their energy levels. Growth hormone therapy is very expensive, but the cost may be covered by private insurance or Trillium/Ontario Drug Benefits.

D) WATCHING THE TUMOUR FOR GROWTH

Many small tumours do not grow over time. These tumours can just be watched to see if they grow bigger. They may not need any active therapy. The growth of the tumour can be followed up by doing MRI scans about once every year. This plan can continue as long as the tumour is not causing symptoms (such as headaches or vision problems), is not growing, and is not affecting hormone production. This plan allows some patients to avoid surgery or radiation.

LONG-TERM PERSPECTIVE

Most patients respond well to treatment and have non-cancerous tumours. For long-term follow-up most patients will need a yearly MRI of the pituitary gland and yearly visual fields eye tests, and regular visits with the endocrinologist and ophthalmologist or optometrist.

Family doctors need to make sure that patients get these tests and appointments on a regular basis so it is essential that patients regularly see their family doctor to arrange the tests. If patients have any new surgical issues, the family doctor should refer you back to the neurosurgeon.

CHECKLIST FOR YOUR 1ST APPOINTMENT

Please use this checklist to prepare for your first visit to the Neurosurgeon or Endocrinologist.

2 weeks before your appointment
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Make sure you have:

- 1) Brought the CD-ROM of your MRI to your Neurosurgeon or Endocrinologist. If your MRI was not done at St. Michael's Hospital, you will need to get the CD-ROM from the film library of the Radiology Department at the hospital where you did your MRI.
- 2) Completed all of your blood tests at St. Michael's Hospital in the morning between 7:30 a.m. and 9:00 a.m.
- 3) Completed your visual tests and the results were sent to your Neurosurgeon or Endocrinologist.
- 4) Completed all special tests that were arranged for you.
- 5) Made sure that notes from any other doctors and specialists were faxed to your Neurosurgeon or Endocrinologist.
- 6) Know the names and addresses of all your doctors, including eye doctors.
- 7) Made a list of all of your medicine and allergies.
- 7) Made a list of all of your questions and thoroughly read this brochure.

1 Week before your 1st appointment

The **Endocrinology Clinic at St. Michael's Hospital at 416-867-3679**. If you do not speak English, please tell the office when you confirm your appointment. Interpreters are free for those who need them. Arrange to bring a family member or friend with you. **Note:** The office needs to book interpreters in advance.

On the day of your 1st appointment

Bring the following:

- 1) All of your medicine and vitamins in their bottles.
- 2) Health card or proof of other insurance.
- 3) A family member or friend.
- 5) Something to do in case you are waiting for a long time.
- 6) A list of your questions.
- 7) Bring your CD-ROM of your MRI.

Before you leave your 1st appointment, make sure you are clear about:

- 1) Whether or not you are having surgery.
- 2) Other tests that you need to do and who is arranging them.

- 3) If you need any changes in your medicine.
- 4) If you need any other appointments such as: ENT, Neuro-ophthalmology, CT scan, or radiation.

After your 1st appointment
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If you are having surgery:

- a) You will get a phone call within 1-2 weeks of your appointment. We will tell you the date we propose for your surgery and any other testing or appointments.
- b) Read this information booklet again. You can also go to our website for more information.
- c) Stop smoking right away to prevent complications after your surgery.
- d) Undertake a regular exercise program to prepare for surgery and see your family doctor to make sure your general health is in order.
- d) Stop taking Aspirin or Clopidogrel (Plavix®) at least 1 week before surgery if this is okay with your family doctor. This will prevent abnormal bleeding during your surgery.
- e) Go to your appointment with the pre-admission facility.

If you are not having surgery:

- Ask your Endocrinologist or referring family doctor about any questions you may have.

After discharge from surgery

If you have had surgery: On average, patients stay in the hospital for 2-4 days after surgery. Once doctors are happy with your course in hospital, you will be discharged home. A family member should arrange to take you home before 11:00 am.

The nurses will teach you:

- how to rinse your nose with salt water on a daily basis,
- explain the follow-up plans and appointments
- provide a discharge summary for your family doctor
- go over “dos and don’t’s”

- the following appointments for after surgery should be made by the staff on the neurosurgical floor:
 - 1-2 weeks – you should see your family doctor
 - 2-3 weeks - ENT – appointment with nose specialist
 - 3-4 weeks - Endocrinologist appointment
 - 4 weeks – Visual tests and ophthalmologist
 - 4-6 weeks MRI
 - 6-8 weeks – neurosurgeon appointment
 - Longer term – usually follow-up with your endocrinologist and neuro-ophthalmologist as determined at your last checkup

Questions for my healthcare team:

Notes:

List of all medicines:

Names, addresses and phone numbers of all doctors:

MEMBERS OF THE TEAM AND HOW TO CONTACT US

Neurosurgeon	Dr. Michael Cusimano	Tel: 416-864-6048; Fax: 416-864-5857
Endocrinologists	Dr. Jeannette Goguen Dr. Gillian Booth	Tel : 416-867-3714; Fax: 416-867-3724 Tel: 416-867-3719; Fax: 416-867-3724
Neuro-Ophthalmologist	Dr. Irene Vanek	Tel: 416-864-5945; Fax: 416-864-5953
Otolaryngologists (ENT)	Dr. John Lee Dr. Jennifer Anderson	Tel: 416-864-5306; Fax: 416-864-5469 Tel: 416-864-5278 Fax: 416- 864-5367
Social Workers	Rebecca Blidner	Tel: 416-864-6060 x2125
Nurse Practitioners (neurosurgery)	Tom Willis Theresa Cook Martine Andrews Jenny Pak Elyse Kalpage	Tel: 416-864-5039 Tel: 416- 360-4000 x2980 Tel: 416-864-6060 x2951; Fax: 416-864-5790 Tel: 416-864-6060x 3409 Tel: 416-864-6060x 6978
Clinics	Neurosurgery Clinic Endocrinology Offices Endocrinology Clinic ENT Clinic MRI Pre-Admission Facility (PAF)	3 rd Floor Donnelly Wing Tel : 416-864-5678; Fax: 416-864-5790 6th Floor/61 Queen Street East 7th Floor/61 Queen Street East Tel : 416-867-3679 8 Cardinal Carter North Tel: 416-864-5276; Fax: 416-864-5694 B2 Cardinal Carter South Tel : 416-864-5661; Fax: 416-864-5820 10 th Floor Donnelly wing Tel : 416-864-5689 / 416-864-6074 / 416-864-5436; Fax: 416-864-5199
Information about blood transfusion	Blood Transfusion Service Transfusion Coordinator for blood transfusion information	Tel: 416-864-5084 Tel: 416-864-6060 x4055

Support Services

- **Telehealth Ontario**
 - 1-866-797-0000 TTY : 1-866-797-0007
 - Free access to a Registered Nurse — 24 hours a day, 7 days a week
- **Canada’s Food Guide**
 - <http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php>
- **Distress Centres of Toronto** (If you are feeling distressed and need to talk)
 - 416-408-HELP (4357)

St. Michael’s Hospital: Research and Teaching

All of the doctors involved in your care are also involved in research and teaching. We are affiliated with the University of Toronto for research and to train future health care professionals. We are always working to improve the care and outcomes of treatment for patients with pituitary tumours.

Members of the team may ask you to participate in a study. As such, a research assistant or student may speak with you during one or more of your visits. You can choose voluntarily whether or not you want to participate. Regardless of your decision, your care will not be affected.

This booklet was written by:

Dr. Michael Cusimano, Dr. Jeannette Goguen, Dr. Claudio De Tommasi, Dr. Jennifer Anderson, Dr. John Lee, Dr. Irene Vanek, Sasha Mallya, Emily Lam, Stanley Zhang, Martine Andrews, Cristina Lucarini, and the Interdisciplinary Pituitary Disorders Centre of Excellence Research Team at St. Michael’s Hospital.

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Updates

We will revise this statement and the information herein as needed

Interdisciplinary Pituitary Disorders Centre of Excellence:

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Fully affiliated with the University of Toronto

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