braintumour foundation OF CANADA

6th Edition

Adult Brain Tumour

Handbook

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 journey with a brain tumour.
- Critical support through one-on-one, pediatric and group support services.
- Research funding to identify 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 tumours are complex. They can affect vision, hearing, memory, behaviours, mobility and more. The effects are physical, emotional, financial, and can last a lifetime. There is no cure.

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

Be a partner in progress and help change the future of brain tumour patient care and research.

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 Resource Is for You

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

This resource aims to provide comprehensive and easy-to-read information about the disease, including brain tumour types, treatment options and what to expect after a diagnosis. The information in this booklet addresses some of the questions and concerns you may have about being diagnosed with a brain tumour, and helps raise awareness about this disease, providing education for family members, friends and health care professionals.

The Adult 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

An estimated 55,000 Canadians currently live with a brain tumour and an additional 10,000 are diagnosed each year. That's 27 new diagnoses per day: more than one person every hour.

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 the 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, staff, patients, survivors, family members and health care professionals determined to make your journey with a brain tumour one full of hope and support. We work collaboratively to serve the needs of all Canadians affected by every type of brain tumour.

If you have been affected by a brain tumour, we are here to help.

Services and Programs

- One-on-one and group support is available to anyone 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 Brain Tumour 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 treatment and quality of life for people affected by a brain tumour.
- Brain Tumour Foundation of Canada funds critical research into the cause of and cure for brain tumours. To date, the organization has funded more than 100 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

The first Adult Brain Tumour Patient Handbook was published in 1988 and in years following the Pediatric version was created to address the specific needs of families with a child diagnosed with a brain tumour. Since then, both publications have become a mainstay of brain tumour information for patients, families, caregivers, and health care professionals alike. We would like to acknowledge all of the incredible work put into the original handbooks and every subsequent edition, as it is with the expertise, insight and consideration of each volunteer writer that these publications are possible. A special thank you to Pam Del Maestro, one of Brain Tumour Foundation of Canada's co-founders and a retired neuroscience nurse, as it was her vision for the handbooks that has allowed them to reach thousands of individuals and help bring hope to anyone affected by this disease.

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- Sunnybrook Health Sciences Centre, Toronto, ON
- The Ottawa Hospital – Civic Campus, Ottawa, ON

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Dr. Joseph Megyesi is currently an associate professor in the Division of Neurosurgery at Western University, and the London Health Sciences Centre – University Hospital. He is a member of the Professional Development Committee of the Canadian Neurological Sciences Federation and was chairman of the organizing committee for The 14th Biennial Canadian Neuro-oncology Meeting. Dr. Megyesi is very involved with Brain Tumour Foundation of Canada. He is the current chair of the Board of Directors, has been instrumental in the formation of Brain Tumour Foundation of Canada's Professional Advisory Group, and has been a speaker at various Brain Tumour Information Day Conferences and Health Care Professionals' Workshops. Dr. Megyesi is also a member of the organization's Research Committee and Information, Support and Education Committee.

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Jamie and Crystal Fairles of London, ON are both brain tumour survivors and volunteered their time to offer insight from a patient's point-of-view. Recently married and expecting a new addition to their family, Jaime and Crystal give of their time to local brain injury mentorship programs and groups, helping those impacted by the after-effects of a brain tumour or neurological injury.

Karen Evjen of Saskatoon, SK provided feedback on the sixth edition handbook from a spouse's perspective. Karen's husband, Gary, was diagnosed with an anaplastic mixed oligoastrocytoma Grade III tumour in 2006. The Evjens have turned this life-changing diagnosis into a positive opportunity by volunteering their time to benefit others affected by the disease. The Evjens are the current convenors for the Saskatoon Brain Tumour Support Group.

For the purpose of this handbook, masculine and feminine pronouns are inter-changed from chapter to chapter to provide a balanced viewpoint to the reader.

For more information or to receive a free copy of this handbook, please contact us:

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

You Are Not Alone

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You Are Not Alone

You have just been given the diagnosis of a brain tumour. The doctor's words have been flashing through your mind. How can this be? What will I do now? How will I cope? Many questions will arise after this diagnosis.

The Adult Brain Tumour Handbook was created for you, your loved ones and family members, and caregivers of people who have been affected by a brain tumour. On the following pages you will find a wealth of information that we hope will help you through this difficult time. This handbook is designed to help you learn more about brain tumours, the associated treatment options, and many of the services available to to help you through this difficult time.

This brain icon will appear throughout this handbook to remind you to refer to the ***Glossary of Terms*** *on* ***Page 267*** *for more definitions.*

In the days, weeks and months ahead you will meet many health care providers. You will also become an active member in your health care team. This team is made up of neurosurgeons, neuro-oncologists, neuro-ophthalmologists, optometrists, nurses, social workers, pharmacists, dietitians and neuropsychologists, to name a few. You will meet medical professionals in fields that may be new to you.

There are many ways that you can be active in your care. Keeping the lines of communication open with your health care team is essential. Do not be afraid to ask questions and write down the answers. It is often easy to forget specific instructions when trying to understand everything that is happening. Having answers and instructions written down will often help.

Keep a journal on your day-to-day care. In diary form, you may want to track your progress and write down any concerns that come up. This will be a valuable tool you can use to report any important information back to your health care team, including symptoms and any side effects from treatments or medications.

Please refer to the Appendices for many great resources and tools to help you through this process.

Keeping a journal is also an effective way to keep track of appointments, medications and dosages, phone numbers and emergency contacts, as well as any questions you may have.

It is important to remember that you must be your own advocate. As it can be a challenging responsibility, you may want to enlist the help of relatives or friends who will encourage and support you through this process.

The Adult Brain Tumour Handbook will assist you in the weeks, months and years ahead, as you and your loved ones live with the brain tumour diagnosis. While it does not provide all the answers, our hope is that with this resource as a guide, you will be able to learn more about your diagnosis, and know where and how to ask for help.

It may be beneficial to talk with other people who have been diagnosed with a brain tumour. There is great comfort in knowing you are not alone. There are also a great deal of hope out there, as many people with brain tumours are living very normal lives.

To learn more about making contacts and the programs that are available to you and your family, contact Brain Tumour Foundation of Canada at 1-800-265-5106 or visit our website at www.BrainTumour.ca. We are here to provide you with information and support throughout your journey.

Reacting to a Diagnosis

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Reacting to a Diagnosis

You've just been diagnosed with a brain tumour and you are trying to comprehend what this means. You are probably asking yourself how this could have happened. Why me? Why now? The shock of this diagnosis is difficult and overwhelming. This chapter will discuss the issues that you will need to address including asking the right questions, telling loved ones, advocating for yourself and finding the right support to help you through this journey.

As you begin to comprehend this illness and its implications in your life, and the life of your family, you will likely experience many thoughts and questions rushing through your mind. It is normal to experience many different feelings and emotions as you go through the process of understanding your diagnosis. You may or may not have developed symptoms that indicated something was wrong. Perhaps symptoms such as headaches, dizziness and visual problems, appeared and worsened over time and led to the diagnosis. Or maybe you were feeling perfectly fine, but suddenly experienced a seizure that led to a quick and unexpected diagnosis.

Many people diagnosed with a brain tumour, and their loved ones, go through a grieving period after they learn about the tumour. Feelings of denial, anger, sadness, fear, and depression may occur. It is not uncommon to experience several, if not all of these emotions as this diagnosis often changes the life, and they once knew.

Absorbing all of the information that has been given to you can be incredibly difficult as the terminology is new and the amount of material is often overwhelming. After having time to digest this diagnosis, you and your loved ones may want to learn more about the tumour and what can be done. Becoming informed can provide a sense of empowerment for some individuals. For others it may be frightening. There is not one correct way of approaching your diagnosis and the treatments that will follow.

Finding your personal comfort level with the amount of information you need is important. Some people want to know a lot about their diagnosis and treatments, while others do not. Having loved ones prepared to take

on the role of gathering information and doing research can remove the fear and burden associated with the overwhelming amount of information. They can then filter the necessary information to you.

Knowing where you can go for support and who you can talk to can also help. As you discover more about your diagnosis, you will learn more about the resources that are available to you. As you begin coping with the changes in your life, there are people who you can turn to that can help you with these transitions. Learning about your disease and the associated implications is a process that takes time.

Brain Tumour Foundation of Canada is available to talk to you and your family about finding support services in your community that could be of assistance. The social work department at your hospital or cancer centre can also be an invaluable resource as they are familiar with the services available in your local community.

Asking Questions

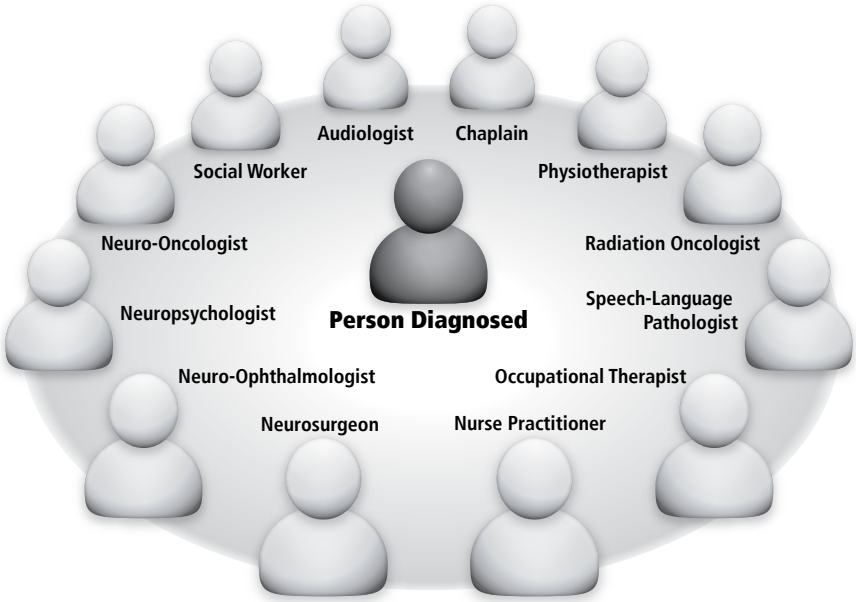
A direct result of learning more about your tumour is that this enables you to ask better, more informed questions and find the answers that you need to guide you through this journey.

Sometimes, you may feel that your doctor is rushed during your appointment; however your concerns are important. Your health care professionals are knowledgeable about the many aspects of a brain tumour diagnosis and can be a valuable source of information about diagnosis, treatment, nutrition, therapy, medications, etc. In order to make the best use of your time with members of your health care team, make sure you are organized for your appointments, as this will ensure that you get the information you need in an efficient way.

Make your questions specific and ask the most important ones first. Write down the answers so you have them for future reference. It is always a good idea to bring a family member or friend to every appointment so they can ask questions on your behalf and remember important information as well.

Write down questions as they come up beforehand, and bring them with you to appointments.

Different members of your health care team can provide support with various aspects of your diagnosis. For example, your pharmacist can answer many of your questions about medications, your social worker can answer questions about the resources and community services available to you, such as driving resources, disability benefits etc., and your nurse can answer questions about symptom management. Your health care team is there for you; make use of their knowledge as best you can.



*Turn to the **Your Health Care Team** section on **Page 183** for more information about your medical team.*

Understanding who will help you with aspects of your care and what support you will have can give you peace of mind. How will you travel to your appointments? How much time will you need to take off of work? Can you return to work? Will you have deficits from the tumour and how can you best accommodate them? Many questions will arise as you go through the process of diagnosis, treatment and recovery. By discussing your questions and concerns with your loved ones, you can prepare for any potential issues before they arise, and possibly avoid them altogether.

Getting a Second Opinion

You will be required to make some very important long and short-term decisions about your medical treatment plan, so it is important that you feel comfortable with those decisions. Consequently, you may want to seek a second opinion, and many people often do.

If you are worried about offending your doctor by requesting a second opinion, it is important to know that doctors understand and recognize the need to feel comfortable with the decisions you are being asked to make. They can arrange for a referral to another physician for a second opinion. Your needs are of primary importance, not whether your physician feels offended. An open discussion with your doctor can usually help to clarify any possible issues. If you do want a second opinion, you must verbalize this request. The doctor will not assume you want a second opinion if you don't ask for one. In the event you do go for a second opinion, make sure your health care team provides the second physician with all the necessary information and paperwork, as this will reduce any risk of confusion.

If the second opinion varies significantly from the first, you may be confused about which treatment plan to follow. In that situation, ensure you thoroughly understand each treatment plan and have the doctors explain the potential outcomes and risks of each treatment.

If you do go for a second opinion, it is a good idea to bring a family member or friend to your appointments: having another person present can often help you clarify what was discussed in the appointments. It is normal not to hear or remember everything that the doctors say when you are dealing with the stress of a diagnosis.

Telling Your Family and Friends

Informing your loved ones about your diagnosis may be difficult. You might 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.

> *Ask a friend to take the lead on organizing a meal schedule. For more information on* ***Nutrition*** *please visit* ***www.BrainTumour.ca/nutrition****.*

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, set up an email that can be shared rather than repeating the information continually. Here are some other suggestions:

- Provide this Adult 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 that will feel down – they will too, and this is common. They shouldn't need to try and hide these feelings from you; rather they should feel free to explain how they feel so you can keep honest and open communication with each other.

Talking to Your Children

Telling your children about your diagnosis can be difficult, but it is important to be open and honest with them. 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 with your children allows them to ask questions about brain tumours and express their feelings about the situation.

> *For more information or resources of how to talk to your children about your diagnosis, please visit* ***www.BrainTumour.ca/ForParents****.*

- 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 is 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.
- 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 your children 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 how they feel.

- 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.

Talking to Your Employer and Co-Workers

Whether or not to tell your co-workers 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 this process.

Advocating for Yourself

Always remember that while your health care team is dedicated to ensuring you receive the best possible care, you and your family are your best advocates. No one knows better than you how you feel, what your needs

are, what questions you have, and what information you need. It is always important to actively communicate with your team, and speak up about your questions and concerns.

It is important to develop a strong partnership with your health care professionals and play an active role in your care. It is also important that you discuss your treatment plan with your health care team and take part in the decision-making process. Educating yourself about your diagnosis and the possible treatments enables you to ask more informed questions of your health care team. If you are unable or uncomfortable with this, have a family member or friend take on this role for you. Caregivers and family members can help advocate for your care as well, and be active in the information and education process. They can be there at appointments to help absorb the information given, to actively speak up on your behalf, and pose questions that you may not have thought of asking.

Building a Strong Support System

A brain tumour diagnosis is a life-altering experience for anyone. Don't be afraid to ask for help. Family members and friends will be eager to help you and will welcome opportunities to assist in concrete ways. A strong support system will allow you to better cope with challenges you may face. Support systems can have a significant impact on both your physical and mental strength while undergoing the shock of your diagnosis, treatment, and ultimately throughout your recovery period.

You can find connections and lean on others who have experienced a brain tumour diagnosis. Find a local support group or connect through our message board at ***www.BrainTumour.ca/support****.*

A support system can include many different people who can provide support in various ways. Family and friends can often give you the emotional support you need as well as help with any day-to-day personal care. Your health care team will provide you with the medical treatment and support that you require according to your treatment plan. They can also provide you with knowledge and understanding of your diagnosis, giving you the support you require through information.

There are other individuals or groups that can be supportive of you during this time. Community organizations, brain tumour-related support groups, other cancer support groups, online support, and the social work department at your health care centre can all help in a multitude of ways.

Brain Tumour Foundation of Canada is a valuable resource for emotional support. Support groups are set up in many centres across the country and can link you to other families affected by brain tumours that have shared similar experiences.

Waiting for Answers

Because results from various tests take time (pathology reports take days to weeks to return), and appointments can be scheduled days to months in advance, obtaining a diagnosis and treatment plan can take time. With many unanswered questions and periods of time between appointments or treatments, it is easy to become anxious and worried – it is human nature to become nervous and fearful of the unknown.

Difficult waiting periods can include the anticipation of and waiting for surgery, radiation and/or chemotherapy, and their outcomes; thinking about recovery times and how they will impact your family; and waiting to hear the results following a treatment.

A certain amount of waiting time is necessary in order for your health care professionals to obtain the answers they need so they can suggest the most appropriate course of treatment. Use this time to learn more about your diagnosis, access the support you need, and to take care of yourself, both physically and emotionally.

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 checklist. 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 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 professional.

Driving After a Brain Tumour Diagnosis

4

Driving After a Brain Tumour Diagnosis

For many people, driving is one of their most valued activities. Whether someone is able to drive or not can impact all areas of their life including employment, how to get groceries, leisure activities, getting to a doctor's appointment and even where they choose to live.

When faced with the diagnosis and treatment of a brain tumour, a health care provider may assess any impact of the tumour on your ability to drive. According to guidelines set by The Canadian Medical Association, should a medical professional deem you are no longer able to operate a motor vehicle safely, your driver's license is considered eligible for suspension.

Alternatively, a health care provider may choose to only advise you not to drive, rather than contact the province's motor vehicle regulatory body and recommend your license be suspended.

> *It is important to know that automobile insurance policies may not cover accident costs if you have simply been advised not to drive due to a medical condition.*

Occasionally, a physician may make a referral to an occupational therapist or other health care providers to further assess your ability to drive. There may also be a referral to a specialized driver-assessment program to further evaluate the impact of the brain tumour on your driving ability. In these programs, you are assessed for physical and cognitive changes and are taken on-road for a driving test. In some cases, particularly when the problems are related to physical functioning, there may be adaptations that can be suggested that will allow a safe return to driving.

What impacts a health care professional's decision?

There are a number of factors that health care providers consider when deciding whether you should continue driving after your diagnosis and/or treatment of a brain tumour. Key aspects of this assessment include whether or not there are significant deficits that impair motor function, if you had a seizure or are at high risk for seizures, or if you have changes to

your vision, perception or thinking skills that can impact driving skills. Other health changes that can impact a medical professional's decision about your ability to drive include:

- Changes in physical abilities such as strength, sensation or reflexes, particularly if the right leg or either arm is affected.
- Difficulty concentrating, which can result from pain, emotional distress or fatigue – all symptoms commonly experienced by those living with a brain tumour.
- Fatigue, which can be related to the effects of the tumour itself or can be a side effect of radiation or other treatments.
- Medications, which often have side effects that impact the ability to drive safely. They can cause someone to feel sedated or overly stimulated and can cause changes in vision, strength, coordination or reaction time.

With malignant tumours, physicians must consider any symptoms that may worsen over time, and how fast those symptoms progress can be difficult to predict. In these cases, patients may proactively decide to stop driving in light of safety concerns for themselves and others.

Finally, brain tumours may cause a seizure disorder which can result in a license suspension due to medical status. Most often an individual who develops a seizure disorder must be seizure-free for a full year before they are allowed to drive again.

While the challenge of not having a driver's license can feel like a loss of independence, it is important to remember that license suspension is common for brain tumour patients to experience, and that you may be eligible to get your license back after a period of time.

Learn more about factors that impact driving with a brain tumour by speaking with your health care team and/or consulting a representative at your local Ministry of Transportation office.

What Is a Brain Tumour?

What Is a Brain Tumour?

Familiarizing yourself with all the terminology used in brain tumour care and treatment can be a daunting task, and it can take time. This section includes some basic information about brain tumours, and helps explain the process involved in making a diagnosis and its associated terminology.

For more information on the brain please turn to ***Appendix A: Overview of the Brain*** *on* ***Page 227****.*

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 or growth. 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 low-grade or high-grade and also as benign, non-malignant or malignant.

What Are the Signs and Symptoms of Brain Tumours?

Every person diagnosed with a brain tumour will have different symptoms and their own unique story about their 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 that, alone or combined, can be caused by a 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

How Do Brain Tumours Become Evident?

Every person diagnosed with a brain tumour will have a different description of how they came to be diagnosed. The tumour may declare itself in a startling or even frightening way. This may include symptoms such as seizures, unexpected loss of function of a limb or limbs, problems with speech or sudden changes in vision. When symptoms such as these occur, a person often seeks immediate medical attention and a diagnosis is usually made quickly.

For others, the onset of symptoms may be gradual and may initially be passed off as more minor ailments. For example, symptoms such as frequent but tolerable headaches, nausea and vomiting, or personality changes can often be attributed to a variety of other causes such as stress, fatigue, the flu or migraine headaches. In these cases, it may take more time to reach a brain tumour diagnosis, as people may not immediately seek medical attention.

The location of the tumour within the brain will have a major impact on the symptoms that arise. The tumour may grow to a size where it is putting pressure on certain areas of the brain. Depending on the location, symptoms can include problems with walking, speech, vision, hearing or even sleeping patterns. Seizures can also present as a symptom of a brain tumour.

Some types of tumours can block the cerebrospinal fluid (CSF) pathways or interfere with the normal absorption of CSF, causing fluid and pressure to build up inside the head. This can result in headaches, often during sleep or upon waking in the morning. The headaches are frequently associated with nausea and early morning vomiting, which may bring some relief of the headache.

Why Do Brain Tumours Occur?

The reason why brain tumours occur is unclear. As with all brain tumours, malignant or non-malignant, researchers continue to look at both environmental and genetic causes for these tumours, and they are studying the genetics of these tumours with the hope that this will help identify the cause. Many believe that the cause of brain tumours may turn out to be a combination of both environmental and genetic factors.

Research is underway to identify genetic markers for brain tumours, that will help physicians predict who is at risk for developing brain tumours.

How Is a Brain Tumour Diagnosed?

How Is a Brain Tumour Diagnosed?

A complete and thorough neurological examination is always important in diagnosing a brain tumour and begins with your doctor, who will ask you a number of questions in order to get a complete history of your 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
- Strength testing of the arms and legs
- Tongue movement, gag reflex tests

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

Scans are done in place of conventional X-rays, as X-rays are not able to show tumours behind bone. Different types of imaging devices are used to perform brain scans. The devices used most frequently for both diagnosis and follow-up are the Computed Tomography scanner (CT / CAT scan) and the Magnetic Resonance Imager (MRI), which are standards of care in a brain tumour diagnosis. MRIs are available at all medical centres, and most people diagnosed with a brain tumour will have one.

CT or CAT Scan

This machine combines a sophisticated X-ray device and computer. An injection of contrast dye is given to the person having the scan, to help make any abnormal tissue more evident. The 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.

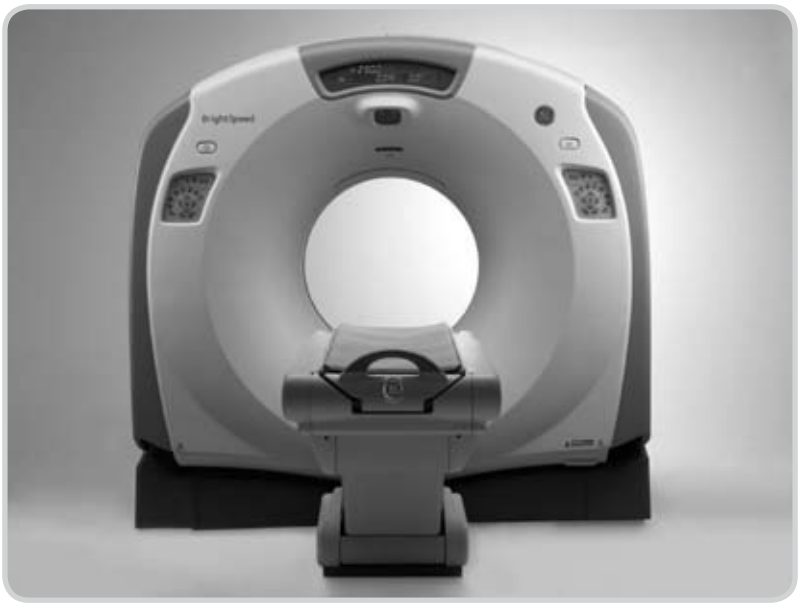

Photo courtesy of GE Healthcare

*For more information about scans please turn to **Page 87**.*

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. MR imaging takes longer than a CT scan, and is very noisy. Like the CT scan, contrast material (Gadolinium) will be used.

An MRI usually produces images that are more detailed than those seen with CT scanning. It is important to know that while the MRI can detect brain swelling, it has difficulty distinguishing swelling from a tumour. Some tumours also have calcification that CT scanning may detect more readily.

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

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 neuropathologist for analysis and accurate diagnosis. A biopsy is the most accurate method of obtaining a brain tumour diagnosis.

Brain Tumour Classifications

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Brain Tumour Classifications

Tumours can be referred to in a number of ways. There are low-grade and high-grade tumours, benign, non-malignant and malignant tumours, and World Health Organization (WHO) classification that goes from Grade I to Grade IV. There are also primary and secondary tumour types.

Low-Grade Tumours

A low-grade tumour is made up of cells that are slow-growing. When a tumour is growing-slowly and can be completely removed by surgery, it usually doesn't grow back. In some instances, however, these tumours cannot be completely removed because they are located too close to parts of the brain that control vital functions (breathing, heart rate, movement). If some tumour is left behind because it cannot be removed during surgery, it may re-grow, and despite its low-grade nature, can be life-threatening if the tumour is in a vital location.

High-Grade Tumours

A high-grade tumour is one that is made up of cells that are fast-growing. These tumours are often referred to as "aggressive." They often infiltrate normal brain structures and can be difficult to remove surgically. Because of their rapid rate of growth, high-grade tumours produce symptoms much earlier than low-grade tumours.

Benign, Non-Malignant and Malignant Brain Tumours

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 non-malignant brain tumours as they can still grow and cause symptoms by compressing brain tissue and other structures inside the skull, causing 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" rather than "benign" to define tumours that are not aggressive or low-grade.

In general terms:

- **Malignant Tumours** = most aggressive, cancerous, fast-growing and typically spread to other parts of the brain or body.
- **Non-Malignant Tumours** = least aggressive, slow-growing and can often be removed. They rarely invade surrounding brain tissue or other structures.

World Health Organization (WHO) Tumour Grading System

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 and malignant tumours under Grade III or IV; however mixed-grade tumours are possible.

For a list of Adult Brain Tumour Types, please turn to ***Appendix C*** *on* ***Page 246****.*

Grade I Tumour

- Slow-growing cells
- Almost normal in appearance under a microscope
- Least malignant
- Usually associated with long-term survival
- Example: acoustic neuroma (vestibular schwanomma) 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 that 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 (or low-grade) can be as serious as those classified as malignant (high-grade) if they are in an inaccessible location, such as the brain stem. Conversely, some malignant tumours can be successfully treated. A treatment plan is often developed with the tumour grade in mind.

To help you better understand the different terms and grading system, please refer to this chart:

WHO	Grade I	Grade II	Grade III	Grade IV
Low-Grade	√	√		
High-Grade			√	√

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

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 treatment plan, symptom management and individual care.

How Is the Tumour Type Determined?

In most cases a pathologic diagnosis is necessary to determine the tumour type, but some tumours can be diagnosed by location, age of the patient, imaging findings and tumour markers.

A pathologic diagnosis will definitively determine the tumour type. A biopsy or surgery is required to obtain a tissue specimen. Once the tissue sample is obtained, a neuropathologist will review the tissue specimen, to determine exactly what type of tumour you have.

A pathology report can frequently take from 7 to 10 business days to finalize. This often means that you may leave the hospital following surgery without a final pathology report. However, once a tissue diagnosis of the tumour has been made, it will be given to your neurosurgeon, physician and oncologist, and they will be able to give you a more specific name for the tumour as well as a treatment plan. The doctor may be able to offer an opinion on the tumour type before a tissue sample is taken, based on how the tumour looks on an MRI or CT scan, however the final diagnosis will be based on the pathology report.

Does the Diagnosis Ever Change?

As researchers become more familiar with the complexities of brain tumours, it is becoming clear that tumours can behave in unpredictable ways. In some cases the tumour may change over a period of time. Some tumours that are initially diagnosed as low-grade can become more aggressive and change their characteristics to high-grade (e.g., they may begin to display more aggressive features under the microscope and in their rate of growth.) Therefore, it is possible for your diagnosis to change.

Visual Changes

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Visual Changes

If you have experienced visual changes or disturbances as a symptom of the brain tumour or as a result of its treatment, the following information will help you understand the visual system and associated conditions. Contact your doctor if you notice any change in your vision or if you feel that it has changed – a change in vision is frequently a symptom that causes a person to seek medical help.

Your visual system includes not only the eye itself but also the visual pathways that travel from the back of the eye (retina) all the way through to the back of the brain, to the occipital lobes.

Doctors that specialize in the eye and visual system are called optometrists and ophthalmologists. A neuro-ophthalmologist has additional training in specific brain conditions that affect the eye and visual system.

An examination of your visual system is important in helping to make the initial diagnosis of a brain tumour and in continuing management once the tumour has been treated. Annual eye exams are useful in early diagnosis of some brain tumours and their ongoing monitoring, or any vision changes.

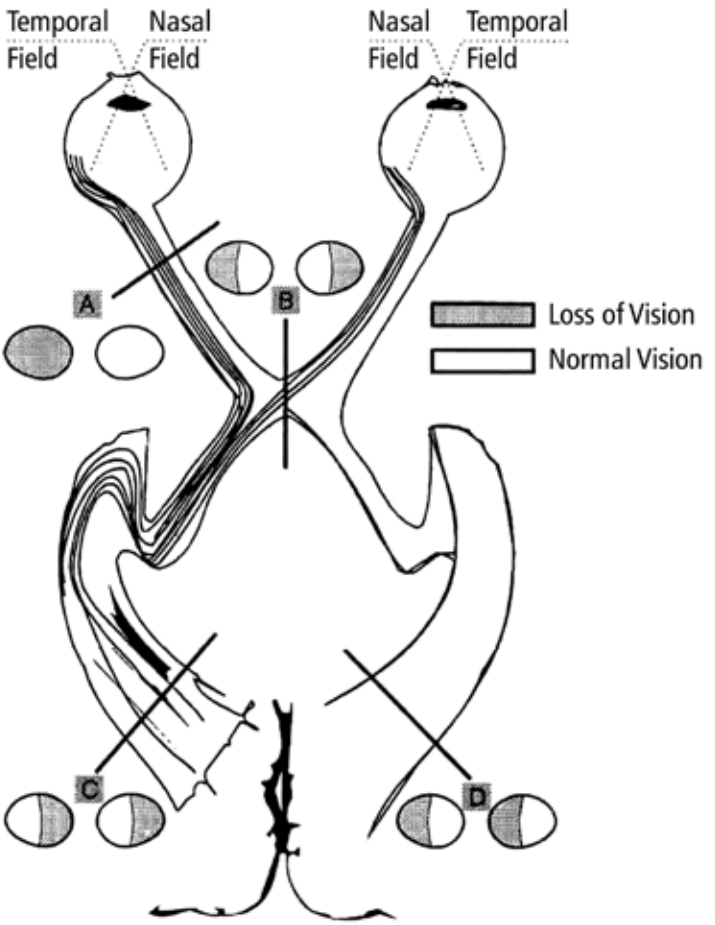
Visual Fields

Visual messages travel from the back of the eye along the two optic nerves and meet near the area of the pituitary gland called the optic chiasm. Here, the two nerves fuse together. Half of the pathways cross and travel back through the brain, through the temporal and parietal lobes, before arriving at the back of the brain (occipital lobes).

*Turn to **Appendix A** for a picture of "**The Lobes of the Brain**" on **Page 235**.*

Visual fields are what you can see in all directions with both eyes open and looking straight ahead. Each eye has a right and left visual field. These overlap the fields of the opposite eye.

Visual Fields



Papilledema

By looking in your eyes, the physician may see swelling of the optic nerves. When swelling is due to increased intracranial pressure, it is called papilledema. It is an extremely important indicator that there may be a growing tumour or an obstruction of cerebrospinal fluid present. Initially, there may be no symptoms, which emphasizes the importance of having a careful examination of the back of the eyes. In severe or persistent cases, papilledema may lead to visual loss involving both eyes.

Optic Disc Pallor

The optic nerves originate in the back of the eyes. The part of the nerve that is visible on ophthalmological examination is called the optic disc. It is normally pink, but may sometimes turn yellowish / whitish, in which case the nerve is said to be pale. If this occurs, it indicates damage to the optic nerve, which may be the result of any type of optic nerve disease.

Vision Loss to One Eye

If a tumour is causing pressure to one optic nerve in the area before it intersects with the other (contralateral) optic nerve, there may be some loss of vision in one eye. You may notice that there is a "missing area" in your vision or that your vision is becoming increasingly blurry. These changes cannot be corrected with glasses. However, many people may not be aware of unilateral vision loss, as they simply see with the contralateral "good" eye. A careful ophthalmological examination is enough to diagnose the ocular problem and indicate if further tests may be required to produce the underlying diagnosis.

Vision Loss to Both Eyes

If there are problems with the visual pathways at the optic chiasm (where the two optic nerves intersect), both eyes will be involved. People with these problems usually find that half of their vision is missing to one side. If the problem occurs right at the chiasm area (e.g., a pituitary tumour), the typical problem would be a loss of vision on both outsides, so that looking straight ahead there is a loss of vision originating with the right eye on the right side, and with the left eye on the left side.

Double Vision (Diplopia)

We see clearly because our eyes always move together. There are many muscles that allow this to occur. The eye muscles receive a signal for movement from nerves that travel from the brainstem to the eye muscles.

A tumour, or the pressure it causes, might hinder the nerve's ability to work, resulting in an imbalance in the action of the eye muscles. When this happens, one or both eyes may fall out of alignment with each other. Double vision may be the result, which should always be regarded as a very important sign of a possible brain tumour.

The nerves involved in diplopia are the third, fourth and sixth cranial nerves. If the third cranial nerve is involved, your eye may move outward and your eyelid may droop. The pupil of the eye may be large and not react well to light. If the fourth nerve is involved, the affected eye will move up. You may not be able to look down and in, and you may tilt your head toward the opposite shoulder. If the sixth nerve is involved, your eye will move inward toward the bridge of your nose.

Nystagmus

Sometimes the eyes move in a continuous, uncontrollable beating movement – this is called nystagmus. Fast movement in one direction, followed by a slower movement in the opposite direction, is called jerk nystagmus. When the eyes move back and forth at the same velocity, it is called pendular nystagmus. Some people may perceive that the images continuously jump or move back and forth, a symptom known as oscillopsia. However, for many people, nystagmus does not cause any visual symptoms.

Nystagmus may signify problems in the area of the brainstem or cerebellum, and may be useful in determining which part of the brain is affected by the tumour.

The examination of the eyes, which involves looking in the eyes, assessing their movement and field of vision, is important in the first assessment and continued follow-up for someone with a brain tumour. Any change in vision should always be reported to your doctor.

Seizures

Seizures

Brain tumours can increase the risk of developing recurrent seizures. However, there are many other causes of epilepsy including head injury, infection, stroke, malformations during development, neurodegenerative disorders and genetic causes.

Having a seizure at anytime can be a frightening experience. Understanding the mechanisms of different types of seizures can help put aside some of the fear. Seizures are actually very common, affecting approximately 1 in 100 people in the general population: 10% of the population will experience a single seizure. Once someone has had two or more unprovoked seizures, they are diagnosed with epilepsy.

Cells called neurons, located within the brain, communicate with one another by way of electrical signals. On occasion, a group of cells may produce abnormal excessive electrical discharges. This misfiring of neurons is known as a seizure. The type of seizure that is seen outwardly will depend upon where in the brain the neurons misfire. People with tumours in the cerebral hemisphere may develop seizures.

There are two main categories of seizures: focal seizures (partial) and generalized seizures.

Focal (Partial) Seizures

Focal seizures begin in a discreet region of the cerebral cortex. Focal seizures usually arise from the lobe where the brain tumour is located.

1. Simple Partial (Focal) Seizures

Simple partial seizures are deemed to have happened when the person remains aware throughout the entire seizure. Many people refer to these seizures as an aura. The symptoms reflect the function of the region of the brain from which the seizures arise. For instance, if someone has a brain tumour in the occipital lobe, then a symptom may be a visual occurrence.

Other symptoms may include:

- Uncontrollable twitching movements in one or several closely related body parts; may move from one area of the body to another.
- Numbness or tingling in one body part or moving from one part to nearby parts of the body.
- Visual hallucinations; seeing things that aren't there or real. Some people may see coloured circles.
- Illusions; distortions of what one is seeing (e.g., walls curving).
- Hallucination (imagining) of a taste or smell; usually unpleasant.
- Auditory changes; hearing sounds that aren't there.
- Mood changes such as fear, anger, sadness, joy.
- Altered memory such as memory playback.

2. Complex Partial (Focal) Seizures

Complex partial seizures manifest as a loss of conscious awareness without convulsion. These types of seizures may be referred to as non-convulsive. The person may have a warning, such as an aura and his awareness of his surroundings become impaired.

During the seizure, a person may wander about, stare or make simple movements of the mouth (e.g., chewing, lip smacking). More complicated behaviours (e.g., the person may pick something up and fumble with it or wander about) may occur. If the person is wandering, stay by his side and gently steer him away from danger.

3. Partial (Focal) Seizures with Secondary Generalizations

Generalized tonic-clonic or grand mal seizures (see Generalized Seizures) may start as a partial seizure. If the person is standing, he will fall stiffly, often with a cry. This stiffness or tonic phase gives way to rhythmic jerking movements on both sides of the body (clonic phase). His breathing may be shallow during a seizure. There may be a loss of bowel and bladder control.

Generalized Seizures

There are several types of generalized seizures. One common type is a generalized convulsive seizure which occurs when there is a loss of consciousness followed by stiffness and then rhythmic jerking movements. These may be called convulsive or tonic-clonic seizures. Prior to 1990, these seizures were known as grand mal seizures, but are now referred to as tonic-clonic seizures. This term is more descriptive of the seizure (tonic means stiffening, and clonic means shaking), and is more respectful of the person having the seizure (in French "grand mal" translates to "the big sick", perpetuating stigma about the individual affected).

Generalized epilepsy disorders where a seizure begins with widespread seizure activity in both hemispheres of the brain are not common in people with brain tumours.

First Aid

If someone experiences a seizure, follow these simple steps:

- Stay calm, never attempt to restrain someone having a seizure, simply let the seizure run its course.
- Move sharp objects out of the way.
- If the person has fallen to the ground, roll him onto his side and place something soft under his head.
- DO NOT put anything in his mouth.

- If the seizure repeats, lasts more than five minutes, occurs in water, or if the person has a head injury, has diabetes, or is pregnant, call for an ambulance.
- If the person is wandering, stay by his side and gently steer him away from danger.
- The person may be confused when the seizure ends. Reassure him and stay with him until the confusion ends. If confusion persists for an hour after the seizure, call 911.

After a Seizure

A person may be very drowsy after a seizure. Depending on the area of the brain involved, there may be temporary confusion, speech difficulty or limb weakness. These effects may last anywhere from a few minutes to hours, and is known as the postictal period. If confusion lasts for more than an hour, call an ambulance.

Safety in Sports and Recreational Activities

A few suggestions:

- Take extra precaution if you are involved in sports with an increased risk of head injury (e.g., football, hockey, soccer).
- Always use proper safety gear.
- Avoid activities that would be considered too dangerous (e.g., scuba diving, rock climbing).
- Ride bicycles on side roads or bike paths; wear a helmet.
- People that experience uncontrolled seizures should swim with constant supervision. Swimming with a companion, preferably an experienced swimmer is recommended for anyone who has seizures.

Effects of Tumours and Their Treatments

10

Neuroendocrine & Cardiometabolic Effects of Tumours and Their Treatments

Many bodily functions are controlled by chemicals called hormones. Hormones are secreted by specialized organs known as glands. Together, the whole process makes up what is referred to as the endocrine system. This system may be affected by tumours and associated treatments.

Neuroendocrinology refers to the interactions between the nervous system (brain) and endocrine system. The primary gland of the neuroendocrine interface that communicates with the brain is called the pituitary gland. It is a pea-sized gland located in a bony cavity below the base of the brain and above the nasal passages.

The pituitary gland produces and stores many hormones that control other glands in the body. It is connected directly to a part of the brain called the hypothalamus, through which information between the pituitary and the rest of the brain flow back and forth.

The pituitary gland releases hormones in response to the signals received from the body, which are communicated to it through the hypothalamus. This system senses the concentration of hormones in the body and automatically switches on and off in order to maintain the right amount of hormones for important body functions. Various hormones produced by the pituitary gland and their functions are listed in Table 1.

Table 1: Pituitary hormones and their actions on target glands

Hormone name	Action
Anterior pituitary gland	
Luteinizing Hormone (LH)	Production of testosterone in men and estrogen in women
Follicle-Stimulating Hormone (FSH)	Production of sperm from testicles and eggs from ovaries
Adrenocorticotropic hormone (ACTH)	Production of cortisol hormone from adrenal glands that functions to cope with stress including injury or illness
Thyrotropin-stimulating hormone (TSH)	Production of thyroid hormone from thyroid gland
Growth hormone (GH)	Production of insulin-like growth factor-1 (IGF-1) from liver that stimulate growth
Posterior pituitary gland	
Prolactin (PRL)	Production of breast milk
Antidiuretic hormone (ADH)	Control of water balance

Tumours may arise within the pituitary gland itself or close to the gland, which puts pressure on the gland, thereby interfering with its function. In addition, surgery or radiation therapy to this area may also lead to pituitary damage. The degree of effect on the hormones depends upon the extent of damage to the pituitary gland. Careful monitoring of the pituitary function will be an important part of your care.

In most centres, there will be a team of endocrine specialists (doctor, nurse and social worker) involved in your care.

Your treatment will vary depending on the extent of the problem: if a tumour is causing pressure on the pituitary gland, surgical removal of the tumour may be all that is required. A tumour arising within the gland itself may require surgery and/or radiation therapy. Drug therapy to replace or supplement hormones may be necessary, or alternatively, drug therapy may be required to suppress overproduction of hormones in certain instances.

Growth Disorders

The pituitary gland produces growth hormone, which is necessary to achieve a normal height in growing children. Growth-related problems could result from either a deficiency in growth hormone due to pituitary damage leading to short stature, or from excessive growth hormone production due to a growth-hormone-producing pituitary tumour which causes gigantism or acromegaly.

If you are a survivor of a pediatric brain tumour, you may be affected by a growth disorder due to treatment. Routine assessment of growth rates and growth hormone levels are appropriate in anyone who has had a tumour involving the hypothalamus or pituitary gland, or who has received cranial radiation.

Short Stature

Short stature due to low growth hormone levels is a common presenting sign of certain brain tumours such as craniopharyngiomas and other tumours that may damage the hypothalamus or the pituitary gland. Treatment with growth hormone may be appropriate for some people with short stature due to growth hormone deficiency.

Gigantism

This is the disease of growing children and adolescents caused by pituitary tumours that secrete excessive amounts of growth hormone, resulting in a striking acceleration of linear growth and height gain. Treatment usually involves surgical removal of the pituitary tumour and occasionally radiation therapy is used. Medications that shrink these tumours and

decrease the response of the body to excessive growth hormone are also available as short-term treatment. Rarely other tumours, which involve the hypothalamus, may also result in excessive growth hormone.

Rarely other tumours, that involve the hytohalamus may also result in excessive growth hormone.

Acromegaly

This is a disease caused by a pituitary tumour that secretes excessive growth hormone in adults. In this condition, the hands and feet become enlarged and the jaw protrudes. The tongue may become thicker and other tissues and organs of the body may become enlarged. This condition, if not treated, can lead to hypertension and heart disease. Acromegaly is diagnosed usually in people between the ages of 30 and 50.

Treatment for acromegaly typically involves surgical removal of the pituitary tumour and occasionally radiation therapy. Medications that shrink these tumours and decrease the response of the body to excessive growth hormone are also available as short-term treatment.

Sexual Function and Fertility

Various brain tumours can result in problems with sexual function. Tumours in the area of the pituitary gland commonly present with sexual dysfunction characterized by loss of interest in sex in both men and women. Impotence and/or inadequate sperm production can also occur in men, and menstrual irregularities in women. These changes can, in some cases, lead to infertility.

Tumours involving the frontal lobes on both sides of the brain can result in changes in personality and on occasion may cause inappropriate sexual behaviour. You may be lethargic, apathetic, and have little interest in sex. Treatment of the tumour may restore normal sexual health.

Loss of sexual function can also be caused by elevated prolactin levels. Increased prolactin secretion is caused by a prolactin-producing pituitary tumour or by tumours that damage the communications between the hypothalamus and the pituitary (called the pituitary stalk). These individuals may also experience galactorrhea (milky discharge from the breasts).

Other pituitary tumours that cause loss of luteinizing hormone (LH) or follicle-stimulating hormone (FSH) production can also lead to loss of sexual function and infertility.

Treatment involves diagnosis of the tumour and an accurate assessment of the hormonal imbalance caused by both the tumour and the treatment. The hormone imbalance can generally be corrected by oral or injectable hormone replacement. With proper treatment, fertility can also be restored in some cases. For some people, suitable psychological support may be helpful in managing these sexual challenges.

Radiation therapy, specifically cranial irradiation, can affect the ability of the pituitary gland to produce LH and FSH, while craniospinal irradiation can affect the testicles, ovaries and uterus. Drugs can also be toxic to the gonads and may impair sexual development and fertility.

Cells that produce testosterone in men are more resistant to radiation than sperm-producing cells; small doses of radiation can affect sperm production. The impact of treatment depends on your gender, age, the dose and type of drug, and radiation received. The more modern treatments aim to reduce the exposure to pituitary gland and gonads, thereby reducing the risk for adverse health effects immediately and in the future.

> *If you undergo treatment for a brain tumour this could adversely affect your fertility or virility, and you may want to consider fertility preservation prior to treatment.*

There are several factors to consider with fertility preservation, including whether or not cryopreservation of sperm or eggs is available and whether a delay in your treatment is possible. If you are considering fertility preservation, you should be counselled prior to treatment.

Fertility

Certain brain tumour treatments are more likely to lead to infertility than others. Thanks to advances in the field of assisted human reproduction, many patients are able to pursue fertility preservation in a timely manner, and can often be completed prior to the start of cancer treatment.

Chemotherapy, radiation and surgery may all result in infertility, depending on the type, dose, length, frequency, or location of treatment.

Infertility is defined as an inability to have children. Not all forms of brain tumour treatment will lead to infertility, but many can. For men, this means being unable to produce an adequate number of sperm, or producing sperm that are irreversibly damaged by treatment and are not able to naturally fertilize a woman's egg. For women, infertility means being unable to produce eggs, the inability to conceive or the inability to carry a pregnancy to term.

In some cases, it is difficult to know if the treatment will cause infertility. In other cases, your physician(s) may be able to tell you with certainty if your fertility will be compromised. The first step is to inform your physician(s) and oncology professionals of your wish to preserve your fertility. Options are available whether you are beginning, have already started, or have recently completed treatment.

To allow for as many options as possible after treatment, it is important to consider fertility preservation prior to beginning treatment.

Many Canadians lead full lives after conquering their brain tumour diagnosis. The ability to have a family of their own is frequently an integral element in the quality of their life.

Talk to your oncologist or fertility specialist to determine the likelihood of infertility associated with your course of treatment.

*For more information on **Fertility** please visit **www.BrainTumour.ca/Fertility**.*

Disorders of Body Weight Balance

Weight Loss

It is not uncommon for people with brain tumours presenting with nausea and vomiting to lose weight and appear under-weight. Weight loss and anorexia are also commonly associated with radiation therapy and chemotherapy. Some tumours involving the hypothalamus and the third ventricle of the brain may result in what is termed diencephalic syndrome. The most obvious features of this syndrome include the complete absence of fat beneath the skin, whether the patient has a normal or increased appetite, cachexia (weight loss, muscle atrophy and lack of appetite) and impaired growth. Treatment of this condition will depend on the control of the hypothalamic tumour.

Obesity

Corticosteroids (steroids) are medications used to control brain tumour swelling but they can have numerous side effects including increased appetite and significant weight gain. The side effects of steroids can usually be reduced by decreasing the steroid dosage. However, prolonged exposure to excess steroids can lead to a constellation of physical features described as cushingnoid. Signs include excessive facial fullness, fat in the neck area, and abnormal obesity particularly at the trunk and abdomen. As the steroid dose is reduced these features usually go away.

In some cases, excessive corticosteroid production can be caused by an adrenocorticotropic hormone (ACTH) secreting pituitary tumour (Cushing's disease), which in turn stimulates the adrenal glands to overproduce steroids. This can lead to excessive weight gain around the torso, muscle weakness, thinning of the skin, purple stretch marks on the skin, and a tendency to bruise easily. If left untreated, this condition can lead to high blood pressure and diabetes. Removal of the pituitary tumour usually corrects the problem.

Damage to certain areas of the hypothalamus that regulate appetite may also lead to excessive appetite (hyperphagia) and severe obesity. In some cases, hypothalamic tumours can cause an unequal distribution of body fat and obesity that is not associated with excessive appetite. The reasons for this are somewhat unclear and treatment is often unsatisfactory for both of these types of obesity.

Other Disorders

Diabetes Insipidus

Antidiuretic hormone (ADH) is important in regulating the body's fluid balance and blood volume by controlling urine concentration and volume. The lack of ADH leads to a condition called diabetes insipidus. Although this problem is rarely seen in conjunction with pituitary tumours, low levels of ADH may occur after pituitary surgery, especially with the removal of a craniopharyngioma.

Deficiency of ADH leads to the inability to retain fluids in the body and, if left untreated, causes excessive urination, depletion of body fluids and extreme dehydration. Mild forms of this condition are common after pituitary surgery, and in most cases the problem resolves on its own and does not require long-term treatment. If treatment is required, it will involve the replacement of ADH, usually in the form of nasal spray.

Syndrome of Inappropriate Antidiuretic Hormone (SIADH)

SIADH results from an excessive secretion of ADH, which in turn causes fluid build-up in the body, excessive dilution of body fluids, and lowering of blood sodium. This syndrome can result from various types of brain tumours and can also occur after brain surgery. Certain tumours in other sites of the body, such as small cell carcinoma of the lung, are known to secrete large amounts of ADH leading to SIADH. Symptoms can include fatigue, confusion, weight gain, and in extreme situations, seizures. Treatment can involve removing the tumour, and restricting fluids in order to correct the fluid overload and return the blood sodium level back to normal. Although rare, if SIADH is chronic, medical treatment may be necessary.

Hypopituitarism ("Hypopit")

Hypopit refers to the partial or complete deficiency of pituitary hormone production. It may be related to a tumour or result from surgery or radiation therapy. If you have hypopit, your pituitary hormone function will be closely monitored. Treatment of hypopit involves restoring the affected hormones to the appropriate levels.

Depending upon the pattern of hormone loss, symptoms of hypopituitarism may range from fatigue, nausea and vomiting, to weight loss and mental changes. If left untreated, hypopit can lead to a state of shock. If you experience any of these symptoms after pituitary surgery or cranial radiation, report them to your doctor, who will do a simple blood test for diagnostic purposes.

Lesions in the area of the hypothalamus and pituitary gland can result in a wide variety of conditions. Medical interpretation and treatment of these conditions depends on a careful assessment of the hormones affected and control of the specific area of the hypothalamus involved.

Imaging

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Imaging

Your doctors will order imaging so they can get detailed pictures of the size and shape of the tumour. The information will be used to plan your treatment.

Magnetic resonance imaging (MRI) and computed tomography (CT) scans are the most common types of imaging techniques used for evaluation of brain tumours.

What is MRI (Magnetic Resonance Imaging) Scan?

An MRI scan uses a magnetic field instead of X-rays to take pictures of your body. No radiation is used. An MRI scan usually takes between 30 minutes and one hour to complete. The procedure is painless. Using computers, the MRI scanner makes a series of pictures of the brain. The images will aid in making a diagnosis and be used in monitoring your treatment response.

What Does an MRI involve?

When you arrive at the diagnostic imaging department an MRI technologist will meet you. He will want to know if you have had previous surgery involving metallic devices (e.g., pacemakers, port catheters, shunts, aneurysm clips). The MRI technologist will also ask you to remove any metals (e.g., jewelry, wallets, pens, hairpins, safety pins) or magnets (e.g., credit cards) prior to entering the testing area. Because these objects pose a potential danger, it is important to remove them whenever possible.

The MRI scanner is a hollow machine with a tube running horizontally (Figure 1). During a head or spine MRI, you will lie on a flat and narrow bed. Your head will be secured with soft Velcro® straps. In addition to the straps, a window device, like a helmet, may also be placed over your head. The table is then moved so that your head lies within a tube-like or doughnut-shaped structure.

If you think you have claustrophobia then make sure your doctor gives you a sedative for the MRI prior to the scan.

Once the scanning process begins, you must remain still – this is very important. Any slight movement will distort the final pictures. The scanner makes a continuous drumming or banging sound during the scan that can be quite loud, but you will be given ear protectors to minimize any discomfort. The MRI technologist is in another room operating a computer and will tell you, via an intercom, when he is taking the images and when the noise will start. When the scan has finished, the MRI technologist will move the bed out of the scanner and you can leave the room.

It may be possible to listen to music to help soften the noise and provide a distraction.

Why Is Contrast Agent Used?

After obtaining a series of routine images, a contrast agent (typically called Gadolinium) will be injected into a vein in your arm.

In general, normal blood vessels of the brain do not allow compounds to enter the brain: they protect the brain through something called the blood brain barrier. However, because tumour blood vessels are abnormal, they allow substances, such as the contrast agent, to cross the blood brain barrier. The contrast enhancement of the tumour is helpful for further characterization of the mass. Not all brain tumours enhance, so this is only one of the many images that are important in determining the accurate dimensions of the tumour.

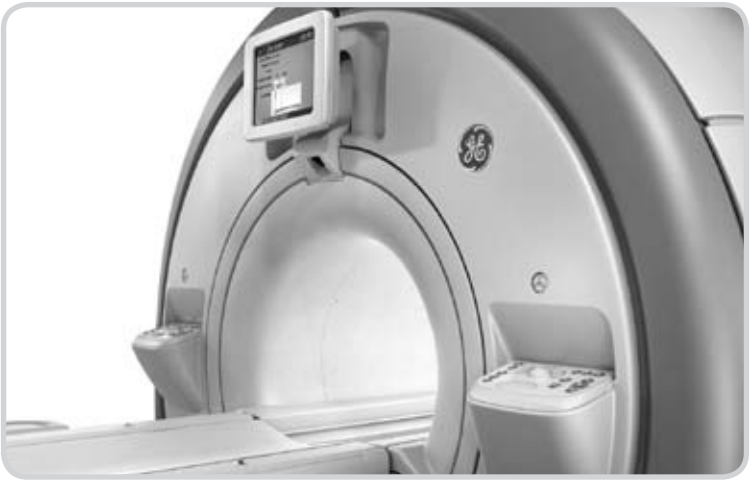

Figure 1. MRI Scan Equipment. Photo courtesy of GE Healthcare.

Image-Guided Neurosurgery

Selected volumetric images from the MRI scan are often used to assist the surgeon during the tumour operation, called image-guided neurosurgery. Images from the MRI scan are transferred to a sophisticated system for planning the surgery. This allows the surgeon to navigate through the cranium and brain using the image for guidance.

Small skin markers, also called fiducials, are attached to the scalp in the morning before surgery or in the operating room just before surgery. Depending on the system used in surgery, the neurosurgeon might want to perform and study a short MRI scan prior to surgery, with the fiducials attached to the skull.

CT or CAT Scan (Computerized Axial Tomography)

A CT scan is a special series of X-rays taken of the body or the brain. It is performed in the radiology or diagnostic imaging department. You will lie on a narrow table and may have to wear straps across your body to make sure you maintain the right position. The table will be moved so that the part of your body to be X-rayed will be situated within a tube-like or doughnut- shaped part of the machine. While the X-rays are being taken, the hum of the machine may be heard. A head scan usually only takes a few minutes as compared with an MRI, which can take 20 to 30 minutes.

Using computers, the CT scanner makes a series of pictures that will be used to make the diagnosis (Figure 2). In the situation where a brain tumour is detected on a CT scan, a radiologist may require an MRI scan of your brain for further assessment of the tumour.

Pregnant mothers are not permitted in the CT room.

CT is an excellent technique for assessment of calcification that is often present in tumours, and to visualize the skull. Calcifications within the tumour may provide some diagnostic evidence to support one type of brain tumour over another.

Figure 2. CT Scan Equipment. Photo courtesy of GE Healthcare

MRI and CT Scans and Radiation Planning

An MRI Scan prior to radiation planning (and post-operatively) is required in order to accurately map out the tumour. This MRI is merged onto the CT scan taken for radiation planning – both imaging modalities are required for accurate radiation delivery. The CT scan taken for radiation planning requires the head to be immobilized in a plastic mask, aas the mask will ensure that the head is in the same position dayt-to-day during treatment. The mask is not required for the MRI.

Other Imaging Techniques

Other types of imaging techniques may be used to obtain further information about a tumour.

> *This is a list of other types of imaging techniques; however, not all centres may have them.*

Functional MRI Scan

Functional MRI scanning is done to define brain anatomy (like regular MRI), and to help localize brain function. For example, when you count out loud, repeatedly move some muscles, or look at certain objects (while in the MRI scanner), specific areas of your brain, which are involved in these activities, can be seen on the MRI images. This is because of a change in oxygen concentration in the blood around those regions of the brain. This technique may be helpful in showing where the speech and motor centres are in relationship to the tumour, and this information can be useful to the neurosurgeon.

MRS (Magnetic Resonance Spectroscopy)

MRS is a type of MR sequence that enables a radiologist to assess the metabolic changes in your brain tissue. It provides complementary biochemical information to structural imaging, and can sometimes provide information about the aggressiveness of a tumour. Instead of displaying an image like conventional MRI, this sequence provides a graph that maps certain metabolites. The most frequently measured metabolites are: N-acetylaspartate, a neuronal marker that is usually reduced in brain tumours; choline-containing compounds (which are used to make cell membranes); creatine (a chemical involved in energy metabolism); and lactate (which is elevated in some tumours).

DTI (Diffusion Tensor Imaging)

DTI is an MRI-based neuro-imaging technique that allows the radiologist to visualize the location and orientation of the brain's white matter tracts. With brain tumours, this type of information can be important for surgical planning as the tracts next to the tumour can become deviated or be pushed aside, or they could be infiltrating the tumour.

PET (Positron Emission Tomography) Scan

PET scanning is only used in a few centres in Canada. PET scanning shows the activity of the brain using radioactive sugar or other specially designed molecules, allowing tumour metabolism and oxygen uptake to be measured. The PET images can be combined with MRI or CT scans. PET imaging can also be useful in differentiating the death of tumour cells (tumour necrosis) from recurrent tumour.

Surgery

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Surgery

The diagnosis of a brain tumour is typically made by a neurosurgeon, neurologist or neuro-specific oncologist. The diagnosis is made based on the symptoms, the findings from a physical examination and the results of tests such as a CT and/or an MRI scan. The usual first step following the diagnosis of a brain tumour is a referral to a neurosurgeon, because most people will require some type of operation.

Do All Patients With a Brain Tumour Require Surgery?

Not all people with brain tumours require surgery. Occasionally the brain tumour specialists may choose to observe the tumour using a series of CT scans or MRI scans. These doctors may be oncologists, (or more specifically neuro-oncologists), neurologists or neurosurgeons (a surgeon that specializes in brain operations). They will tell you why they have chosen the observational approach.

What Types of Surgery Might Be Offered?

There are two types of surgery that might be offered: the first is called a brain tumour biopsy, and the second, a brain tumour resection.

Brain Tumour Biopsy

The goal of a brain tumour biopsy is to get a small amount of the tumour tissue to determine the type of brain tumour. A biopsy is done to either confirm or clarify the information from the CT and MRI scans. It is important that your doctors are certain about the tumour type because it will affect your treatment.

A diagnosis of the tumour type can be made by a pathologist or neuropathologist who examines the tissue from the biopsy under a microscope. Genetic testing can also be done on some tumours.

Brain Tumour Resection

The goal of a brain tumour resection is to remove as much of the brain tumour as is safely possible. Removing all (gross total) or part of (sub-total) a brain tumour might help to reduce symptoms. Resection may also help to prevent or delay the onset of other symptoms. Similar to a biopsy, there will be a brain tumour specimen for the neuropathologist to view under a microscope.

What Determines Whether a Biopsy or a Resection is Offered?

Ultimately, it is the neurosurgeon that decides whether to recommend a brain tumour biopsy or a resection. Factors that the surgeon considers when making a recommendation include the location of the tumour, the size of the tumour, the types of symptoms that you may be experiencing, and sometimes your age and general physical health.

How Is a Brain Tumour Biopsy Performed?

There are different methods that a neurosurgeon can use to perform a brain tumour biopsy, specifically stereotactic brain tumour biopsy, open brain tumour biopsy, and endoscopic brain tumour biopsy.

Stereotactic Brain Tumour Biopsy

A stereotactic brain tumour biopsy is usually performed using a neuroleptic anesthetic. First, a special stereotactic head frame is placed on your head. Then, you have either a CT scan of your head or an MRI. This allows the neurosurgeon to calculate with precision the exact part of the brain tumour from which to obtain the biopsy.

*To see an example of a stereotactic head frame, please turn to **Page 129**.*

When the scans are complete, you are taken into the operating room and the surgeon makes a small incision in the scalp and then a small hole through the skull. A special probe is then attached to the stereotactic head frame and passed through the hole in skull and into the brain

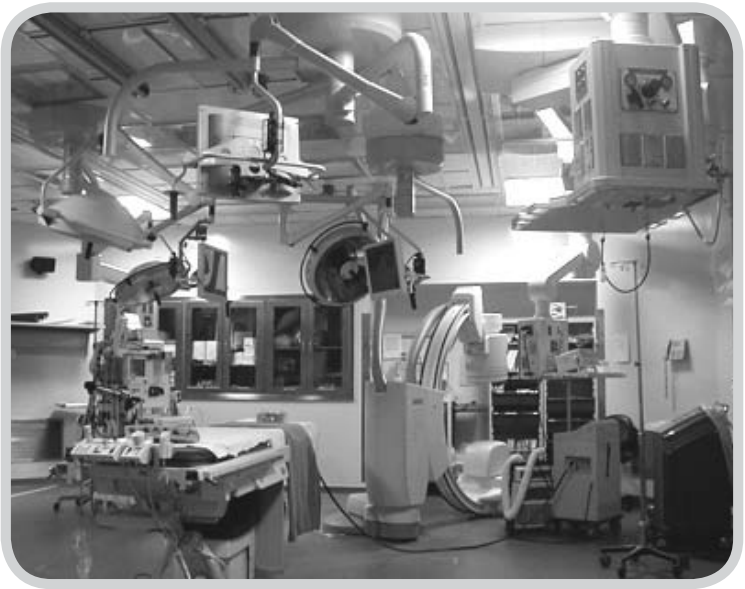
tumour. A small piece of the brain tumour is then removed and given to the neuropathologist who determines the type of brain tumour by looking at it under a microscope. Some people can go home the same day as the biopsy, while others may stay in hospital overnight: this decision will be up to your doctor.

Some centres use a frameless system which involves intra-operative neuro-navigation.

Open Brain Tumour Biopsy

Sometimes the neurosurgeon will perform an open brain tumour biopsy, which is usually done using a general anesthetic. During this type of biopsy the neurosurgeon actually removes a small portion of the skull overlying the brain tumour. The neurosurgeon then obtains the biopsy of the brain tumour by directly visualizing the brain tumour. The removed portion of skull is then replaced. Most people stay in hospital for a day or more after an open brain tumour biopsy.

The Operating Room



Endoscopic Brain Tumour Biopsy

Certain brain tumours may have a connection to the ventricles of the brain (the spaces near the centre of the brain where cerebrospinal fluid is made). Sometimes the neurosurgeon may choose to biopsy these tumours using an endoscope, which is a fibre optic instrument that is placed into the ventricle through a small hole in the skull. The neurosurgeon can then direct the endoscope through the cerebrospinal fluid in the ventricle under direct vision. The neurosurgeon can actually see the brain tumour through the endoscope and then remove a small fragment of the tumour. Most people stay in hospital for a day or two after an endoscopic brain tumour biopsy.

What Type of Anesthesia Is Used for Brain Tumour Surgery?

General Anesthesia

When general anesthesia is performed, you are unconscious for the surgery. Most brain tumour operations are done using this type of anesthesia. Anesthetists administer the anesthetic, and perform an intubation once you are put to sleep. An intubation is the placement of a flexible plastic tube into the trachea (windpipe) to maintain an open airway. Then, monitors are applied and lines are inserted (arterial lines or central lines) to observe blood pressure, heart rate, oxygen levels, blood volumes and cardiac output. You will then be placed in the position required for surgery. Anesthesiologists are experts in physiology, and carefully monitor and correct all of the previously described features during the course of the operation. Any blood lost during the operation will be replaced by blood products while in surgery.

Neuroleptic Anesthesia

In some cases, such as neuroleptic anesthesia, the person is "awake" for the surgery. Although you may be "awake" during the procedure, appropriate intravenous sedation with a local anesthetic will make you comfortable. The nerves in the scalp are injected with a local numbing agent that anesthetizes the entire scalp.

Neuroleptic anesthesia is often used when the brain tumour is located in an "eloquent" area of the brain. Eloquent areas of the brain include those that are involved with functions such as movement (motor area) or speech.

Since any damage to these areas could result in a neurological problem later, you remain awake during the operation in order to help the surgeon in assessing these functions as the tumour is removed. Your functions are assessed continually during surgery.

How Is a Resection Performed?

Since the goal of a brain tumour resection is to remove as much of the brain tumour as is safely possible, the operation is usually more involved and takes more time than a brain tumour biopsy. A brain tumour resection may be done using a general anesthetic or a neuroleptic anesthetic. In some cases, a patient is admitted to hospital prior to undergoing a brain tumour resection. However, more often patients are admitted to hospital on the day of the operation.

During the operation, an incision is made in the skin, and a section of bone is removed to expose the area where the brain tumour is growing. The section of bone removed is called a bone flap. A layer of tissue between the bone and the brain, called the dura mater is then opened. The brain tumour is identified and as much of the tumour as possible is carefully removed. The removed portion of the brain tumour is given to the neuropathologist for identification. The dura mater is then closed. If the bone is replaced after surgery (which is usually the case) and the skin closed, the procedure is called a craniotomy. If the bone is not replaced after surgery but the skin is closed, the procedure is called a craniectomy.

Craniotomy is done when, at the end of the surgery, there is no issue with raised intracranial pressure, as replacing the bone for optimal coverage and protection is always preferred. However, craniectomy is done when:

1. Bone is removed in pieces and cannot be reconstructed; or
2. There are issues with raised intracranial pressure even after tumour debulking, such that leaving the bone out is seen as a safer option, or if the person's brain should swell after surgery.

Most people spend a few days in hospital after a brain tumour resection, during which time a post-operative CT or MRI scan may be performed.

What Are the Possible Side Effects of Surgery?

Surgery to remove a brain tumour is always major surgery. Possible side effects include infection, bleeding, seizures and injury to normal brain function. The likelihood of certain side effects depends on where the tumour is located and whether it invades or grows into sensitive areas of the brain.

Your neurosurgeon will explain the benefits and risks of surgery to you before proceeding with surgery.

What Equipment Is Used to Remove a Brain Tumour?

The neurosurgeon may use different types of equipment during an operation to remove a brain tumour. A cautery device is used to stop blood vessels from bleeding and to remove portions of the tumour. The ultrasonic aspirator is frequently used: it works by using high frequency sound waves to break up the tumour. The brain tumour fragments are then suctioned away. A laser is rarely used during brain tumour surgery.

What Is an Ommaya Reservoir and Does it Require an Operation to Insert?

An Ommaya is similar to a shunt. A shunt drains CSF fuild whereas the Ommaya sits under the skin to inject drugs.

An Ommaya reservoir is a device that consists of a reservoir (a plastic bubble that can hold fluid) attached to a small tube (catheter). An Ommaya reservoir is inserted by the neurosurgeon in the operating room, with the patient under a general anesthetic.

The reservoir is implanted under the skin and the catheter is inserted either into a brain tumour cyst (fluid portion found in some brain tumours) or into a ventricle of the brain. In the case of a brain tumour cyst, the Ommaya reservoir can be used to withdraw fluid from the cyst. If the catheter is inserted into a ventricle, it can be used to deliver chemotherapy directly into

the cerebrospinal fluid. The doctor administering the chemotherapy takes great care to ensure that sterile precautions are maintained while giving chemotherapy through an Ommaya reservoir.

Neuro-Navigation (Image Guidance)

Before undergoing surgery, you will likely have an MRI scan for the purpose of image guidance. Image guidance, or neuro-navigation, is a technique used by the neurosurgeon to help find the brain tumour during surgery and to help the neurosurgeon remove as much of the brain tumour as possible. In this technique, the MRI scan is entered into a computer and the information from the scan is integrated with a sterile probe that the neurosurgeon can use during the operation. The neurosurgeon can place the sterile probe on the brain and at the same time look at the MRI scan to see its location.

Images from the MRI scan can be registered into the neuro-navigation computers either on the day of the operation or in the days before the surgery. If the imaging is done on the same day as the operation, special markers are attached to your scalp before the MRI scan called fiducial markers. If the scan is performed days before, special points on the skull surface are used, such as nose, inner and outer aspects of eyes and ears.

Special Monitoring During Surgery

Because of the length and complexity of brain tumour surgery, special monitoring is usually required during the operation. For this reason, a number of special lines are used, including one or more intravenous (IV) lines, a line into an artery to monitor blood pressure (art line), and a small tube into the bladder to measure urine output (catheter). These lines are placed before the operation begins.

"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 involve 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 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 brain tumours that may disappear 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.

Surgery may not be appropriate

There are times when a brain tumour appears so extensive on an MRI scan that surgical removal is not only unsafe but also inappropriate. These types of tumours are usually malignant and so extensive that even a big operation will leave large amounts of tumour behind. A neurosurgeon may advise against even a first operation. However, the neurosurgeon might recommend a smaller procedure, such as a biopsy.

In cases where multiple brain surgeries have been done, as well as radiation therapy and chemotherapy, and the tumour still recurs (and quickly), it is an indication that the tumour is malignant and aggressive. In this circumstance, the neurosurgeon may advise against further surgery.

Hydrocephalus and Shunts

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Hydrocephalus and Shunts

What Is Hydrocephalus?

Cerebrospinal fluid (CSF) is a naturally occurring fluid found within and around the brain and spinal cord. CSF bathes the brain providing nutrients to the cells, and provides a protective barrier to these delicate structures. Specifically, CSF circulates through channels around the spinal cord and brain, and is constantly being absorbed and replenished.

The brain normally maintains a balance between the amount of CSF that is absorbed and the amount that is produced. However, a brain tumour can disrupt this system and cause blockages in these channels and pathways. When the CSF cannot circulate properly, excess fluid begins building up in the brain tissue surrounding the tumour. This build-up causes an increase in intracranial pressure, which in turn causes symptoms such as headache, irritability, drowsiness and vomiting. This accumulation of excess fluid in the brain causing clinical symptoms is called hydrocephalus.

Brain tumours that occur in the back of the brain – in the posterior fossa region – can fill or compress the fourth ventricle, causing a blockage of the CSF. Similarly, tumours in other areas of the brain can also cause a blockage or compression to the ventricular system leading to hydrocephalus.

Symptoms of Hydrocephalus

Hydrocephalus can be serious and require treatment. Symptoms to watch out for will vary but the signs to be aware of are detailed below:

- Balance problems
- Difficulty walking
- Headaches
- Lethargy
- Nausea
- Seizures
- Vision problems (e.g., double vision)
- Vomiting

Hydrocephalus Treatment

Hydrocephalus is most often treated with the surgical placement of a shunt system into the ventricular system. These shunts are usually placed in the lateral (right) ventricle, but at times, depending on the location of the tumour, other ventricles may need to be shunted. The shunt will remove excess CSF and drain (shunt) it to another area of the body.

A shunt is a narrow, soft and pliable piece of tubing (approximately 0.25 cm in diameter) that is surgically implanted into the ventricle through a small hole made in the skull (a burrhole). The tubing is tunneled under the skin from the burrhole in the skull, down the neck to the distal drainage site (abdomen, peritoneum, lung or heart).

All shunts have a valve system that regulates the pressure of the CSF and prevents backward flow of fluid into the ventricles. Many shunts have reservoirs that can be used for removing CSF.

Types of Shunts and Treatments

There are different types of shunts and placement procedures. To get a better idea of what a shunt looks like, ask to see one. Be sure to write down the name and type of the shunt, as this could be important information, if you run into difficulty when you are away from your medical centre.

Ventriculo-Peritoneal Shunt (VP Shunt)

The most frequently used shunt is a VP shunt because it ends in the abdomen, which is capable of absorbing the excess fluid.

The tubing that is connected to the valve is threaded underneath the scalp and down the neck. The shunt may be placed behind the ear or behind the hairline in the front part of the skull. A small incision may be made in the neck, along the pathway, in order for the surgeon to pass the shunt beneath the skin. The shunt is placed in the fatty tissue, which lies just below the skin. A further incision is made in the abdomen and in the peritoneum, a thin membranous sac that covers all of the organs in

the front of the abdomen. The shunt is placed into the peritoneum, so the cerebrospinal fluid can drain into the abdominal cavity (not the stomach), where it can be absorbed.

Ventriculopleural Shunt (VPI Shunt)

If the abdomen cannot absorb fluid, another option may be to drain the fluid to the pleural space. The pleura is the membranous covering of the lung, and is also good for absorbing excess fluid.

In this system, the shunt tubing is passed to an opening made in the skin and pleura between the fourth and fifth ribs, where the CSF will drain and be re-absorbed.

Ventriculo-Atrial Shunt (VA Shunt)

The VA shunt provides another alternate site to the abdomen. In this system, the shunt tubing is passed from the valve to the neck where it is inserted into a vein. It is then passed through the vein until the tip of the catheter (shunt) is in the atrium (a chamber) of the heart. In the heart, the CSF passes into the blood stream and is filtered along with other body fluids.

Endoscopic Third Ventriculostomy (ETV)

ETV is a standard surgical alternative to ventricular shunt placements for obstructive hydrocephalus; that is, the type of hydrocephalus where the CSF blockage is at or above the level of the fourth ventricle. ETV involves making a hole in the floor of the third ventricle to allow the CSF to flow freely from the third ventricle into the normal fluid chambers below the base of the brain, and across the surface of the brain where it can be reabsorbed into the bloodstream. The surgery is performed with an endoscope. The advantage of this approach is that no hardware is left in place, reducing the risk for infection.

Shunt Care

When at home, make sure the area where the shunt was inserted remains clean. Do not put direct pressure on the shunt.

Occasionally, the shunt system may become blocked or infected. Shunt malfunction means that the shunt is not able to divert enough CSF away from the ventricles of the brain.

When a shunt malfunction occurs, there is a problem with a partial or complete blockage of the shunt. It can occur in any component of the shunt, from the tip in the ventricle to the valve (upper end), or in the catheter in the abdomen (lower end). Surgery is required to fix the blocked part of the shunt.

If a shunt becomes infected, you will usually need to have the shunt system removed and an external ventricular drain put in place until the infection clears. Antibiotics will also be required to treat the infection.

> *Shunt infection is usually caused by bacterial organisms and is not acquired from exposure to other people who are ill.*

Signs that an infection has occurred vary. The symptoms are similar to those mentioned in the *Symptoms of Hydrocephalus* section, but will sometimes include classical signs of infection such as fever and redness or swelling along the tract of the shunt. If symptoms develop, contact your medical team immediately.

Clinical Trials

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Clinical Trials

Clinical trials have allowed the medical community to improve treatments and the quality of life of patients everywhere. As part of your treatment, your surgeon or oncologist may present you with the option of participating in a clinical trial. For this reason it is important to know what they are, what it means to be part of one, and what your rights and responsibilities are if you choose to participate in a clinical trial.

For the purposes of this chapter, cancer treatment is referenced as the primary type of clinical trial.

What Is a Clinical Trial?

In cancer research, a clinical trial is an organized study designed to answer specific questions. Clinical trials that focus on treatment may be evaluating a completely new way of treating cancer, or may be developing different ways to administer an existing treatment, such that it improves the overall survival or quality of life of people with cancer. Besides studying new anti-cancer drugs, clinical trials can look at new combinations of drugs and radiation already used in cancer treatment.

Clinical trial can also compare the best known and routinely used standard therapies with new therapies to see if one produces more cures or remissions with fewer side effects that the other. Since clinical trials involve people, the main concern is the safety and effectiveness of the treatments being evaluated.

Why Are Clinical Trials Important?

Clinical trials may not yield favourable results, but with each trial, important questions may be answered. This ensures the medical community builds on existing knowledge and experience, in order to make progress in the treatment of brain tumours.

A rigorous process ensures that before a new treatment is tested in people, it is carefully studied in the laboratory. First, a drug is considered because it changes cells or parts of cells in a way that suggests it will destroy cancer or help the body deal with the side effects of cancer treatment. Then, the new treatment is tested in animals to learn what it does in the body. But this early research cannot predict exactly how a new treatment will work in people or define all the side effects that might occur.

Each person who participates in a clinical trial provides information on the effectiveness and risks of the new treatment. Advances in medicine and science are the result of new ideas and approaches developed through research. New cancer treatments must prove to be safe and effective in scientific studies with a number of patients before they can be made available to everyone.

Treatments now being used (standard treatments) are the base for building new and improved treatments. Many standard treatments were first shown to be effective in clinical trials. Clinical trials show researchers which therapies are more effective than others. This is the best way to identify an effective new treatment. New therapies are designed to take advantage of what has worked in the past and to improve on this base.

If you are offered the opportunity to enter a clinical trial, your participation is completely voluntary and your treatment will not be affected regardless of your choice to participate or not.

In order for you to make an informed decision, you will need to learn as much as possible about the trial being offered to you as well as other treatment options.

What Types of Clinical Trials Take Place?

There are many types of clinical trials ranging from studies of ways to prevent, detect, diagnose, control and treat cancer, to those studies examining the psychological impact of the disease and ways to improve people's comfort and quality of life (including pain control).

Clinical trials for central nervous system tumours (brain and spinal cord tumours) deal with new approaches for treatment. These treatments most often use surgery and/or radiation therapy. Chemotherapy may involve giving one or more types of drug in combination to treat cancer or stop its growth.

Clinical trials usually progress through a series of steps called phases. Each phase answers specific types of questions and leads to the next phase. At any given time there are numerous clinical trials underway in various phases.

Participants in clinical trials do not have to go through each phase. Instead they may participate in a particular phase based on a certain set of criteria. In general, clinical trials progress through three phases.

Phase I Studies

Phase I studies are the first step in testing a new treatment approach in people. At this stage, researchers are mainly trying to determine a safe dose of the study drug for human administration. They may also test the best way to give the drug (e.g., by mouth or by an injection). Phase I studies usually involve a small number of people and may even include different tumour types.

Participants are first started on the lowest dose possible, and are observed closely for any harmful effects. The dose is slowly increased until a safe dose is established.

Since the drugs have only been used in the laboratory and in animal studies prior to the Phase I study, the risks to people are not completely known, and for this reason are often greater. Therefore, Phase I participants usually include people who are no longer responding to standard treatment. In some cases, a drug in Phase I trials may not produce immediate anti-cancer effects, but over the years some people benefit from them. Once the best dose is found, the drug is studied for its ability to shrink tumours in Phase II studies.

Phase II Studies

Phase II studies are designed to evaluate the safety and effectiveness of an agent or intervention, and evaluate how it affects the human body. These studies usually focus on a particular type of cancer. Drug safety is evaluated closely in both Phase I and II studies, and a database of all side effects thought to be caused by the agent is built. People in Phase II studies are carefully followed with objective measurement of their tumours to detect a response, whether partial or complete.

In order for a treatment to be called effective, it has to affect the size of the tumour not once, but over time. If a certain number of the participants in a Phase II study respond to treatment, the treatment is judged to be effective against their tumour and requires further research. Each new phase of a clinical trial depends and builds on the earlier phase. If treatment has shown activity against a tumour in a Phase II study, it will generally become part of a Phase III study.

Phase III Studies

To establish that a treatment is truly effective against a tumour type, its safety and effectiveness are compared to the safety and effectiveness of the standard treatment in a large population. Phase III studies look for longer life, better quality of life, fewer side effects and fewer cases of cancer returning.

These studies are randomized (where a participant is assigned a treatment based on random selection) so that the group receiving the standard therapy is the control group and those that receive the newer therapy are the experimental group. Randomization is essential in eliminating any potential bias on the parts of the treating physicians and participants to ensure accurate results. The results seen in the experimental group are compared to those seen in the control group.

Adjuvant Studies

Adjuvant studies are done to determine if additional therapy will improve the chance for a cure in patients at risk for the tumour coming back after surgical removal of all visible disease. For example, in a person with a high-grade brain tumour, the first treatment approach used or attempted is

surgery to remove the largest extent of tumour without affecting function. If this is not possible, a biopsy is done to identify the type of tumour. An adjuvant study may look at the benefit of giving chemotherapy following surgery instead of just surgery. If the study results are better with the addition of chemotherapy, then this will be adopted as standard therapy.

Neoadjuvant Studies

Neoadjuvant treatment is given first to try to reduce the cancer to a size where standard therapy is effective. For example, the standard therapy for head and neck cancer is radiotherapy and/or surgery. Sometimes the cancer is too large to safely treat by either of these methods. In these circumstances, chemotherapy may be used to shrink the tumour to a size that can be treated with radiotherapy or that can be removed surgically.

Supportive Care Studies

Clinical trials also try to find better ways of caring for the side effects caused by cancer treatment (such as nausea and vomiting) and the side effects of the cancer itself (such as pain or sleeplessness). Some supportive care studies use drugs to treat side effects, and such studies will have phases (Phase I, II or III), like cancer therapy clinical trials. Other studies look at whether support groups help ease a person's discomfort. Supportive care studies sometimes try to find better ways to help families cope with the illness of a loved one.

How to Find Out About Clinical Trials

Your oncologist or surgeon may approach you about participating in a clinical trial at their centre. Even if you have not been approached, feel free to ask your team if a clinical trial is open or expected to open for someone in your situation.

> *Participation in clinical trials is voluntary and a decision not to participate will not influence your treatment in any way. For more information on **Clinical Trials** please visit **www.BrainTumour.ca/clinicaltrials**.*

Important Questions to Ask About Clinical Trials

If you are thinking about participating in a clinical trial, here are some important questions to ask:

- What is the purpose of the study?
- What does the study involve? What kinds of tests and treatments are involved? (Find out what is done and how it is done)
- What is likely to happen with or without this new research treatment?
- What might the cancer do and what might the treatment do?
- What other choices exist, and what are their advantages and disadvantages?
- What are the standard treatments for my brain tumour and how does the clinical trial compare to the standard treatment?
- How could the study affect my activities of daily living?
- What side effects could be expected from the study drug? (There can also be side effects from standard treatments and from the disease itself.)
- How long will the study last? Will it require extra time on my part?
- Will I have to be hospitalized? If so, how often and for how long?
- If I'm harmed as a result of the research, what treatment would I be entitled to?
- What type of long-term follow-up care is part of the study?
- If the clinical trial ends earlier than planned, can I remain on the therapy after the trial closes?
- How is safety monitored in the study?

Chemotherapy

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Chemotherapy

What Is Chemotherapy?

Chemotherapy is the term given to drugs that treat cancer. Previously, chemotherapy played a smaller part in the overall treatment of brain tumours, compared with other cancers, because many chemotherapy drugs were unable to pass through the blood brain barrier to enter the brain.

Over recent years, chemotherapy has played an increasingly larger role in the treatment of brain tumours, and is sometimes the only treatment for a given disease. More typically, however, it is used in combination with radiation therapy and surgery.

How Does Chemotherapy Work?

There are many types of chemotherapy. Traditional chemotherapeutic agents work by stopping the division of tumour cells, which decreases the chance of tumour growth. Other chemotherapeutic agents make tumour cells more sensitive to the effects of radiation therapy.

Some newer types of chemotherapy stop blood vessels from growing into the tumours (anti-angiogenesis), thereby starving tumours of nutrients and oxygen, and causing the tumour cells to die. Other new agents target specific proteins or genes in the tumour cells, slowing down their growth and/or making them more susceptible to other drugs and/or radiation therapy.

Because different chemotherapeutic agents work in different ways, several are often given simultaneously. This results in different types of damage to the tumour cells, improving the likelihood of destroying more of the tumour or preventing its growth and spread. This also enables doctors to give drugs with varying side effects so that each course of treatment is easier to manage.

How Are Chemotherapy Drugs Given?

Chemotherapy can be given either orally or intravenously.

Oral Chemotherapy

Oral chemotherapy is given either as pills or capsules to be swallowed. If your chemotherapy is oral, you will be given specific instructions and side effect information by your physician and/or nurse before you begin taking the drug(s). One chemotherapeutic agent that is frequently used in the treatment of brain tumours is temozolomide, also known by its trade name Temodal® in Canada or Temodar® in the United States. Studies show that it is effective in many people. Temozolomide can be given daily for many weeks, during radiation therapy, or daily (5 days out of 28) for many years. It has fewer side effects compared with many other chemotherapeutic agents.

Intravenous (IV)

Chemotherapy drugs may be given directly into a vein in the hand or arm. Before the advent of orally administered temozolomide, IV administration of chemotherapy was the most common method of drug delivery. The length of each treatment, the number of treatments and the frequency of treatments are different for each drug. Some people's veins are more difficult to access than others. Usually the chemotherapy nurse makes an assessment of your veins at the time of the initial treatment. For long-term IV administration of chemotherapeutic agents many people undergo the insertion of a special intravenous line called a peripherally inserted central catheter or PICC line.

Intra-arterial

Chemotherapy drugs may be given directly into an artery. However, this is a rarely used experimental method that requires hospitalization.

Intrathecal (Into the Cerebrospinal Fluid)

Chemotherapy drugs may be given directly into the cerebrospinal fluid using a lumbar puncture (spinal tap). Alternatively, the drug may be given through an Ommaya reservoir that is inserted directly into the ventricle, which requires an operation. See **Surgery** section on **Page 95**.

Direct Anti-Tumour Therapy

As technologies improve, methods have been developed to administer chemotherapeutic agents directly to a brain tumour. This requires placement of the chemotherapeutic agent directly in the area where the tumour was located at the time of initial resection, or administration of the chemotherapeutic agent at a later date as part of a specific operation designed for drug delivery.

One technique of direct anti-tumour therapy is the use of biodegradable wafers, also known as Gliadel® wafers. Gliadel is a biodegradable implant that is placed into the surgical cavity after a brain tumour is removed. As the wafer slowly dissolves, it releases a chemotherapeutic drug called Carmustine or bis-chloroethylnitrosourea (BiCNU®). The drug remains in high concentration near the tumour site for an extended period of time. The wafers are approximately 14mm in diameter and 1mm thick (about the size of a dime). Up to eight wafers can be placed at one time. Gliadel wafers are not suitable for everyone or all tumours types, and there are side effects.

Another direct anti-tumour therapy is called Convection Enhanced Drug Delivery. In this technique, small catheters are surgically placed around a tumour cavity after resection and brought out through the skull and skin. The catheters are attached to a pump that can deliver chemotherapeutic drugs directly to the brain surrounding the tumour cavity. Currently, this technique is generally only used in clinical trials.

What Side Effects Are Associated With Chemotherapy?

Some general side effects are common with several chemotherapeutic agents, but there are also side effects specific to each individual drug. Your oncology team will discuss in detail with you, any potential side effects.

The oncologist will give you detailed information about your chemotherapy treatment. Your physician and pharmacist are also able to answer any questions you may have about the drugs being used.

Side effects can include:

Immediate

Occurring within the first 24 hours after the drug is given:

- Nausea
- Vomiting

Short-Term

Occurring within a few weeks after the drug is given:

- Myelosuppression

Long-Term

Occurring months or years after the drug has been given, long-term effects will often need to be monitored and followed up carefully for many years after treatment. There may be long-lasting implications for your health and medical care, such as hearing loss or kidney impairment.

General Side Effects

There are many different chemotherapy agents used to treat cancer, and the possible side effects are unique to each drug and may vary. The neuro-oncologist giving the chemotherapy will carefully explain the possible side effects to you and what to do if they occur. Some common side effects are listed below.

Nausea or Vomiting

This may occur 30 minutes to several hours after the administration of some (not all) chemotherapy drugs. If the chemotherapy is known to cause nausea or vomiting, you will be given other medications (anti-emetics) to prevent it. New, very effective antinausea medications are now available that usually control this side effect.

Hair Loss

Some chemotherapeutic agents will cause hair loss, which can happen over your entire body. This does not happen immediately, but two to three weeks after chemotherapy has been given. Occasionally, the scalp will feel tender as hair is lost. Some people choose to cut their hair short, to make it easier to manage. Your hair will usually grow back once your chemotherapy is completed.

Myelosuppression

The bone marrow is the factory that makes blood cells. Many chemotherapy drugs affect the bone marrow and cause a drop in blood counts. This usually happens 10 to 14 days after a course of chemotherapy is given, and takes another seven days to return to normal.

There are three types of blood cells that may be affected:

- **Red blood cells** carry oxygen around the body. If these cells are reduced in number, you may become anemic, signs of which include paleness and fatigue or feeling tired. Some people become short of breath with exercise and find their activity is limited. A blood count will show a low level of hemoglobin (Hb). If hemoglobin becomes too low, a blood transfusion may be needed. Your doctor will talk to you about this, if necessary.

- **White blood cells** fight infections and make up the body's immune system. Many chemotherapy drugs cause low white blood cell counts, particularly one type of white blood cell called neutrophils. This condition is called neutropenia and essentially means the body cannot fight infections properly. If you develop neutropenia, antibiotics will likely be required. If you develop a fever or become sick after receiving chemotherapy, you should contact the hospital to be examined immediately.
- **Platelets** are small cells that stick together and help the blood to clot when you cut yourself. If your platelet count becomes low, you are at risk of bruising and bleeding. Other signs of a low platelet count include tiny pinpoint purplish spots (petechiae), nosebleeds, or gum bleeding when you brush your teeth. A platelet transfusion may be needed to increase your platelet count.

Peripheral Neuropathy

Some chemotherapy agents (especially Vincristine) may cause damage to the ends of the nerves in the hands and feet causing numbness, tingling or weakness. Autonomic neuropathy causing constipation sometimes occurs with some medications. If you experience any of these side effects, report them to your oncologist. They are usually temporary and disappear gradually once you have completed your chemotherapy.

> *Autonomic neuropathy is a group of symptoms that occur when there is damage to the nerves that manage everyday bodily functions such as blood pressure, heart rate, bowel and bladder emptying, and digestion.*

Hearing Loss

A few chemotherapy agents (especially cisplatin) may cause hearing loss. If you are receiving a drug that might cause hearing loss, special hearing tests (audiograms) may be done to monitor any loss of hearing, so that your treatments can be changed before any serious hearing loss occurs.

Radiation Therapy

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Radiation Therapy

Therapeutic radiation is similar to that of diagnostic X-rays (e.g., chest X-ray) but of a much higher energy and similar to an X-ray in that it cannot be seen or felt. Radiation therapy works by destroying tumour cells by inducing damage to their inner structure (DNA). The cells die when they attempt to reproduce (divide) because the DNA is damaged, and are then absorbed into the body. Not all tumour cells are sensitive enough to the radiation, and this is why tumour cells can grow back or the tumour does not shrink completely. We are limited in the amount of radiation that can be delivered to the tumour because of the surrounding normal brain tissue, as normal brain tissue cells will also be exposed to the radiation as a consequence of targeting the tumour.

Healthy brain tissue cells have the ability to repair the radiation-induced DNA damage; however, there is always some proportion of cells that will be permanently damaged. This is why there can be both short-term and long-term side effects from the radiation. Radiation therapy is delivered using a machine called a linear accelerator, or linac.

Modern radiation techniques allow doctors to accurately focus radiation therapy to the area(s) of the brain requiring treatment, and minimize the amount of radiation hitting the normal tissue. This new radiation technique can best be described as conformal radiotherapy and includes many different specific technologies:

- 3D radiotherapy means that the full dose region can be shaped around the tumour in all three dimensions.
- Stereotactic radiation therapy refers to the use of stereotactic frames (the same ones used in neurosurgery) to help guide the radiation beams to the correct area of the brain.
- Intensity-modulated radiation therapy (IMRT) refers to a relatively new technique where the intensity of each radiation beam can be modified to better exclude important parts of the brain (such as optic nerves, the brain stem, and the pituitary gland that are near the tumour) while maximizing dose to the tumour.

- Image-guided radiation therapy (IGRT) refers to the use of some form of daily imaging on the linear accelerator itself that helps guide the therapists in accurately delivering the daily doses of radiation to the exact areas intended. This involves the use of 2D images, optical tracking techniques and mini-CT scans done on a daily basis right in the treatment unit.

External Beam Radiation Therapy

Radiation therapy involves external beams of high energy X-rays (or particles) accurately aimed at the tumour. External beam radiation therapy is delivered via machines called linear accelerators (linac).

Through precise planning and the use of shields and masks, the amount of normal tissue within the treatment field is kept to a minimum. Radiation is generally given in many doses (fractions) over a period of time. Depending on the type of tumour, as well as its location in the brain, the frequency of each dose of radiation as well as the length of treatment may vary. Patients usually receive radiation treatments once a day, five days a week, for a certain number of weeks, which is determined by your radiation oncologist. Radiation is not given on weekends unless it is an emergency.

You are expected to remain still while receiving radiation treatments. A mask will be made to ensure that your head is stable during treatment. This will require one visit, during which a CT scan will be done with the mask on (simulation appointment). Radiation is planned based on this information. This planning can sometimes take a few days, so there may be a waiting time between planning and treatment. Your radiation oncologist will decide on the radiation target area and the amount of radiation to be administered. When radiation is given, you will not feel or see anything during the treatment. The radiation therapy session will usually last no more than 10 to 30 minutes. Although you will be in the treatment room by yourself, your health care team will monitor you closely.

*For more information on your **Health Care Team** please turn to **Page 183**.*

Generally, a patient can have external beam radiation therapy only once in the same spot. Other types of radiation therapies, such as stereotactic radiation, may allow for further radiation in a very focused area. Additional radiation can also be given in another area of the body.

What Is 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 the XKnife®, Axesse®, 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 person's head by a neurosurgeon.

Stereotactic radiosurgery may not be suitable, depending on the size of the tumour; if the tumour is too large then it may be unsafe. Anyone who is a candidate for this treatment must be well enough to undergo it. The procedure may be done either in the out-patient setting or may involve a brief admission to the hospital, but this situation is rare.

New techniques to deliver stereotactic radiation are being developed and focus on replacing the existing head frame with new, non-invasive systems, and delivering the radiation in a few precise treatments rather than a single treatment. The advantage of delivering the radiotherapy over several sessions is that it could provide a large enough dose to treat large tumours, something for which a single treatment is not suited for.

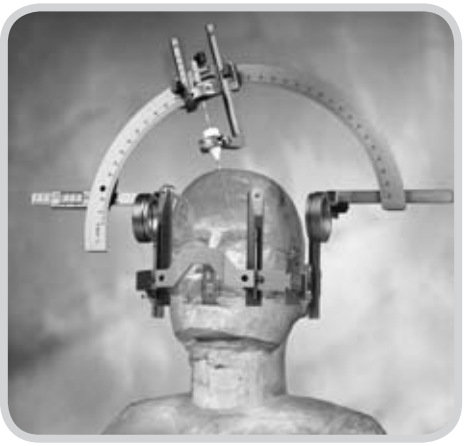

Photo courtesy of Elekta Canada Inc.

Gamma Knife®

The Gamma Knife is a specialized unit used for intracranial radiosurgery. It was developed to deliver a single high dose of radiation precisely to a target. The technology is based on using an invasive stereotactic head frame, however recent technology has been developed to allow for "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.

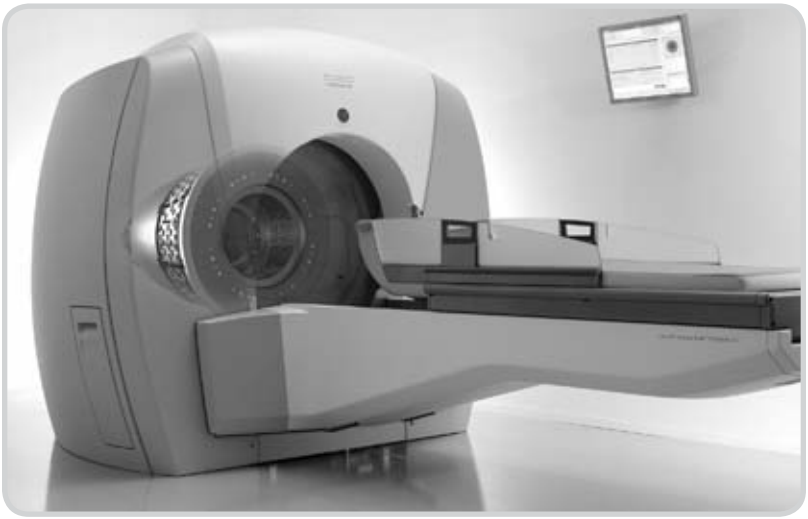

Photo courtesy of Elekta Canada Inc.

For more information on Gamma Knife® locations in Canada visit ***www.BrainTumour.ca/gammaknife****.*

CyberKnife®

The CyberKnife is a robotic radiosurgery system that delivers highly targeted beams of radiation to a tumour. This machine allows for both intracranial and extracranial body radiosurgery. With its integrated image-guidance solution, there is no need for an invasive head frame. Instead, the procedure uses a more comfortable thermoplastic mask. Each treatment session may last between 30 to 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.

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

Standard linear accelerators (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.

Potential Side Effects of Radiation Therapy

There are some common side effects associated with radiation therapy. The following information outlines some of the frequently reported acute side effects. You should discuss potential long-term side effects with your radiation oncologist or nurse.

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.

Swelling

Since radiation may cause some swelling (edema) in the tissue around the tumour site, you may be placed on steroid medications to reduce this swelling. See **Page 146** for more information about steroid medication.

Headache

Radiation therapy may cause swelling and this increased intracranial pressure can result in headaches. If you are taking steroids, continue to do so as prescribed. If you experience headaches, tell your radiation oncologist, in case your medications need to be adjusted.

Hair Loss

Radiation to the head may cause hair loss in the area treated. The loss of hair usually does not begin until two weeks after the start of radiation. The hair may re-grow over several months after treatments are completed, but sometimes the loss of hair is permanent, depending upon the amount of radiation received.

> *You can help prepare by looking into wigs or finding some colourful and comfortable scarves or hats for yourself.*
> *For more information on Wig and Hair Donation please visit* ***www.BrainTumour.ca/hairandwig****.*

Nausea and Vomiting

Nausea and vomiting are known side effects and can occur 30 minutes to several hours after treatment. If you experience radiation-induced nausea and vomiting, your doctor will prescribe an anti-emetic medication that should relieve this side effect. See **Page 139** for more information about anti-emetic drugs.

Fatigue

Fatigue is the feeling or sensation of tiredness. It is a common symptom in people who undergo radiation therapy. It is reported as the most severe side effect of radiation during the last week of treatment. The signs that you are experiencing fatigue include feeling weary or exhausted. This may be experienced as physical, emotional, or even mental exhaustion. Getting enough rest, eating healthily, and doing light exercise are all helpful in combating this side effect. Radiation-induced fatigue should resolve within several weeks after therapy is complete; however, persistent fatigue should be reported to your doctor.

Skin Irritation

You may experience local skin irritation including redness, dryness and itching. You will be assessed daily during treatment as effects vary in intensity for each individual. These changes to the skin usually happen 1 to 2 weeks after your treatment begins and may last 1 to 2 weeks after your last treatment. Be gentle with this area and ask your radiation oncologist or nurse for a list of recommended products and those to avoid.

Supportive Medications

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Supportive Medications

Do not stop any medications without the approval of your physician.

This section provides general information about the medications that are commonly used in the treatment of brain tumours, including anticonvulsants, anti-emetics, chemotherapy medications and steroids. Please discuss all medication use with your doctor and pharmacist.

Consult with your doctor or pharmacist before taking other medications, including over-the-counter products, and herbal or alternative medications.

Anticonvulsants / Anti-Epileptics

In order for the seizure medications to be effective, they must be taken exactly as prescribed. The dose and time of administration is very important. In order for the drug to work, it must reach a certain level in your bloodstream known as the therapeutic level. The bloodstream carries the medication to the areas of the brain where the seizures begin. If there is too little of the drug, you are at risk of having a seizure, and if there is too much, there could be side effects.

It is advisable to discuss your anticonvulsant medication with your physician and your pharmacist. Each of these drugs can have different side effects, often due to a toxic level of the drug in your body. Reducing the dosage can reduce the side effects. See the chart below for side effects.

Women should be aware that some anticonvulsants interact with birth control pills, reducing the effectiveness of both medications. If you are a woman of reproductive age who is taking or will be taking anticonvulsants, discuss your birth control otpions with your physician.

Medication: Anticonvulsants / Anti-Epileptics	**Potential Side Effects**
Carbamazepine (Tegretol®)	Carbamazapine can be taken with food to prevent an upset stomach. When you begin taking this medication, you may experience some dizziness, drowsiness, headache, double vision and nausea. If you develop a skin reaction or rash, inform you doctor right away. Report all additional medications you are taking to your doctor. Carbamazapine can have interactions with other medications causing an increase or decrease in this medication's effectiveness.
Clobazam (Frisium®)	Clobazam is currently used only in combination with other anticonvulsant medications. Inform your doctor if you are on any other anticonvulsants. Common side effects include drowsiness, dizziness and fatigue. This medication can also cause an upset stomach. Take this medication with food to minimize this side effect. Women should avoid taking this medication during the first trimester of pregnancy as well as while breast-feeding.
Divalproex Sodium (Epival®)	Divalproex sodium is another form of valproic acid and therefore the side effects from divalproex sodium are identical to valproic acid. See the section for Valproic Acid for potential side effects.

Gabapentin (Neurontin®)	Gabapentin is generally well tolerated. If side effects do occur, the most common include headache, fatigue, nausea, drowsiness, blurred vision and cause trouble in thinking. Make sure you understand how this medication affects you before you drive. This medication can be taken safely with other anticonvulsants without risk of interactions.
Lamotrigine (Lamictal®)	Lamotrigine is often well tolerated; however some potential side effects include headache, fatigue, dizziness, and blurred vision. There is a possibility that a rash may develop within the first six weeks of taking lamotrigine. If a rash occurs, inform your doctor immediately but do not stop taking this medication on your own.
Levetiracetam (Keppra®)	Levetiracetam is generally well tolerated. However side effects can include, dizziness and loss of strength. Occasionally, decreased blood cell counts may occur.
Oxcarbazepine (Trileptal®)	Oxcarbazepine can be used on its own or in combination with other anticonvulsants. The most common side effects include dizziness, sleepiness, fatigue, nausea, and tremors. Oxcarbazepine can also cause sodium blood levels to drop. If your doctor feels that you are at risk, your sodium blood levels may be monitored closely on regular basis.

Phenobarbital (Phenobarbital®)	Phenobarbital has several possible side effects that may go away as your body adjusts to this medication. The more common side effects include dizziness and unsteadiness, as well as drowsiness. The less common side effects include anxiety, headache, irritability, and trouble sleeping. Make sure that you are aware of how this medication will affect you before you attempt to operate a vehicle. This medication causes many people to feel dizzy and less alert than normal.
Phenytoin / Dilantin®	Side effects from phenytoin are common. Some of these effects include drowsiness, headache, weight loss and increased hair growth. Irritation of the gums may occur. Excellent personal dental care is important as well as regular supervision by a dentist. At times, if you are on steroids, you may require a higher phenytoin dose. This medication can also cause an upset stomach. Take this medication with food, and drink plenty of water. All additional medications taken should be reported to your doctor. The levels of this drug in your blood can be increased or decreased depending on which other medications you are taking.

Valproic Acid (Depakene®)	Although side effects from this medication are not common, valproic acid can cause drowsiness. Do not drive a vehicle or operate machinery until you know how this medication will affect you. Other possible side effects include hair loss, weight gain, tremor and liver toxicity (rare). This medication can also cause an upset stomach. Take this medication with food, and drink plenty of water. Before taking this medication, tell your doctor if you are pregnant or planning to become pregnant. Talk to your doctor about the risks of taking this medication during pregnancy, as well as breast-feeding.

Anti-emetics / Antinauseants

Some brain tumour treatments may cause nausea or vomiting that can range from mild to severe. These are commonly reported side effects that can impact daily functioning and quality of life. Medications called anti-emetics are often given to prevent or minimize these side effects and control nausea effectively. One or more anti-emetics can be given before and/or after each treatment.

Ask your doctor, nurse or pharmacist how and when to take the anti-emetics, how long each drug takes to work, and what to do if the medications are not working.

There are several anti-emetic drugs available in Canada and your doctor will assess which medication is best for you. Some common anti-emetics include Ondansetron (Zofran® , Granisetron (Kytril®) and Prochlorperazine (Stemetil®).

Always tell your doctor or nurse if you experience nausea or vomiting. You should ask questions about your anti-emetic drug to learn how long the medication will take to work, how and when to take the medication, and what you should do if the medication is not working.

Medication Anti-emetics / Antinauseants	Potential Side Effects
Dimenhydrinate (Gravol®)	Dimenhydrinate is available as an oral tablet, liquid, rectal suppository, and as an injection. Tablets can be taken with or without food. Common side effects include drowsiness, dry mouth and possible constipation.
Granisetron (Kytril®)	Granisetron is available as an oral tablet or as an injection. Tablets can be taken with or without food. Side effects include constipation and headache.
Metoclopramide (Maxeran®)	Metoclopramide is available as an oral tablet, liquid and injection. Tablets can be taken with or without food. Common side effects include diarrhea, abdominal cramps and drowsiness. Rarely, it may cause jaw, neck or back spasms.
Ondansetron (Zofran®)	Ondansetron is available in three different oral formulations (tablet, liquid and oral-dissolve tablet) or as an injection. Tablets can be taken with or without food. Side effects include constipation and headache.
Prochlorperazine (Stemetil®)	Prochlorperazine is available as an oral tablet, injection or a rectal suppository. Tablets can be taken with or without food. Common side effects include drowsiness and dizziness. Rarely may it cause jaw, neck or back spasms.

Chemotherapeutic Agents

Chemotherapy is defined as any treatment involving the use of drugs or medications to kill tumour cells. It is often used to treat higher grade, malignant brain tumours, but may also be used to treat lower grade, non-malignant tumours in some people.

Chemotherapy can be prescribed individually or, in some cases, in combination. Chemotherapeutic drugs work by changing the ability of the tumour cells to reproduce themselves, by killing existing cells, or by altering the environment in which the tumour grows. Chemotherapy is usually administered orally (by pills) or intravenously (by injection into a vein).

Your doctor will prescribe an individual treatment plan for you, and the treatment schedule will be specific to the type of chemotherapy that you are given, and the type and grade of your tumour. Some tumour types are known to react very well to chemotherapy and are considered chemo-sensitive.

> *For complete information about these medications, it is important to talk to your doctor and your pharmacist.*
>
> *For more information turn to the **Chemotherapy** section on **Page 119**.*

There are many different types of chemotherapeutic drugs to treat brain tumours. The chart below is not necessarily a complete list of all possible medications, but will provide you with some general information about several chemotherapeutic agents available in Canada. It is important to speak with your doctor for complete information about these medications.

Medication Chemotherapy Agents	Potential Side Effects
Bevacizumab (Avastin®)	Bevacizumab is delivered by injection into the blood stream over 30 to 90 minutes by a chemotherapy nurse. This medication can be used alone. Side effects include infusion-related reactions, impaired wound healing, bleeding, high blood pressure and blood clots.
Carmustine (BCNU®)	Carmustine is delivered by injection into the bloodstream. It is usually administered over 1 to 2 hours by a chemotherapy nurse. Nausea and vomiting are common side effects from carmustine, but typically last no longer than 4 to 6 hours. This medication may also lower your resistance to infections by lowering your white blood cell count. Signs of an infection include fever, chills, cough and sore throat. Less common side effects of this medication include diarrhea, dizziness, and loss of appetite. Some people may experience temporary loss of hair. After treatment has ended, hair growth should return to normal.

Cisplatin (Platinol® and Platinol AQ®)	Cisplatin is delivered by injection into the bloodstream and is normally administered over a period of 30 minutes to two hours by a chemotherapy nurse. Cisplatin usually causes nausea and vomiting, which may be severe. Ask your health care professional for ways you can lessen these effects. Other common side effects include loss of appetite, loss of balance, weakness and fatigue and joint pain. This medication may also lower your white blood cell count, which may increase your risk of infections.
Lomustine (CeeNU®, CCNU)	Lomustine is an oral chemotherapy in capsule form. This medication should be taken at bedtime, on an empty stomach with a glass of water. Some of the more common side effects from this medication include nausea and vomiting, loss of appetite or weight, weakness and lethargy. It is important to note that this medication may reduce your white blood cell levels. This can result in a greater risk of infections. Your doctor will order tests frequently to monitor your blood cell count.

Procarbazine (Natulan®)	Procarbazine is taken as a capsule by mouth with a full glass of water. Avoid alcohol and caffeine while you're taking this drug. You will also be asked to follow diet restrictions to avoid certain foods that contain tyramine. Common side effects of procarbazine include nausea and vomiting, weakness, loss of appetite, headache, and difficulty swallowing. This medication may also lower your white blood cell count, which may increase your risk of infections.
Temozolomide (Temodal®)	Temozolomide is an oral medication that comes in capsule form. The capsules should be swallowed whole with a full glass of water. Taking this medication on an empty stomach before bedtime can help reduce nausea, a common side effect from temozolomide. Other common side effects include headache, constipation, fatigue, and weakness.
Vincristine (Oncovin®)	Vincristine is delivered by injection into the blood stream by a chemotherapy nurse. It is often used in combination with other chemotherapy drugs. Common side effects include nausea and vomiting, changes in hearing, headache, jaw and joint pain, visual disturbance and constipation. Like many other chemotherapeutic drugs, vincristine may lower your white blood cell count, which may increase your risk of infections.

Steroids

Steroids, also called corticosteroids, are frequently prescribed when a person is diagnosed with a brain tumour, or before or after surgery as well as during radiation therapy. They work to reduce swelling. Brain tumours cause tumour associated edema (brain swelling) in the surrounding tissue. Edema is the accumulation of cerebrospinal fluid (CSF) in the tissue around the tumour and is very common with brain tumours.

Steroids reduce the swelling (edema) in the normal tissue by decreasing the flow of fluid across the abnormal blood vessels of the tumour; this will temporarily relieve symptoms such as headache, nausea and vomiting, and seizures. It may also improve neurological function. The full effect of the steroids in reducing edema becomes evident between 24 and 72 hours after administration.

Common steroids include dexamethasone (Decadron®), prednisone and methylprednisolone. Dexamethasone is the most frequently prescribed steroid because it is more potent and can be given orally or intravenously. All corticosteroids have similar side effects.

Steroids can alter the gastric lining of your stomach and cause stomach upset or irritation. These medications should be taken with milk or preferably food. Ranitidine (Zantac®) can be found at any pharmacy or your doctor can prescribe other medications to help prevent this irritation. If you are taking steroids, you may be told not to use other medications, such as acetylsalicylic acid (ASA, aspirin), which can also irritate the stomach. Drinking alcoholic beverages while on steroids can also cause stomach problems.

If you are having surgery, it is important to mention that you have been, or are on steroids.

Medication **Steroids**	**Potential Side Effects**
Dexamethasone (Decadron®)	Steroids have several positive effects such as relieving intracranial pressure causing a decrease in symptoms. Often there is a temporary improvement in functioning abilities and an improvement in appetite. Steroids can have negative effects including lowering your resistance to infections by affecting your immune system. Speak with your doctor as soon as possible, if you notice any signs of a possible infection, such as sore throat, fever, sneezing or coughing. Steroids can cause weakness in the muscles, especially in the legs, arms, neck and chest. This weakness should be reported to your physician.Usually, these effects resolve when the medication is discontinued.
Prednisone	Personality changes or mild depression and irritability may occur. Talk to your doctor about these symptoms. If you are placed on steroids for an extended period of time, there are medications that can relieve some of these changes. Appetite is often affected and can increase with steroid use, which could lead to weight gain. Alternatively, some people may experience a loss of appetite and should monitor their weight to avoid weight loss.

At the Hospital

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At the Hospital

Parking

Most facilities have daily, weekly or monthly parking rates, but check the availability and cost at your facility.

Accommodations

Most major neuro centres have reduced rate accommodations. Check with either your social worker or nurse about these kinds of accommodations at your hospital.

Preparation for Surgery

When you are diagnosed with a brain tumour, your surgeon may feel it is best for you to go home for a few days to allow the steroids (anti-swelling drug) to work, and then come back to the hospital the day of your surgery. Alternatively, the surgeon may admit you to the hospital if the surgery needs to be done on an urgent basis. Either way, the preparation for surgery is generally the same.

You will be asked to go to the admitting department where a clerk will ask you for your health insurance card and then you'll either be escorted to your room (if you are staying in-hospital) or to the pre-admission clinic (if you are an out-patient).

All blood work, X-rays, CT scans, MRI scans, and any other tests will be done "in house" or on an out-patient basis, prior to your surgery date, and results will be ready the day of your surgery.

The nurse will meet with you and ask you about past surgeries, medical history, current medications, allergies, special physical needs and phone numbers for your next of kin. It is advisable to bring a written record of all this information with you. You may also want to write down any questions you have for the doctor or nurse, as this is often a time of anxiety and uncertainty, and you may forget to ask important questions. Remember, there are no "silly questions" and any question you have is important to the medical staff, to you, and to your family.

Before surgery, your surgeon or her delegate will explain the surgical procedure, the risks, and any potential complications to you and your family. Don't be afraid to ask questions – it is important that you have a clear understanding of your surgery. Once the consultation is over and everything is explained to your satisfaction, you will be asked to sign a consent form.

An anesthesiologist (the doctor who will be putting you to sleep for the surgery) may visit the night before your surgery or in the pre-admission clinic. He will ask you questions about your general health, any specific health issues you may have such as diabetes, high blood pressure, heart disease or any family history of adverse reactions or allergies to an anesthetic. The physician will answer any questions or concerns you may have about the anesthetic, and help you with anxiety.

Your head may be partially shaved. Sometimes the neurosurgeon will clip a narrow band of hair, just where the skin will be incised, in the operating room.

You can have a shower and wash your hair before surgery.

You may have a mild sedative the night before surgery and you will be asked not to have anything to eat or drink after midnight, as this would interfere with safe anesthetic care and could cause the surgery to be cancelled.

Surgery Day

The majority of people come to the hospital the morning of their surgery. As mentioned earlier, you will likely have been to the pre-admission clinic beforehand, so all of your history, X-rays and blood work will more than likely be in the day surgery department.

When you arrive, the day surgery nurse will greet you and your family. You will be asked to change into a hospital gown. The nurse will ask you questions about previous surgeries, allergies, medical history, phone numbers for the next of kin and current medication. She will take your blood pressure, pulse, respiratory rate, temperature and perform a neurological assessment which involves asking you questions about

orientation, testing the strength of your arms and legs, and flashing a light into your eyes for pupil contraction. This neurological assessment will be done frequently during your hospital stay. An intravenous will be started. Often, both the surgeon and the anesthesiologist will visit you before you are called to the operating room.

When you go to the operating room, your family will be asked to leave a telephone number where they can be reached by the doctor after surgery. This will be documented on your chart. If your family wishes to speak to the doctor in person after the surgery, they should let the nurse or doctor know where they will be. In some hospitals, your family can wait in the patient's room; however, there often is a waiting room near the operating suites where they can wait and usually there is a volunteer who can give your family updates.

Your family may have to be patient, as the surgery could take longer than scheduled. This can be a very stressful time for your family or loved ones, so taking walks, reading a book or going home for a little while may relieve some of the anxiety.

The Operating Room

You will be brought to a waiting area outside the operating room, by stretcher, where a nurse will meet you. The nurse checks you in by asking basic questions about your last surgery date, false teeth (which need to be removed), allergies, metal plates, last food or drink taken and any other special needs.

You will be introduced to the staff. General equipment in the room (intravenous, blood pressure cuff, etc.) is explained. You will again meet the anesthesiologist who will explain the procedures used to put you to sleep for the surgery. If you are able to move yourself, you will be asked to move from the stretcher to the operating room table.

After the surgery, you will be transferred to the recovery room where you will awaken.

The Recovery Room

You will be brought to the recovery room for close observation following your surgery. In some hospitals, patients stay overnight in the recovery room. In others, they remain until they have recovered from the anesthetic and are stable (approximately 1 to 2 hours) and are transferred to a special care unit or back to their rooms.

A registered nurse will be assigned to care for you while you are in the recovery room. As you begin to wake up you may feel cold and you may begin to shake – this is a normal reaction. Warm blankets will be given to you to help relieve this discomfort. You will also be aware of an oxygen mask on your face. This could stay on overnight or it may be switched to a more comfortable oxygen device called nasal prongs. You will be encouraged to breathe deeply and cough to maintain enough oxygen in your bloodstream. The head of your bed will be elevated 30 degrees or higher. You will probably feel a turban-like head dressing that could feel tight.

Your vital signs (blood pressure, temperature, respiratory rate) and your neurological signs (orientation, pupils, strength of your limbs) will be monitored frequently while you are in the recovery room and later in the special care unit. You will still have the intravenous running to help keep you hydrated and allow the staff to administer certain drugs such as corticosteroids to decrease brain swelling, antinausea drugs and painkillers. You will probably have a urinary catheter to drain the urine from your bladder. It is normal to feel like you have to urinate; this sensation will gradually subside. You will have an arterial line (which looks like an intravenous in your wrist) used to monitor your blood pressure and take blood samples, if necessary.

You may experience a headache and/or nausea and vomiting. This is quite normal after surgery. You will be given pain medication and antinausea drugs.

While you are in bed, you will have special stockings on to promote circulation and prevent clots in your legs. These stockings will automatically tighten and release around your legs every few minutes. You will be encouraged to move your legs until you are up and walking.

Visiting hours and restrictions for recovery rooms vary from hospital to hospital. Check with your nurse on the floor or in the pre-admission clinic before going to the operating room, how your family will receive information about your condition while in recovery room or making phone calls to the recovery room.

The surgeon will usually come and talk to your family after surgery and will visit you on a regular basis during your hospital stay.

The Post-Operative Period

Once your condition is stable, you will be transferred to a special care unit or to your room. Your condition will be closely monitored while you are in the special care unit. You may remain in the special care unit overnight and be transferred to your own room when you are considered stable, for the rest of your stay in the hospital.

A neurological assessment will be done at least every hour, or more frequently, depending on your condition. Your blood pressure, temperature, pulse, respiratory rate and your head dressing will be closely watched as well. If you experienced deficits such as speech difficulties or some kind of motor dysfunction before your surgery, these may not improve immediately following the operation. These symptoms may be caused by brain swelling, which may improve with time. Whatever your difficulties may be, the medical staff is fully equipped to help you with aids such as communication boards or devices to help you get around.

Eye swelling is quite common after surgery, so don't be alarmed if you are unable to open your eyes. The swelling will go down with time.

It is quite normal to have a CT or MRI scan the morning after your surgery, to help the medical staff determine whether there is any bleeding, fluid collection or residual tumour.

The head dressing usually stays on for 24 to 48 hours.

Sutures (Stitches)

There are three types of sutures that may be used; sutures, self-absorbing sutures, and staples.

Your surgeon may also use a special type of surgical glue.

- Self-absorbing sutures are absorbed by your body within 10 to 21 days, so they do not need to be removed. As the sutures age, they turn dark in color.
- Sutures and staples: If this is your first brain tumour surgery, the stitches or staples should be removed approximately 7 to 10 days after surgery. If this is not your first surgery, or if you had radiation, the stitches and staples will be removed in approximately 14 days.
- Your neurosurgeon will inform you when to have your stitches or staples removed.
- Your nurse will provide you with a special instrument called a staple remover or a suture removal kit.
- You can have your staples or sutures removed by your family doctor, by the home care nurse, or in a medical clinic. Your nurse will discuss the options with you.

Taking a Bath and Washing Your Hair

- Once you can get in and out of the tub comfortably, you can take a bath or a shower. You can rent a chair for the bathtub.
- Do not let your incision soak in water.
- Do not go swimming.
- You may wash your hair starting the fourth day after surgery – or sooner if your neurosurgeon indicates it's alright. You may have your first hair wash while in hospital.
- You can use any brand of mild shampoo like baby shampoo.
- Gently pat soapsuds over your incision – do not rub it. Let the water and soap run down over the incision – do not spray water right on it. Gently pat the incision dry with a towel.

- Do not use a hair dryer, cream, ointment or hair products on your incision unless your health care provider tells you so.
- Cover your head with a hat, cap or scarf, if you go out in the sun.
- The wound heals better if left open to the air.

A bald spot – or absence of hair at the suture site, even if minimal, can be quite devastating, especially for younger people and women. If you undergo further treatment (radiation), your hair may not grow back until your treatment is finished.

Most of the chemotherapy drugs used for brain tumours do not cause hair loss.

Importantly, there are many innovative ways to deal with temporary and treatment-related hair loss. You can restyle the hair that remains, wear hats or scarves, or you may want buy a wig (wigs are not recommended until after the incision is fully healed). Wigs can cost anywhere from one hundred dollars (synthetic) to thousands of dollars (real hair). Some insurance plans cover some of the cost, so it is best to check with your insurance company.

*For more information on **Wig and Hair Donation** please visit **www.BrainTumour.ca/hairandwig**.*

For Family Members and Loved Ones

It is important that family members understand what will happen during the post-operative period. During the initial post-operative period, having a quiet environment helps to prevent unnecessary stimulation and reduces the risk for stress caused by headaches, photophobia (sensitivity to light), agitation, or speech and motor deficits. If your family or loved ones are present, they can help by sitting quietly by your bedside. Sometimes gentle music may help to reduce agitation. Familiar objects, such as family photos, clock radios and calendars are also useful in helping with post-surgical re-orientation.

Setting up a visiting schedule among family members will help you manage your visitors so you do not become over-tired or overwhelmed. It is also wise to have one or two loved ones act as liaisons between the doctor or nurse and your family. In some units there may be restrictions as to the number of visitors and the hours during which people can visit. Make sure your family and your loved ones are aware of any visitors' restrictions and that they understand those restrictions are meant to allow you time to rest.

As with all types of surgeries, complications are possible, although these problems are rare. Your surgeon will go over any potential complications with you and your family before surgery.

Below is a list of possible complications for easy reference. The medical staff will monitor you for these complications.

GENERAL COMPLICATIONS	
Pneumonia	During surgery, secretions can accumulate in the lungs, and pneumonia and other respiratory difficulties can follow if the lungs are not kept clear. The nurses and physiotherapists will teach you deep breathing and coughing exercises and they will remind you to do these exercises regularly post-surgery. Another way to avoid this is to get out of bed as soon as possible and walk around the halls of the hospital.
Urinary Tract Infection	These infections are usually related to the presence of the catheter in the bladder and are treated with antibiotics and increased fluid intake. The catheter is usually removed 12 to 24 hours post-surgery.

Deep Vein Thrombophlebitis	This is an inflammation of the veins caused by a decreased blood flow through the veins. It can occur after long stretches of immobility, either on the operating room table or in bed. To help prevent this, patients wear anti-embolic or heavy support hose along with mechanical leg stockings, which give a prescribed alternating rhythmical massage up and down the leg. Although the environment is kept quiet after surgery, a certain amount of movement is essential to keep the blood flowing throughout the body, preventing the formation of a clot. The level of activity will depend upon the ability of the patient. Typically the patient will be assisted out of bed the following morning, and as soon as possible, the patient will be encouraged to get up and walk. For those patients who are unable to get out of bed, simple leg exercises will be taught.
Swelling of the brain	After surgery, the brain can swell to a different degree. The swelling can be controlled to some extent by anti-swelling medication. The patient will have a post-operative CT scan or MRI to check the extent of the swelling. The patient will be monitored closely with the doctors and nurses performing neurological assessment to detect any deterioration.

Bleed	After surgery, there is a remote possibility of a bleed at the surgical site. This is why patients are monitored closely for any sign of deterioration. A CT scan or MRI post-operatively can help detect this complication.
Stroke	A stroke (ischemic) is a blockage of the blood supply in a specific arterial territory of the brain, leading to deficit such as speech deficit or motor deficit. All precautions would have been taken to avoid a stroke. Your surgeon would have discussed with you the possible complications of the operation, and the likelihood of occurrence.

Nutrition

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Nutrition – During and After Treatment

Treatment for brain tumours can include a combination of surgery, radiation and chemotherapy. Radiation and chemotherapy work to destroy tumour cells, but they also cause side effects that affect your ability to eat. Nutrition plays an important role when you are experiencing these side effects. Eating a balanced diet can help you:

- Avoid weight loss or excessive weight gain
- Feel better
- Fight off infections
- Manage the effects of treatment
- Repair cells and heal wounds by building new tissues

Good Nutrition

Protein, carbohydrates and fat provide energy for your body. They also provide the building blocks that help your body heal and stay healthy. While vitamins, minerals and water help your body use energy from these nutrients, they do not provide energy themselves. And single food can provide all the essential nutrients that your body needs. Therefore, it is important to enjoy a variety of foods as shown in Canada's Food Guide to Healthy Eating.

*For more information on **Nutrition and Fitness** please visit **www.BrainTumour.ca/nutrition**.*

Recommended Number of Food Servings Per Day

Food Group	Serving Examples and Sizes	
Grain Products	**1 Serving**	**2 Servings**
5-12 servings per day	1 slice of bread	1 bagel, pita, or bun
	30g cold cereal	1 cup of pasta or rice
	¾ cup hot cereal	
Vegetables & Fruits	**1 Serving**	
5-10 servings per day	½ cup fresh, frozen or canned vegetables	
	½ cup cooked leafy vegetables	
	1 cup raw leafy vegetables	
	½ cup fresh, frozen or canned fruits	
	½ cup 100% juice	
Milk Products	**1 Serving**	
2-4 *servings per day*	1 cup of milk	
	50g of cheese = 2 cheese slices	
Pregnant and breastfeeding women: 3-4	¾ cup of yogurt	
Meat & Alternatives	**1 Serving**	
2-3 servings per day	50-100g of meat, poultry or fish	
	1-2 eggs	
	50-100g of tuna	
	125-250ml of beans	
	1/3 cup of tofu	
	2 Tbsp of peanut butter	

Source: Canada's Food Guide, Health Canada

Managing Side Effects During Treatment

Diabetes

Some people receiving treatment for their brain tumour may develop temporary diabetes. Diabetes is a condition in which the body cannot use sugar properly. It may be due to the disease itself or result from certain drugs, such as Decadron® or Prednisone. Therefore, a proper diet is important, as it helps to control your blood sugar.

Use the following as a guide, and consult with a registered dietitian about designing a plan that meets your personal requirements.

- Eat three meals a day and snacks as planned with your registered dietitian.
- Eat at the same time every day.
- Avoid skipping meals.
- Have a starchy food at each meal such as whole bread, cereal, rice, pasta, or potato.
- Choose snacks that are high in protein, such as skim cheese or mixed nuts.
- Avoid sugar and foods that are high in sugar, such as jam, jelly, honey, regular soft drinks and candy.
- Choose fresh fruits and vegetables daily.
- Choose canned fruits in juice only.
- Drink fruit juice at mealtime, if you like fruit juice.
- Drink sugar-free fluids to quench your thirst, such as water, mineral water, club soda or sugar-free soft drinks.

Weight Gain

Not all people undergoing treatment for their brain tumour lose weight. Weight gain can be a result from eating too much, a decline in physical activity, or from certain medications such as steroids. With some chemotherapy drugs, weight gain may be mostly water. If your body is holding fluid, discuss this with your doctor. You may also reduce water retention by using less salt and eating fewer salty foods.

If you want to lose weight, talk with your doctor or dietitian before starting a weight-reduction diet. In many situations, a more realistic goal is to prevent more weight gain. Weight loss is stressful to the body.

If you want to lose weight you should wait until you have completely recovered from your treatment. Losing weight is not easy and requires effort. A weight-loss diet needs to be balanced, and provide enough protein and other nutrients to rebuild strength and support the immune system. Successful weight-loss means making life-long changes in diet and exercise.

Use the following as a guide, and talk to your registered dietitian for advice that suits your personal needs.

- Try to stay active and increase physical activity if you are able (e.g., take longer walks).
- Reduce the amount of fat you eat:
    - Avoid fried foods
    - Choose fresh fruits instead of cakes, pies and pastries
    - Choose low-fat or skim dairy products
    - Choose low-fat snacks such as vegetables, low-fat yogurt, popcorn and pretzels
    - Decrease use of butter, margarine, mayonnaise and salad dressings
    - Remove skin from poultry
    - Trim all visible fat from meats
- Try eating several smaller meals throughout the day.
- Avoid skipping meals; you will likely overeat later in the day.
- Reduce consumption of beer, wine or liquor.

Loss of Appetite

Loss of appetite is one of the most common problems people with brain a tumour can experience. You may lose your appetite because you feel sick from treatment or because you are upset about your diagnosis. Short periods of loss of appetite may not be an issue, but if prolonged, it can pose a problem.

Try the following, and see what works best for you:

- Eat more when you are hungriest (e.g., make breakfast your main meal).
- Use small portions of food and get the satisfaction of finishing a meal.
- Eat a number of small meals and snacks during the day instead of three large meals.
- Eat the foods you enjoy most.
- Have ready-to-eat snacks handy, such as cheese and crackers, pudding, ice cream, yogurt, muffins, nuts and seeds.
- Eat in a pleasant atmosphere with family or friends.
- Get back to a normal meal schedule, which will remind you to eat.
- If you find yourself missing meals on treatment or clinic days, plan ahead. Take a sports bottle filled with a beverage or thermos of soup and a snack with you.
- Visit or order take-out from a grocery store or restaurant.
- If food is not appealing at all, choose a liquid nutritional supplement at meal or snack time.
- A glass of wine before meals may help to stimulate your appetite. Ensure that you check with your doctor before drinking any alcohol.

Make Every Bite Count

When your calorie intake is affected, try calorie- and protein-rich foods.

Calorie Booster Guide

Add	To
Cream - 10% or 18%	Soups, cereals, milkshakes, puddings
Whipping cream	Custards, fruit, cakes, pie, Jell-O®
Butter, margarine, oil	Eggs, potatoes, rice, pasta, pancakes, waffles, french toast, muffins, hot cereal, breads, buns, soups
Sour cream, yogurt	Fresh or canned fruits, vegetables, potatoes, rice, pancakes, casseroles, stews, soups, vegetable and fruit dips
Mayonnaise	Sandwiches, vegetable or fruit salads
Ice cream	Fresh or canned fruits, milkshakes, cake, pies, custard, pudding, gelatin desserts
Cheese (Brick, processed, cream)	Crackers, bagels, vegetables, fruits, sauces, casseroles
Jam, jelly, marmalade, honey	Crackers, muffins, pudding, ice cream, yogurt
Syrups, honey, sugar	Milkshakes, pancakes, waffles, french toast, cereals

Protein Booster Guide

Add	To
Skim milk powder (30-60ml or 2-4 Tbsp)	Hot cereals, scrambled eggs, sauces, mashed potatoes, soups, cream sauces, milk, milkshakes, puddings, custards
Eggs	Sandwiches, salads, sauces, soups, omelettes, quiche, french toast, soufflés, devilled eggs
Cheese (Brick, processed, cream and cottage)	Sauces, and casseroles, sandwiches, crackers, bagels, muffins, fruits and vegetable dips
Yogurt	Fresh or canned fruits, vegetables, potatoes, rice, pancakes, casseroles, stews, soups, vegetable and fruit dips
Peanut Butter	Cookies, milkshakes, sandwiches, crackers, muffins, toast, fruit slices
Tofu, soy beverages	Milkshakes, soups, casseroles, stir fries, salads
Dried peas and beans	Casseroles, baked beans, soups, bean stews, salads
Nuts and seeds	Salads, cereals, ice cream

High-Calorie / High-Protein Snack Ideas

Suggestions for snacks to help you increase your calorie and protein intake include:

If you're unable to maintain proper nutrition, your doctor or dietitian may recommend nutritional supplements. These are high-calorie, high-protein drinks that are ready-to-use and come in a variety of flavours.

- Banana bread / muffins
- Biscotti
- Buttered popcorn
- Cheese, hard or cream
- Crackers, tortilla chips, pita bread
- Cream soups
- Custards and puddings
- Dips such as hummus, guacamole, or yogurt based dips
- Dried fruits
- Granola
- Hardboiled egg or devilled eggs
- Hot or cold cereal
- Ice cream or frozen yogurt
- Milk, white or chocolate
- Milkshakes or smoothies
- Nuts and seeds
- Peanut butter and banana sandwich
- Peanut butter cookies
- Peanut butter or oatmeal cookies
- Trail mix
- Yogurt

Nutritional Supplements

If you are unable to eat enough to maintain proper nutrition, your doctor or dietitian may recommend nutritional supplements. These high-calorie, protein drinks and puddings provide complete and balanced nutrition that includes vitamins, minerals, carbohydrates and fat. These can be ready-to-use or homemade, and come in a variety of flavours.

Try a small amount, like 1/3 to 1/2 carton at first. This way you don't feel too full.

Refrigerate the unused portion and use within 48 hours. Once you find a supplement you like best, you can gradually increase the amount you drink at a time. You can also add different flavoured syrups, such as chocolate or strawberry, or fruits to the supplement. If you have trouble digesting milk or milk products, or have diabetes, please talk to your dietitian before using any nutritional supplements.

Overcoming Side Effects

The following are suggestions to help you overcome common feeding problems. For further information, alternative treatments and suggestions, discuss these with your doctor, dietitian or nurse.

Mouth Sores

Avoid:

- Acidic foods: tomatoes, citrus fruits (oranges, grapefruits)
- Dry coarse foods: chips, pretzels
- Hot foods
- Raw fruits and vegetables
- Spicy foods: pepper, chili

Try bland soft foods including:

- Cooked cereals
- Cream soups
- Ice cream
- Mashed bananas

- Mashed potatoes
- Popsicles
- Sherbert / sorbet
- Slushes, milkshakes
- Soft eggs
- Watermelon

Using a wide straw to drink liquids or liquefied foods can be helpful, this way the mouth is not injured further by chewing.

Taste Changes

Foods that once were enjoyed may no longer taste the way they should to you. You may find you no longer like the taste of protein foods, such as meats.

- Serve foods chilled or at room temperature to reduce strong tastes and smells.
- Try a mouth rinse before and after eating to clear your taste buds. Use a solution of ¼ tsp baking soda to 1 cup of water or club soda.
- Some people find that meats have a bitter, metallic taste. Try chicken, dairy foods, peanut butter, eggs, tofu, fish, legumes and nuts as other protein sources.
- Add sugar to increase the taste of foods or decrease the salty taste of other foods.
- Try using plastic cutlery and glass cooking pots, if foods taste metallic.
- Fruit sorbet, sherbet and fruit smoothies usually taste good.
- Mustard and ketchup are some favourite condiments.
- If you do not have mouth sores, try tart foods such as lemonade, cranberry juice, pickles and spices.
- If water tastes funny, add fresh mint leaves or lemon slices to flavour it.

Nausea

- Clear liquids are recommended, such as:
  - Chicken broth
  - Flat gingerale or cola
  - Flavoured ice cubes
  - Jell-O®, sherbet
  - Peppermint tea
  - Popsicles, watered down juices, Gatorade®
- Avoid an empty stomach as you may feel more nauseated. Try bland, dry foods such as plain cookies, crackers and dry toast.
- When your stomach begins to settle, try soft eggs, rice, mashed potatoes, light soup with chicken and rice, boiled or baked lean meat or poultry.
- To prevent vomiting:
  - Save liquids for drinking one hour before or after meals
  - Eat your food slowly
  - Avoid foods high in fat such as cream soups, whole milk, gravy, fried foods
  - Try to keep from lying down after eating

Diarrhea

- Try to eat 5 to 6 smaller meals instead of three larger meals each day.
- Increase fluids between meals to prevent dehydration. Aim for 6 to 8 cups daily.
- Choose low-fibre foods such as white bread, bagels, rice and pasta.
- Reduce high-fibre foods such as whole grains, bran, seeds, popcorn, raw vegetables, raw and dried fruits.
- Avoid high-fat, greasy and spicy foods.
- Try low-lactose products such as Lactaid® or Lacteeze® milk.
- Reduce caffeine drinks such as regular coffee, tea, colas and chocolate beverages.
- Try boiled rice, bananas, oatmeal, dry toast, mashed potatoes, and other small portions of these foods at room temperature.

Constipation

- Drink plenty of liquids at least eight cups per day.
- Hot beverages may help to stimulate bowel activity. Try hot prune juice with your breakfast.
- Try caffeine-containing beverages such as coffee, tea and colas.
- Choose vegetables and fruits including dried fruit.
- Try legumes such as cooked dried peas, beans and lentils.
- Add nuts, seeds, or dried fruits to salads, yogurt, fruit cups, baked goods and casseroles.
- Add two tablespoons of natural bran or ground flax seeds to meatloaves, casseroles, salads or cereals.
- Choose whole grain breads, crackers, muffins, bagels, pasta and brown rice.
- Try sesame seed sticks, oatmeal cookies, granola, date nut bread and popcorn.
- Try to include a light physical activity into your daily routine, such as walking.

Decisions About Complementary and Alternative Medicine (CAM)

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The Challenge of Making Decisions About Complementary and Alternative Medicine (CAM)

Living with a brain tumour means facing some difficult decisions. Often there are multiple treatment options that have benefits and risks attached to them. These decisions can be even more challenging when you also consider adding complementary and alternative medicine (CAM) to your treatment plan.

> *Complementary therapies are products and practices used along with conventional medical treatment. Alternative therapies are treatments that are used instead of conventional treatment.*

You may have heard about the research and evidence that exists for conventional cancer treatments. This evidence lays out what is known about the treatment and what the expected benefits are, as well as possible risks.

In contrast, research about CAM is in the early stages. For example, for many natural health products (e.g., vitamin or herbal supplements), there is only cellular (pre-clinical) or animal research available. You may ask whether you can trust this evidence and apply it to your unique situation. How can you make an informed decision when there is little credible human research evidence available and there may be little known about the risk of the CAM therapies? It can be hard to know where to begin.

Making Safe CAM Decisions

One approach to managing complicated decisions is called shared decision-making. Shared decision-making means that you and your health care provider work together to make the decision with your goals, preferences, and values in mind. The result is that the goals and values are known and included in the development of your treatment plan. The clinical judgment of health care providers, as well as input from their social network and the available research evidence is considered. The result is an informed, value-based decision that reflects your beliefs and clinical recommendations.

If you choose to use a CAM therapy or a CAM practitioner in conjunction with your treatment plan, it is important to tell your oncologist and family doctor. Knowing all the therapies you are using, including CAM, allows your health care team to provide care that is comprehensive and safe.

The following information is important to consider before you decide to use CAM therapies or visit a CAM practitioner:

- Consider the goals you are trying to achieve by using the CAM therapy. Does the therapy have the potential to help you achieve these goals? Remember that goals may be physical, emotional, and/or spiritual. Be cautious of therapies that claim to "cure" the tumour.
- What are the risks and benefits of the CAM therapy? Are there any side effects? Consider the scientific evidence behind the therapy. How credible and current is the available information? It is important to balance and consider what is known as well as what is not known about a therapy. Also, make sure to find out what dose of the therapy is safe. More is not always better.
- Will the CAM therapy interact with other treatments or health conditions you may be experiencing? For example, grapefruit can slow or speed up the liver's processing of chemotherapeutic drugs, resulting in higher or lower than desired levels in your body. Many CAM therapies can interact with each other, creating unexpected results.

- Consider what will be involved if you use the CAM therapy. Will there be travel, repeat appointments, self-care that is required, or any procedures that will have to be carried out? How will the CAM therapy be monitored?
- What are the training, credentials and experience of the CAM practitioner? What are the costs of using the therapy? Consider whether you and your family can afford the financial, time, and energy costs of using the therapy.
- What CAM support or services can you get from your local health care agency or hospital? Many conventional health care agencies now offer mind-body and exercise therapies. Ask to see a registered dietitian or pharmacist if you have special questions about your diet or the safety of natural health products.
- After reviewing all the information, consider whether the CAM therapy will meet the goal you hope to achieve, without interfering with conventional treatment, and with risks acceptable to you.

Once you have made a decision about a CAM therapy or a CAM practitioner, it is important to tell your oncologist and family doctor. Knowing all the therapies you are using, including CAM, allows health care providers to provide care that is comprehensive and safe. It is also important to have a plan about how you will monitor your use of CAM to see if it is meeting your goals, and is not causing any unintended side effects.

CAM therapies can be an important part of your overall health care experience. Make sure you have the support and information you need to make a decision that is right for you.

It's important to have an open dialogue with your physician or nurse about any and all natural products that you may take.

For more information about ***Complementary and Alternative Medicine****, please visit* ***www.BrainTumour.ca/cam****.*

Your Health Care Team

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Your Health Care Team

Audiologist

You may be referred to an audiologist if your tumour is affecting the acoustic (eighth nerve). The acoustic nerve is responsible for transmitting sound and balance information from the inner ear to the brain. An acoustic neuroma / vestibular schwannoma is a non-malignant intracranial tumour that can cause hearing loss or deafness in one or both ears, tinnitus (ringing in the ears), balance problems or vertigo (spinning) with nausea and vomiting and/or pressure buildup in the ears.

An audiologist specializes in the assessment and treatment of hearing and balance disorders including helping those who are deaf or hard of hearing. By assessing the extent of hearing loss, balance and related disorders, audiologists can recommend appropriate treatments and rehabilitation such as the use of hearing aids, aural training, speech reading, vestibular rehabilitation, and/or tinnitus management.

Chaplain

Religious or pastoral care, sometimes referred to as spiritual care, is provided by hospital chaplains, community clergy and leaders in religious communities. Religious and spiritual care is provided in a respectful manner. Hospital chaplains are trained in providing support and assistance to people facing a health crisis in a clinical setting.

Religious and spiritual care is offered in a multi-faith setting (unless someone wants the support of their particular religious faith community), through specific prayer, ritual, ceremony or celebration.

As a member of an inter-professional team, a chaplain's primary role is the provision of spiritual and religious care, and support for you and your family members. Chaplains support the religious and spiritual element in the medical model.

Clinical Dietitian

Living with a brain tumour and associated treatments can present a variety of nutritional challenges from weight gain to weight loss, nausea and vomiting, taste changes, lack of appetite, and steroid-induced diabetes to name a few.

A consultation with a registered dietitian can be very helpful. These members of the allied health care team can provide you, your family and your caregivers with comprehensive nutrition care by translating the complex science of nutrition into practical dietary advice. The registered dietitian provides high-quality and evidence-based nutritional therapy to help patients manage their treatment-related side effects through diet. The responsibilities of the registered dietitian include assessing nutritional status; identifying specific nutritional concerns; reviewing current treatments and medications; developing individualized nutrition care plans; and applying appropriate intervention including modification of therapeutic diets, nutrition counselling for patients, families and caregivers, and monitoring clinical progress.

Most centres involved in the treatment of patients with brain tumours will have the services of a registered dietitian. If not, private consultations can usually be arranged. Ask your health care team for guidance.

Hospital Social Worker

Social workers are members of the health care team who are professionally trained in providing individual, family and group therapy. The onset of illness frequently presents patients and their families with significant lifestyle changes. These changes may be accompanied by new or unexpected stress. Social workers can help you in managing any difficulties that may result from a hospitalization or adjustment to a medical condition.

A social worker may be consulted for:

- Counselling for adjustment to illness and treatment, relationship and family issues and grief and loss.
- Addressing sources of stress and conflict.
- Preparing for admission to hospital or out-patient procedures.

- Discharge planning – assisting with plans to leave hospital including residential placement.
- Making connections to services within the hospital and in the community.
- Assisting families to obtain financial help, accommodations or home support services.
- Planning and providing health education and support groups.

The entire family may wish to consider counselling to help prepare for the short- and long-term implications of a brain tumour diagnosis, now and in the future. Preventative work is usually better than waiting for symptoms of stress to appear. When a crisis occurs, learning to adapt to a new normal allows you to carry on with your life as fully as possible.

A referral can be made by your physician, nurse or other health care professional, or you or your family may call the social work department in the hospital or clinic directly.

Neuro-Oncologist

A neuro-oncologist is a physician trained in either neurology or medical oncology who usually has specialty training in the care of people with brain tumours.

Neuro-oncologists provide advice and treatment on primary brain tumours, especially low- and high-grade gliomas. Most neuro-oncologists provide advice on medical treatment of brain tumours, and prescribe chemotherapy and targeted therapy. Typically, it is the neuro-oncologist who provides ongoing symptom management (steroids, anti-seizure medications). Lastly, neuro-oncologists are usually the principal investigators in clinical trials. Consequently, your neuro-oncologist may be able to offer you the opportunity to participate in a study testing new approaches to the treatment of brain tumours, should a suitable study be available.

Neuro-Ophthalmologist

You may experience visual difficulties resulting from involvement of tumour in the areas of the brain that control vision. In this case, you will be referred to a neuro-ophthalmologist for evaluation.

Ophthalmology is a branch of medicine specializing in the anatomy, function and diseases of the eye. A neuro-ophthalmologist examines the relationship between a neurological disease and visual problems, and deals with local pathology affecting the optic nerve, visual pathway and the ocular motor system.

A neuro-ophthalmologic evaluation is a very comprehensive exam and may take a few hours to complete. The doctor will review all of your records and scans from previous evaluations and discuss the need for any additional testing and possible treatment.

Many people who experience visual loss due to compression on the optic nerve or chiasm by a tumour have visual improvement when the compression or pressure is relieved. Similarly, if you have difficulty moving your eyes or experience double vision, appropriate treatment may improve or resolve the symptoms.

Neuropsychologist

Neuropsychology is an applied science that examines the impact of both normal and abnormal brain functioning on a broad range of cognitive, emotional and behavioural functions. A clinical neuropsychologist uses objective neuropsychological tests, systematic behavioural observations, and knowledge of the neuropsychological manifestations of brain-related conditions to help diagnose problems related to brain dysfunction and disease.

A neuropsychological evaluation can identify any changes in learning, memory, thinking, reasoning, concentration, perception and self-expression you may experience as a result of the brain tumour or its treatment. The results of the assessment may be helpful to you, your family or physicians, in dealing with problems related to these changes.

The first neuropsychological assessment can serve as a basis for comparison with other assessments to determine if there is any change over time. Testing usually takes 5 to 6 hours, but may be shortened or lengthened depending on the purpose of the assessment.

Please check with your health care team regarding your options for neuropsychology as not all facilities have these services.

Neurosurgeon

Neurosurgery is a branch of medicine specializing in the anatomy, function and diseases of the brain and spinal cord. A neurosurgeon performs surgical procedures that aim to relieve the pressure of a mass on the brain or spinal cord, and at the same time obtain tissue for diagnosis. Neurosurgeons operate to remove tumours from the brain and spinal cord, either totally or partially, to relieve symptoms of compression.

Following surgery, the neurosurgeon will continue to monitor you through regular clinic visits and neuro-imaging studies (usually MRI scans).The doctor will review all of your records and scans from previous evaluations and will discuss the need for any additional testing and possible treatment, such as further surgical procedures.

Nurse Practitioner

Nurse practitioners (NPs) are nurses with additional education and training who work with your physician and other health care members to manage your medical care. In the hospital setting, NPs usually specialize in one clinical area or work with specific patient populations. For example, an NP who works in neurosurgery will follow you before and after your operation. An NP who works in oncology may do special procedures or assess how well you are tolerating the prescribed chemotherapy or radiation therapy.

NPs can perform a history and physical examination, order diagnostic tests or blood work, perform certain medical procedures, and prescribe medications. NPs can also provide education or answer questions you might have about your diagnosis or treatment. An NP can help manage your symptoms, arrange referrals to other specialists, and help to navigate or coordinate your care following discharge from hospital.

Occupational Therapist

Occupational therapists work with you and your family to address how the brain tumour may affect your everyday function.

The occupational therapist will listen to your concerns and focus therapy on what is most important to you.

Assessment involves looking at how any changes in thinking, visual processing or physical abilities may impact your ability to perform your usual activities.

Therapy may involve working on performing personal care activities, such as toileting or dressing yourself. It may also address concerns you may have about being at home, such as making meals or preventing falls.

Treatment examples include:

- Providing aids to make tasks easier
- Teaching new ways of doing things

Occupational therapists may also provide advice on how to manage specific concerns related to changes in thinking, limb weakness or decreased energy.

Occupational therapists also play an important role in discharge planning. Together with your medical team, they may provide important recommendations to support or optimize your safety and independence when you leave hospital. An occupational therapist may also help arrange follow-up occupational therapy services for you through community agencies.

Optometrist

An optometrist is an independent primary health care provider who specializes in the assessment, diagnosis, treatment, management and prevention of disease and disorders of the eye and visual system, and associated structures. An optometrist also diagnoses ocular manifestations of systemic conditions, such as cancer. Vision treatments, including prism

therapy and partial occlusion, may be recommended for some people to assist in balance or to eliminate double vision. The optometrist may work in partnership with the neuro-ophthalmologist.

Patient Cancer Navigators

The patient cancer navigator assists you and your family in accessing care throughout the treatment process – from diagnosis to integration back into your community. The person in this role, whether it be a nurse or another health care professional, provides education and support throughout your diagnosis, hospitalization, surgery and post-hospital care periods. Liaising with other disciplines, both hospital and community-based, to support optional patient care, the patient cancer navigator's role is one of caring and compassion, and is your contact person throughout your entire journey.

Please check with your health care team as to who is the dedicated person who may liaise with other disciplines – it may be a nurse or a social worker on your health care team.

Pharmacist

The hospital pharmacist is an important member of your interdisciplinary health care team, and plays a key role in ensuring the safe and effective use of medications.

The pharmacist will collaborate with other members of your health care team to provide comprehensive drug therapy management including drug selection, and monitoring for side effects and drug interactions, as well as assessing outcomes of drug therapy.

Your hospital pharmacist will work directly with you to identify your medication needs. He will provide you with information about your medications so that you are aware of the benefits and risks of each drug.

Your hospital pharmacist will also provide discharge counselling when it is time for you to go home, instructing you on how to administer the medications at home, and answering any questions you may have about your drug therapy.

Hospital pharmacists also participate in the development of evidence-based guidelines for safe and consistent administration of medications, and may also be involved in research designed to optimize benefits from or reduce risks of therapies involving medications.

Not all hospitals have pharmacists that are easily accessible for patient education. If this is the situation at your hospital, your nurse or your community pharmacist can also be a valuable resource.

Physiotherapist

A physiotherapist can assess and treat a variety of conditions and physical disabilities. In neurological disease, the main goals of physiotherapy treatment are to maximize independent function and ensure a smooth transition from hospital to home. A physiotherapy program focuses on joint movement, strength, coordination, balance, transfers from bed to wheelchair and walking. In some cases, the physiotherapist will prescribe walking aids and braces.

When surgery is necessary, a physiotherapist will also be involved in the prevention of lung and circulatory complications post-operatively.

Patient and family education is another important part of physiotherapy. Family and friends can help a great deal and are encouraged to participate in the physiotherapy treatment program.

After discharge, physiotherapy follow-up will be arranged through an outpatient clinic or home care services as necessary.

Radiation Oncologist

A radiation oncologist is a doctor who specializes in the treatment of cancer using radiation therapy as the main method of treatment. A radiation oncologist develops a treatment plan through a process called treatment planning, which begins with simulation. The first step in the simulation process is to create a patient-specific immobilization device. For the brain, a custom plastic head mask is made. Then a treatment-planning CT scan is done with the patient immobilized in the custom head mask. This serves to ensure that the patient's head stays more or less in the same position each day during treatment, as compared to that referenced during simulation.

In addition to the CT scan, an MRI is usually performed, and that information is merged with the CT in order to properly see the tumour to be treated and the normal tissue to be spared.

The radiation oncologist then determines the exact area that needs to be treated and the amount of radiation to be given. Behind the scenes, radiation dosimetrists and physicists are creating the plan that will ultimately be approved by the radiation oncologist before treatment can begin.

During treatment, the radiation oncologist will see you weekly to make sure the treatment is being delivered as intended, and manage any side effects that occur.

Radiation Therapist

Radiation therapists are responsible for the actual delivery of radiation therapy on a daily basis. Radiation therapists are also responsible for creating the radiation plan to be delivered. Because patients will have daily contact with their radiation therapist, they should feel free to ask any questions about radiation therapy, its side effects and how to manage them. In addition, the radiation therapists are a good link to other members of the health care team. In particular, radiation therapists are instrumental in alerting the radiation oncologist to any concerns you or your family may have, or if you feel that something has changed and requires immediate medical attention.

Speech Language Pathologist

A speech language pathologist (SLP) is trained to evaluate and treat disorders of speech, language, cognition and swallowing. In some cases, a brain tumour may be located in, or cause pressure on, parts of the brain involved with these functions. Alternatively, the tumour may interfere with your ability to understand what is being said or make it difficult to find the words to express your thoughts. The SLP can provide help in adjusting to these changes. For example, using picture or word boards, using gestures, or reducing the complexity of conversations are all ways in which you and your loved ones can improve communication.

If the area of the brain affected by the tumour is the motor speech area, you may have difficulty forming the sounds for speech. Helpful strategies include writing, pointing, or typing messages.

The SLP may also help you with memory, orientation, problem-solving and attention difficulties, and in many instances, may collaborate with other members of your health care team, such as the occupational therapist, to develop strategies to minimize the effect of these difficulties.

A major component of any successful program is education. Making sure families and friends know the best ways to interact with you to ensure successful and comfortable communication is key.

The SLP also has special training in the area of swallowing. Should swallowing problems arise, the SLP may provide an assessment and counsel you and your family regarding the status of the swallow, potential risks to health and nutrition, and treatment options. Suggestions may include changes to your diet or strategies to make meal time a safe and comfortable experience. In some cases, eating by mouth may be unsafe. In these situations, other options (e.g., tube feeding) may be discussed.

Don't forget… As an important part of your health care team, nurses are involved in your care throughout the course of your hospital stay and/or treatment. Nurses provide education and clarification about the treatments you will undergo, and guidance about how to effectively manage symptoms and side effects, both while you are in hospital and once you are home. Nurses may also visit you in your home once discharged from the hospital to ensure you are managing well between doctor's appointments.

Leaving the Hospital

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Leaving the Hospital

After your treatment course comes to an end, you will want to restore your life to normal. Understanding that there are going to be some changes, large and small, will help both you and your loved ones to adjust and seek out any support that you may need.

It is advisable to familiarize yourself with the services and options available, should you require them. Your health care team will assist you in organizing your transition home by making appropriate referrals.

> *The social work department of the hospital, or, in some cases, the nursing staff, can help you plan for your homecoming.*

It is often difficult to predict exactly how you will manage in your home setting, and you will not know until you actually get there and live each day. Try to maintain daily routines and keep up with the outside world as much as possible.

You will continue to have regular appointments with your doctors to assess your progress. Continue with your daily journals and arrive at each appointment prepared to ask questions about any new concerns or for a re-explanation of previous ones. It is likely that you will have regular CT or MRI scans, frequently at first, and then once or twice a year thereafter. Periodic blood work may also be required.

When to Contact Your Doctor

You should contact your medical professional or health care team immediately, if you notice new symptoms or changes in your current condition. The following symptoms should be reported immediately:

- Any symptoms not previously experienced
- Changes in energy level (increased fatigue)
- Changes in mood or behaviour
- Changes in sensation, including one or both sides of your body

- Decreased consciousness (confusion, drowsiness)
- Decreased use of arms or legs (difficulty walking, picking things up)
- Difficulty in swallowing
- Headaches that have changed (more frequent, increased intensity, different location)
- New speech problems
- Seizures
- Significant morning headache associated with nausea and vomiting
- Unexplained double vision
- Unexplained nausea or vomiting

How to Contact Your Doctor or Health Care Professional

If at all possible, you should try to contact your physician or health care worker during regular business hours. If your physician or health care worker is not immediately available to discuss the situation, your call will be returned at the earliest possible opportunity.

It may be useful to keep individual phone numbers at the back of this handbook, as well as by the telephone, for quick reference. There will be a system to contact your physician or his team during non-working hours and this will be explained by someone on your health care team at your centre. Some physicians may have you call them directly, while others may ask you to call their residents or other team members who will then notify your physician.

You should clarify in advance how to reach your physician or health care worker outside regular business hours.

*Please see **Appendix I: Health Care Team Contact Information** on **Page 265** to list contact names and phone numbers of your health care team.*

Ask each professional that you deal with what to do when you have an urgent problem, and then record each suggestion for future reference. Should an emergency arise however, do not hesitate to visit the Emergency Clinic at your local health care facility.

Your Family Physician

Your family physician plays an important role in your care. You should not assume that all of the information pertaining to your diagnosis, treatment and prognosis has been communicated to your family doctor.

Check with your family physician's office to ensure that he has received updates from your specialist. Sometimes information is delayed through clerical channels, and a simple phone call to the specialist's office can remedy the problem. It is essential that you have a good line of communication. Have your family physician act as a link between you and your specialist to help explain the medical terminology and treatments. It is unrealistic to expect your family physician to know everything about your particular brain tumour – he is a general practitioner, not a specialist. He will try to assist you in receiving the best care available.

Does your general practitioner have a copy of this handbook to use as a reference? If not, encourage your physician to order one.

Your family physician has access to many support services in the community to aid you and your family. Many of these services require a physician's signature on medical assistance forms or a referral. Drug information and prescription renewals can also be obtained through your family physician. If you are unwell, it is advisable to call your family physician first. He can decide whether or not the problem is related to your brain tumour or treatment. Your family physician is still the primary physician for your general health care needs and is usually available when the need arises.

If you are scheduled for admission to hospital for treatment of your brain tumour, inform your family physician. He may wish to visit you or keep in close contact during your hospital stay.

Which Pharmacy Should We Use?

Pharmacies within hospitals differ considerably from community pharmacies. Some hospital pharmacists may have more complex clinical medication management issues, whereas pharmacists in community pharmacies often have more complex business and customer relations issues.

Because of the complexity of medications including specific indications, effectiveness of treatment regimens, safety of medications (e.g., drug interactions) and patient compliance issues (in the hospital and at home), many pharmacists practicing in hospitals gain more education and training after pharmacy school through a pharmacy practice residency. Those pharmacists are often referred to as clinical pharmacists and frequently specialize in various disciplines of pharmacy.

Cancer centres also have pharmacists that may be available to patients for education and consultation. Depending on the centre, patients may have their prescriptions filled at the cancer centre, in the hospital out-patient pharmacy or in their community pharmacy.

It is best to get your medication filled at a pharmacy that is familiar with specialized brain tumour treatments. Some of your medications may not be readily available at community pharmacies so check with your health care team where it is best to get your prescriptions filled.

Dealing with one pharmacy is recommended, so that your pharmacist can keep records of your complete medication history and deal with any problems that arise both with prescription medications and any over-the-counter drugs that you may purchase. In addition, if you have any dietary restrictions, your pharmacist can help you avoid potential interactions between foods and drugs.

The pharmacist's role lies in the preparation and dispensing of medications prescribed for you, together with any information regarding using the drugs. Pharmacists consult with the physician on a regular basis and are trained to discuss with your doctor all matters related to your health and drug therapy.

Many people have questions about their drugs, the dosages and short and long-term side effects, and don't know who to ask. Often people assume that pharmacists and physicians are too busy and therefore hesitate to ask questions. However, as a health care professional, your pharmacist can assist you with any drug information you may require, and is prepared to spend time to address your concerns. Questions can be answered when picking up prescriptions or by telephone at a later time. The pharmacist will be able to explain the medication, the appropriate dosage interval, how best to take the drug, common side effects you may experience, as well as those side effects requiring medical attention.

From time to time your physician may order a new prescription you may not be familiar with. In these cases, a few days trial of the new drug may be appropriate. Feel free to ask your pharmacist if this trial period is suitable for your prescription. Perhaps the pharmacist can assist you with a trial quantity while holding the balance of the prescription in the pharmacy until the response to the new medication is determined.

Making sure you have an adequate supply of your medication is very important. Obtaining refills from your physician well in advance is a good way to avoid running out of the necessary medicines. On those rare occasions when you find yourself out of medicine, perhaps on a weekend or evening, explain the situation to the pharmacist and ask for assistance.

The Cancer Clinic Pharmacy

Some drugs prescribed by your oncologist are only carried by the pharmacy at the cancer clinic and therefore it is advisable to have the prescription filled there. You have the option of checking with your local pharmacy, and if they are willing to stock a particular drug, you can have it filled there. Some drugs have financial assistance programs available. At some cancer centres there are drug access facilitators to assist you.

Treatment-Related Fatigue

Fatigue is the feeling or sensation of tiredness that many people diagnosed with a brain tumour experience at some point during their treatment process.

Experiencing fatigue can keep you from doing your normal activities. Signs that you are experiencing fatigue include feeling weary or exhausted. This may be experienced as physical, emotional, or even mental exhaustion. Concentration and thinking clearly may be compromised due to fatigue. Many patients rate fatigue as the most significant symptom that affects their quality of life.

Fatigue is a common symptom in people who are recovering from surgery, and can often be experienced for months. It has also been reported as the most severe side effect of radiation during the last week of treatment and is frequently reported as a side effect of chemotherapy. Factors such as age, diagnosis and pre-treatment condition may influence the severity of fatigue experienced during treatment.

There are several ways to manage fatigue and it is important to incorporate these activities into your routine. Management includes educating yourself and incorporating lifestyle changes. Ways to manage your fatigue include:

Getting Some Rest

Include short periods of quiet rest (30 to 90 minutes) in your day. Everyone is different and this may be trial and error for you. You may have a difficult time regaining your energy levels when you're over-tired. Try to avoid situations that contribute to pushing yourself beyond your comfort level. Give yourself time to figure out your new baseline for how much activity and rest you require. By including rest in your daily routine, you will allow your body to recuperate, decrease stress and improve your energy levels.

Conserving Energy

Some patients may notice their level of energy is best after they have had a good night's sleep. Plan a more difficult activity after you are well rested. It is important to select activities that match your energy level. You may be able to get more done by spreading activities throughout the day

and taking a rest in between. Do not be afraid to ask for help from others when you're feeling tired, and don't force yourself to do more than you can manage.

Staying Active

Allow yourself time to recuperate from treatment then slowly return to a comfortable level of activity. To evaluate your progress ask yourself, "Am I doing better than I was three weeks ago, two months ago?" and so on. By staying active and exercising lightly on a regular basis, you allow your body to revitalize while reducing fatigue.

Eating Healthy

Eating nutritious foods and drinking plenty of liquids will allow you to increase your energy levels. By eating a well-balanced diet, your body will be able to withstand the effects of treatment including fatigue, fighting off infections, and avoid weight loss. Eating foods that are high in carbohydrates and proteins will give your body a quick boost in energy.

Many patients are faced with fatigue. However, it is important to understand how fatigue affects you personally and what you need to do to cope with this symptom effectively. By trying the above tips, you may be able to recognize your body's abilities and adjust to the change.

Control of Pain and Other Symptoms

The first sign that a brain tumour exists may be when you have had a headache, nausea, vomiting or drowsiness. After diagnosis of the tumour, you may be concerned that these symptoms will remain or return.

Pain and other symptoms occur for two reasons:

1. The tumour occupies space reserved for the brain, and therefore increases pressure within the head. Surgery can alleviate pressure by removing the actual mass of a tumour. Corticosteroids are often used to assist in controlling swelling before and after surgery.

2. There may be a disruption in the flow of cerebrospinal fluid (CSF) in the brain. An excessive collection of CSF will result in increased intracranial pressure. Intracranial pressure can be controlled by placing a shunt in the fluid containing areas of the brain. A shunt will reduce pressure and thereby may lessen headache, nausea, vomiting and drowsiness.

Headaches may return post-treatment. A physician must assess the presence and cause of the headaches. A combination of medications along, with other measures, can be used to control the pain. If you have pain or other symptoms, call your family physician, neurologist, neurosurgeon or clinic nurse. If you are experiencing a great deal of pain, it is likely that more can be done to help. Major centres usually have a pain specialist, such as a neurologist, on staff. If you develop pain in another area of the body, be sure to report it promptly for assessment.

Pain control may include:

- Anti-inflammatory medications
- Steroid medications
- Antidepressants or mood-elevating medications
- Narcotic medications. All narcotic-containing medications may cause constipation and drowsiness
- Pain pumps and subcutaneous injections (where you can self-administer a regular infusion of pain medication)
- Nerve blocks (permanent or temporary)

The vast majority of pain syndromes can be controlled using a personalized medication program adapted to your needs.

Returning to Work

After diagnosis and treatment, patients are encouraged to have a conversation with their oncologist about returning to work. If you have difficulty performing your role at work, please discuss this with your oncologist as you may need to continue on disability.

If you have disability insurance (short-term or long-term disability) with your current employer and decide to look for new employment, you may not be eligible for disability with your new employer because your brain tumour diagnosis is a pre-existing health problem.

After diagnosis and treatment of a brain tumour, your thoughts may eventually return to resuming your normal lifestyle. Returning to work is a necessary consideration for many people. There are a number of problems or concerns that can arise after being off work. You may be afraid of losing your present job or you may find that you have new limitations (e.g., physical, cognitive or psychological) that make returning to work difficult. One option is to speak with your employer; you may find that arrangements can be made to fit into your new situation. For example, returning part-time initially might be helpful as you overcome fatigue related to your treatments. Your employer might be willing to change your job requirements as you adjust to your new limitations.

The following suggestions may be helpful, as you make the transition back to employment:

- If at all possible, return to work on a part-time basis at first.
- Be sure to get a good night's sleep each day and take frequent rests. It may be possible to lie down during your coffee break or lunch hour.
- Be careful not to push yourself past your limits.
- Be creative; adjust your schedule. It may be possible to do some of your work at home.
- Eat properly while on the job. Large amounts of coffee and quick-fix chocolate bars should be replaced with frequent and nutritious snacks.
- Be patient with yourself. Remember that things take time.

You may find you are no longer able to do your former job and need help seeking alternative employment. It is often helpful to have some assistance with this. Vocational rehabilitation counsellors help people return to work

after an illness or an injury. This type of help may be provided by your employer or your long-term disability insurer. Assistance may also be available from a private company, or your oncologist may provide a referral.

Returning to work may seem like one more hurdle in the road to recovery after a brain tumour, and it may cause considerable stress. Seeking assistance from trained professionals may be helpful as you make this step.

If you find that returning to work is impossible, consider looking at alternate activities that could be fulfilling.

Fertility and Pregnancy

*For more information, please turn to the **Fertility** section on **Page 80**.*

If fertility and pregnancy are a concern, it is important that you learn about your options for preserving fertility from your oncologist. Each patient and family situation is different and recommendations will vary. Some treatments can cause difficulties in fertility. Do not be afraid to ask questions as the answers will help you plan for your future.

Cognitive Deficits

Cognitive deficits can occur as a result of the tumour, its treatment, or both. Cognition is the process by which you become aware of, perceive, or comprehend ideas. It involves all aspects of perception, thinking, reasoning and remembering.

Research shows that brain fitness helps with cognitive difficulties such as memory and retention.

*For more information on **Brain Fitness**, please visit **www.BrainTumour.ca/brainfitness**.*

Some of the deficits you may experience include difficulties with memory, attention, orientation, language abilities, problem solving and creativity. These functions could be affected either temporarily or, in some cases, permanently.

Depending on the tumour size and location, as well the treatment given, these changes can be quite unique. If you experience changes in your cognitive function, you or your loved one can ask for an assessment from a neuropsychologist. Neuropsychological testing, which is tailored to your situation, will provide an in-depth assessment of your cognitive and behavioural functions. The examination will test for strengths and weaknesses. Strategies can be put in place to help you cope with changes and regain cognitive functionality.

Memory Loss

Short-term memory loss is a frequent challenge reported by people diagnosed with a brain tumour. Often, it is attributed to radiation therapy; however, surgery, chemotherapy and the tumour itself may play a role. Some short-term memory loss will get better with time, but all too frequently it becomes a permanent reality of daily life.

There are many tools that can be used to help adapt to short-term memory loss:

- Write things down, carry a pad and pencil in your pocket or purse.
- Keep a pad of paper beside all telephones.
- Keep a calendar or daily planner of your activities.
- Put a blackboard in your kitchen.
- Use an alarm clock, a watch alarm or a stove timer to remind you of a task.
- Ask others to help you with reminders.

Travel

If you are thinking of travelling out of province or internationally, make sure that you have insurance.

> *With your pre-existing health problem, it is unlikely you will be approved for medical insurance.*
> *For more information on **Financial Resources**, please visit **www.BrainTumour.ca/finances**.*

Talk to your doctor about your travel plans. If you are a patient and have been advised not to drive, you must take this seriously. And if you are a parent, the health care professionals on your team have an obligation to report your driving status to the Children's Aid Society, should they feel they have cause. We encourage you to have an open and honest conversation with all your family members about driving.

*For more information on **Driving**, turn to **Page 41**.*

Sleep Difficulties

It is apparent that people with brain tumours seem to have at least some difficulty with sleep patterns.

The most common complaint seems to be that the person falls asleep easily but awakens 2 to 4 hours later. Some people are able to return to sleep but continue to awaken at two-hour intervals throughout the night. Others consistently have a great deal of difficulty returning to sleep.

Another common complaint is sleeping too much, and feeling fatigued throughout the day. This is natural, and in many cases it is your body's way of telling you that it is time to stop and allow yourself time to heal. Sleep is necessary for healing, and should be encouraged whenever possible.

There are many factors that can influence sleep such as surgery, anesthesia, chemotherapy, radiation and medications. Some of these treatments may cause sleep difficulties that last many months.

Because living with a brain tumour changes the course of your life, there are many factors that contribute to sleep difficulties, such as coping with a life-threatening illness, depression, financial concerns and family worries.

If you are taking several medications, it may be wise to review them with your physician to make certain that they are not contributing to your fatigue, insomnia or wakefulness. Your pharmacist may be able to give you more detailed information about your medications.

Relaxation

It may be a good idea to consider some form of active relaxation before bedtime. Obviously, it's not a good idea to go to bed after exercise, a frightening movie or an animated conversation. Gearing down prior to bed with a quiet book, a cup of hot milk or a calming leisurely activity is advisable and could be considered passive relaxation.

Active relaxation involves consciously helping your body to attain a state of calmness and includes various methods such as guided imagery, meditation, breathing exercises and progressive relaxation (where you actually train yourself to relax through various techniques). There are many excellent books written on these subjects and it can be enlightening to explore the possibilities. Classes on meditation and relaxation are often available through your local community centre, hospital or cancer care facility.

Sleep

Sleep is necessary for healing.

Things That Can Disrupt Sleep Rhythms

- A room that is too cool, too hot or too bright
- Alcohol (frequent awakenings in the night to use the restroom)
- Background noise
- Caffeine (coffee, tea, colas, chocolate)
- Hunger
- Sleeping pills
- Some medications
- Stress
- Tobacco (nicotine contains a stimulant)
- Vigorous exercise prior to bed

Things That Can Enhance Sleep Rhythms

- A dark, quiet room
- Keeping paper and pen by the bedside to write down items that cause you to wake
- Regular eating habits, with good nutrition
- Regular sleeping patterns
- Relaxing activities prior to bed
- White noise (soft music, the hum of a fan)
- Writing down plans for tomorrow

Why Attend a Support Group?

Brain Tumour Support Groups are a valuable opportunity for people with a brain tumour and their loved ones to share experiences and gain peer support in a safe and relaxed atmosphere.

You can find connections and lean on others who have experienced a brain tumour diagnosis. Find a local support group or connect through our message board at ***www.BrainTumour.ca/support****.*

Groups run by Brain Tumour Foundation of Canada meet regularly and are open to those 18 years of age or older. Participants are encouraged to share joys, fears, and day-to-day experiences in this confidential, inclusive environment. Each person chooses whether or not to take part in the discussions, and new members are always welcome.

Palliative Care

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Palliative Care

The aim of palliative care is to promote well-being and optimize quality of life while living with serious illness. Many people have fears and doubts about palliative care, based on misunderstandings of what it means. People living with high-risk or progressive brain tumours often benefit by receiving concurrent cancer-directed treatments and palliative care services. Care is guided by you, your wishes, and what is important to your family, culture and community. The key elements of care are to minimize suffering, maintain dignity, and support you and your family over the weeks, months or sometimes years ahead. This care can help you:

- Navigate difficult decisions
- Develop plans of care
- Relieve physical or psychological symptoms
- Address social, emotional and spiritual needs
- Optimize communication and coordination of services
- Obtain continuity of care across care settings (e.g., cancer clinic, hospital, doctor's office, and home)
- Provide the highest quality of end-of-life care
- Address loss and grief

Palliative care involves interdisciplinary care and collaboration to address your needs and provide the highest quality of care and support. Nurses, social workers, family doctors, physiotherapists, home care workers, hospice volunteers, palliative care specialists, pharmacists and spiritual leaders are just some of the people who may be involved. The people contributing to your care will vary depending on your specific needs and the services available where you live. Integrating palliative care into your overall care helps establish relationships between you, your family, your primary health care provider(s) and palliative care team.

Communicating Your Needs and Perspectives

The diagnosis of a brain tumour can be overwhelming for individuals and their families. Open and honest communication with your physician and other members of the team is very important. Communicating your needs and concerns to your health care team will help them to understand your concerns and what is most important to you and your family, so they can help and make an individualized plan of care.

> *The better the team knows you, the better able you and your team can create an individualized plan of care.*

You may not automatically know what information is important to share and this is fine. The following questions may help you think of what to ask or communicate to your health care team over the course of your illness. Key times during your illness may include: immediately following diagnosis; before and after treatment; before further tests; when symptoms return or worsen; upon hearing test results that the tumour has progressed, or when your overall condition and activity level is changing.

It is helpful for the health care team to know your level of understanding about your disease, prognosis, goals and treatment options, as treatment begins and at other key points in time. Your understanding can shift during any and all of these events, and your goals of care may change as well. The health care team will not be aware of these changes unless you tell them. Be sure to inform the care team if any changes occur when you consider these questions.

Subject	Questions to Consider
Understanding your perspective	What does good quality of life mean for you and your family? If you are unable to achieve your original goals, are there other things you hope for? What is most important for you and your family? What are you hoping for? What is your family hoping for? What are you most concerned about?
Information and decision-making	What information do you or your family need right now? How do you like information to be delivered and decisions handled?
Symptoms	What are your most concerning or distressing symptoms?
Spiritual	Are you experiencing spiritual distress? Are your spiritual or religious beliefs being affected? Are you searching for meaning in your current circumstances?
Emotional	Are you or family members experiencing emotional stress?
Social	Are there family needs that, if left unaddressed could lead to increased distress or require attention? Are there family or friends that are impacted by your illness who you feel require resources, information or support?

Chance for treatment success (Prognosis)	What do you and your family understand about your current disease and overall life expectancy? What is the expected outcome of any specific therapy?
Goals	What are your goals for treatment? What other life goals are important to you?
Treatment alternatives	What is your understanding of the availability of cancer-directed treatment options? What treatment options are available to enhance your quality of life?

Establishing Goals of Care and Making Difficult Decisions

Most people start with the hope of attaining a cure or control of their disease. Over the course of an illness, you may be repeatedly challenged with re-framing or adjusting your hopes.

> *Having hope is very important; it sustains you and your family during difficult times.*

While maintaining hope for the best possible outcome, it is helpful to reflect on and plan for all potential outcomes, including the possibility that the tumour will continue to grow or spread, despite everyone's best efforts. Whether this occurs early on, or at a later time after a course of treatment, it can feel overwhelming and difficult. These circumstances may challenge you to re-adjust what you hope for. One approach is to develop a care plan for the worst possible outcome, but also hope for the best.

> *Every attempt should be made to develop a plan of care, balancing medical interventions with comfort and the best possible quality of life.*

It may be easier for you to make decisions at this time if you think about whether or not the possible treatment options presented to you will help you achieve the goals you have identified for you and your family. Palliative care is considered a valuable treatment option or approach to care in this decision-making process. You may choose to stop certain treatments that may not be helpful in achieving your primary goals of care. This may include avoiding invasive tests or treatments, avoiding further admissions to hospital, transferring to an intensive care unit, or other aggressive and potentially uncomfortable life-sustaining treatments.

Making the decision to stop disease-directed treatment may be very difficult. Often, we experience pressures we place upon ourselves or from family, friends or health care providers to continue. Decisions around stopping treatment may be associated with feelings of guilt. It is important to recognize these feelings and understand them to be normal. It is also important to recognize that stopping disease-directed treatment in the face of progressive disease is not about giving up, but rather about accepting the incurable nature of the disease and shifting to treatment focusing on palliative care.

While these are some of the most difficult decisions you will make, your health care team can help guide you and your family as you seek information and ask questions. The key to establishing goals of care is to have open communication between you, your family and health care providers. Some examples of goals of care include:

- Curing the disease
- Prolonging life with the best possible quality of life
- Providing comfort
- Maintaining or improving ability to perform activities of daily living
- Attaining specific life goals (taking a trip, visiting family, attending a wedding, living to see an expected grandchild)
- Support for family and loved ones
- Advancing medical knowledge (helping contribute to a cure)
- "Knowing we did all we could"

These goals are not necessarily mutually exclusive. Many individuals and families will choose different goals of care at different points in time, and the list above is only a sample of the large number of possibilities.

As your disease progresses, it may impact your ability to speak, or your ability to clearly think through decisions. If that does become the case, it is important to have discussed and documented your wishes around both broad and specific goals of care with your family and health care providers. Similarly, it is important to designate someone who can represent your goals accurately, if you are unable to do so.

While broad goals of care such as "I want to be kept comfortable" are important for family and caregivers to be aware of, they may be so general that they are difficult to interpret in the context of a particular problem that has arisen. It can be very helpful to anticipate specific issues that may arise, and discuss and document a preferred approach to care.

As an example, as end of life nears people tend to eat and drink less. They are often sleeping more, and are typically not experiencing hunger or thirst. Swallowing may not be very effective or safe. At such times, family and caregivers may become concerned about the poor oral intake, and may consider placing a feeding tube (usually through the nose into the stomach) in order to continue to administer fluids and nutrition. Although many people would not want such measures for themselves as their illness reaches its natural end, it is very difficult for families to decide on behalf of a loved one whether or not to insert a feeding tube feed or provide fluids. It would be very helpful to document your wishes regarding artificial feeding and hydration (providing water) when you are no longer able to swallow and it appears that end of life is near.

What Is "Advance Care Planning"?

Advance care planning is the process of thinking about and discussing personal values and health care options, and communicating those thoughts and wishes to your health care team and people important to you. It also involves choosing a "substitute decision maker," someone to speak for you and direct your health care, if you become unable to speak for yourself.

> *For more information on **Advance Care Planning** please visit **www.BrainTumour.ca/acp.***

What Is a "Do Not Attempt Resuscitation" Order?

A "Do Not Attempt Resuscitation" (DNAR) order, also referred to as "Do Not Resuscitate" (DNR), is a request to allow a natural death to occur rather than performing cardiopulmonary resuscitation (CPR), should your heart or breathing stop. It is best to make this decision when your disease is progressing and the goals of care are transitioning, rather than during a time of crisis.

In considering a DNAR order, it is helpful to know that usually, when someone's heart or breathing has stopped at the end of a progressive illness such as cancer, it is because the body's systems have become too weak for the heart to keep beating. Unless there is a way to fix the problems that resulted in the heart stopping, CPR cannot be successful in restarting the person's heart or breathing.

If you decide a DNAR order fits with your personal goals of health care, it is placed in the orders of your medical record by your health care team and/or should be documented appropriately in the community setting (e.g., on an advance directive or living will). A DNAR order is most appropriate when medicines or procedures to restart your heart or breathing (aggressive resuscitative measures) are unlikely to be successful, and when such measures may actually be harmful. This is usually the case when your physical decline is due to the growth and/or spread of the tumour.

Where Is Palliative Care Provided?

Palliative care is an approach to care that can be provided anywhere. Many palliative care programs offer two main types of service:

1. Consultation service for assessment and symptom management, provision of information and guidance with difficult decisions. Visits may occur wherever the person is currently located, or at out-patient pain and symptom management clinics.
2. Registration on a palliative care program for ongoing coordination of care, services and support for individuals wherever they are living at home, in a residential hospice, hospital or in a long-term care facility.

Discuss the location of care that you feel best suits your needs and wishes with your care team, and be aware of the necessary support you will require in that setting. The best place to receive care is usually the place that most suits your needs.

You and your family's desired location of care may change based on disease progression, symptom control and your family's comfort level in providing care. It will also depend on the options and services available where you live. Many people choose to stay in their own home for as long as possible, and some may wish to remain at home until they die. If this is your choice, you and your family may want to explore what services are available to ensure you have access to home care assistance, medical equipment, medications and any medical follow-up you may require. For those individuals and families that feel care at home is not the best option, it will be important to discuss with your health care team how to make arrangements or access care in hospitals, long-term care facilities, and/or hospices where palliative care is provided.

What Palliative Care Resources are Available In Your Community?

Canada does not have a national palliative care program, so services vary between locations. Discuss what resources are available to you with your primary oncology team and they will know how to help you get connected.

> *For more information on **End of Life Care** please visit **www.BrainTumour.ca/eolc**.*

Is there a cost associated with palliative care?

Knowing who pays for what can help to alleviate some stress and worry when looking out for the best interests of a loved one. Many services and specialty equipment items can be provided in the home by a provincial health plan, although it is important to inquire about the type and extent of costs that are covered. Many provincial health care plans also include drug coverage programs. Palliative care within a hospital is usually covered by your provincial health plan. This would include medications, equipment and medical supplies during your stay. However, there may be some costs associated with care in residential hospices or long-term care facilities, as the funding for these facilities varies across Canada. Financial questions can be discussed with the social worker on your health care team.

Grief and Bereavement

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Grief and Bereavement

This section is intended for family and loved ones of a brain tumour patient.

The death of someone close to you seems so unfair and the grief that a family feels is part of the normal healing process. Unfortunately, this is a reality that some families will face when a loved one is lost to a brain tumour.

It is normal to feel a mix of emotions during bereavement. Feelings of grief can come up at unexpected times and families often feel intense emotional pain, loneliness and a loss of purpose; their lives will never be the same again. And, you may also experience a sense of relief knowing that your loved one is no longer suffering.

The way a person grieves will depend on their personality, their relationship with the person who has passed away, their coping skills, and their support system. It is important to understand that those around you may grieve differently than yourself. The time that is needed for each individual will also be unique. Sometimes grieving starts before someone dies; this is known as anticipatory grief.

It may help to speak with a counsellor about your experience and the feelings that you have. Consider joining a grief support group. Many people find it helps to know they're not the only ones grieving, to see how others are grieving, and to hear how they're managing grief. If there's a hospice or palliative care association in your area, or if you were involved in such a program before the death of your loved one, you may want to reconnect with them: they may provide grief programs, or be able to refer you to services that meet your needs.

*For more information and resources on **Grief and Bereavement** please visit **www.BrainTumour.ca/grief**.*

Appendices

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Appendix A: Overview of the Brain

The brain is one of the largest and most important organs of the human body and is the control centre for everything that we do and feel. The following pages contain an in-depth explanation of the brain and how it works.

The brain is an organized structure serving many important functions. For example, it gives meaning to things that happen in the world surrounding us. Let's say an oven burner has been left on. By accident you touch the burner. Your brain receives a message from skin sensors on your hand which it interprets as harmful. Instead of leaving your hand on the burner, your brain gives meaning to the signal and tells you to quickly remove your hand. If you were to leave your hand on the burner, pain and injury would result. As an adult, you have a store or memories that your brain uses in times of need to guide your actions and reactions to avoid harm.

With the use of our five senses, sight (eyes), smell (nose), touch (skin), taste (taste buds on our tongue), and hearing (ears), the brain receives many messages at one time and selects those which are most important to guide our behaviour.

Our brain also controls our emotions (e.g., depression, happiness), our sleeping patterns, our imagination, how we move (e.g., walk, run, skip), our organ function (e.g., heart, kidneys, pancreas, lungs), our endocrine system (e.g., pituitary gland, thyroid), our breathing and heart rates, and how we react to stressful situations (e.g., writing an exam, loss of a job, birth of a child, illness).

Understanding the Nervous System

The nervous system is divided into the central nervous system and the peripheral nervous system. The central nervous system is made up of the brain and spinal cord. The peripheral nervous system is composed of the cranial nerves and spinal nerves, which branch from the spinal cord, and the autonomic nervous system (divided into the sympathetic and parasympathetic nervous system) which controls our response to stressful situations. The central and peripheral nervous systems play many interconnected and complex roles. Here is a list of brain structures and general terminology listed in alphabetical order to learn more about the nervous system:

Brainstem

The brainstem consists of the midbrain, pons, medulla oblongata and the reticular formation. It is the lowest part of the brain and connects the cerebrum with the spinal cord. The brainstem is located in front of the cerebellum and may be considered as a "stem" or structure connecting the cerebellum to the cerebrum. It serves as a relay station, passing messages back and forth between various parts of the body and the cerebral cortex.

The pons and the medulla oblongata control our breathing, blood pressure and heart rhythms. These functions are important to our survival. Messages from the cortex to the spinal cord and nerves that branch from the spinal cord are sent through the brainstem. Destruction of these regions of the brain will cause "brain death" which can affect survival.

The reticular activating system is found in the midbrain, pons, medulla and part of the thalamus. It controls our level of wakefulness, the attention we pay to what happens in the world that surrounds us, and our pattern of sleep.

Ten of the 12 cranial nerves that control hearing, eye movement, facial sensations, taste, swallowing and movement of the face, neck, shoulder and tongue muscles originate in the brainstem. The cranial nerves for smell and vision are extensions of the cerebrum. *See Figure:* Cranial Nerves

Cerebellum

The cerebellum fine-tunes our motor activity or movement (e.g., the fine movements of our fingers as they play the piano or grasp an object). It helps us maintain our posture, our sense of balance or equilibrium by controlling the tone of our muscles, and senses the position of our limbs. A tumour affecting the cerebellum may cause a person to stagger and sway when he walks, or to have jerky movements of the arms and legs (a drunken appearance). A person trying to reach an object may misjudge the distance and location of that object and fail to reach it. The cerebellum also enables us to perform rapid and repetitive actions such as typing. In the cerebellum, right-sided abnormalities produce symptoms on the same side of the body.

Cerebrospinal Fluid (CSF)

CSF is present within the brain and surrounds the brain and the spinal cord. It is a clear, watery substance that helps cushion the brain and spinal cord from injury. This fluid circulates through channels around the spinal cord and brain, constantly being absorbed and replenished. CSF is produced within hollow channels in the brain, called ventricles. The brain normally maintains a balance between the amount of cerebrospinal fluid that is absorbed and the amount that is produced, however disruptions or blockages in the system can occur.

Cerebrum / Cerebral hemispheres

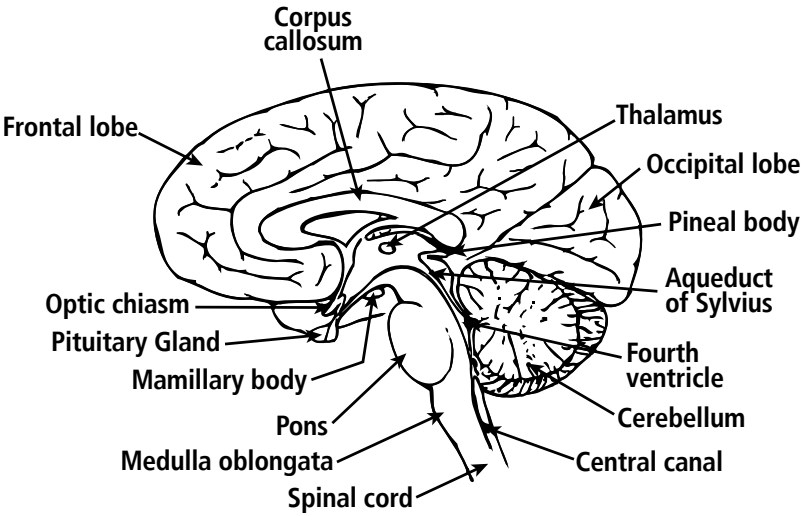
The term cerebrum is often used to describe the entire brain. It forms the bulk of the brain and is divided into two major parts: the right and left cerebral hemispheres. Generally speaking, the left side of the brain controls the right side of the body and the right side of the brain controls the left side of the body.

There is a fissure or groove that separates the two hemispheres, called the great longitudinal fissure. The two sides of the brain are joined at the bottom 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. The surface of the cerebrum (brain) is covered by billions of neurons and glia that together form the cerebral cortex.

Called the gray matter, the cerebral cortex appears greyish brown in colour and wrinkled. The cerebral cortex consists of small grooves (sulci), larger grooves (fissures) and bulges between the grooves (called gyri). Decades of scientific research have revealed the specific functions of the various regions of the brain and scientists now have specific names for the bulges and grooves on its surface. These names serve as landmarks and are used to help isolate very specific regions of the brain. Beneath the cerebral cortex or surface of the brain, neurons form the white matter.

The cerebral hemispheres have several distinct fissures. By finding these landmarks on the surface of a brain, the brain can effectively be divided into pairs of lobes. *See Figure:* Lobes of the Brain and Structures Deep Inside the Brain.

Structures Deep Inside the Brain



Choroid Plexus

The choroid plexus is situated deep within each cerebral hemisphere in the ventricles. It produces spinal fluid that flows through the ventricles and meninges surrounding the brain and spinal cord.

Corpus Callosum

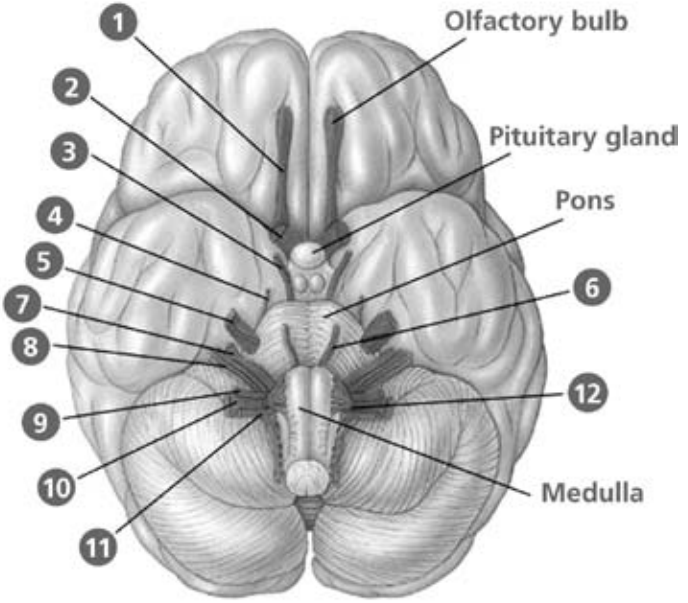
The corpus callosum connects the two halves of the brain and delivers messages between them.

Cranial Nerves

There are 12 pairs of nerves that come from the brain itself. These are called the cranial nerves. *See Figure:* Cranial Nerves.

These nerves are responsible for some very specialized features and they are both named and numbered.

Cranial Nerves



Cranial Nerve	Function
1 Olfactory	Smell
2 Optic	Visual fields and ability to see
3 Oculomotor	Eye movements; eyelid opening
4 Trochlear	Eye movements
5 Trigeminal	Facial Sensation
6 Abducens	Eye movements
7 Facial	Eyelid closing; facial expression; taste sensation
8 Acoustic	Hearing; sense of balance
9 Glossopharyngeal	Taste sensation; swallowing
10 Vagus	Swallowing; taste sensation
11 Accessory	Controls neck and shoulder muscles
12 Hypoglossal	Tongue movement

Cranium

The brain is found inside the bony covering called the cranium. The cranium protects the brain from injury. Together, the cranium and bones that protect the face are called the skull.

Frontal Lobes

The areas of the brain that produce movement in various parts of the body are found in the primary motor cortex or precentral gyrus, which in turn, are located in the frontal lobes. The prefrontal cortex plays an important part in our memory, intelligence, concentration, temper and personality. It helps us set goals, make plans and judge our priorities. The premotor cortex is a region found beside the primary motor cortex. It guides our eye and head movements and sense of orientation. Broca's area, important in language production, is found in the left frontal lobe. *See Figure:* Lobes of the Brain

Glial Tissue or Neuroglia

The principal cellular elements of the nervous system are neurons and glial cells. The neuron is responsible for sending and receiving nerve impulses or signals. Neuroglia provide neurons with nourishment, protection and structural support. The most common glial cells are astrocytes and oligodendrocytes. Astrocytes are involved with the blood brain barrier and brain metabolism. Oligodendrocytes maintain the myelin sheath covering nerve cells. Other glial tissue such as ependymal and microglial are also found in the brain.

Glial cells are the most common type of cell involved in tumours that have originated in the brain. The name given to a brain tumour may reflect the type of cell that is involved (e.g., an astrocytoma has astrocyte cell involvement).

Hypothalamus

The hypothalamus is a small structure that contains nerve connections that send messages to the pituitary gland. It makes up part of the wall of the third ventricle and is the base of the optic chiasm. The hypothalamus handles information that comes from the autonomic nervous system. It plays a role in controlling behaviours, such as eating, sleeping, body temperature, emotions, secretion of hormones, movement and sexual behaviour.

Limbic System

This system involves our emotions and comprises of the hypothalamus, part of the thalamus, the amygdala (active in producing aggressive behaviour) and hippocampus (which plays a role in our ability to remember new information).

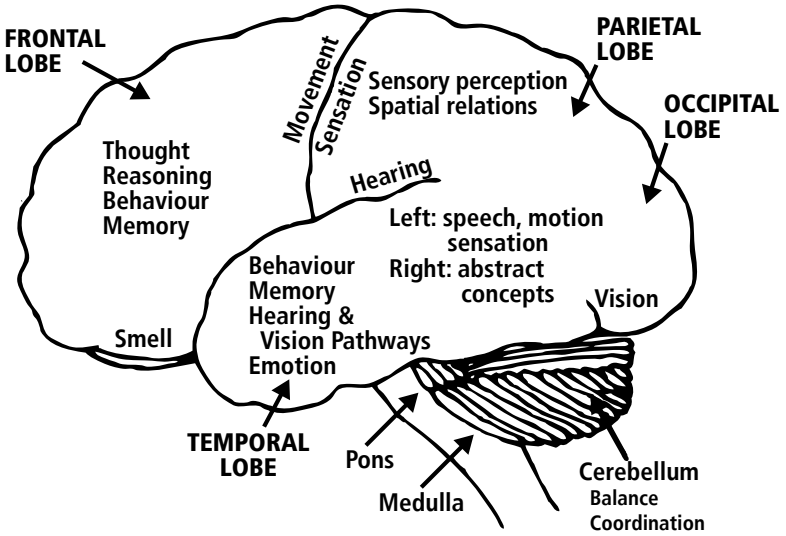
Lobes of the Brain

Lobes are simply broad regions of the brain. The cerebrum or brain may be divided into pairs of frontal, temporal, parietal and occipital lobes. To state this in another way, each hemisphere has a frontal, temporal, parietal and occipital lobe. *See Figure:* The Lobes of the Brain. Each lobe can be divided, once again, into areas that serve very specific functions. The lobes of the brain function together, through a series of very complex relationships.

Messages within the brain are delivered in many ways. Signals are transported along routes called pathways. Any destruction of brain tissue by a tumour can disrupt the communication between different parts of the brain. The result will be a loss of function such as speech, the ability to read or to follow simple spoken commands. Messages can travel from one side of the brain to the other, from one bulge on the brain to another (gyri to gyri), from one lobe to another, from one lobe of the brain to structures that are found deep within the brain (e.g., thalamus), or from the deep structures of the brain to another region in the central nervous system.

Specific regions of the motor and sensory regions, when electrically stimulated will cause movement or sensation to occur in a very specific part of the body. Touching one side of the brain sends electrical signals to the other side of the body. For example, touching the motor region on the right side of the brain causes the opposite side or the left side of the body to move. Stimulating the left primary cortex causes the right side of the body to move. The messages for movement and sensation will always cross to the other side of the brain and cause the opposite limb to move or feel a sensation. If your brain tumour is located on the right side of the brain in an area that controls the movement of your arm, your left arm may be weak or paralyzed. One side of the brain controls the opposite side of the body.

Lobes of the Brain



**For right-handed individuals*

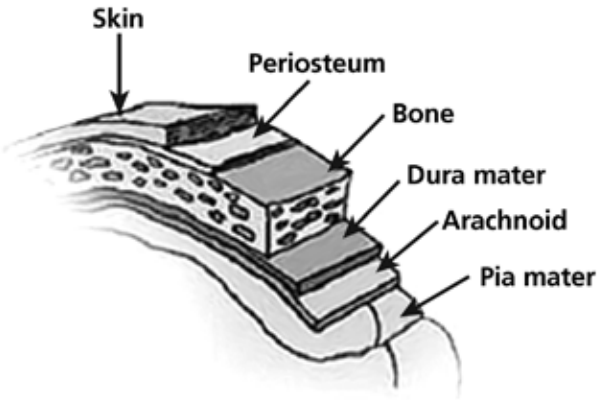
Medulla Oblongata

The medulla oblongata is part of the brainstem. It connects the brain with the spinal cord (see Brainstem).

Meninges

The meninges are three layers of tissue that cover the brain and protect the spinal cord. From the outermost layer inward they are: the dura matter, arachnoid and pia mater. *See Figure:* Meninges.

Meninges



Midbrain

The midbrain is part of the brainstem and is located between the pons and the cerebral hemispheres. The top portion is called the tectum.

Occipital Lobes

These lobes contain regions that contribute to our visual field, or how our eyes see the world around us. They help us see light and objects and allow us to recognize and identify them. The occipital lobes contain the visual cortex. The occipital lobe on the right interprets visual signals from the left visual space, while the left occipital lobe does the same for the right visual space. Damage to one occipital lobe may result in a visual field deficit in the opposite visual field. *See Figure:* Lobes of the Brain.

Optic Chiasm

The optic nerves join to form the optic chiasm where half the fibers of each optic nerve cross to the opposite side of the brain. The optic chiasm is located near the pituitary gland.

Parietal Lobes

The parietal lobes simultaneously interpret signals received from areas of the brain involved with vision, hearing, motor skills sensory perception, and memory. Together with memories, the new information that is received give meaning to objects. A furry object touching your skin that purrs and appears to be a cat will have a different meaning than a furry object that barks and appears to be a dog. *See Figure:* Lobes of the Brain.

Pineal Gland

This gland produces the hormone melatonin, which is believed to be involved in the control the biological rhythm of the body. It is located below the corpus callosum.

Pituitary Gland

The pituitary gland is attached to the hypothalamus and produces various hormones.

Pons

The pons is part of the brainstem. It relays information between the cerebrum and cerebellum, and has some control over sleep.

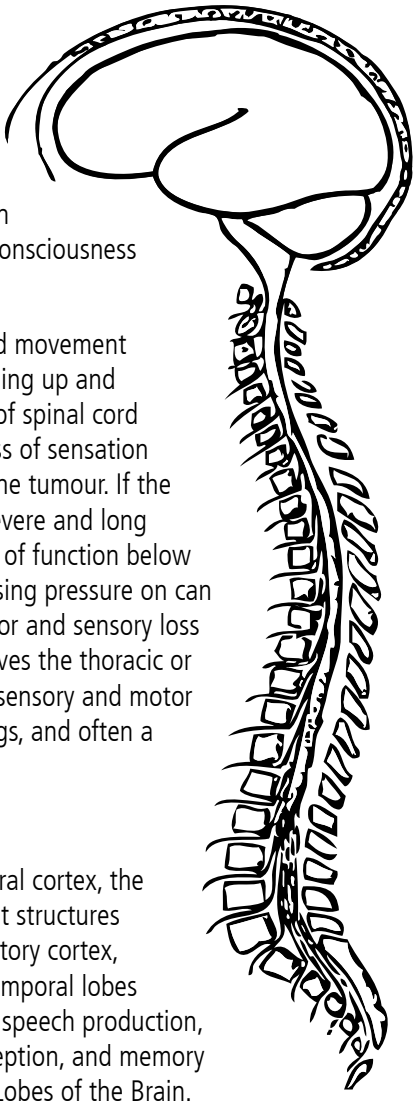
Reticular Formation

The reticular activating system is found in the midbrain pons, medulla and part of the thalamus. It controls your level of wakefulness, the attention you pay to what happens in the world that surrounds you and your pattern of sleep.

Spinal Cord

The spinal cord is an extension of the brain. It is protected by a bony structure called the vertebral or spinal column. The spinal cord is covered with the same three membranes as the brain, called the meninges. There is a subarachnoid space that surrounds the spinal cord. This space contains the cerebrospinal fluid. *See Figure:* The Brain and Spinal Cord.

The Brain and Spinal Cord



All the information going from the brain to the limbs travels through the spinal cord. This process allows for movement. The spinal cord is the first relay station for sensory information (e.g., our arms and legs) on its way to consciousness in various centres of the brain.

Bladder functions, sensory functions and movement are all dependent on information travelling up and down the spinal cord. Any interruption of spinal cord function by a tumour may result in a loss of sensation and motor function below the level of the tumour. If the pressure on the normal spinal cord is severe and long lasting, a complete and permanent loss of function below the level of the tumour or area it is causing pressure on can occur. Paraparesis occurs when the motor and sensory loss is below the level of the arms and involves the thoracic or lumbar region. Quadraparesis refers to sensory and motor malfunction involving both arms and legs, and often a problem in the cervical area (neck).

Temporal Lobes

One of the four main lobes of the cerebral cortex, the temporal lobes houses several important structures of the limbic system, including the olfactory cortex, amygdala, and the hippocampus. The temporal lobes play an important role in language and speech production, organizing sensory input, auditory perception, and memory association and formation. *See Figure:* Lobes of the Brain.

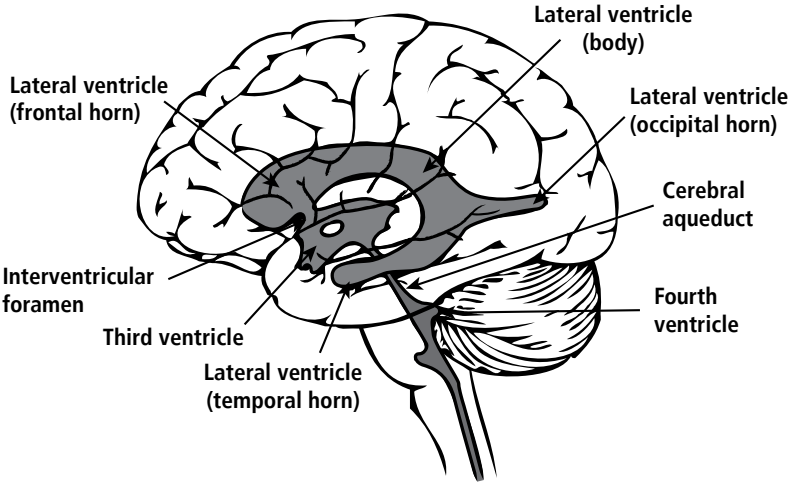
Thalamus

The thalmus serves as a relay station for almost all information that comes and goes to the cortex. It plays a role in pain sensation, attention and alertness. It surrounds the third ventricle.

Ventricles

There are four ventricles or cavities that are connected within the brain, and they contain the cerebrospinal fluid produced by the choroid plexus. There is one lateral ventricle in each hemisphere. A third ventricle is located beneath the corpus callosum and the fourth ventricle is located in the area of the brainstem. *See Figure:* The Ventricles.

The Ventricles



Appendix B: Brain Facts and Brain Fitness

The brain is perhaps the most fascinating organ in the human body. It controls everything from breathing to emotions to learning.

Here are some fun facts about the brain:

- The human brain is like a powerful computer that stores our memory and controls how we think and react. It has evolved over time and features some incredibly intricate parts that scientists still struggle to understand.
- With evolution, the human brain has become more and more complicated; many of its interesting properties are still not well understood by scientists.
- The brain, the most complex structure of the human body, weighs about three pounds (3 lbs).
- The brain encases 100 billion or more nerve cells, and can send signals to thousands of other cells at a rate of about 320kms per hour.
- Brain researchers have learned more about the workings of the brain in the past 10 years than did they in the previous century.
- The energy used by the brain is enough to light a 25 watt bulb.
- More electrical impulses are generated in one day by a single human brain than by all the telephones in the world.
- The human brain is estimated to generate 70,000 thoughts on an average day.
- After age 30, the brain shrinks a quarter of a per cent (0.25%) in mass each year.
- Albert Einstein's brain weighed 2.71 lbs, significantly less than the human average of 3 lbs.
- Your brain uses approximately 20% of the total oxygen pumping around your body and about 750ml of blood pumps through your brain every minute.
- The human brain is approximately 75% water.
- The human brain continues to grow until about age 18.

- The human brain is over three times as big as the brain of other mammals that are of similar body size.
- The human brain is protected by the skull (cranium), a protective casing made up of 22 bones that are joined together.
- The brain is suspended in cerebrospinal fluid, effectively floating in liquid that acts as a cushion to physical impact and a barrier to infection.

Source: Nursing Assistant Central: http://www.nursingassistantcentral.com/blog/2008/100-fascinating-facts-you-never-knew-about-the-human-brain/

Brain Fitness

What is Brain Fitness?

For years we have been encouraged to stay physically active to increase our chances of living longer and avoiding various diseases. Now we are receiving similar recommendations about brain health and fortunately, there is a lot we can do to engage our brains on a daily basis.

Science is unlocking many of the mysteries of the brain and research is showing that the brain is continuously changing and improving itself. In fact, research is showing that physical brain change occurs every time we learn something new. This ability for continuous physical, chemical and functional brain change is known as brain plasticity or neuroplasticity. Brain plasticity describes the ability to reprogram the brain to bypass an area with an injury and learn new skills or relearn old ones, no matter the age of the person or disability. This means that rehabilitation is worthwhile and that those affected by a brain tumour may be able to improve their quality of life.

In our day-to-day lives, we rely on our memories for both simple and complex tasks, but the ability to remember can change after undergoing brain tumour treatment. Working on brain fitness may help enhance our memory skills and concentration and our ability to organize information, or help us compensate for memory impairments in daily life. Research shows that brain fitness activities and programs may be used to evaluate and combat a variety of conditions including brain tumours.

Whether you are feeling the effects of "chemo brain" or experiencing difficulties with concentration and recall due to a non-malignant brain tumour, there are some brain fitness tips that may help you in coping with memory or cognitive changes.

Brain Fitness Tips

- Have fun with puzzles, number games, brain teasers, visual illusions, take up a new hobby or master a new skill.
- Stay organized: Use calendars or planners to help keep yourself on track, make lists or use a chart board / wipe board in your kitchen or bedroom to 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 memory problems: Schedule difficult tasks when feeling your best.
- Try stress-relief techniques: Try visualizations, meditation, yoga or Pilates.
- Food for thought: Our brains work best when we eat well-balanced meals.
- Have a good laugh: Read a new joke or watch a comedy.

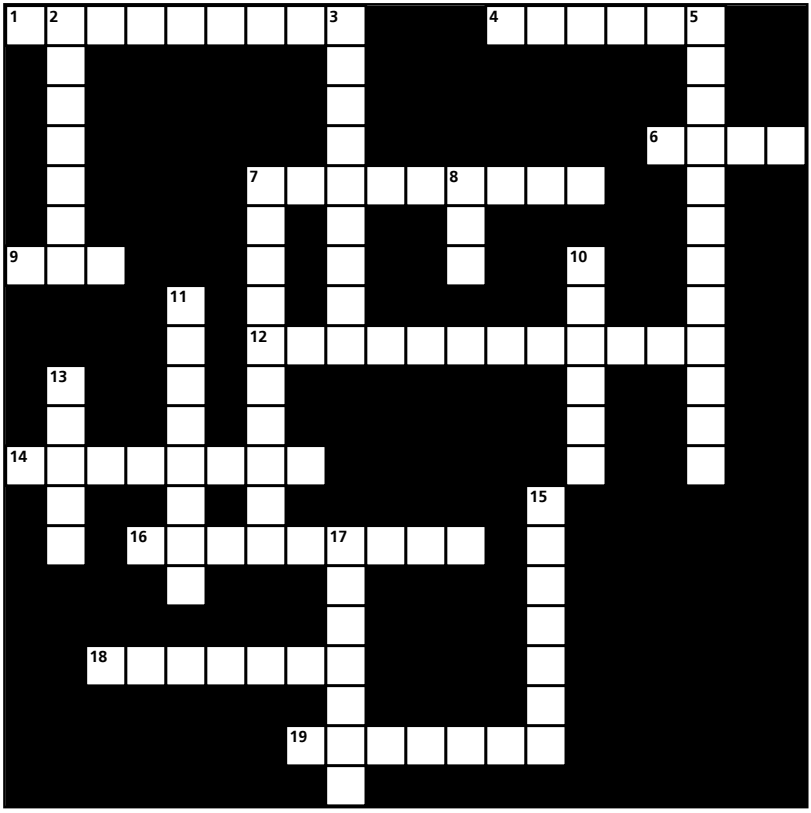
Brain fitness is for everyone, regardless of whether or not you have memory problems related to a health condition. Consult a member of your rehabilitation team, such as an occupational therapist, for more information about incorporating brain fitness activities into your life.

Word Search

E	U	C	L	H	S	T	E	R	O	T	A	C	T	I	C	L	H	J	R
P	C	E	R	E	B	E	L	L	U	M	O	E	T	I	O	L	O	G	Y
G	R	C	R	A	N	I	O	T	O	M	Y	R	X	Z	D	J	T	K	P
L	A	V	R	E	H	A	B	I	L	I	T	A	T	I	O	N	S	S	W
V	D	H	E	P	E	N	D	Y	M	O	M	A	S	A	A	T	E	V	D
G	I	Y	F	P	G	C	F	E	F	Z	L	E	I	N	N	S	S	X	U
A	O	W	S	A	H	R	A	Z	S	A	V	S	G	A	A	U	W	N	S
I	S	I	U	P	G	A	T	Y	I	R	E	I	S	T	M	C	S	U	N
T	U	N	B	I	L	N	I	L	E	H	L	L	S	A	X	H	L	X	A
C	R	F	R	L	I	I	G	N	T	A	U	A	L	N	W	A	S	A	X
H	G	I	A	L	O	A	U	S	M	V	T	A	O	S	H	I	M	F	Y
R	E	L	I	E	B	L	E	N	N	E	H	I	I	P	S	O	N	G	M
O	R	T	N	D	L	N	O	O	M	T	S	S	E	E	T	O	R	C	E
M	Y	R	S	E	A	N	C	H	O	S	O	C	R	Y	I	A	L	T	D
O	B	A	T	M	S	I	Q	P	I	R	O	A	C	T	H	E	O	I	E
S	R	T	E	A	T	H	Y	M	C	R	P	O	C	T	I	X	B	S	M
O	A	I	M	N	O	H	E	E	D	I	R	E	E	G	C	R	E	S	A
M	I	N	A	B	M	R	N	Y	M	T	S	L	C	I	T	K	S	U	U
E	N	G	I	Y	A	N	H	E	S	E	T	M	E	N	I	N	G	E	S
S	D	E	B	U	L	K	H	A	R	U	C	A	L	L	O	S	U	M	S

ANESTHESIA
ANTICONVULSANTS
ASTROCYTOMA
BRAIN
BRAINSTEM
CEREBELLUM
CHROMOSOMES
CRANIAL
CRANIOTOMY
DEBULK
EDEMA
EPENDYMOMA
ETIOLOGY
FATIGUE
GAIT
GLIOBLASTOMA
HEMIPARESIS
HYDROCEPHALUS
HYPOTHALAMUS
INFILTRATING
LETHARGY
LOBES
MENINGES
METASTASES
NECROSIS
NERVES
NONMALIGNANT
PAPILLEDEMA
RADIOSURGERY
REHABILITATION
REMISSION
RESECTION
STEROTACTIC
TISSUE

Crossword Puzzle



Across

1. This is one way to get involved with the brain tumour community through Brain Tumour Foundation of Canada
4. The season in which Brain Tumour Foundation of Canada's largest fundraiser is held
6. The main character's name in Brain Tumour Foundation of Canada's storybook for children
7. The name of Brain Tumour Foundation of Canada's support program for children and teens diagnosed with a brain tumour
9. A type of imaging device used to perform brain scans
12. Another term for benign (2 Words)
14. The name of one of Brain Tumour Foundation of Canada's online, social media communities
16. BBQs, dances, golf tournaments and trivia nights are community fundraising events
18. Calling the 1-800# or attending one of Brain Tumour Foundation of Canada's groups will provide you with this
19. A general term that refers to a sudden malfunction in the brain that causes someone to collapse, convulse, or have another temporary disturbance of normal brain function, often with a loss or change in consciousness and may be a sign or symptom of a brain tumour

Down

2. This is Brain Tumour Foundation of Canada's brain tumour awareness month
3. One of the three most common treatment options for a brain tumour
5. The most common type of primary malignant brain tumour
7. Brain Tumour Foundation of Canada's main newsletter, printed twice a year and available electronically ten times a year
8. Brain tumours are classified by this international health organization
10. The city in Ontario in which Brain Tumour Foundation of Canada's head office is located
11. Brain Tumour Foundation of Canada's informative, free resource available to anyone in Canada affected by a brain tumour
13. A type of funding that doctors and scientists receive to help further their critical brain tumour research
15. Either in memory or in honour of someone special, this is a meaningful way to recognize a loved one
17. The last name of one of the founders of Brain Tumour Foundation of Canada

*Please turn to **page 296** of the handbook for the answers to the crossword puzzle.*

Appendix C: Adult Brain Tumour Types

This section provides the names of many different types of adult brain tumours. General information about these tumours is provided to help you in learning more about your diagnosis. However, this list is not comprehensive and some rare types of tumours and mixed tumour types may not be listed.

If you are unable to find information on a particular brain tumour type within this alphabetical list, please contact Brain Tumour Foundation of Canada and your health care team for more information

Acoustic neuroma (also known as Schwannoma)

WHO Grade I

An acoustic neuroma, also known as a schwannoma, vestibular schwannoma or neurilemmoma, affects the nerves responsible for hearing. This type of non-malignant tumour manifests itself on the sheath surrounding the eighth cranial nerve, affecting 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 undetected.

Anaplastic astrocytoma

WHO Grade III

The cells of these tumours are moderately fast-growing and less well defined than an Astrocytoma (Grade I or II), and are typically diagnosed in adults. They can occur anywhere in the brain. They are sometimes found in the brainstem, making a histological diagnosis difficult.

Anaplastic ependymoma

WHO Grade III

See Ependymoma

Anaplastic meningioma

WHO Grade III

See Meningioma

Atypical meningioma

WHO Grade II

See Meningioma

Brainstem glioma

WHO Grade I, II, III or IV

This is a term used for glial tumours located in the brainstem. These are far more common in children than in adults. Brainstem gliomas are located in the area of the brain and spinal cord that is responsible for many vital body functions, including vision, balance, strength, gagging, coughing and swallowing.

Butterfly glioma

When a glioma spreads across the corpus callosum into both hemispheres, it often has the appearance of a butterfly on a CT or MRI scan and so is given the general term "butterfly glioma."

Central neurocytoma

WHO Grade II

Central neurocytoma is a tumour of young adults composed of uniform round cells with neuronal differentiation, typically arising from the septum pellucidum and walls of the lateral ventricles.

Choriocarcinoma

See Germ cell tumours.

Craniopharyngioma

WHO Grade I

Craniopharyngiomas are intracranial tumours that usually consist of cystic and solid components. They typically develop near the pituitary gland (a small endocrine gland at the base of the brain) and often remain undetected until they press on important structures around them.

Diffuse astrocytoma

WHO Grade II

Diffuse astrocytomas are very uncommon in children and rarely undergo malignant transformation (compared to the adult population).

Dysembryoblastic neuroepithelial tumour (DNT or DNET)

WHO Grade I

Usually located in the temporal lobe, DNET is often associated with a seizure disorder.

Embryonal carcinoma

See Germ cell tumours.

Ependymoma

- Myxopapillary ependymoma

  WHO Grade I

- Ependymoma

  WHO Grade II

- Anaplastic ependymoma

  WHO Grade III

These tumours originate from the cells lining the ventricles (hollow channels) of the brain (most commonly the fourth ventricle).

Fibrillary astrocytoma

See Diffuse astrocytoma

Ganglioglioma

WHO Grade I

This is a rare tumour type which can be localized within the CNS.

Germ cell tumours (GCTs)

- Choriocarcinoma
- Embryonal carcinoma
- Germinoma
- Mixed germ cell tumour
- Teratoma
- Yolk sac tumour

Intracranial GCTs are typically found in the midline sites such as pineal and the suprasellar regions and present in adolescents. Incidence rates are much higher in Asian people as compared with North Americans and Europeans. Tumour markers (alpha 1-fetoprotein AFP and human chorionic gonadotropin HCG) should be obtained in the serum as well as in the craniospinal fluid and if significantly positive for this tumour type, no histological confirmation may be required.

Germinoma

See Germ cell tumours

Glioblastoma multiforme (GBM, Glioblastoma)

WHO Grade IV

These tumours contain various cell types, hence the name "multiforme," the most common being astrocytes. Most of these tumours occur in the cerebral hemispheres and often involve the corpus callosum. The cells of these tumours grow quickly, are not well defined, and can spread throughout the brain.

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 part of a genetic syndrome called Von Hippel-Lindau (VHL) or they may occur separately from the VHL syndrome.

Meningioma

- Meningioma

  WHO Grade I

- Atypical meningioma

  WHO Grade II

- Anaplastic meningioma

  WHO Grade III

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 originate in the middle layer, called the arachnoid. As they grow, meningiomas can compress nearby brain tissue, cranial nerves and blood vessels. Meningiomas are usually diagnosed in the middle-aged and the elderly.

Metastatic or Secondary Brain Tumours

The brain is frequently the site of metastasis (spread) from a tumour elsewhere in the body. In major referral centres, metastatic disease is the most frequent type of brain or spinal cord tumour seen. The most common sites of cancer that spread to the brain are the lung, breast, kidney and skin (melanoma). The spread of a tumour to the brain may produce symptoms before the primary tumour is diagnosed. Tumours that spread to the brain may be single (solitary metastasis) or multiple.

Mixed germ cell tumour

See Germ cell tumours

Mixed glioma

A brain tumour may be made up of two or more cell types. When this is the case, it is referred to as a mixed glioma and is graded according to the most aggressive cell type found within the specimen.

Myxopapillary ependymoma

See Ependymoma tumours

Pineal region tumour

The pineal gland is located centrally in the brain and is an out-pouching of the third ventricle. Hydrocephalus is usually a presenting symptom of tumours arising from the pineal gland, resulting from a blocked cerebrospinal fluid pathway.

Pituitary adenomas

WHO Grade I or II

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

Teratoma

See Germ cell tumours

Yolk sac tumour

See Germ cell tumours

World Health Organization (WHO) Grading System

The following chart outlines both pediatric and adult brain tumours using the World Health Organization (WHO) Grading System. The tumours are also grouped by tumour type.

	I	II	III	IV
Astrocytic Tumours				
Subependymal giant cell astrocytoma	*			
Pilocytic astrocytoma	*			
Pilomyxoid astrocytoma		*		
Diffuse astrocytoma		*		
Pleomorphic xanthoastrocytoma		*		
Anaplastic astrocytoma			*	
Glioblastoma				*
Giant cell glioblastoma				*
Gliosarcoma				*
Oligodendroglial Tumours				
Oligodendroglioma		*		
Anaplastic olgiodendroglioma			*	
Oligoastrocytic Tumours				
Oligoastrocytoma		*		
Anaplastic oligoastrocytoma			*	
Ependymal Tumours				
Subependymoma	*			
Myxopapillary ependymoma	*			
Ependymoma		*		
Anaplastic ependymoma			*	

	I	II	III	IV
Choroid Plexus Tumours				
Choroid plexus papilloma	*			
Atypical choroid plexus papilloma		*		
Choroid plexus carcinoma			*	
Other Neuroepithelial Tumours				
Angiocentric glioma	*			
Chordoid glioma of the third ventricle		*		
Neuronal and Mixed Neuronal-Glial Tumours				
Gangliocytoma	*			
Ganglioglioma	*			
Anaplastic ganglioglioma			*	
Desmoplastic infantile astrocytoma and ganglioglioma	*			
Dysembryoplastic neuroepithelial tumour	*			
Central nuerocytoma		*		
Extraventricular neurocytoma		*		
Cerebellar liponeurocytoma		*		
Paraganglioma of the spinal cord	*			
Papillary glioneuronal tumour	*			
Rosette-forming glioneuronal tumour of the fourth ventricle	*			
Pineal Tumours				
Pineocytoma	*			
Pineal parenchymal tumour of intermediate differentiation		*	*	
Pineoblastoma				*
Papillary tumour of the pineal region		*	*	

	I	II	III	IV
Embryonal Tumours				
Medulloblastoma				*
CNS primitive neuroectodermal tumour (PNET)				*
Atypical teratoid / Rhabdoid tumour				*
Tumours of the Cranial and Paraspinal Nerves				
Schwannoma	*			
Neurofibroma	*			
Perineurioma	*	*	*	
Malignant peripheral nerve sheath tumour (MPNST)		*	*	*
Meningeal Tumours				
Meningioma	*			
Atypical meningioma		*		
Anaplastic / malignant meningioma			*	
Haemangiopericytoma		*		
Anaplastic haemangiopericytoma			*	
Haemangioblastoma	*			
Tumours of the Sellar Region				
Craniopharyngioma	*			
Granular cell tumour of the neurohypophysis	*			
Pituicytoma	*			
Spindle cell oncocytoma of the adenohypophysis	*			

Source: 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

Appendix D:
Brain Tumour Related Conditions

Cysts

Abnormalities that may resemble brain tumours, such as cysts, contain abnormal accumulations of fluid, tissue or tumour cells enclosed in a lined sac. There are specific types of cysts and they are named for their tissue type and their content, such as:

- Arachnoid cyst
- Colloid cyst
- Dermoid and Epidermoid cyst
- Rathke cleft cyst

Hamartoma

A Hamartoma is a type of abnormality that can resemble a brain tumour. It is a collection (or clumping) of a particular normal tissue or cell type in areas where they are not typically found. Hamartomas are not considered to be fast-growing or malignant, and are presumed to be congenital (existing before birth). The tissue included in the mass are normal, but may be highly disorganized. They can cause seizures and/or hydrocephalus. Treatment may be surgical, although many the lesions cannot be completely removed. These tumours have a tendency to grow during childhood and less frequently after puberty.

The following are examples of multi-system genetic disorders:

Neurofibromatosis Type 1

Neurofibromatosis Type 1 is an autosomal dominant disorder that is passed from one generation to the next, but occurs spontaneously in about 50 per cent of cases. Classical signs of a Neurofibromatosis Type 1 include skin changes with cafe-au-lait spots, freckling and cutaneous neurofibromas. Learning disabilities and attention deficit hyperactivity disorder may also occur. Many types of brain tumours are associated with Neurofibromatosis, but the most common are optic pathway tumours, cerebral astrocytomas, and focal areas of signal intensity (FASI).

Neurofibromatosis Type 2

Neurofibromatosis Type 2 is an autosomal dominant disorder that is passed from one generation to the next but in 50% of the cases it is a spontaneous new mutation. It is usually diagnosed by the presence of acoustic neuromas (schwannomas) arising on both the right and left vestibular-cochlear nerves and patients often presents with deafness. The second most common type of brain tumour in children with this disorder is meningiomas.

Appendix E: Information About My Brain Tumour

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

_____

My doctor's name is: _____

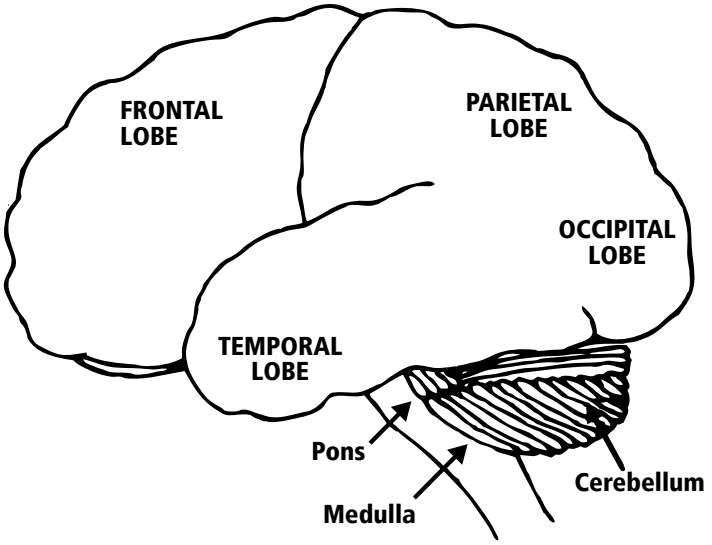
My nurse's name is: _____

Name of other health care providers on my team: _____

_____

_____

Where is my brain tumour? Circle area on brain where tumour is located.



Options for treatment: _____

_____

_____

_____

Risks and benefits of treatment: _____

_____

_____

_____

I take these medications: _____

_____

_____

_____

When is my next appointment? With whom? _____

_____

Other comments: _____

_____

_____

Appendix F: Questions to Ask the Doctor

Having open communication with your health care 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 to 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?

_____

Is the tumour malignant or non-malignant? _____

_____

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 this 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 we 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? Our 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 with these concerns?

_____

_____

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

_____

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

_____

Would you recommend a second opinion? _____

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

_____

Additional Notes: _____

_____

_____

_____

_____

_____

_____

_____

Appendix G: 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 seems different? _____

_____

When did it start? _____

What time of day does it happen? _____

_____

How long does it last? _____

_____

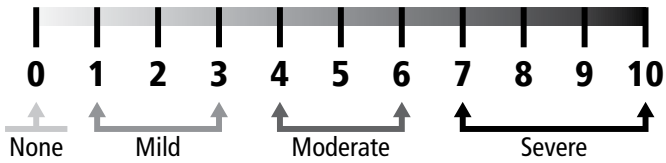
How often does it happen? _____

_____

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 H: Prescribed Medications

Medication	Instructions / Dose	Date		Prescribing Doctor
		Started	Stopped	

* It is strongly recommended that you take all of your medications to each doctor or hospital visit.

Appendix I:
Health Care Team Contact Information

Name / Title	Telephone	Working Hours	After Hours & Emergency

Appendix J: Appointments

Who	When	Where

* Remember to take medication bottles to all appointments.

Glossary of Terms

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

Acoustic neuroma / schwannoma (now called vestibular schwannoma): Usually a non-malignant tumour of the eighth cranial nerve that controls hearing and balance. These tumours tend to grow slowly and do not normally invade healthy tissue.

Acromegaly: A condition caused by excess growth hormone (GH) produced by the pituitary gland, which is usually due to a pituitary adenoma. Untreated, this condition can cause bone and soft tissue changes, enlargement of the hands and feet, and sleep apnea. Acromegaly can also cause more serious conditions such as cardiovascular disease and hypertension.

Adenoma: Most often a non-malignant tumour that originates from a gland. An example of an adenoma would a pituitary adenoma.

Adjunctive treatment: Treatment given in conjunction with the primary treatment to improve the therapeutic response; for example, if radiation is the primary treatment, chemotherapy given at the same time is an adjunctive treatment.

Adjuvant treatment: Used following the primary treatment to improve the overall therapeutic response; for example, chemotherapy and radiation following cancer surgery are adjuvant therapies.

Agnosia: The loss of the ability to recognize objects, people, spatial relationships, shapes or smells. This can result from a tumour in the parietal lobe.

Agraphia: A form of aphasia that results in the loss of the ability to write. This is often a symptom of tumours in the parietal lobe.

Alkylating agent: A drug that interferes with a cell's DNA and discourages cell growth; for example, temozolomide.

Alopecia: Partial or complete loss of hair, which is often a side effect of radiation and certain chemotherapies.

Amenorrhea: Absence or suppression of normal menstrual flow.

Analgesic: Any medication administered to treat pain.

Anemia: A deficiency of red blood cells. Symptoms include fatigue, shortness of breath, and weakness.

Anesthesia: The administration of medications, both intravenous and gaseous, to provide pain relief and/or unconsciousness during surgery. Anesthesia can be general (the patient is asleep and unaware of surroundings), local (the patient is awake and aware but feels no pain), or neuroleptic (the patient is given medications to make him drowsy and diminish memory and awareness but is not actually asleep).

Angiogenesis: Blood vessel formation, particularly the growth of new blood vessels from surrounding tissue into tumour tissue. Angiogenesis is necessary for a tumour to grow larger and for metastases to grow at secondary sites.

Angiogram: An angiogram is the most effective means available of studying the blood vessels of the brain and detecting any abnormalities. The test is performed by a neuroradiologist. The procedure takes place in the X-ray department. Sedation is usually given before the procedure begins. Periodic injections of a contrast agent ("dye") are administered through a catheter. The dye makes the X-ray images clearer and easier to read.

Anosmia: The absence of the sense of smell. This is a symptom common to tumours of the frontal lobe.

Anti-angiogenesis: A therapy to halt the growth of new blood vessels that bring nutrients to the tumour cells.

Anticonvulsants: Medications used to treat seizures.

Antidiuretic hormone: Controls the ability of the kidney to concentrate urine and helps with the maintenance of the fluid and electrolyte balance in the body.

Anti-emetic: Any medication used to control nausea and vomiting.

Aphasia: The loss of the ability to speak or write and/or the loss of the ability to understand the speech or written words.

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.

Astrocytoma: Tumours originating from the star-shaped astrocyte cells, which are the supportive tissue of the brain.

Astrocytic tumours: Low-grade astrocytic tumours are the most common brain tumours in children. They can occur at any age, but are more common in children under 10 years. The most common location for astrocytic tumours is the posterior fossa / cerebellum, but they can occur anywhere within the CNS including the spine. Low-grade astrocytic tumours within the optic pathway are called optic pathway gliomas (OPG) and are often seen in children with underlying type I neurofibromatosis.

Ataxia: Inability to coordinate movements and maintain posture; a tendency to lose balance.

Basal ganglia: Masses of nerve cells found deep within the cerebral hemispheres.

Basic research: Laboratory studies that explore the ways in which cells live, grow and die.

Benign: 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.

Biomarker (also called a tumour marker): A substance sometimes found in the blood, other bodily fluids, or tissue. A high level of biomarker may mean that a certain type of cancer is present in the body.

Biopsy: A process whereby a small amount of tumour tissue is removed, usually through a thin needle, and microscopically examined to determine tumour type. A biopsy may be done during surgery.

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

Blood brain barrier: A filtering mechanism made up of blood vessels and glial cells, which protects the brain by keeping out many harmful substances. Only certain types of chemotherapy can effectively cross this barrier to reach a brain tumour.

Brainstem: Located at the bottom of the brain, it 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.

Brainstem glioma: A phrase used for glial tumours located in the brainstem. These are much more common in children than adults.

Broca's area: Located in the opercular and triangular sections of the inferior frontal gyrus. The function of this area of the brain is the understanding of language and formulation of speech.

Burr hole: A small opening in the skull made with a surgical drill.

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

Cancer: A term used to describe more than 100 diseases characterized by uncontrolled, abnormal growth of cells. Cancerous tumours or malignant tumours can spread or metastasize either locally into the lymph nodes or through the bloodstream to other parts of the body.

Carcinogen: Any contributing cause of cancer.

Carcinoma: A malignant tumour that arises from epithelial tissue.

Cells: The body is made up of tiny functioning units called cells, which can be observed under a microscope. Each cell plays a specialized role in the body. Groups of cells are organized together to form tissue. Tissues are organized to form organs in the body, e.g., our heart has very specialized cells that work together, causing our heart to beat and pump blood to other regions of the body.

Central nervous system (CNS): A term that refers to the brain, cranial nerves, and spinal cord.

Central sulcus: The central sulcus is the large, deep groove or indentation that separates the parietal and frontal lobes.

Cerebellum: Located at the lower back of the head and 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.

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.

Cerebrum / cerebral hemispheres: This is the largest area of the brain and is located in the front portion of the forebrain. It is divided into two hemispheres, which are further divided into four lobes: frontal, temporal, parietal, and occipital.

Chemotherapy (chemo): The term chemotherapy is used to describe the drugs used to treat cancer. Depending on the type of tumour, the drug or drugs will vary in the amount and frequency with which they are given. They may be given through an intravenous tube, by mouth or other route. They are prescribed by a physician, but may be given by a specially trained nurse.

Chondroma: A rare, slow-growing, non-malignant tumour of cartilaginous origin.

Chondrosarcoma: The extremely rare, malignant form of chondroma. It is a locally invasive tumour, arising from bone and composed of cartilage.

Chordoma: These are usually non-malignant, slow-growing tumours occurring at the base of the skull or at the end of the spine. They affect the adjacent cranial nerves and brainstem and are most common in younger and middle-aged adults. These tumours can be locally invasive.

Choroid plexus: Areas in the ventricles where cerebrospinal fluid is formed.

Choroid plexus papilloma: About 90% of choroid plexus tumours are papillomas, which are slow-growing and non-malignant. Ten per cent are choroid plexus carcinomas, which are malignant. This tumour occurs most often in children.

Chromosomes: Chromosomes are paired segments of DNA contained within the nucleus of each cell. In humans, there are 23 pairs of chromosomes.

Cingulate cortex: A bundle of nerve fibers in white matter located over the surface of the corpus callosum.

Clinical trials: Research studies done to determine whether new drugs, treatments, or vaccines are safe and effective.

Cognition: A generic term involving perceiving, recognizing, conceiving, judging, sensing, reasoning, remembering and imagining.

Congenital: Existing before or at birth.

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.

Corticosteroids (also called steroids): Medications used to reduce brain swelling, such as dexamethasone (Decadron) and prednisone. Side effects can include weight gain, depression, mood swings, agitation, and difficulty sleeping.

Corticotrophin: A hormone produced by the anterior pituitary gland that stimulates the adrenal cortex.

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

Craniectomy: An operation which involves penetrating the skull and removing small pieces of bone to gain access to the brain. This is used for tumours of the posterior fossa. Unlike a craniotomy, the removed pieces of bone are not reinserted into the skull. Following surgery, a soft spot may be felt in the area of the scar.

Craniopharyngioma: These brain tumours typically affect infants and children and are usually located near the pituitary gland. They often involve the optic nerve, the third ventricle, and the pituitary gland.

Cranioplasty: An operation in which a bony defect in the skull is replaced by plastic or mesh. It can be done during the initial brain surgery or delayed for months or years, if reason for bone removal was related to a tumour or infection involving bone.

Craniotomy: An operation which involves penetrating the skull and removing small pieces of bone to gain access to the brain. The bone is put back into place at the end of the surgical procedure.

CT or CAT (Computerized Axial Tomography) scan: This is a specialized X-ray machine. It uses a computer to assemble many tiny X-rays to produce a clear, accurate picture of a thin slice of hard and soft tissue inside the body. A contrast dye is sometimes used to enhance the resulting image.

Cyst: A fluid-filled sac, similar to a balloon, filled with water. Types of cysts found in the brain include the arachnoid cyst, colloid cyst, dermoid cyst and epidermoid cyst.

Debulk: A surgical procedure with the goal of decreasing the mass effect of a tumour by removing dead tissue or a portion of the tumour.

Diabetes insipidus: Caused by the inability of the kidneys to conserve water, which leads to frequent urination and pronounced thirst.

Dietary supplement: These are typically vitamins, but also include minerals, amino acids and herbs.

Diplopia: Double vision.

Drug resistance: The ability of a tumour cell to survive in the presence of drugs that are normally toxic.

Dura mater: The outer membrane covering the brain.

Dysphagia: Difficulty with swallowing or the inability to swallow. This can be a symptom of a tumour involving the lower brainstem.

Dysphasia: A language disorder that involves an inability to think of correct words or an inability to understand spoken or written words. This can be a symptom of tumours located in the cerebral hemisphere.

Edema: An excessive amount of fluid within the brain tissue, which is not related to an increased amount of cerebrospinal fluid. Brain tumours may affect the blood vessels in their vicinity allowing extra fluid to seep into normal brain tissue. Steroids such as dexamethasone (Decadron) are commonly used to treat edema.

Electroencephalogram (EEG): A test that measures the electrical activity in the brain. Small electrodes are attached to the scalp. A machine will record the electrical activity as brain cells send signals or messages to each another. Abnormal signals can be detected from the tracings made by the machine. These abnormal signals may indicate that there is seizure activity occurring or that damage has occurred to the brain cells in a particular region of the brain.

Endocrine dysfunction: With brain tumours, this usually refers to a decrease or absence of hormone production by the pituitary gland.

Endocrine-inactive adenoma: These typically create pressure on the normal pituitary gland and/or on structures near the pituitary such as the optic nerves and optic chiasm. They do not cause excess hormone production.

Endocrine therapy: Treatment by removing, blocking, or adding hormones: also called hormone therapy.

Endotracheal intubation: A medical procedure in which a tube is placed into the windpipe (trachea), through the mouth or the nose.

Enhancement: Being able to see a tumour more clearly after the injection of contrast material for CT or MRI. This is used in specific tumours, because of an abnormality in the vessels that nourish them.

Enteral feeding: Feeding by the gastrointestinal tract. Patients cannot swallow food if they have a breathing tube in their throat; they are fed through a feeding tube for proper nutrition during recovery.

Ependymoma: Brain tumours originating from cells lining the ventricles of the brain and the centre of the spinal cord. They usually occur in children, but can occur in adults as well.

Epidemiological studies: Studies designed to examine disease in large groups of people. They are usually looking for patterns that can be used to prevent illness or detect its source.

Epilepsy: A physical condition characterized by sudden, brief changes in how the brain works. It is a symptom of a neurological disorder: a disorder that affects the brain and shows itself in the form of seizures.

Etiology: The study of the cause of a disease.

Familial: Tending to occur repeatedly among family members, but not considered genetic or inherited. It can indicate a common environmental cause.

Focal areas of signal intensity (FASI): Typically found in the white matter and deep gray matter brain on MRI in children with NF1.

Fatigue: A common side effect experienced by many people with brain tumours, and results from the tumour, swelling, and/or treatment. Enough rest, proper nutrition, and moderate exercise can all help to combat this symptom.

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, judgment, coordinated movements, muscle movements, smell, physical reactions, and personality.

Gait: A pattern of walking.

Gamma knife®: A dedicated brain radiation unit that is designed to deliver high doses of radiation in a single treatment session.

Ganglioglioma: A rare, non-malignant tumour that contains abnormal neurons and supportive cells.

Gastronomy (G-Tube): A tube inserted into the stomach for feeding purposes, if swallowing is a problem.

Gene: A gene contains hereditary information encoded in the form of DNA and is located at a specific position on a chromosome in a cell's nucleus. Genes determine many aspects of anatomy and physiology by controlling the production of proteins. Each person has a unique sequence of genes, or genetic code.

Gene therapy: This treatment seeks to replace or repair defective or abnormal genes through the use of a biologic response modifier (BRM).

Genetic: Inherited, or transferred, from parent to child via genes.

Glial tissue (neuroglia): Glial cells make up the supportive tissue of the brain. Glial cells can reproduce themselves and are the origin of the largest percentage of brain tumours.

Glioblastoma (GBM): A high-grade astrocytoma containing necrotic or dead tumour cells. GBM tumours aggressively invade surrounding healthy tissue.

Glioma: A general name for tumours arising from the glial cells, the gluey / supportive tissue of the brain. There are many types of gliomas, including astrocytomas, oligodendrogliomas, and ependymomas. Gliomas make up about 60% of all primary brain tumours and are frequently malignant.

Gonadotropin: Hormone secreted by the anterior pituitary gland and placenta; stimulates the gonads and controls reproductive activity.

Grade: Brain tumours are often given a grade from 1 through 4 (I-IV). A Grade I is given to the most non-malignant tumours, and this increases to a Grade IV, which is given to the most malignant tumours.

Grand mal seizure (also called a tonic-clonic seizure): A type of epileptic seizure characterized by a loss of consciousness and convulsions.

Gray matter: The part of the brain made up of nerve cells and blood vessels. The outer layer of the cerebrum and areas deep within the brain are made up of gray matter.

Gross total resection (GTR): No evidence of residual or remaining tumour on post-operative scans.

Growth hormone: Also called Somatotropin, growth hormone stimulates human growth. It is produced by the pituitary gland. In cases where it becomes deficient, replacement therapy may be given.

Health care professional: Any medical team member involved in your care. e.g., nurse, physician, dietitian, pharmacist, physiotherapist, occupational therapist, social worker, or psychologist.

Hemangioblastoma: These non-malignant and rare tumours develop from the blood vessels of the brain and spinal cord. The inherited condition, Von-Hippel Lindau (VHL) disease, can predispose people to this tumour.

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).

Hemiparesis: Muscle weakness on one side of the body; may be permanent or temporary.

Hemiplegia: Complete paralysis on one side of the body. This may improve with time.

Hospice: A program that provides comfort and supportive care for terminally ill patients and their families, either directly or on a consulting basis with the patient's physician or another community agency. The whole family is considered the unit of care, and care extends through their period of mourning.

Hydrocephalus: Often referred to as "water on the brain." Cerebrospinal fluid, also known as CSF, is found within the brain and spinal cord. It is a watery substance that helps cushion the brain and spinal cord from injury. When there's a blockage of CSF flow, the CSF backs up and the ventricles become dilated and this is referred to as hydrocephalus.

Hypogonadism: When the gonads including the testes and ovaries produce little or no testosterone and estrogen. The absence of these hormones impairs bone formation and can lead to reduced bone density.

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

Hypotonic: Decreased muscle tone or limp muscles.

Immune system: The body's natural defense mechanism, which is composed of different types of white blood cells, and has the purpose of attacking and destroying harmful substances in the body.

In vitro: Occurs outside of a living organism (e.g., experiments based on tumour in a dish as opposed to a mouse or human).

In vivo: Occurs inside a living organism (e.g., experiments based on tumour within a mouse or human).

Incidence: The number of new instances of a specific condition occurring during a certain period in a specified population.

Increased intracranial pressure: This refers to increased pressure within the brain. It can be caused by the brain tumour and/or edema (swelling) in the surrounding brain tissue. It can also be caused by hydrocephalus.

Infiltrating: Refers to a tumour that invades normal surrounding tissue.

Intracellular: Inside a cell.

Intracranial: Inside the skull.

Intravenous (IV): A method of giving medicine, fluids or nutrition through a needle, small tube, or butterfly placed directly in a vein.

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

Lethargy: An extreme lack of energy and vitality.

Linear accelerator (linac): A machine used to deliver high-energy radiation beams to a targeted tumour site.

Lumbar puncture (LP): Also known as a Spinal Tap. This is a procedure that draws cerebrospinal fluid from the lower back. Spinal fluid is sent to various laboratories for analysis. The pressure within the system may be measured. Excess fluid may be drained through a needle. No pain is felt but a pressure feeling may occur. The procedure may take 15 to 30 minutes. Sample tubes of the spinal fluid will be taken as it slowly drips from the back. Mild analgesics and sedatives may be given prior to the procedure.

Malignant: A tumour that tends to grow quickly and spread, causing harm to surrounding and/or distant tissue.

Mass effect: This can occur when tumour or blood takes up space in a specific area of the brain, and can cause distortion and pressure on portions of normal brain. If severe, neurological symptoms such as headache, nausea, vomiting and alterations in level of consciousness can occur. A weakness on the opposite side may also occur due to distortion of the brain caused by pressure. In extreme cases, the pupil of the eye on the same side of the mass may dilate and alerts the physician to the situation of severe distortion of the brain.

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

Medulloblastoma: A form of primitive neuroectodermal tumour (PNET), it is one of the most common tumour types seen in children.

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 originates in the meninges.

Meningioma: Tumours originating from the meninges. They tend to grow slowly and are not usually malignant. They are rare in children, and more common in women than men.

Metastasize: To spread to another part of the body; for example, breast cancer can metastasize to the brain.

Metastatic brain tumour: A cancer that has spread from its primary site to the brain. Cancers of the lung, colon, kidney, breast, and skin (melanoma) can metastasize to brain tissue. Metastatic brain tumours can appear years after a primary cancer was diagnosed and treated.

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

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

Mixed gliomas: These tumours contain more than one type of cell. Treatment focuses on the most malignant type of cell found in the tumour.

Modality: A method; for example, chemotherapy is a treatment modality.

Morbidity: A disease or illness or the incidence of disease or illness within a population. Morbidity can also refer to adverse effects caused by a treatment.

Motor cortex (precentral gyrus): An area located in the middle, top part of the brain that helps control movement in various parts of the body.

Mouse model: A mouse breed genetically engineered to be missing particular genes. These mouse models are the closest science can come to duplicating the human tumour environment. A "spontaneous" mouse model is one engineered to grow a brain tumour without any tumour cells being introduced into its body.

MRI (Magnetic Resonance Imaging) scan: A scan that uses a magnetic field, a computer and radio waves to create an image that differentiates between normal and diseased tissue.

Myelosuppression: A condition in which bone marrow activity is decreased, resulting in fewer red blood cells, white blood cells, and platelets. Myelosuppression is a side effect of some cancer treatments.

Necrosis: This means "dead tissue." These dead cells are caused either by a lack of blood supply, because the tumour grows so fast that it outgrows its blood supply, or by radiation therapy. Necrosis is common within a glioblastoma.

Neo-adjuvant treatment: A treatment, such as chemotherapy or radiation, which is given before the primary treatment.

Neoplasm: A tumour.

Nervous system: The system of nerve tissue in the body, which includes the brain, brainstem, spinal cord, nerves, and ganglia.

Neuro-endocrinology: A scientific discipline involved in the study of the relationship between brain function and hormonal control.

Neuropsychological testing: Tests administered to assess the possible cognitive impact of tumour and treatment, and to determine how the brain and nervous system are affecting thinking and behaviour.

Nystagmus: A condition of voluntary or involuntary eye movement, acquired in infancy or later in life that may result in reduced or limited vision.

Observation: When a patient's condition is monitored closely, but treatment does not begin until symptoms appear or change, or there is a change in their MRI or CT scans.

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: Are responsible for the detection of odor.

Oligodendroglioma: A type of glioma that usually occurs in young and middle-aged adults. They are usually composed of oligodendrocyte cells.

Oncogene: These are genes that are believed to cause cancer.

Oncology: The science pertaining to and the study of malignant tumours and cancer.

Optic chiasm: Located beneath the hypothalamus, this is where the optic nerve crosses over to the opposite side of the brain.

Optic nerve glioma: This is a type of glioma originating in the optic nerve.

Oscillopsia: A visual disturbance in which objects in the visual field appear to oscillate.

p16, p53, etc.: The "p" preceding a number indicates this is a gene. p16 and p53 are two of the many genes known to be altered in brain tumours. Studies are looking for abnormal genes, measuring the substances given off by those genes, looking at the impact of gene by-products on the patient's outcome, and studying how abnormal genes interact with other genes and proteins around them.

Palliative care: An approach to care that focuses on comfort and quality of life for those affected by progressive, life threatening illness. The goal of palliative care is to control pain and other symptoms, support emotional, spiritual and cultural needs and maximize functioning.

Papilledema: Swelling of the optic nerve usually caused by pressure. This can be seen during an eye examination and may be an indication of increased intracranial pressure, possibly associated with a brain tumour.

Paralysis: The loss of voluntary motor or muscle movement due to an injury or disease of the nervous system.

Paraplegia: Paralysis of the legs.

Paresis: Weakness of specific muscle group.

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

Pathologist: A physician who recognizes the causes, processes and effects of disease. A pathologist microscopically examines tissue taken from a tumour to determine the type of tumour.

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

Peripheral nervous system: This includes the nerves in the body, but not the brain and spinal cord.

PET (Positron Emission Tomography) scan: A scanning device that uses a low-dose radioactive glucose to measure metabolic brain activity.

Petit mal seizure (also called an absence seizure): This is a type of epileptic seizure characterized by a brief impairment of consciousness.

Photodynamic radiation therapy (PRT): Prior to a surgical procedure, a light-sensitive drug is injected through a vein and concentrates in the tumour. During the PRT, a special light is activated and the drug then kills tumour cells.

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

Pineal gland: Controls the response to light and dark. The exact role of the pineal gland is not completely understood.

Pineal tumours: These very rare tumours represent less than 1% of all primary brain tumours. They arise from the pineal gland, which is a small structure deep in the middle of the brain.

Pituitary gland: A small, bean-sized organ 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.

Pituitary tumours: These tumours are usually non-malignant. Because the pituitary gland secretes hormones, some pituitary tumours mimic this and may flood the body with abnormal amounts of hormones.

Placebo: An inactive and harmless substance that has no biological effect: may be used in a clinical trial.

Polycythemia: A disorder characterized by an abnormal increase in the number of red blood cells in the blood.

Pons: A bridge of nerve fibers forming part of the brain stem. It has some control over sleep as well as relaying information between the cerebrum and the cerebellum areas of the brain.

Positron emission tomography: See PET scan.

Postcentral gyrus: A gyrus of the parietal lobe located just posterior to the central sulcus, lying parallel to the precentral gyrus of the temporal lobe, and comprising the somatosensory cortex.

Posterior fossa: The shallow hollow of the occipital bone in which the cerebellum and fourth ventricle are located.

Postictal state: The altered state of consciousness that a person enters after experiencing a seizure.

Preclinical testing: A process in which scientists test promising new agents in the laboratory and in animal models to determine whether the agents have an anti-cancer effect and are safely tolerated in animals. If a drug proves promising in the lab, the sponsor applies for FDA / Health Canada approval to test it in clinical trials involving people.

Prevalence: The total number of cases of a particular disease at a given moment in time, in a given population.

Primary therapy / treatment: The initial treatment.

Prognosis: A prediction of the probable cause and outcome of a disease.

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 on surrounding tissue caused by the tumour.

Protocol: A standardized combination of therapies developed specifically for particular tumours.

Quadriplegia: Paralysis of both arms and legs.

Quality of life: Overall enjoyment of life. Often used when discussing or considering treatment options to refer to the person's level of comfort, sense of well-being and ability to perform various tasks.

Radiation necrosis: Cell death due to radiation. Radiation necrosis is usually the result of higher doses of radiation and is more common with aggressive tumours.

Radiation therapy / radiotherapy: This therapy uses radiation energy to interfere with tumour growth. Radiation may come from a machine outside the body or from radioisotopes, which can be placed in or near the tumour and is called internal radiation therapy, implant radiation, interstitial radiation, or brachytherapy. Systemic radiation therapy uses a radioactive substance, such as a radiolabeled antibody, that circulates through the body.

Radioresistant: Resistant to radiation therapy.

Radiosensitive: Responsive to radiation therapy.

Radiosurgery: See Stereotactic radiosurgery.

Randomized clinical trial: A study in which each patient is selected by chance to receive one of the various treatment options to compare different treatments. Using chance to assign people to groups means that the groups will be similar and that the treatments they receive can be compared objectively.

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 develop properly.

Recurrence: The reappearance of a tumour and its symptoms after treatment.

Red blood cells: These cells carry oxygen throughout the body. If too few are produced, anemia can result. Because chemotherapy can reduce the number of red blood cells, they are monitored during treatment.

Rehabilitation: Therapy or therapies often utilized with the assistance of trained health care professionals, such as physical therapists; it is the return of function after illness or injury.

Remission: Complete or partial disappearance of the signs and symptoms of a tumour in response to treatment.

Resection: The surgical removal of tissue or a tumour. The goal of surgery is usually complete resection of the tumour.

Residual tumour: The tumour remaining after resection.

Schwannomas (also called vestibular schwannomas or acoustic neuromas): These tumours arise from myelin, the sheath that protects nerve cells, and are usually non-malignant. Schwannomas often affect the eighth cranial nerve, which governs balance and hearing.

Second-line treatment: Treatment that is given after the cancer has not responded to a first course of therapy or after a patient ceases first-line therapy.

Seizures: These are sometimes a symptom of a brain tumour and result from abnormal electrical activity within the brain. Seizures may cause convulsions, loss of consciousness, or sensory distortions.

Sella (sella turcica): The hollowed extension of the sphenoid bone that contains the pituitary gland.

Sensory cortex: Located in the front part of the parietal lobe, or in other words, the middle area of the brain. The sensory cortex receives information from the spinal cord about the sense of touch, pressure, pain, and the perception of the position of body parts and their movements.

Shunt: A surgically implanted tube that is used to relieve increased intracranial pressure. Most shunts go from the brain ventricle to the abdominal cavity.

Signaling pathways: The molecular steps preceding and following an action by any gene or gene by-product. Researchers may study the signaling pathways of proteins or enzymes found in elevated quantities in brain tumours. These studies look at what precedes and what follows the release of proteins or enzymes.

Single blind clinical trial: A study in which the doctor, but not the patient, knows which treatment is being given.

Spasticity: Increased involuntary muscle contraction.

Spinal cord: A bundle of nerve fibers that extends down from the brainstem and continues to a 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.

Spinal fluid: See Cerebrospinal Fluid (CSF).

Standard treatment: Treatment that has consistently been proven effective and so has become the "standard of care" or standard treatment.

Stem cells: New cells capable of developing into one of a variety of cell types. While most cells have a specific function, such as heart or brain cells, stem cells are blank, immature cells that can develop into virtually any kind of cell in the human body. They are the focus of research because it is hypothesized that scientists could theoretically grow stem cells to repair damaged cells.

Stereotactic: A surgery or radiation therapy that is directed by a scanning device for precise positioning in a three-dimensional space.

Stereotactic needle biopsy: A biopsy done using the stereotactic guidance of computers, such as MRI or CT scanning procedures.

Stereotactic radiation: A treatment in which a rigid head frame is attached to the skull, and a single high dose of radiation is delivered with extreme precision to the tumour. It is used in tumours of smaller dimensions, and ideal for small non-malignant tumours like an acoustic neuroma.

Stereotactic surgery: Using a computer, a three-dimensional image is created to provide precise information about the location and position of a tumour within the brain. The resulting information is used as a map for surgeons to rehearse the actual surgery and to localize the target during surgery.

Stereotaxis: A method used to accurately find specific areas within the brain, using a special frame, computer program and CT images.

Steroids: Drugs such as dexamethasone (Decadron), used in the treatment of brain edema or swelling caused by a brain tumour.

Stimuli: Agents or actions that cause a physiological response.

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

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

Study arm: A treatment offered in a clinical trial.

Subtotal resection: Removal of most, but not all of a tumour.

T-cells: White blood cells that regulate immune response by attacking virus-infected cells, foreign cells and cancer cells. Helper T-cells enhance the response of other effector cells by secreting cytokines. Cytotoxic T-cells can directly kill virus-infected cells and tumour cells.

Targeted therapy: Treatment that uses drugs or other substances to identify and attack specific cancer cells, while limiting the effect on normal cells.

Temozolomide: An oral chemotherapy drug for brain tumours. The Canadian brand name is Temodal®, Temodar® is the American brand name.

Temporal lobe: One of the four lobes of the cerebral hemisphere. It controls auditory and visual memories, language, some hearing and speech, plus some behaviour.

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.

Tinnitus: A buzzing or ringing in the ear that can be a symptom of a tumour of the acoustic nerve.

Toxicity: Harmful side effects from an agent being tested.

Translational research: Studies that provide the bridge between basic research and human testing. Translational research provides the data to support the opening of a clinical trial or additional scientific evidence as to how a substance in a clinical trial works.

Trans-sphenoidal surgery: A surgical approach often used for pituitary adenomas and sometimes craniopharyngiomas. Trans-sphenoidal means through the sphenoid bone – the bone under the eyes and over the nose.

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

Tumour grading: See Grade.

Tumour marker: See Biomarker.

Tumour progression / promotion: The process of a tumour expansion or metastasis.

Ultrasound: A technique using sound waves, which is used in the diagnosis of a wide variety of conditions. In neurosurgery it may be used to localize a tumour during the operation. It can help in the diagnosis of tumours in infants by placing the sensor directly over the infant's soft spot (fontanelle).

Unresectable: Unable to be removed (resected) by surgery.

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.

Vinca alkaloids: Used in the treatment of cancer. They are a class of cell-cycle-specific cytotoxic drugs that work by inhibiting the ability of cancer cells to divide.

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. People with VHL are at a higher risk for developing some types of cancers.

VP shunt and VA shunt: A plastic catheter with a reservoir used to divert cerebrospinal fluid from the ventricles of the brain to the abdominal cavity or the heart.

Wernicke's area: Part of the temporal lobe that surrounds the auditory cortext. It is thought to be essential for understanding and formulating speech. Damage in Wernicke's area causes deficits in understanding spoken language.

White blood cells: The body's primary defense against infections. While people are on chemotherapy, these are monitored because if too few white blood cells are produced, infection can result.

White matter: Brain tissue composed of nerve cell fibers that carry information between the nerve cells in the brain and spinal cord.

Wound: This refers to any site where the skin has been cut and is undergoing a healing process.

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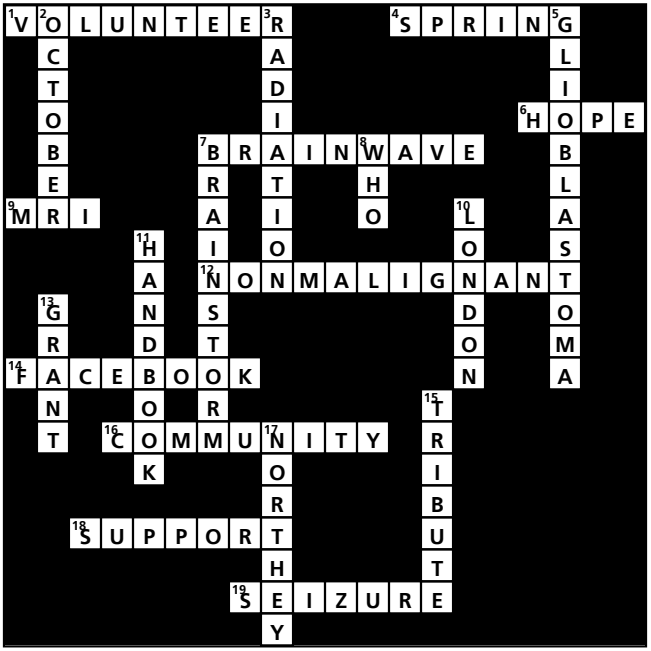
Answers to Crossword Puzzle



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