Information on Pituitary Tumours
# TABLE OF CONTENTS

- Introduction ........................................................................................................................................................................... 5
- What is the Pituitary Gland? ........................................................................................................................................................... 5
- What is a Pituitary Tumour? ........................................................................................................................................................... 6
- Types of Tumours and Symptoms .................................................................................................................................................... 7
  - Prolactin-Producing Tumours (Prolactinoma) ........................................................................................................................................ 8
  - Growth Hormone-Producing Tumours (Acromegaly) ......................................................................................................................... 8
  - ACTH-Producing Tumours (Cushing’s Disease) ............................................................................................................................... 10
  - Non-Functioning Tumours ............................................................................................................................................................... 11
- Other Common Pituitary Diseases .................................................................................................................................................... 12
- How can a tumour affect your vision? .................................................................................................................................................. 12
- How can a tumour affect your mood? .................................................................................................................................................. 13
- Your Healthcare Providers ................................................................................................................................................................. 14
- Tests ........................................................................................................................................................................................................... 15
  - Blood Tests .......................................................................................................................................................................................... 15
  - Vision Tests ........................................................................................................................................................................................ 15
  - Imaging ................................................................................................................................................................................................ 16
  - Other Tests ....................................................................................................................................................................................... 17
- Types of Treatment .............................................................................................................................................................................. 17
- Surgery ...................................................................................................................................................................................................... 18
  - Types of Surgery ............................................................................................................................................................................... 18
  - The Process for Transphenoidal Surgery ........................................................................................................................................ 19
  - Success Rate .................................................................................................................................................................................... 20
  - Risks .................................................................................................................................................................................................. 20
  - What Happens in Hospital After Surgery .................................................................................................................................... 21
  - How to Care for Your Nose After Surgery .................................................................................................................................. 21
  - Things to be Careful about After Your Surgery ................................................................................................................................ 22
Being Active After Your Surgery ................................................................. 23
Eating After Your Surgery ........................................................................ 23
Symptom Improvement ............................................................................. 24
Follow-up Appointments ......................................................................... 25
When to Contact Your Doctor or Nurse .................................................... 25
Radiation Therapy .................................................................................... 26
Medicine .................................................................................................... 27
  To Treat Prolactinoma ........................................................................... 27
  To Treat Acromegaly ............................................................................. 28
  Hormone Replacement ......................................................................... 28
Watching the Tumour for Growth ............................................................... 29
Long-Term Perspective ............................................................................. 29
Checklist for Your 1st Appointment ......................................................... 30
  Before Your 1st Appointment ............................................................... 30
  On the Day of Your 1st Appointment ................................................... 31
  After Your 1st Appointment ................................................................. 32
Your Notes & Questions ........................................................................... 33
Members of the Team and Contact Information ......................................... 34
Support Services ....................................................................................... 35
  Telehealth Ontario ............................................................................... 35
  Canada's Food Guide .......................................................................... 35
  Distress Centres of Toronto ................................................................. 35

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.pituitaryinfo.com
INTRODUCTION

Read this booklet to learn about:

- pituitary tumours
- symptoms you may experience
- tests you will need
- specialists you will be seeing
- treatment options
- a checklist for your 1st appointment
- 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 (see Figure 1).

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 large amounts of certain hormones. Non-functioning adenomas do not make hormones. Both types of tumours can cause the pituitary gland to stop its normal hormone functions.

Both types of tumours can cause vision problems. Vision problems can occur because the pituitary gland is close to the nerves of the eyes and the tumour can press on these nerves.

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 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 needed to be sure, such as brain scans (MRIs) and biopsy (taking a small sample of tissue from your gland).
TYPES OF TUMOURS AND SYMPTOMS

There are two types of pituitary tumours: functioning (tumours that make large amounts of hormones) or non-functioning (tumours that do not make extra hormones). Both types can press on the nerves of your eyes and cause problems.

Types of functioning tumours:

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

Non-functioning tumours:

- Non-functional pituitary adenoma
- Craniopharyngioma

The following are other common pituitary diseases:

1. Rathke’s cleft cyst
2. Pituitary apoplexy

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

- the size of the tumour
- how it affects the making of hormones in your body
- how the tumour affects your brain and eyes.
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
- lose peripheral (or side) vision

Loss of side vision can feel like ‘tunnel vision’ (able to see only straight forward and not to the sides).

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

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
- snoring
- breathing problems during sleep (known as sleep apnea)
- sweating
- skin tags (little growths on the skin; see Figure 4)

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 can result in “gigantism”. Gigantism makes children and teens very tall, like a “giant”. The reason why acromegaly results in gigantism in children and teens only (and not adults) is because their 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” (adrenocorticotropic 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 many tests 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 below listed effects (see Figure 5).

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
- hardening of the arteries

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.
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 quite large. They may continue to grow and cause the pituitary gland to stop making some or all hormones. This is called hypopituitarism.

Hypopituitarism can cause:

- low energy levels
- tiredness
- dizziness
- 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 hormone replacement medicine.

A **craniopharyngioma** is a rare non-cancerous tumour that develops above or in the pituitary gland. This type of tumour can cause headaches, vomiting, reduced growth and vision problems. 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.
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 decrease in hormones 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.

WHAT ARE SOME WAYS THAT A PITUITARY TUMOUR MAY AFFECT MY VISION?

How your tumour affects your vision depends on the size of the tumour and how quickly it has grown. As the tumour grows, it presses on the nerves of your eyes, which causes you to have trouble with your vision. In less common cases, the tumour may also affect how your eyes and eyelids move.

You may have any of these changes:

- 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

These symptoms may happen all at once or slowly over time. 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.

You will need to see a neuro-ophthalmologist, who is an eye specialist. The neuro-ophthalmologist will examine your eyes and order visual field testing and other tests as needed.
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.

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
• 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 big changes in mood. 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 WILL HELP ME MANAGE MY PITUITARY TUMOUR?

More than one kind of doctor 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** - 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 your 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 health care workers, such as nurses, social workers, physiotherapists, and pharmacists may help with your care as well. You will meet many nurses with different roles. You will meet nurses at the pre-admission clinic prior to your surgery (who can help with questions you have), nurses at the time of surgery and also nurses in the hospital after surgery. Each nurse is an expert in different areas and will help you through your treatment.
TESTS

Blood tests
You will have blood tests before your visits with the neurosurgeon and endocrinologist, before your surgery, right after surgery, and when you return for follow-up visits.

Before your surgery:

- Come to St. Michael’s Hospital’s blood lab for all of your blood tests if possible. Come between 7:30 a.m. and 9:00 a.m. You do not need an appointment. However, if you live too far away, you can do the blood tests at a location closer to where you live.

- You will also have a blood test right before your surgery. You will have this blood test during your pre-admission appointment.

Other blood tests:
You will have blood tests right after your surgery and when you return for follow-up visits with your doctor. These blood tests help your doctor check your hormone levels. The results of these tests can let your doctor know whether your hormones are affecting your body.

These blood tests should be done at 8 a.m. If you are taking the hormone medicine Cortef®, hydrocortisone, or prednisone, the blood tests should be done 24 hours after your last dose of medicine. If you have questions about your blood tests, ask your doctor.

Vision tests
It is important for you to have a vision test. A vision test will help your doctors know if your tumour is pressing on the nerves of your eyes.

Visual Field Test
Ask your family or referring doctor to refer you for a visual field test if you have not had one before. The Visual Field Test checks your peripheral (side) vision. During the test you will hit a button every time you see a flash of light.

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.
Heidelberg Retinal Tomography (HRT) and Optical Coherence Tomography (OCT)

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

What to bring when you have an HRT:

• bring your eyeglasses
• bring your sunglasses to wear home after the test
• please arrange for someone to drive you home from the appointment. The eye drops used during the visit will make it hard to focus.

The HRT is not 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.

Imaging

Magnetic Resonance Imaging Scan (MRI)

This test gives your doctors pictures of your pituitary gland. The test is often done in 2 steps. First they take one set of pictures. Then right after, they inject a dye into your body and take another set of pictures. The dye will be injected into your body through an IV (intravenous) line. This test is done before and after surgery. After surgery you will need more MRIs to help the doctors check your condition.

Computed Tomography Scan ("CT" or "CAT scan")

Computed tomography (CT) is a test that combines X-rays and computer scans. The pictures are very detailed and can show problems with your pituitary gland. The pictures from this scan will be used during your surgery to help the surgeons find their way through your body during the surgery.
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

Note: If the MRI or CT scan was done at a hospital other than St. Michael's Hospital, make sure to bring a copy of the MRI or CT scan (loaded on to a CD-ROM or DVD) to your appointment with the neurosurgeon or endocrinologist.
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 large
- is of a certain type
- goes off to the sides
- lies deeper in the brain

**How does transphenoidal surgery work?**

1. Just before your surgery, you will be given a general anesthetic (to put you to sleep) and the doctors will make sure you are fully asleep.

2. During your surgery, the surgeon will use a small telescope with a tiny video camera at the end. This telescope is called an "endoscope". The surgeon uses it as a guide through your nostril to the tumour.

3. The surgeon will remove a small piece 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. You will have “grafting” (taking fat from the side of your thigh or lower abdomen to close and seal the surgical area).

6. The surgeon will check for any leaking from your nose. If cerebrospinal fluid (CSF is leaking from your nose, the incision the surgeon made inside your nose will not heal. If this incision does not heal, you could get meningitis. If this fluid is leaking from your nose, the surgeon may place a drain in your lower back. This drain will allow the cerebrospinal fluid to drain out into a bag. Draining the cerebrospinal fluid will relieve the pressure in your nose and allow your incision to heal.

7. Once the surgical area is sealed, two small plastic sheets are put in to your nose to prevent the growth of scar tissue. These sheets will be removed by your ENT surgeon 2 to 3 weeks after surgery. At the end of the surgery, your nostrils will be packed with Vaseline gauze or a sponge to prevent your nose from bleeding. The surgery usually lasts a total of 3 to 6 hours but it depends on the tumour size, 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, texture (firm or soft), and type of tumour. In most cases, if you have limited vision before surgery, vision is improved (or at least won’t get worse), even if you have large tumour(s).

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. Discuss the risks and benefits of your surgery with your doctors and your surgeons before surgery. Some of the risks and the potential outcomes of these risks are listed below:

<table>
<thead>
<tr>
<th>Risks</th>
<th>Potential Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Damage to pituitary gland</td>
<td>Loss of hormones in your body. You may then need hormone replacement medicine (for replacing 1 to 6 hormone(s) in your body). You may need the medicine either temporarily or permanently.</td>
</tr>
<tr>
<td>Damage to large blood vessels (i.e. carotid arteries) that are around the pituitary gland</td>
<td>Stroke, a lot of blood loss, or death</td>
</tr>
<tr>
<td>Damage to lining of the brain</td>
<td>Leakage of brain fluid and may cause an infection called meningitis</td>
</tr>
<tr>
<td>Vision problems due to damage to the nerves of the eyes</td>
<td>Partial or complete blindness in one or both eyes</td>
</tr>
<tr>
<td>Scar tissue formation or crusting in the nose</td>
<td>This can lead to nasal obstruction or bad smells because the nose is not being cleaned properly</td>
</tr>
<tr>
<td>Sinus infection</td>
<td>Loss of smell and/or taste</td>
</tr>
</tbody>
</table>
What happens in hospital after surgery?

- Your hormone levels will be checked through blood tests once or twice a day.
- You will be involved with checking how much liquid you drink and how much urine (pee) you produce. You will be asked to write down how much fluid you are drinking. The nurse will accurately measure how much urine you produce every day. Checking the amount of urine your produce after surgery is very important to ensure good hydration.
- If you get very thirsty and make too much urine, you may need to take a medicine called DDAVP. DDAVP will help your kidneys keep water in your body to prevent you from being dehydrated. Dehydration may cause low blood pressure.
- After your surgery, the same day or a day after, the nasal packing will be removed. You may have mild bleeding. The nurses will show you how to gently wash your nose with salt water (saline) rinse once mild bleeding stops.

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 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 surgical incision in your nose is very weak. The pressure from blowing your nose will prevent the incision from healing. If you blow your nose, the fluid that surrounds the brain (called cerebrospinal fluid) may leak out.

You may have a stuffy nose for a few weeks. You will need to do 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 2-3 times per day. You can buy the spray at a local drugstore.

Once the small plastic sheets in your nose are removed by the ENT Surgeon (usually 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 Saline Wash

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 twice a day (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.pituitaryinfo.com

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
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 visual field test before you are legally allowed to drive again. In many cases, the law requires your doctor to report your case to the Ministry of Transportation.

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 2 to 4 weeks after your surgery. Once your surgeon says 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 weeks, but some are off for more or less time.

Being active after your surgery

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

Walking often is the best exercise. Walk 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://tynyurl.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 4 weeks
- Endocrinologist in 2 to 4 weeks
- Neurosurgeon in 6 to 8 weeks (along with an MRI of the pituitary gland before you see your neurosurgeon)
- Ophthalmologist or optometrist for visual field testing in 4 weeks
- 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)
• You feel very weak, nausea (dizzy) or are vomiting
• Confusion |
|---|---|
| Call your neurosurgeon or nurse if you notice any of the following: | • Worsening pain
• 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) |

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 therapy 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:

- Fractionated radiation
- Intensity modulated radiation therapy (IMRT)
- Single dose radiation therapy (called “radiosurgery”)

Fractionated radiation

In fractionated radiation therapy, you will get a small amount of radiation 5 times a week for 4 to 6 weeks. You come to the hospital and your treatment may last for 15 to 20 minutes per day.

Intensity modulated radiation therapy (IMRT)

In intensity modulated radiation therapy, the radiation is given precisely to an area slightly bigger than the tumour. This makes sure that all of the tumour gets radiation. The treatment is carefully planned using MRI images of the tumour and other methods.

Your radiation doctor will decide on the length of the treatment. This treatment may follow the same schedule as fractionated radiation (see the section above).

Single dose radiation: radiosurgery

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.
Since the gamma knife can target very tiny spaces, the tumours come under control faster 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. Gamma-knife radiosurgery is usually a one-time therapy completed in a single day.

**Side effects of radiation**

All forms of radiation can damage normal pituitary and brain cells, which may lead to a loss of hormones. 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, even years after treatment.

**C) MEDICINE**

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

- block the tumour from making too much hormone and sometimes reduce the size of certain types of pituitary tumours (prolactinomas and acromegaly)
- 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.

**1) To treat prolactinoma**

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

Cabergoline is more expensive but both are generally covered by most drug insurance plans. Bromocriptine is covered for patients on Trillium or Ontario Drug Benefits (ODB).
2) To treat acromegaly

Octreotide (or Sandostatin®) reduces the release of growth hormone in acromegaly. 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.

3) 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

Cortisone (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.

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 medicine, 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) or is not affecting hormone production. This plan allows some patients to avoid surgery or radiation.

LONG-TERM PERSPECTIVE

Most patients respond to treatment and have non-cancerous tumours. For long-term follow-up you will need a yearly MRI of the pituitary gland. This usually starts about a year after your treatment. You will also need an eye test, and regular visits with your endocrinologist and ophthalmologist or optometrist.

Work with your family doctor to make sure you get these tests and appointments on a regular basis. If you have any new surgical issues, your family doctor should refer you back to your surgeons.
CHECKLIST FOR YOUR 1ST APPOINTMENT

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

2 weeks before your 1st appointment

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.

1 week before your 1st appointment

☐ Confirm your appointment. Call the Neurosurgery Clinic at 416-864-5678 or 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. 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.

☐ 4) Something to do in case you are waiting for a long time.

☐ 5) A list of your questions.

**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.
If you are having surgery:

☐ a) You will get a phone call within 1 week 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) 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.
Questions for my healthcare team:

_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________

Notes:

_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________

List of all medicine:

_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________

Names, addresses and phone numbers of all doctors:

_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________
_____________________________________________________________________________________________________


**MEMBERS OF THE TEAM AND HOW TO CONTACT US**

<table>
<thead>
<tr>
<th><strong>Neurosurgeons</strong></th>
<th>Dr. Michael Cusimano</th>
<th>Tel: 416-864-6048; Fax: 416-864-5857</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dr. Sunit Das</td>
<td>Tel: 416-864-5548; Fax: 416-864-5596</td>
</tr>
<tr>
<td></td>
<td>Dr. Loch MacDonald</td>
<td>Tel: 416-864-5452; Fax: 416-864-5442</td>
</tr>
<tr>
<td><strong>Endocrinologists</strong></td>
<td>Dr. Jeannette Goguen</td>
<td>Tel: 416-867-3714; Fax: 416-867-3724</td>
</tr>
<tr>
<td></td>
<td>Dr. Gillian Booth</td>
<td>Tel: 416-867-3719; Fax: 416-867-3724</td>
</tr>
<tr>
<td><strong>Neuro-Ophthalmologist</strong></td>
<td>Dr. Irene Vanek</td>
<td>Tel: 416-864-5945; Fax: 416-864-5953</td>
</tr>
<tr>
<td><strong>Otolaryngologists (ENT)</strong></td>
<td>Dr. John Lee</td>
<td>Tel: 416-864-5306; Fax: 416-864-5469</td>
</tr>
<tr>
<td></td>
<td>Dr. Jennifer Anderson</td>
<td>Tel: 416-864-5278; Fax: 416-864-5367</td>
</tr>
<tr>
<td><strong>Social Workers</strong></td>
<td>Ingrid Kuran</td>
<td>Tel: 416-864-6060 X6282; Fax: 416-864-5250</td>
</tr>
<tr>
<td></td>
<td>Lindsay Elin</td>
<td>Tel: 416-864-6060 X3979</td>
</tr>
<tr>
<td><strong>Nurse Practitioners (neurosurgery)</strong></td>
<td>Tom Willis</td>
<td>Tel: 416-864-5039</td>
</tr>
<tr>
<td></td>
<td>Theresa Cook</td>
<td>Tel: 416-360-4000 X2980</td>
</tr>
<tr>
<td></td>
<td>Martine Andrews</td>
<td>Tel: 416-864-6060 X2951; Fax: 416-864-5790</td>
</tr>
<tr>
<td><strong>Clinics</strong></td>
<td>Neurosurgery Clinic</td>
<td>4 Shuter Wing</td>
</tr>
<tr>
<td></td>
<td>Endocrinology Offices</td>
<td>Tel: 416-864-5678; Fax: 416-864-5790</td>
</tr>
<tr>
<td></td>
<td>Endocrinology Clinic</td>
<td>6th Floor/61 Queen Street East</td>
</tr>
<tr>
<td></td>
<td>ENT Clinic</td>
<td>7th Floor/61 Queen Street East</td>
</tr>
<tr>
<td></td>
<td>MRI</td>
<td>Tel: 416-867-3679</td>
</tr>
<tr>
<td></td>
<td>Pre-Admission Facility (PAF)</td>
<td>8 Cardinal Carter North</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tel: 416-864-5276; Fax: 416-864-5694</td>
</tr>
<tr>
<td><strong>Information about blood transfusion</strong></td>
<td>Blood Transfusion Service</td>
<td>B2 Cardinal Carter South</td>
</tr>
<tr>
<td></td>
<td>Transfusion Coordinator</td>
<td>Tel: 416-864-5689 / 416-864-6074 / 416-864-5436; Fax: 416-864-5199</td>
</tr>
<tr>
<td></td>
<td>Apheresis/Autologous Lab</td>
<td>Tel: 416-864-5084</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tel: 416-864-6060 X4055</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tel: 416-864-5614</td>
</tr>
</tbody>
</table>
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


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.

We may ask you to participate in a study by a research assistant or student during one or more of your visits. You can choose whether or not you want to participate. Regardless of your decision, your care will not be affected.

This booklet was written for you 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.