



2nd Edition

braintumour
foundation

OF CANADA

Non-Malignant Brain Tumour Handbook

For people diagnosed with non-malignant
or low-grade brain tumours

Our Promise to You

At Brain Tumour Foundation of Canada you will find accurate, up-to-date, free information to help you and your loved ones through this difficult time. Additional programs and services include:

- Educational events to help manage the brain tumour journey.
- Critical support through one-on-one, pediatric and group support services.
- Research funding into the cause of and potential cures for brain tumours.

Call us at **1-800-265-5106** or visit **www.BrainTumour.ca** for details and more information.

How You Can Help

Brain Tumour Foundation of Canada is funded entirely through contributions from individuals, corporations and foundations. Without the help of this community of supporters, dedicated assistance for Canadians affected by a brain tumour would not be possible.

You Can Give By:

- General Donation – A single or monthly gift designated to the area of your choice or allocated by the organization to where the need is greatest. Donations can be made by phone, by mail or online.
- Legacy Giving – When updating your will or your life insurance coverage, leave a legacy by including Brain Tumour Foundation of Canada as a beneficiary.
- Tribute Gifting – Tribute gifts, either in memory or in honour of someone special, are a meaningful way to recognize a loved one.
- Hosting a Community Event – Organize and run an event in your community with proceeds benefiting Brain Tumour Foundation of Canada and Canadians affected by a brain tumour.

This Brain Tumour Handbook is for You

When you or a loved one is diagnosed with a brain tumour, life changes in an instant.

This handbook aims to diminish the misconception that non-malignant or low-grade brain tumours do not alter the lives of those affected. In fact, these tumours do have a significant impact on your health and well-being.

The information in this booklet addresses some of the questions and concerns you may have about being diagnosed with a non-malignant or low-grade brain tumour, and helps raise awareness about this disease, providing education for family members, friends and health care professionals.

The Non-Malignant Brain Tumour Handbook is written for a patient's perspective but is a tool for anyone affected by a brain tumour diagnosis including loved ones and family members.

About Brain Tumour Foundation of Canada

If you have been affected by any type of brain tumour, we are here to help.

An estimated 55,000 Canadians currently live with a brain tumour and an additional 10,000 people are diagnosed each year. That is 27 new diagnoses per day. Thousands of people affected by brain tumours find emotional support and comfort through Brain Tumour Foundation of Canada while gaining a better understanding and knowledge of their disease.

Brain Tumour Foundation of Canada is the only national, not-for-profit organization committed to reaching every Canadian affected by a brain tumour through support, education, information and research. We are led by a dedicated team of volunteers, patients, survivors, family members, health care professionals and staff, determined to make your brain tumour journey one full of hope and support. We work collaboratively to serve the needs of all Canadians affected by every type of brain tumour.

Services and Programs

- One-on-one, personal and group support is available to any Canadian affected by a brain tumour. Details about these programs can be found under the **“You Are Not Alone”** section of this resource.
- Educational events such as Information Day Conferences give you the opportunity to connect with others in the brain tumour community while learning about recent developments in areas such as brain tumour treatment and quality-of-life for patients.
- Brain Tumour Foundation of Canada funds critical research into the cause of and cure for brain tumours. To date, the organization has directed more than \$3.5 million to projects through the Brain Tumour Research program.

*Information about programs and services is available at www.BrainTumour.ca/help or by calling **1-800-265-5106**.*

Acknowledgements

Brain Tumour Foundation of Canada would like to take this opportunity to acknowledge the many individuals who have contributed to this unique resource.

We wish to thank the people across Canada who completed the “Experience of Non-Malignant Brain Tumour Survivors” exercise in 2010. Your experiences helped guide the creation of this resource and we thank you for being so open and honest about your brain tumour diagnosis and journey. We also thank the groups who participated in the 2010 Information Day Conference brainstorming sessions in London, Halifax and Calgary – your input was invaluable in building this handbook.

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For the purpose of this handbook, non-malignant and low-grade brain tumours are referred to as non-malignant.

Editors

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Monika Pantalone, Nurse Practitioner and Advanced Practice Nurse (APN) of Neurosurgery at The Ottawa Hospital (Civic Campus), provided us with a health care professional's perspective. Monika has also been a speaker at the Ottawa Brain Tumour Information Day Conference.

Karen Metcalfe provided feedback as a mother of a child diagnosed with a non-malignant brain tumour.

Jennifer Brewe provided feedback as a survivor of a non-malignant brain tumour.

"This is a unique resource for a unique population, so speaking as both an advanced practice nurse in Neurosurgery at The Ottawa Hospital and as a nurse practitioner in primary health care, I wanted to help out any way I could. I was very honoured to partake in the focus group as well as contribute as one of the editors in the creation of this new booklet for patients and families who have experienced the diagnosis of a non-malignant brain tumour.

I believe this new booklet will help dispel some myths and misconceptions about non-malignant brain tumours and provide a greater education and knowledge base to all patients, families and other health care professionals. The need for this type of resource is long overdue!"

Monika Pantalone, Advanced Practice Nurse (APN) in Neurosurgery

"As to why I wanted to work on this document...I believe that once Mckenna was diagnosed with a brain tumour we formed a lifelong commitment to the organizations that helped us and continue to help us through our journey. Brain Tumour Foundation is the main one. It is an opportunity to help others and to give back, yet I find that as I do that I seem to get more out of it than I probably give."

Karen Metcalfe, mother of child diagnosed with a non-malignant brain tumour

"I wanted to contribute to this resource because I found the original Brain Tumour Foundation of Canada's patient handbook so helpful. However, even with that resource I was left with difficult questions I couldn't quite answer surrounding benign vs. malignant tumours, what is considered cancer, treatments needed, etc. I hope that this resource, specific to non-malignant brain tumours, will help clarify these answers for others diagnosed with brain tumours as they face similar questions."

Jennifer Brewwe, non-malignant brain tumour survivor

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This handbook is available in print or electronically. To request an electronic version of the Non-Malignant Brain Tumour Handbook, please call 1-800-265-5106 or visit www.BrainTumour.ca/help.

You Are Not Alone



You Are Not Alone

Whether you, a family member or a friend have been diagnosed with a brain tumour, experiencing a range of emotions is a normal reaction. Talking with a close friend, family member or someone with whom you feel comfortable can help reduce some of the emotional stress you may be feeling. Similarly, meeting others who are also experiencing life with a brain tumour can be especially helpful. Together you can share feelings and experiences, and offer each other social and emotional support.

Brain Tumour Foundation of Canada works with volunteers to provide support groups across the country and also works with affiliated groups in areas in which a Brain Tumour Foundation of Canada group is not available.

Children with a non-malignant tumour and their immediate families can also join *BrainWAVE* – an event-based support program that offers families the opportunity to connect with one another and provides respite and fun during what can be a difficult period in their lives. Information about *Support Groups* and *BrainWAVE* is available online at www.BrainTumour.ca/help.

If you would like to join a Brain Tumour Support Group or Program but none are currently available in your area, please contact Brain Tumour Foundation of Canada at 1-800-265-5106.

Brain Tumour Foundation of Canada offers two additional support resources:

- Toll-Free Support Line:
From Monday to Friday, 8:30am – 4:30pm EST, one-on-one confidential support is available by calling 1-800-265-5106.
- Online Communities:
To learn more about Brain Tumour Foundation of Canada's various online communities, like Facebook or the Online Peer Support Centre, visit www.BrainTumour.ca.

"Once you experience something like this, you re-evaluate what is important to you and how you want to live your life. I enjoy attending the Calgary Support Group. Not only has it been helpful, it is also a great way to connect with others in similar situations. As a survivor, nurse and volunteer, my best advice to those affected by a brain tumour is to be an advocate for your own health; you know your body better than anyone. If you feel something is wrong, then be persistent about your health until you get answers that make sense."

*Lori Wilson, survivor of a meningioma,
diagnosed at the age of 36
Calgary, AB*

Accessing Information on the Internet

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Accessing Information on the Internet

Accessing information and support by way of the Internet has become quite commonplace, and more and more Canadians refer to the Internet as a source of health information.

With thousands of websites containing information about brain tumours and treatments, the Internet can provide a great opportunity to learn more about treatment, to communicate with other people, to find clinical trials, and to gain access to support services.

This process can be overwhelming and not all information on the Internet is reliable.

Before you search online for information, refer to the following list of questions. Think about the information you are searching for and what you are going to do with the information you find.

For example:

- Is the information for you or someone else?
- Are you trying to find information about a disease or condition?
- Are you looking for research?
- How do you plan to use the information?

Take a printout of the information you find to your next doctor's appointment. Think about the best way to present the information, and avoid the temptation to diagnose or treat any disease, sign, and symptom or condition yourself.

If you are seeking expert medical information and advice, you should always refer to the services of a registered health care provider.

Reliable Websites

Websites of reliable organizations provide the most credible, accurate and complete information. Many non-profit organizations and hospitals have websites with an extensive list of links to other web-based resources that may provide you with the information you need.

Brain Tumour Foundation of Canada's website, www.BrainTumour.ca, has links to many reliable websites that cover a wide range of topics including advanced care planning, clinical trials, nutrition and complementary and alternative medicine, as well as other brain-tumour-related websites.

Please visit **The Northey Library** for online information on a variety of topics and resources at www.BrainTumour.ca/northeylibrary.

Searching the Internet

There are three main kinds of search tools on the Internet:

1. Search engines index the content of websites. Several good search engines exist including Google, Yahoo and Bing.
2. Subject directories group various resources on the Internet by topic and can be used to find websites about brain tumours.
3. Specialty sites are major sites devoted to a particular subject. Many specialty health sites exist: some are quite extensive covering a wide range of resources and health topics; others are smaller and deal with a single topic such as brain tumours or clinical trials.

When you are looking for health information, you will want to use all of these Internet search tools.

How to Use a Search Engine

- Learn how a particular search engine works. Spend a few minutes reading the help pages, search tips and FAQs (frequently asked questions).
- Ask yourself what you really want to know, then:
 - Try to put your question or phrase into three or four words.
 - Review the first 10 or 20 results.
 - Identify the ones that seem the most relevant.
 - Note the words that are used on the pages you like.
 - Rerun your search with some of those words. Do this a few times to make sure you get the results you want.

Here are questions to consider that will help you judge whether a website is reliable:

- Who is responsible for the website?
- What is the purpose of the website?
- Can you understand the website?
- Is the information accurate, objective and trustworthy?
- How current is the information? (Check the date at the bottom of the web page – is it up to date?)

If you do not have a computer or access to the Internet at home, check with your local library as they often provide this service free to the public.

Family members and friends may be able to help search for articles or provide you with access to a computer. Some hospitals now provide access to the Internet for patients and their families.

Last but not least, when looking for information about your diagnosis on the Internet, be wary of those who express personal opinions about causes, treatments and cures, and know that these are simply opinions, not medical facts. If you are unsure about the content offered on any website, print the information and discuss it with your health care team.

What is a Brain Tumour?



What is a Brain Tumour?

A brain tumour is a growth of abnormal cells that is either within or around the structure of the brain. Alternate terms used to describe tumours include *lesion*, *neoplasm* or *growth* and these terms are often used when the pathology of a tumour is unknown.

Brain tumours are classified or categorized to help identify their origin, behaviour and type. Brain tumours can be primary or secondary in nature, and referred to as benign, non-malignant or malignant.

What do “primary” and “secondary” mean?

When a tumour originates in the brain it is considered primary, and can be malignant or non-malignant. A secondary tumour is cell growth that has formed in the brain having spread from elsewhere in the body and is always malignant.

What is the difference between a benign, non-malignant and malignant brain tumour?

Often times, you may hear the word “benign” used in reference to tumours considered to be non-life-threatening or non-aggressive. This is not entirely accurate in the case of brain tumours as they can compress brain tissue and other structures inside the skull and cause serious health complications, no matter their classification. In this resource, and throughout the health care community including the World Health Organization (WHO), there has been a considered shift toward using “non-malignant” or “low-grade” rather than “benign” to define tumours that are not aggressive.

“People were distraught, shocked, overwhelmed, didn’t know what to say or do. Most people were supportive and showed their support in so many different ways. Some people, when they heard it was non-malignant, acted like we should be celebrating and told us we should be thankful. This was hurtful.”

Non-malignant brain tumour survivor

The WHO classifies brain tumours by cell origin and how the cells behave, from the least to the most aggressive. Some tumour types are assigned a grade to signify their rate of growth and to help predict behaviour. Many non-malignant tumours are classified under Grade I or II; however mixed-grade tumours are possible.

WHO Tumour Grading System

Grade I Tumour:

- Slow growing
- Almost normal in appearance under a microscope
- Least malignant
- Usually associated with long-term survival
- Example: acoustic neuroma or typical meningioma

Grade II Tumour:

- Relatively slow-growing cells
- Slight abnormal appearance under a microscope
- Can invade nearby healthy tissue
- Can recur as a higher grade tumour
- Example: atypical meningioma

Grade III Tumour:

- Actively reproducing abnormal cells
- Abnormal appearance under a microscope
- Affects nearby healthy tissue
- Tumour tends to recur, often becoming a higher grade tumour
- Example: anaplastic astrocytoma

Grade IV Tumour:

- Abnormal cells which reproduce rapidly
- Very abnormal appearance under a microscope
- Form new blood vessels to maintain rapid growth
- Areas of dead cells in centre (necrosis)
- Example: glioblastoma multiforme (GBM)

The distinction between non-malignant and malignant tumours can be challenging. Some non-malignant tumours can be as serious as those classified as malignant if they are inoperable or in an inaccessible location, such as the brainstem. Conversely, some malignant tumours can be successfully treated.

There are 120 different types of primary brain tumours and although each type will fall into a particular classification or category, brain tumours are specific to each individual and therefore treatment plans will vary, as will signs and symptoms. Always refer to your health care provider or team for information about your personal treatment plan, symptom management and individual care.

*WHO Tumour Grading System from Louis, DN, Ohgaki, H, Wiestler, OD, Cavenee, WK.
World Health Organization Classification of Tumours of the Central Nervous System.
IARC, Lyon, 2007*

Signs & Symptoms



Signs & Symptoms

Every person diagnosed with a brain tumour will have different symptoms and their own journey to a diagnosis. While some people do not develop symptoms that would indicate a tumour, others may have symptoms that worsen over time eventually leading to a diagnosis. Others still may feel perfectly fine but experience a sudden onset of symptoms, such as a seizure, which leads to a quick and unexpected tumour diagnosis.

The following is a list of common symptoms which, alone or combined, can be caused by a non-malignant brain tumour:

- Behavioural changes
- Cognitive changes
- Dizziness or unsteadiness
- Double or blurred vision
- Frequent headaches
- Hearing impairment
- Morning nausea and vomiting
- Seizures
- Weakness or paralysis

“At first, it just seemed like she had a really bad flu, but when the symptoms kept coming back and no one else in the house was getting sick, we knew there must be something else wrong. We also noticed that she was throwing up in the morning and was hungry after. She was also complaining of a pain in her neck. Looking back it seems obvious but at the time you convince yourself that it could be something simple.”

*Karen Metcalfe, whose daughter was diagnosed at the age of four with a pilocytic astrocytoma
Windsor, ON*

Testing & Diagnosis



Testing & Diagnosis

For some, a brain tumour diagnosis is a shock. For others, there may be an initial sense of relief at finally putting a name to their symptoms.

Whatever your immediate response to your diagnosis, over time you will likely find yourself experiencing a variety of emotions.

“I was scared; I was very young at the time, so I was confused about what was happening. I didn’t understand the difference between surgery and a biopsy.”

“I received the diagnosis over the phone and was really unaware of what the specialist was telling me. It wasn’t until my wife told me that I realized how serious it could be (she’s a nurse).”

“When my daughter was diagnosed with a brain tumour it was shock and fear. When we found out it was ‘benign,’ it was guarded relief.”

Sharing your feelings with someone close to you may help alleviate some of the emotional stress that can accompany testing and diagnosis.

Testing For and Diagnosing a Non-Malignant Brain Tumour

A complete and thorough neurological examination is always important in diagnosing a brain tumour.

The diagnosis of a brain tumour begins with your doctor who will ask a number of questions in order to get a complete history of symptoms. A basic neurological exam then follows, which may include:

- Balance and coordination tests: Heel-to-toe walking, heel-to-shin movements; balance with feet together and eyes closed; rapid alternating movements such as touching the finger to the nose with eyes closed
- Eye movement, pupil reaction and eye reflex tests
- Facial muscle tests: Smiling, grimacing
- Head movement tests
- Hearing tests
- Reflex tests using a rubber hammer
- Sense of smell tests using various odours
- Sense of touch tests using a pin point and cotton ball
- Tongue movement, gag reflex tests

If the results of this examination lead your doctor to suspect a brain tumour, additional testing (including scans) is typically scheduled.

Scans are done in place of conventional X-rays, which are not able to show tumours behind bone. Different types of imaging devices are used to perform brain scans. The most commonly used devices for both diagnosis and follow-up are the Computed Tomography scan (CT / CAT scan) and the Magnetic Resonance Imager (MRI). Some non-malignant tumours may be found by CT but most commonly require a MRI brain scan. In both cases contrast dye is usually required.

CT or CAT Scan

This machine combines a sophisticated X-ray device and computer. An injection of iodine (contrast dye) is given to the person having the scan, to help make any abnormal tissue more evident. That person then lies very still on a table that slides into a doughnut-shaped opening. The CT scanner circles the head, and X-rays penetrate the brain.



Photo courtesy of GE Healthcare

MRI

The MRI is a tunnel-shaped piece of equipment. The person being examined lies on a table that slides into the tunnel. Inside the scanner, a magnetic field surrounds the person's head while radio energy is beamed to the area. No X-rays are used. The magnetic field causes atoms in the brain to change direction while the radio waves cause another change of direction. When the beam stops, the atoms relax and return to their original position. MRI imaging takes longer than a CT scan, and it is very noisy. Like the CT scan, a contrast material (Gadolinium) may be used.

Because the MRI ignores bone, which can obstruct CT images, this device provides clearer pictures of tumours located near bone than CT does. It's important to know that while the MRI can detect brain swelling, it has difficulty distinguishing swelling from a tumour. Some tumours also have calcification, which the MRI cannot detect.

Patients with cardiac monitors, pacemakers or surgical clips cannot undergo an MRI because of the magnetic fields.



Photo courtesy of GE Healthcare

Biopsy

A biopsy is a surgical procedure used to remove a small amount of tumour tissue. The neurosurgeon submits samples of the tumour tissue to a neuro-pathologist for analysis and accurate diagnosis. A biopsy is the most accurate method of obtaining a brain tumour diagnosis.

Waiting for Answers



Waiting for Answers

Waiting for information and answers can be a challenge. The diagnostic process may be lengthy as CT or MRI scans take time to process, pathology reports take days to weeks to return, and appointments can be scheduled days to months in advance. Treatment can also take time to start and complete; difficult waiting periods can include the anticipation of surgery or radiation. With many unanswered questions and periods of time between appointments, treatment and recovery time, feeling anxious and worried is completely understandable.

In order for your health care professionals to obtain the information needed to assist in making the right treatment decisions, some waiting time is unavoidable. Use this time to learn more about your diagnosis; access the support you need and take care of yourself, both physically and emotionally.

“Wait and See” Approach

Occasionally, a person diagnosed with a brain tumour will not undergo an operation. Instead, doctors may choose to monitor the brain tumour with a series of CT or MRI scans. In such instances, the patient is monitored by doctors who are brain tumour specialists, for example neurologists or neurosurgeons. These doctors will explain why they have taken an observational approach.

Remember...

You need to act as your own health care advocate. This may mean requesting second opinions, asking many questions and coming to appointments prepared with a list of topics you would like to discuss. Your medical team looks to you to tell them about your health as you know your body best. They want to help you understand your health concerns and what you need to do for treatment.

Treatment Options



Treatment Options

Non-malignant tumours are rarely untreatable, with treatment being very similar to that for other brain tumours, except that chemotherapy is seldom required.

Although non-malignant tumours are not cancerous, treatments that are typically used, such as radiation, are delivered at cancer centres. Surgery is done in hospitals.

Treatment protocols are based on a person's age and overall condition, and the location and size of the tumour. Brain surgery, or a craniotomy, which encompasses the surgical removal of the tumour, is the main treatment for non-malignant tumours. Courses of radiation therapy may also be required. There are several types of radiation therapy including conventional radiation, radiosurgery, intensity modulated radiotherapy and brachytherapy. Drugs, such as corticosteroids, are also used to reduce edema (swelling) and help the brain heal.

Surgery

Surgery relieves brain tumour symptoms and establishes a definitive diagnosis that can guide your health care team's decisions about the need for additional treatment. If the tumour can be completely removed by surgery, often no other treatment is required. However, non-malignant tumours can occur in parts of the brain, such as the base of the skull, where complete removal by surgery may not be possible or is associated with high-risk complications.

Following complete removal by surgery, a patient is typically monitored with regular MRI or CT scans every 6 to 12 months to ensure the tumour doesn't re-appear. If the tumour was only partially removed, brain scans are used to monitor for tumour re-growth.

"After my surgery, my behaviour changed and many friends and some family members drifted away. They felt that since my tumour was non-malignant, there shouldn't be anything wrong with me."

Non-malignant brain tumour survivor

“Inoperable” Brain Tumour

Medical technology and surgical techniques have evolved over the past 50 years such that, from a purely technical viewpoint, any area of the brain is surgically accessible. However, that does not mean that surgery is the best treatment option for everyone. Some possible reasons why surgery may not be suitable are given below.

Surgery may not be safe

Many areas of the brain are important because they are involved in your ability to carry out everyday functions. These areas are sometimes referred to as “eloquent” areas of the brain. Examples are the brainstem (which controls consciousness, breathing, swallowing), parts of the temporal lobe (that control speech), and parts of the frontal lobe (that control movement).

Depending on the location of the tumour, your neurosurgeon may determine that surgery could cause irreparable neurological damage and therefore advise against it. For example, if a tumour is deep in the brain, surgery would mean going through large portions of the brain that do not involve the tumour and have intact neurological function. The neurosurgeon may determine that the risk of neurological damage posed by cutting through these normal areas of the brain is unacceptably high and therefore advise against surgery.

Surgery may not be the best treatment option for certain types of brain tumours

There are types of low-grade brain tumours that may be treated with radiation therapy or chemotherapy and do not require surgical removal. Occasionally, it is possible to identify these types of tumours with an MRI scan; sometimes a biopsy is required.

Radiation

In instances where a non-malignant tumour cannot be removed surgically or is only partially removed, radiation treatment may be recommended to stop the tumour from growing.

Stereotactic Radiosurgery

Stereotactic radiosurgery (SRS) is a non-invasive, specialized technique designed to deliver a large single dose of radiation to small areas within the brain. You may hear different names associated with radiosurgery, including Gamma Knife®, CyberKnife®, and linac-based systems like XKnife®, Synergy®, Trilogy® or Novalis®. These are the brand names of the equipment used by physicians. SRS includes the term “surgery” because it requires the use of a stereotactic head frame, which is physically attached to a patient’s head by a neurosurgeon.

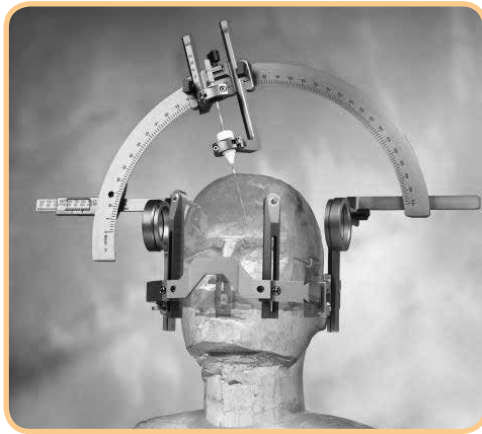


Photo courtesy of Elekta Canada Inc.

SRS is most appropriate for small, non-malignant brain tumours, generally no larger than 3-4 cms. It is not usually considered appropriate for tumours that involve many different areas of the brain, tumours that are close to certain structures like the eyes or optic nerves, or tumours that are spreading within normal brain tissue.

Gamma Knife®

The Gamma Knife is a specialized unit used for intra-cranial radiosurgery. It was developed to precisely deliver a single high dose of ionizing radiation to a target. The technology is based on using an invasive stereotactic head frame, however recent technology has been developed to allow for other “frameless” radiosurgery, and to deliver multiple fractions of radiation. Most patients return home the same day and resume full activities within one or two days.



Photo courtesy of Elekta Canada Inc.

CyberKnife®

The CyberKnife is a robotic radiosurgery system that delivers highly targeted beams of radiation to a tumour. This machine allows for both intra-cranial and extra-cranial body radiosurgery. With its integrated image-guidance solution, the patient does not need an invasive head frame to be applied and instead uses a more comfortable thermoplastic mask. Each treatment session may last between 30 and 90 minutes depending on the type of tumour treated. The CyberKnife was also designed to deliver treatments over several days (daily fractions) in an out-patient setting.

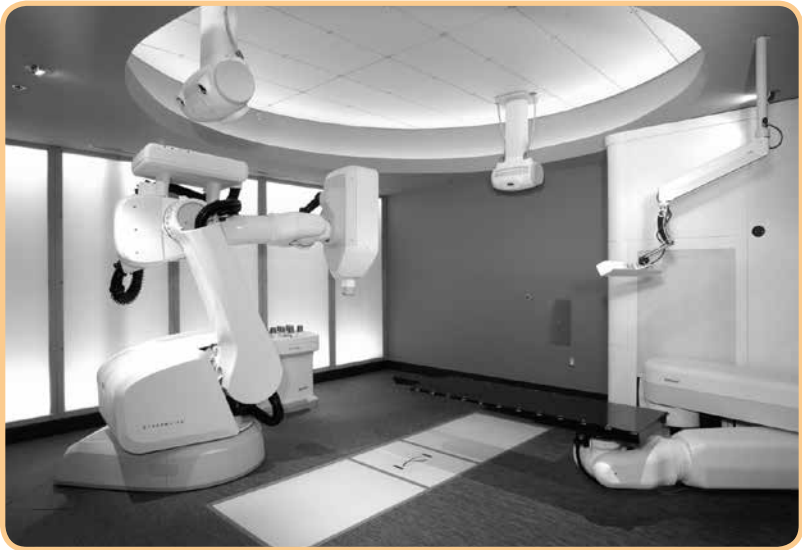


Photo courtesy of Accuray Inc.

Linac (XKnife®, Synergy®, Trilogy® and Novalis®)

Standard linear accelerators (shortened to “linac”) can also be equipped to deliver radiosurgery, and some have been developed as dedicated units for stereotactic delivery. The unit must be fitted with the appropriate equipment to ensure millimetre precision. Linac-based radiosurgery is the most frequently used form of radiosurgery.

Side effects associated with SRS can include tiredness, headaches, short-term memory loss and, infrequently, nausea, vomiting and seizures. Weeks to months after radiosurgery, swelling in the treated part of the brain may occur which can contribute to headaches, tiredness or new symptoms that may require medication. Radionecrosis is the most important late effect of radiosurgery and refers to damaged tumour or normal tissue that may cause brain swelling and require treatment with steroids, hyperbaric oxygen or surgery.

Stereotactic Radiotherapy (SRT)

SRT refers to linac-based technology that delivers multiple daily treatments over five to six weeks using stereotactic technology and principles. It is recommended for larger tumours or tumours located near critical structures such as the brainstem or optic nerves. SRT uses many of the same radiation technologies as SRS, but applied over multiple treatments. It is typically administered daily, five days a week, over the course of one to six weeks, depending on the tumour and its location. Importantly, patients are immobilized using either a plastic mask system or a mouth-bite based head frame. An invasive frame is not used for SRT.

Chemotherapy

Although chemotherapy is not typically used to treat non-malignant brain tumours, it can be administered to help control the growth of the tumour. Chemotherapy consists of chemicals designed to kill tumour cells, which are more vulnerable to the chemicals than healthy cells. Chemotherapy may be used before, during or after surgery and radiation therapy.

Some types of chemotherapy use drugs that help other drugs reach the tumour in greater concentration, and may involve the drugs spreading through your system via the bloodstream. This form of chemotherapy is called “systemic therapy.” Other methods focus on placing the drug within or around the tumour – this is called “local delivery.”

“At first my family was relieved when they found out that my brain tumour was non-malignant. But after watching me battle it for 10 years and seeing me go through so many surgeries, chemotherapy and radiation, they don’t think that way anymore. In the end, my non-malignant brain tumour wasn’t treated any differently than a malignant tumour and there were many times along the way that I could have died from a type of tumour many people think isn’t dangerous.”

*Brandon Dempsey, survivor of a pilocytic astrocytoma, diagnosed at the age of four
Moncton, NB*

Talking to Your Doctor or Health Care Provider



Talking to Your Doctor or Health Care Provider

The best source of information about your non-malignant brain tumour is your health care team, which typically includes a primary-care doctor, neurosurgeon, neurologist, radiologist and nurse. Your team could also include an occupational therapist, physiotherapist or social worker.

Many different professionals could be part of your health care team depending on where in Canada you are receiving treatment. Please visit our website at www.BrainTumour.ca for role descriptions of each team member.

Audiologist	Neuro-Psychologist
Chaplain	Neurosurgeon
Child Life Specialist	Nurse
Dietitian	Nurse Practitioner
Hospital Pharmacist	Occupational Therapist
Hospital Social Worker	Physiotherapist
Interlink Nurse	Radiation Oncologist
Neuro-Oncologist	Radiation Therapist
Neuro-Ophthalmologist	Speech Language Pathologist
Neuro-Pathologist	

Remember: Your health is important and you are the most important person on your health care team.

There are many ways to prepare for what to expect with a brain tumour diagnosis. A valuable and essential step is to ask questions: people who ask more questions get more information. Sometimes it is difficult if you feel rushed during a doctor's visit, however your concerns are valid and you have the right to have your questions answered.

The following are some suggestions to help you prepare for meetings with members of your health care team.

Before your visit:

- Write a list of your questions, current medications and symptoms. This will help ensure your concerns are addressed and can act as a checklist to help keep you better organized. If possible, bring two copies of your list with you to your visit – one for you and one for your health care provider.
- Ask a family member or friend to go with you. Their support can make a difference if you are faced with difficult topics and they may have questions that you had not previously considered.

During your visit:

- Tell your health care provider what you want to talk about and give them a copy of your list of medications, symptoms and questions.
- Discuss different ways to manage your diagnosis and treatment.
- Ask for brochures and materials about medication, treatment options and information on the type of non-malignant tumour with which you have been diagnosed.
- Make sure you understand the pros and cons associated with your treatment choices and take the time to fully understand your options.
- Write down information and instructions you are given before you leave the office so that you can review and ask any additional questions if needed.
- Find out how your health care provider gets you the results of any tests and how long this will take. It is important to know what to expect so you can follow up with your team as needed.
- It's okay to ask for explanations. There is no need to feel embarrassed if you have trouble understanding the information your health care team is providing.

After your visit:

- Call back. Do not hesitate to call your health care provider if:
 - You have further questions.
 - Your symptoms get worse.
 - You have problems with your medication.
 - Your provider's policy is to call you back with test results or to schedule an appointment to talk about them and you have not heard back in the time agreed upon.

Who to Tell and What to Share



Who to Tell and What to Share

While the non-malignant brain tumour journey is one you should not have to make alone, choosing who and what to tell is a personal decision. Many people who have made the journey point out that it's important to ask for and accept help.

The most common misconception about having a non-malignant brain tumour is that it "isn't serious." It is essential those with whom you choose to share your diagnosis understand that while your tumour is not cancerous, it does have a significant impact on your health and well-being.

Telling family and friends

Telling loved ones about your diagnosis is often difficult as you may be unsure about how much information to disclose or you may feel that you are burdening family or friends with the news.

It is important to have the people closest to you available for support during this time. Sharing information with loved ones helps remove some of the emotional weight and allows you to move past the initial shock of a diagnosis and on to thinking about treatment.

Be honest about the information that you have been given and don't be afraid to express your feelings.

Your family and friends will want to be there for you and offer their support. You may even ask them to help communicate your news with others. For example, have an email that can be shared rather than repeating the same information continually. Here are some other suggestions:

- Provide this non-malignant brain tumour handbook to your loved ones to give them an opportunity to learn more about your diagnosis, how you are feeling and possible next steps.
- Make it easy to have a private, quiet conversation. Turn off the TV and cell phones, close the door, and try to limit interruptions.

- Ease into the conversation by saying something like: “I think it would be good to tell you what’s going on. Is that okay?” or “I have something serious to talk to you about.”
- Provide small pieces of information, a few sentences at a time. Check regularly to make sure the person understands. You can ask: “Is this making sense?”
- Tell them that while you aim to be positive, inevitably there will be times when you will feel down and frustrated. Ask for your loved ones’ support and understanding during these times.
- Encourage those close to you to share their feelings with you. You are not the only one who will feel down – they will too, and that is common. They shouldn’t need to try and hide these feelings from you, but explain how they feel so you can keep honest and open communication with each other.

Talking to your children about your diagnosis

While telling your children about your diagnosis can be difficult, it is important to be open and honest. Children and teens are extremely perceptive and often sense that something is different or has changed. A child’s age and maturity should help determine how much information and detail to share. Discussing the diagnosis also allows your children to ask questions about brain tumours and express their feelings about the situation.

- It is important to tell your children about your diagnosis as soon as possible. Children can sense that something is wrong and it is better for them to hear the news from you than find out another way.
- Take your time and go step by step. Admit when you don’t know the answer to a question.
- Choose a good time to talk, when you are feeling calm.
- Consider what your child is capable of understanding. Very young children can only comprehend what’s going on at the moment. Be prepared to repeat the information, possibly many times. Keep checking that your child understands what is being said. Take cues from their questions, eye contact or body language.

- Try to have another adult present. That way, your children will know that there are other adults they can talk to who will support them. In a two-parent home, try to talk to children together. A single parent might ask a close relative or friend to be there. A doctor, nurse or social worker can also help with difficult discussions.
- Use words they will hear and understand, like: "I have a sickness (disease) called..."
- Be open and honest with your children. Do not be afraid to tell them about your feelings, as your honesty can help them express their feelings.
- Tell your children that you will keep them informed and up to date, and if anything changes, you will let them know. Encourage them to ask questions and talk about what they are feeling.
- Be aware that adolescents may have more difficulty coping with an illness than younger children because they may feel the need to stay close to home when they should be striving for independence from their parents.

Talking to your employer and co-workers

Whether or not to tell people at work about your diagnosis is an individual decision. There are advantages and disadvantages in sharing your diagnosis. Although you have the right to keep medical information private, it may be difficult to keep your situation hidden in the workplace, especially if you are gone for long periods or if your health or appearance changes.

If your diagnosis or treatment will interfere with your ability to perform your job, you will likely have to tell your managers and possibly people who work closely with you. They will need to know if:

- You need to take time off for appointments or illness.
- Your productivity will be affected.
- You need to change how you do your work.

If you are the employer, you may need to explain the situation to at least some, if not all employees – especially if the day-to-day running of the company or department will be affected.

If you don't know where to begin, or if you're concerned about how your employer will react, try starting with your human resources department or personnel manager. You can use their experience and support to guide you through the telling process.

Talking to a child about their diagnosis

It is important to be open and honest with your child because children who are not told about their diagnosis often imagine things that are not true. For example, a child may think he or she has a tumour as punishment for doing something wrong. Telling children the truth about their illness leads to less stress and guilt for everyone concerned. Your child has likely gone through many tests by now and understands that something is wrong. His / her level of understanding is often underestimated.

Discussing the diagnosis openly allows your child to ask questions about what is happening and express feelings he / she may want to share. Children who know the truth are also more likely to cooperate with treatment. Talking about the disease often helps bring a family closer and can make coping easier for everyone.

Children are naturally curious about their disease and have many questions about brain tumours and treatment. Your child may expect you to have answers to most questions. Children can begin to ask questions right after diagnosis or may wait until later. Some common questions include:

- Why me?
- Will I get better?
- What will happen to me?

If it is too difficult to address some of these questions, members of your child's health care team will have support staff (for example: a physician, social worker, psychologist or child life specialist) available to help with the words or to talk directly to your child about their non-malignant brain tumour. This is a great way to help your child understand their diagnosis, as well as allow them to ask any questions they might have.

Talking to your child's school

When a child is diagnosed with a brain tumour, it ultimately affects activities of daily living including attendance at school. Open communication with your child's school is essential from the beginning. Shortly after diagnosis, it is important to contact your child's teacher and principal to inform them about what is happening and the expected attendance of your child in the coming days. Your child's teacher can send home lesson plans and homework to try to keep your child up to date on what is happening in the classroom while away.

Classmates can be educated about non-malignant brain tumours by the teacher or the school's social worker in an age-appropriate way, to inform them of your child's absence. Brain Tumour Foundation of Canada provides a free children's storybook called "A Friend in Hope" that you can offer to your child's teacher to read to the class to help promote understanding and support from classmates.

*To request a copy of "A Friend in Hope," please call 1-800-265-5106 or visit **www.BrainTumour.ca/help**.*

Brain Fitness

10

Brain Fitness

Physical fitness comes in countless forms, from aerobics to jogging, swimming and more. It is important to remember fitness for your brain, too, especially as someone with a non-malignant brain tumour.

There are many exercises you can do to engage your brain on a daily basis. Research shows that the brain is continuously changing and improving itself. This ability for constant physical, chemical and functional brain change is known as “brain plasticity” or “neuroplasticity.”

In people’s day-to-day lives, memory is one of the key functions most often relied upon. However, the ability to remember may change after undergoing brain tumour treatment. Brain fitness may help build your memory skills and concentration, enhance your ability to organize information or help you compensate for memory impairments in your daily life.

Whether you have difficulties with concentration and recall due to a non-malignant brain tumour, or experience the effects of “chemo brain,” the mental cloudiness some people describe during chemotherapy, there are brain fitness tips that can help you cope with memory or cognitive changes:

- Exercise your brain: Try crossword puzzles, number games, brain teasers, visual illusions, take up a new hobby or master a new skill.
- Stay organized: Use calendars or planners to keep on track, make lists or use a chalkboard or whiteboard in your kitchen to help develop a system of reminders.
- “Neurobics”: Use your brain in non-routine ways. For example, if you are right handed, try brushing your teeth with your left hand every morning.
- Understand what influences your memory issues: Schedule difficult tasks when you feel your best.

- Use stress-relief techniques: Visualizations, meditation, yoga or Pilates.
- Food for thought: Brains work best when you eat well-balanced meals.
- Use humour to have a good laugh: Read a new joke or watch a funny TV show or movie.

For more tips, information and resources on Brain Fitness, visit www.BrainTumour.ca/help.

"About three weeks after an operation for my meningioma, I was told by a peer 'People who have had a brain tumour will never be right in the head again' and with my witty and funny attitude, my reply was 'I was never right in the head to begin with so it will not make a difference!' This comment bothered me for a long time and so it made me work that much harder on my memory skills and I utilized Post-it notes. Needless to say, I am well over that statement now!"

***Marianna Hope**, survivor of a meningioma,
diagnosed at the age of 55
New Glasgow, NS*

Appendix



Appendix A: Non-Malignant & Low-Grade Brain Tumour Types

The following is a list of non-malignant brain tumours. Some occur primarily in children and others more commonly affect adults. For more information on brain tumour types, please visit www.BrainTumour.ca/BrainTumourTypes.

Acoustic neuroma (also known as a schwannoma)

An acoustic neuroma, also known as a schwannoma, vestibular schwannoma or neurilemmoma, affects the nerves responsible for hearing and balance. This type of non-malignant tumour manifests itself from the sheath surrounding the eighth cranial nerve and can affect the functions of the inner ear. Because many of the symptoms are also indicative of other, less serious ailments, acoustic neuromas are often misdiagnosed or remain undetected.

WHO Tumour Grading System: Grade I

Signs & Symptoms:

- Dizziness or vertigo
- Hearing loss in one ear
- Lack of coordination
- Tingling or numbness in the face
- Tinnitus (ringing in the ear)
- Walking and balance problems

Treatment: There are three treatment options available to a patient. These options are:

- Observation (monitoring)
- Microsurgical removal (partial or total)
- Stereotactic radiosurgery (single fraction) or radiotherapy (multiple daily fractions delivered using stereotactic techniques)

Choroid Plexus Papilloma

This tumour affects the choroid plexus tissue (the tissue responsible for the production of cerebrospinal fluid or CSF) and develops as a mass that blocks cerebrospinal fluid flow. It usually presents in children and adolescents.

WHO Tumour Grading System: Grade I

Signs & Symptoms:

- Headache
- Hemianopsia or hemianopia (Visual field loss that respects the vertical midline and usually affects both eyes but can involve just one eye)
- Hydrocephalus
- Morning nausea and vomiting

Treatment:

- Complete tumour removal is often curative, eliminating the need for additional treatments.
- A shunt may be needed to treat hydrocephalus caused by blockage of the ventricles.

Craniopharyngioma

A tumour that usually develops near the pituitary gland (a small endocrine gland at the base of the brain). Craniopharyngiomas are intracranial tumours that are typically both cystic and solid in structure. They usually occur in childhood, adolescence and in adults over the age of 50.

Craniopharyngiomas are often not discovered until they press on important surrounding structures. These tumours are closely related to another cystic mass occasionally seen in the pituitary, called Rathke's cleft cyst.

WHO Tumour Grading System: Grade I

Signs & Symptoms:

- Delayed development in children
- Headaches
- Visual changes
- Weight gain

Treatment:

- Surgery is the most common treatment.
- Radiation therapy is often used following surgery or if there is a recurrence of the tumour.
- Complete removal of this tumour is possible if it is in a favourable location.

Ependymoma

These tumours arise from the cells lining the ventricles (hollow channels) of the brain (most commonly the fourth ventricle). As these tumours grow and fill the ventricle, they obstruct the flow of cerebrospinal fluid (CSF) through the brain. These tumours are more common among younger children.

WHO Tumour Grading System: Can manifest as Grade I (mossopillary ependymoma), Grade II (ependymoma) or as a Grade III (anaplastic ependymoma)

Signs & Symptoms:

- Difficulty walking
- Fatigue and sleepiness
- Hydrocephalus
- Morning nausea and vomiting
- Neck pain or stiffness
- Problems with coordination
- Severe headaches
- Visual changes

Treatment:

- Surgery followed by radiation therapy is the usual course of treatment.
- A shunt may be needed to treat hydrocephalus caused by blockage of the ventricles.

Hemangioblastoma

Hemangioblastomas are typically made up of stromal cells which are connective tissue cells that support certain organ functions. They usually occur in the cerebellum, brainstem or spinal cord. Hemangioblastomas may be associated with other diseases such as polycythemia (increased blood cell count), pancreatic cysts and von hippel-lindau syndrome (VHL syndrome). Hemangioblastomas typically occur in adults, with symptoms appearing from age 30 into the 50s.

WHO Tumour Grading System: Grade I

Signs & Symptoms:

- Difficulty with balance
- Dizziness / vertigo
- Headaches
- Morning nausea and vomiting

Treatment:

- Radiation therapy may be useful to reduce tumour size or to delay growth.

Meningioma

These tumours grow from the meninges, the layers of tissue covering the brain and spinal cord. There are three layers of tissue; the dura mater, the arachnoid and the pia mater. Meningiomas grow out of the middle layer called the arachnoid. As they grow, meningiomas can compress nearby brain tissue, cranial nerves and blood vessels. Meningiomas are most common in the middle-aged and the elderly, although these tumours can also occur in children.

Meningiomas are graded from low (Grade I) to high (Grade III); the lower the grade, the lower the risk of recurrence and aggressive growth.

WHO Tumour Grading System: Grade I, II or III

Signs & Symptoms:

- Behavioural and cognitive changes
- Headaches

- Morning nausea and vomiting
- Seizures
- Vision changes
- Occasionally no symptoms occur and the tumour is detected incidentally

Treatment:

- If there are neither symptoms nor the appearance of a classic meningioma, the doctor may monitor the tumour using MRI.
- Surgery is the standard treatment.
- If the tumour cannot be completely removed, if it recurs or if it is high grade, radiation therapy may be given as well.

Pilocytic Astrocytoma

These tumours arise predominantly in the cerebellum of children and young adults. Many pilocytic astrocytomas are cystic in nature, which means they have a fluid-filled cyst component to the tumour.

WHO Tumour Grading System: Grade I

Signs & Symptoms:

- Headache
- Hydrocephalus
- Problems with balance and coordination
- Vomiting

Treatment:

- Surgery is the standard treatment.
- If the tumour cannot be completely removed, radiation may be given.
- Radiation may be given initially for inoperable tumours or in cases where tumour progression would be harmful. Otherwise, radiation is typically given as a salvage therapy should tumour progression occur after surgery.
- Chemotherapy may be given to very young children instead of radiation therapy to avoid damage to the developing brain.
- Some of these tumours can progress to a higher grade. Follow-up after treatment is very important.

Pituitary Adenomas

These tumours occur in the pituitary gland, which secretes several crucial hormones including corticotrophin, thyroid stimulating hormone, growth hormone, prolactin, gonadotropins and anti-diuretic hormone. While certain pituitary tumours secrete abnormally high amounts of one or more of these hormones and cause related symptoms, others are hormonally inactive and do not secrete hormones. Both types of tumours can grow and compress the surrounding tissue, such as the brain and optical nerves.

WHO Tumour Grading System: Grade I or II

Signs & Symptoms:

- Abnormal growth of hands and feet
- Abnormal hair growth pattern in women
- Abnormal weight gain
- Behavioural and cognitive changes
- Cessation of menstrual periods (amenorrhea)
- Depression
- Headache
- Impotence in men
- Morning nausea or vomiting
- Vision loss

Treatment:

- For the great majority of patients with symptomatic endocrine-inactive adenomas, surgery is the preferred therapy (trans-sphenoidal surgery is preferred to minimize the morbidity associated with an open craniotomy when possible).
- For recurrent pituitary endocrine-inactive adenomas, radiation may be used as either radiosurgery (single fraction) or fractionated daily radiotherapy (using stereotactic techniques), or when significant residual tumour is observed where critical structures are compromised and further surgery is not indicated.
- For hormone-secreting pituitary adenomas, surgery may be curative (steroid-producing adenomas), or endocrine therapy alone may be sufficient (prolactinomas). Radiation may be required in tumours resistant to surgical and medical management (given as either radiosurgery or fractionated daily radiotherapy).

“After being diagnosed with a Grade II ependymoma, I was often asked by friends and family if the tumour was malignant or non-malignant – a not very straightforward question to answer, as it turns out.

‘If the tumour is non-malignant, do you have cancer? You won’t need radiation or chemotherapy than, right?’ Because the association between non-malignant meaning ‘good’ and malignant meaning ‘bad’ has been so dominant, the assumption is made for brain tumours as well. But of course a so-called ‘non-malignant’ tumour in the brain can be anything but benign!

A change in terminology is needed to match our increased understanding of cancer in general, and the development and treatment of brain tumours specifically. The original Brain Tumour Foundation of Canada Brain Tumour Handbook was a great asset to me throughout my treatment, and this new non-malignant resource will go a step further to help clarify some of the myths and confusion surrounding ‘benign’ brain tumours.”

*Jennifer Brewé, survivor of an ependymoma,
diagnosed at the age of 19
London, ON*

Appendix B: Symptom Tracking Sheet

If you notice any changes with your health and symptoms, use this Symptom Tracking Sheet to document and bring to the next appointment with your health care team.

What in your body feels bad or what in your body seems different? _____

When did it start? _____

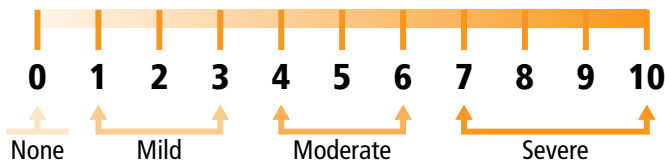
What time of day does it happen? _____

How long does it last? _____

How often does it happen? _____

If you have pain, describe it. Is it sharp, dull, shooting, aching? _____

On a scale of one to ten, how would you rate your pain?



Is there anything that makes you feel worse or better? _____

Is there anything you cannot do because of how you feel? _____

Appendix C: Information About My Brain Tumour

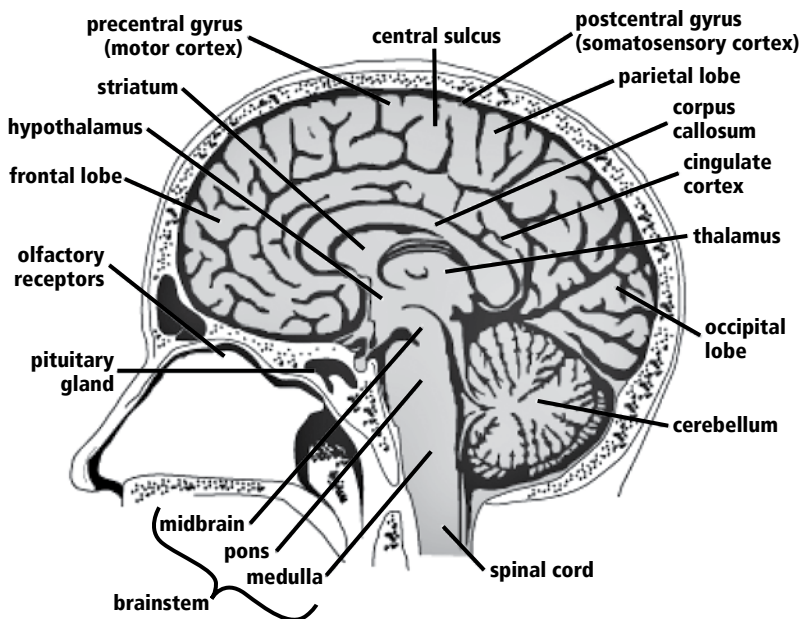
The type of tumour I've been diagnosed with is: _____

My doctor's name is: _____

My nurse's name is: _____

Name of other health care providers on my team: _____

Where is my brain tumour?



Appendix D: Questions to Ask the Doctor

Having open communication with your medical team is important in making informed decisions about your health care. However, it is not uncommon to feel nervous or only hear part of what is said at a doctor's appointment or hear information differently from someone else. It can also be a challenge to get answers to all your questions at one doctor's appointment. Consequently, it is a good idea to take a family member or friend with you to your medical appointments so they can take notes.

Knowing what to ask is also important, and the following suggested questions are meant for you and your family to think about and discuss with various members of your medical team. You are also encouraged to ask additional questions that are important to you:

What type of brain tumour do I have? What is its most common name?

What is the tumour grade? What does this mean? _____

Can you explain the pathology report (laboratory test results) to me?

What treatment plan do you recommend? Why? How long will the treatment take to complete? _____

How will the recommended treatment affect my prognosis? _____

What is the goal of my treatment plan? _____

What are the expected benefits of this treatment? _____

What are the expected risks of this treatment? _____

What are the possible side effects of each treatment, both in the short and long-term? _____

What quality of life can I expect during and after this treatment?

What are the chances that the tumour will recur? If it does, will there be other treatment options available to me? _____

How often will I get an MRI? _____

What clinical trials are available? _____

Who will be coordinating my overall treatment and follow-up care?

What support services are available to me and my family? _____

Do you know of a local support group for people affected by brain tumours? _____

If I'm concerned about managing finances related to my treatment (e.g., travel or lodging costs), who can help me?

Who answers medical questions at your office if you are unavailable?

What are your thoughts about complementary and alternative medicine (CAM)? _____

Can I continue to take over-the-counter medications and supplements?

Would you recommend a second opinion? _____

Additional Notes:

Handwriting practice lines consisting of 24 horizontal lines.

Appendix E: Glossary

Abnormal Cells

Cells that do not look or act like the healthy cells of the body.

Amenorrhea

Absence or suppression of normal menstrual flow.

Antidiuretic Hormone

Controls the ability of the kidney to concentrate urine and assist in the maintenance of the fluid and electrolyte balance in the body.

Arachnoid

The middle of three layers of meninges, the membranes covering the brain and spinal cord. It forms the outer border of the subarachnoid space.

Benign (Non-Malignant)

A slow growing, non-malignant tumour that does not spread to other parts of the body. If completely removed, benign lesions do not tend to recur. Incompletely removed tumours may recur but will not spread.

Blood Vessels

A tubular structure carrying blood through the tissues and organs; a vein, artery or capillary.

Brainstem

Located at the bottom of the brain and connects the cerebrum to the spinal cord. The brainstem controls many vitally important functions including motor and sensory pathways, cardiac and respiratory functions, and reflexes.

Calcification

The deposit of calcium associated with certain types of tumours, such as meningiomas, astrocytomas, oligodendrogliomas.

Central Sulcus

The central sulcus is the large deep groove or indentation that separates the parietal and frontal lobes of the brain.

Cerebellum

Located at the lower back of the head and is connected to the brainstem. It is the second largest structure of the brain and is made up of two hemispheres. The cerebellum controls complex motor functions such as walking, balance, posture and general motor coordination.

Cerebral Hemispheres

Either of the two symmetrical halves of the cerebellum, as divided by the longitudinal cerebral fissure.

Cerebrospinal Fluid (CSF)

A clear substance that circulates through the brain and spinal cord. It provides nutrients and serves to cushion the brain and therefore protect it from injury. As this fluid gets absorbed, more is produced from the choroid plexus, a structure located in the ventricles. A brain tumour can cause a build-up or blockage of CSF.

Choroid Plexus

Areas in the ventricles where cerebrospinal fluid is formed.

Cingulate Cortex

A bundle of nerve fibres in white matter located over the surface of the corpus callosum.

Corpus Callosum

The two sides of the brain are joined by the corpus callosum. The corpus callosum connects the two halves of the brain and delivers messages from one half of the brain to the other.

Cranial Nerves

The 12 pairs of cranial nerves control functions such as taste, hearing, sensation in the face, smell and swallowing.

Cyst

A fluid-filled sac, similar to a balloon filled with water. Cysts occurring in the brain include the arachnoid cyst, colloid cyst, dermoid cyst and epidermoid cyst.

Dura Mater

The outer membrane covering the brain.

Endocrine Therapy

Treatment by removing, blocking or adding hormones. Also called Hormone Therapy.

Endocrine-Inactive Adenoma

These tumours do not result in excess hormone production. Instead they typically cause symptoms due to pressure on the normal pituitary gland and/or on structures near the pituitary such as the optic nerves and optic chiasm.

Fractionated

Dividing the total dose of radiation to be given into several smaller, equal portions delivered over a period of days or weeks. Each portion is called a fraction.

Frontal Lobe

One of the four lobes of the cerebral hemisphere. It controls: attention; behaviour; abstract thinking; problem solving; creative thought; emotion; intellect; initiative; judgement; coordinated movements; muscle movements; smell; physical reactions; and personality.

Gonadotropins

Hormone secreted by the anterior pituitary gland and placenta; stimulates the gonads and controls reproductive activity in men and women.

Growth Hormone

Stimulates physical growth; produced by the pituitary gland. If deficient, can be provided by replacement therapy. Also called somatotropin.

Gyrus

An interior convoluted folding or ridge of the surface of the cerebral cortex. The precentral gyrus is a fold of the frontal lobe and the postcentral gyrus is a fold of the parietal lobe.

Hemianopsia or Hemianopia

Loss of one-half of the field of vision (the area that can be seen by each eye when staring straight ahead).

Hydrocephalus

Often referred to as "water on the brain."

Hypothalamus

A region of the brain in partnership with the pituitary gland that controls the hormonal processes of the body as well as temperature, mood, hunger and thirst.

Intracranial

To mean "within the skull."

Lesion

A general term that refers to any change in tissue such as a tumour, blood, malformation, infection or scar tissue.

Longitudinal cerebral fissure

The deep groove that separates the two hemispheres of the brain.

Malignant

A tumour that tends to grow quickly and spread causing harm to surrounding and / or distant tissue. Another word for cancerous.

Medulla Oblongata

The part of the brainstem that directly connects with the spinal cord.

Meninges

Meninges are three layers of tissue that cover the brain and protect the spinal cord. From the outermost layer inward they are: the dura mater, arachnoid and pia mater. A meningioma tumour arises from the meninges.

Microsurgery

The use of a high-powered microscope during surgery. Microsurgery is widely used for brain tumour surgery.

Midbrain

The portion of the brain between the pons and the cerebral hemispheres.

Morbidity

The incidence of disease or the rate of sickness (as in a specified community or group).

Neoplasm

This is another term for tumour or lesion.

Occipital Lobe

One of the four lobes of the cerebral hemisphere. It is located in the back of the head and controls vision.

Olfactory Receptors

Responsible for the detection of odour.

Parietal Lobe

One of the four lobes of the cerebral hemisphere. It controls tactile sensation, response to internal stimuli, sensory comprehension, plus some language, reading and visual functions.

Pathology

The scientific study of the nature of disease and its causes, processes, development, and consequences.

Pia Mater

The innermost layer of the meninges; the thin membrane covering and in direct contact with the brain and spinal cord.

Pituitary Gland

A small, bean-sized organ that is located at the base of the brain and is connected to the hypothalamus by a stalk. The pituitary gland controls the function of many other glands.

Pons

A bridge of nerve fibres forming part of the brainstem. It has some control over sleep, as well as relaying information between the cerebrum and the cerebellum areas of the brain.

Prolactin

A hormone released from the anterior pituitary gland that stimulates milk production after childbirth.

Prolactinoma

A non-malignant tumour (adenoma) of the pituitary gland that produces a hormone called prolactin. It is the most common type of pituitary tumour. Symptoms of prolactinoma are caused by too much prolactin in the blood (hyperprolactinemia) or by pressure of the tumour on surrounding tissues.

Rathke's Cleft Cyst

A non-malignant growth found on the pituitary gland in the brain, specifically a fluid-filled cyst in the posterior portion of the anterior pituitary gland. It occurs when the Rathke's pouch doesn't properly develop.

Resection

Surgical removal of a tumour.

Residual Tumour

The tumour remaining after surgery or treatment.

Shunt

A surgically-implanted tube that is used to relieve increased intracranial pressure.

Spinal Cord

A bundle of nerve fibres that extends down from the brainstem and continues to the hollow centre of the spinal column. The spinal cord is the first relay station for sensory information on its way to consciousness in various centres of the brain.

Striatum

A subcortical (i.e., inside, rather than on the outside) part of the forebrain.

Stromal Cells

Connective tissue cells of an organ found in the loose connective tissue.

Thalamus

Located near the centre of the brain and controls input and output to and from the brain, as well as the sensation of pain and attention.

Thyroid Stimulating Hormone

A pituitary hormone that stimulates the thyroid, leading to increases in metabolism and heart rate.

Trans-sphenoidal Surgery

Performed to remove tumours from the pituitary gland, sellar region, and sphenoid sinus of the skull. The surgeon approaches the pituitary through the nose. The surgery can be performed with a microscope or more commonly with an endoscope; this is a minimally invasive technique.

Tumour

An abnormal growth that can be non-malignant or malignant.

Ventricles

The four cavities of the brain that contain the choroid plexus, which produces cerebrospinal fluid.

Vertigo

Dizziness; a common symptom of tumours of the acoustic nerve.

Von Hippel-Lindau Syndrome (VHL)

A rare inherited disorder in which blood vessels grow abnormally in the eyes, brain, spinal cord, adrenal glands and other parts of the body. Those with the syndrome are at a higher risk for developing some types of cancers.



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