



braintumour
foundation

OF CANADA

6th Edition

Pediatric 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 benefitting Brain Tumour Foundation of Canada and Canadians affected by a brain tumour.

This Brain Tumour Resource Is for You

When your child 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 also addresses some of the questions and concerns you may have about your child being diagnosed with a brain tumour, and helps raise awareness about the disease, providing education for family members, friends and health care professionals.

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, many of whom are children. 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 child's 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 your child has 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 pediatric 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 pediatric patients.
- 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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Karen Metcalfe of Windsor, ON provided feedback as the mother of a child diagnosed with a non-malignant brain tumour. Karen also served as one of the editors for Brain Tumour Foundation of Canada's Non-Malignant Brain Tumour Handbook in 2011.

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.

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

Young children who have been affected by a brain tumour diagnosis, either personally or through someone close to them, can gain support and information with our children's storybook, *A Friend in Hope*.

To order a copy of *A Friend in Hope* to read to your child or to order for your child's school, please contact us at 1-800-265-5106 or order online at www.BrainTumour.ca/requestinfo.



You Are Not Alone



You Are Not Alone

Your child has 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 we do now? How will we cope? Many questions will arise after this diagnosis.

This Pediatric Brain Tumour Handbook has been created for you – parents, family members and caregivers of children who have been affected by a brain tumour. On the following pages you will find a wealth of information that we hope helps you through this difficult time. This handbook is designed to help you learn more about brain tumours, their associated treatment options and many of the services available to your child and family to help you.

*This is Hope. You will see her pop up throughout this handbook. She is here to remind you to refer to the Glossary of Terms for more definitions on **Page 282**.*



In the days, weeks and months ahead you will meet many health care providers involved in your child's care. You will also become an active member in your child's health care team. This team may be made up of pediatric neurosurgeons, neuro-oncologists, radiation 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 child's care. Keeping the lines of communication open with your child's 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 child's day-to-day care. In diary form, you may want to track your child's 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 child's health care team, as it will include symptoms and any side effects from treatments or medications.

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

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

You must be an advocate for your child during this journey. 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.

Because trust is the most important link between you and your child, it is best to always tell him the truth about procedures and answer his questions honestly, as it will help him understand. Building his trust will provide you both with strength to face the challenges ahead.

This Pediatric Brain Tumour Handbook will assist you in the weeks, months and years ahead, as you and your child 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 child's diagnosis, and know where and how to ask for help.

It may be beneficial to talk with other families that have a child with a brain tumour. There is great comfort in knowing you are not alone. There is also a great deal of hope out there, as many children 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 www.BrainTumour.ca. We are here to provide you with information and support throughout your child's journey.

Reacting to a Diagnosis

2

Reacting to a Diagnosis

Your child has 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 our family? Why my child? The shock of a diagnosis is difficult and overwhelming. This chapter discusses issues you may need to address including asking the right questions; telling family and loved ones; talking to your child's school; advocating for your child; and finding the right support to help your family through this journey.

As you begin to comprehend this illness and its implications in your child's life and the life of your family, you will likely experience many thoughts and questions rushing through your mind. Your health care team is there to help you with all aspects of your child's diagnosis, treatment and long-term care, and will always answer your questions honestly and as comprehensively as possible. Don't hesitate to ask any questions you may have and don't be afraid to repeat a question.

It is normal to experience many different feelings and emotions as you go through the process of understanding the diagnosis. Your child may or may not have developed symptoms that indicated something was wrong. Perhaps signs such as headaches, vomiting, visual problems and other possible symptoms had developed and worsened over time, which led to the diagnosis. Or maybe your child was feeling perfectly fine but suddenly experienced a seizure that led to a quick and unexpected diagnosis.

Many families commonly go through a grieving period after they learn about the tumour. This is completely normal. 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 you once knew.

Absorbing all of the information you have been given can be incredibly difficult as the terminology is new and the amount of material is often overwhelming. After having time to digest the diagnosis, many families want to learn more about the tumour and what can be done. Becoming informed can provide a sense of empowerment for some people, but can also be frightening to others. Family members and friends may be able to

take on the role of gathering information and doing research, and can then filter the necessary information to you. This can help reduce your fear and any sense of being overcome by information.

Knowing where to find support and who you can talk to can also be helpful. As you discover more about your child's diagnosis, you will also learn more about the resources available to your family. As you begin coping with the changes in your lives, there are people that you can turn to that can help you with these transitions.

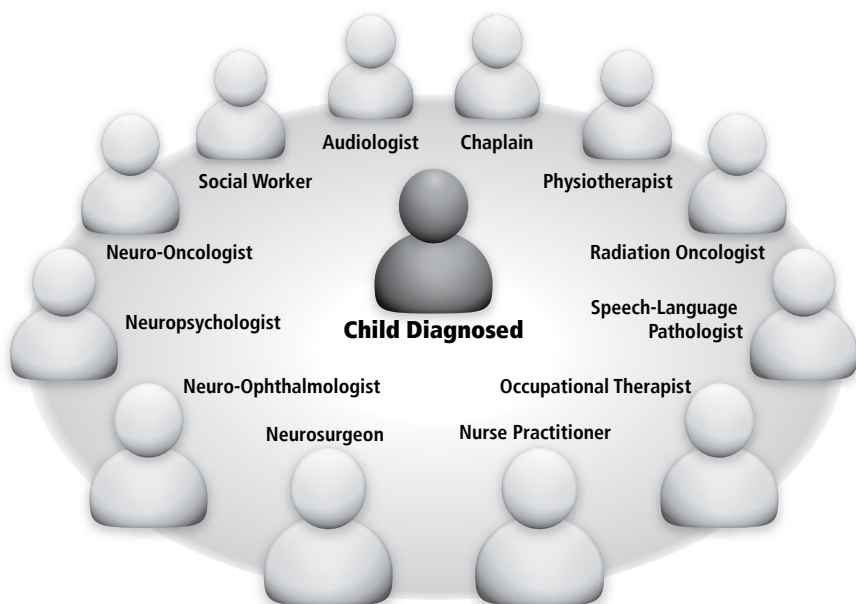
Brain Tumour Foundation of Canada is available to talk to you and your family about finding support services in your community that could be of assistance. The social work department at your children's hospital or cancer centre can also be an invaluable resource as they are familiar with the services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

Asking Questions

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

You will have many questions as you go through the process of diagnosis, treatment and recovery. Your child's health care professionals are well-informed about the many aspects of a brain tumour diagnosis and they can be a valuable source of information about diagnosis, treatment, medications, nutrition, etc. Make sure you are organized for your child's appointment; this will ensure that you get the information you need in an efficient way. Write down questions as they come up beforehand, and bring them with you to appointments. Make your questions specific and ask the most important questions first. Write down the answers for future reference.

Different members of the health care team can provide support with various aspects of your child's diagnosis. For example, the pharmacist can answer many of your questions about medications; the social worker can answer questions about the resources and community services that are available to your child and your family; and your child's nurse can answer questions about symptom management. Your health care team is there for you, so utilize their knowledge to help yourself and your child. Understanding who will help you with the various aspects of your child's care can give you peace of mind.



*For more information on **Your Child's Health Care Team**, please turn to **Page 175**.*

Getting a Second Opinion

You will be required to make some very important long and short-term decisions about your child's medical treatment plan, so you will want to feel comfortable with your decisions. Consequently, you may want to seek a second opinion, and many parents 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 child's needs are of primary importance, not whether your physician feels offended. An open discussion with your child's 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.

Talking with Your Child

Your child has likely gone through many tests by now and understands that something is wrong. Because a child's level of understanding can be underestimated, it is important to be honest and build trust with your child as you go through the process of diagnosis and treatment. Your child's age and maturity should help you determine how much information and detail to disclose. Discussing the diagnosis openly allows your child to ask questions about what is happening and helps him express any feelings he may want to share. A child life specialist will guide you through the process of talking with your child and his siblings.

*Turn to **Appendix K: Helping Children Understand a Diagnosis** for more information and suggestions on how to talk to your child about his diagnosis on **Page 276**.*

Sometimes, reading stories encourages discussion with young children. Brain Tumour Foundation of Canada offers a free children's storybook called *A Friend in Hope*. This story takes you through a little girl's diagnosis of a brain tumour through the eyes of her best friend Danny.



To order a copy of *A Friend in Hope* to read to your child or to order for your child's school, please contact us at 1-800-265-5106 or order online at www.BrainTumour.ca/requestinfo.

Telling Your Family and Friends

Informing your loved ones about your child's diagnosis may be difficult. You might be unsure about what to say and how much information to disclose. Your health care team can help you and your family with this. Often, people do not want to burden other family members or friends with this news. However, it is important that you have the people closest to you available to support your family through this time.

*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 should not have to face the diagnosis alone. Sharing information with those closest to you will help you move past the initial shock to helping your child. Do not be afraid to express your feelings with those who are close to you. Your family and friends will want to be there to offer their support. They may ask how they can help. Do not be afraid to take them up on this offer as the days, weeks and months ahead may become very busy and tiring. Create a list of things you might need help with such as laundry, picking up groceries, or dropping off a meal once a week. Offer tangible things that your family and friends can do for you to make daily activities easier.

Siblings should be involved right from the beginning and will be a support system for your child. The age and maturity of any brothers and sisters should help you decide how much information and which details to disclose. By involving them, they will be able to ask questions, express their feelings, and provide support to their sibling. Also, they will not feel excluded or left out, and will have a better understanding about why more attention may be temporarily given to their sibling.

Talking to Your Child's School

When a child is diagnosed with a brain tumour, it ultimately affects daily activities including attendance at school. Open communication with your child's school is essential from the beginning. Shortly after diagnosis, it is important to contact your child's teacher and principal to inform them about what is happening and the expected attendance of your child in the days and weeks ahead. If your child has to miss some school, his teacher can send home lesson plans and homework to help keep him up to date on what is happening in the classroom. You may also want to consider homeschooling your child through this period. Classmates can be told, by the teacher, in an age-appropriate way, about your child's absence.

Advocating for Your Child

Always remember that while your child's health care team is dedicated to ensuring he receives the best possible care, you and your family are his best advocates. You know your child better than anyone and understand what his needs are. It is always important to actively communicate with your child's health care team and speak up about your questions and concerns.

As a parent and valuable member of your child's "team," it is important to develop a strong partnership with the health care professionals, and play an active role in your child's care. It is also important that you take part in the decision-making process concerning your child's treatment plan. Family members can help by being active in the information and education process. They can be there at appointments to help absorb the information given, and to actively speak up and ask questions you may not have thought of asking.

Educating yourself about your child's diagnosis and treatments options will allow you to be a better advocate. Research, investigate, and bring this information back to your child's treating physician. If you are unable or uncomfortable with this, have a family member or a friend take on this role for you.

Building a Strong Support System

A brain tumour diagnosis is a terrifying experience for anyone but when it happens to a child, it can be devastating for everyone. A strong support system will allow your family to better cope with the challenges that you may face. Support systems can have a significant impact on your family's physical and mental strength while experiencing the initial shock of your child's diagnosis, treatment, and throughout your child's recovery period.

*You can find connections and lean on others who have experienced a brain tumour diagnosis. Find a local support group, connect on the message board or learn more about the BrainWAVE pediatric program at **www.BrainTumour.ca/support**.*

A support system can include many different individuals who provide support in various ways. Family and friends can often provide both the emotional support you need as well as help with any day-to-day activities. Your health care team will provide you with the medical treatment and support that you require according to the treatment plan. The members of the medical team can also provide you with knowledge and understanding of your child's diagnosis, giving you support you require in the way of information.

Other individuals or groups that can provide you with support include community organizations, brain tumour-related support groups, other cancer support groups, online / Internet support, and the social work department of your health care centre. They 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

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; thinking about recovery times and how they will impact the lives of your child and loved ones; 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 care for your child. Use this time to learn more about your child's diagnosis, access the support you need, and to take care of yourself and your family, both physically and emotionally.

Accessing Information on the Internet



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 parents, 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 child's 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.

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 239.*

What Is a Brain Tumour?

A brain tumour is a growth of abnormal cells located 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.

Are Brain Tumours Common in Children?

Fortunately, among the general population, brain tumours are rare. Approximately 300 new diagnoses are made in children in Canada each year. Brain tumours can occur in children of both genders and of all ages, cultures and socio-economic groups.

What Are the Signs and Symptoms of Brain Tumours?

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

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

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

How Do Brain Tumours Become Evident?

Every individual 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; however this does not occur often in children.

For most children, the onset of symptoms may be gradual and may initially be passed off as more minor ailments. The most common symptoms in children result from an increase in intracranial pressure, such as headaches, morning vomiting, ataxia and visual symptoms.

With these symptoms, it may take more time to make a diagnosis of a brain tumour, as parents may not immediately seek medical attention. Furthermore, given the low incidence rate of pediatric brain tumours, health care professionals may investigate other potential causes of the symptoms first.

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.

In addition, the majority of tumours in children may 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, which 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. It begins with your child's doctor, who will ask a number of questions in order to get a complete history of your child's 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 touch tests using a pin point and cotton ball
- Tongue movement, gag reflex tests

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

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

CT or CAT Scan

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



Photo courtesy of GE Healthcare

MRI

The MRI is a tunnel-shaped piece of equipment. Your child lies on a table that slides into the tunnel. Inside the scanner, a magnetic field surrounds the child's head while radio energy is beamed to the area being examined. 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 it is very noisy. Like the CT scan, a contrast material (Gadolinium) will be used.



Photo courtesy of GE Healthcare

Brain Tumour Classifications



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 which go 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 slow-growing 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 etc.). 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 a 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 which 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 brain tumours as they can compress brain tissue and other structures inside the skull and cause serious health complications, no matter their classification. In this resource, and throughout the health care community including the World Health Organization (WHO), there has been a considered shift toward using "non-malignant" rather than "benign" to define tumours that are not aggressive, or low-grade.

In general terms:

- **Malignant Tumours** = most aggressive, cancerous, fast-growing and which 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 the list of Pediatric Brain Tumour Types, please turn to **Appendix C** on **Page 258**.*

Grade I Tumour

- Slow-growing cells
- Almost normal in appearance under a microscope
- Least malignant
- Usually associated with long-term survival
- Example: juvenile pilocytic astrocytoma

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: diffuse astrocytoma

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: medulloblastoma

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 child's 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 resection is required to obtain a tissue specimen. Once the tissue sample is obtained, a neuropathologist will evaluate tissue samples from your child's brain tumour to determine exactly what type of tumour your child has.

A pathology report can frequently take from 7 to 10 business days to finalize. This often means that your child may be leaving 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 child's neurosurgeon and oncologist and they will be able to give you a more specific name for the tumour as well as a treatment plan.

Visual Changes



Visual Changes

If your child has experienced visual changes or disturbances as a symptom of the brain tumour or as a result of its treatment, the following section will help you understand the visual system and conditions that may result. Being aware and sensitive to your child's visual abilities and/or restrictions will help you determine if any change has occurred. Contact your doctor if your child mentions any change in her 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.

A person's 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 ongoing monitoring, or any vision changes.

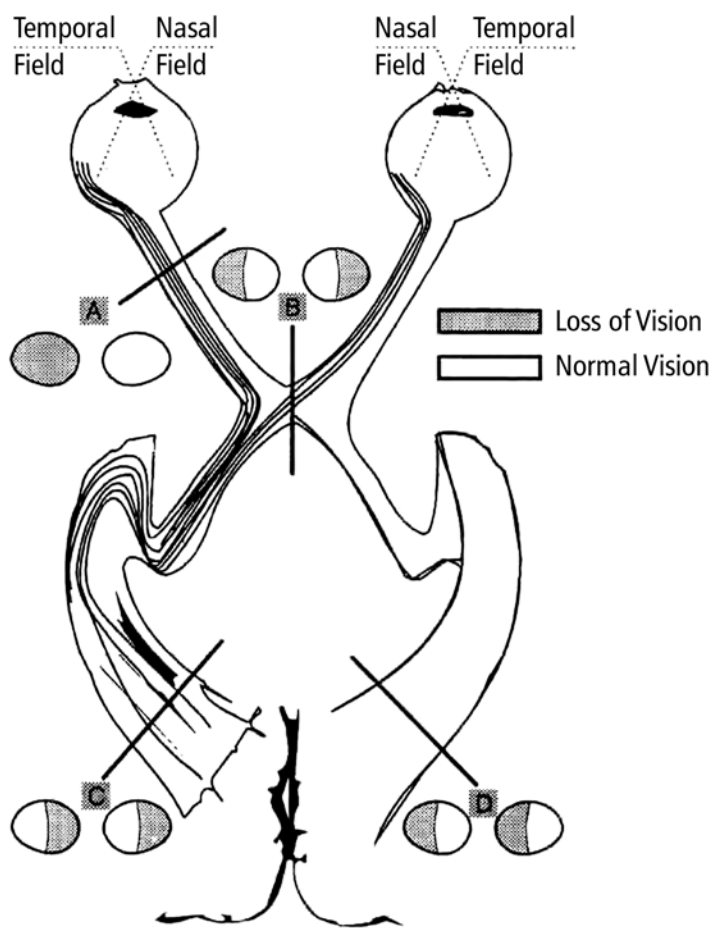
Visual messages travel from the back of the eye along the two optic nerves and meet near the area of the pituitary gland called the optic chiasm. Here, the two nerves fuse together. Half of the pathways cross and travel back through the brain, through the temporal and parietal lobes, before arriving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



Turn to **Appendix A** for a picture of "**The Lobes of the Brain**" on **Page 247**.

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: each overlaps the fields of the opposite eye.

Visual Fields



Papilledema

By looking in your child's eyes, the doctor may see swelling of the optic nerves. When swelling is due to increased intracranial pressure, it is called papilledema. It is an extremely important sign, as it may be caused by the growing tumour or obstruction of cerebrospinal fluid. Initially, there may be no symptoms, which emphasize the importance of performing 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 to the examiner 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. Your child may notice that there is a "missing area" in her vision or that her vision is becoming increasingly blurry. 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, the eye may move outward and the 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. Your child may not be able to look down and in, and may tilt her head toward the opposite shoulder. If the sixth nerve is involved, the eye will move inward toward the bridge of the 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 of children with brain tumours. 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. Children 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 discrete 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 to another.
- Numbness or tingling in one 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; hearing sounds that aren't there.
- Mood changes such as fear, anger, sadness or 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. Your child may have a warning, such as an aura and his awareness of his surroundings becomes impaired.

During the seizure, your child may wander about, stare or make simple movements of the mouth (e.g., chewing, lip smacking). More complicated behaviours (e.g., your child may pick something up and fumble with it or wander about) may occur. If this happens with your child, 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 below) 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 are not common in people with brain tumours.

First Aid

If your child 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 your child 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 your child has a head injury, or has diabetes, call for an ambulance.
- If your child is wandering, stay by his side and gently steer him away from danger.
- Your child may be confused when the seizure ends. Reassure him and stay with him until the confusion clears. If confusion persists for an hour after the seizure, call 911.

After a Seizure

Your child 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 your child is involved in sports that increase the 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



Neuroendocrine & Cardiometabolic Effects of Tumours and Their Treatments

The neuroendocrine system refers to a group of specialized cells within an area of the brain called the hypothalamic-pituitary area.

The hypothalamus is connected to the pituitary gland via a portal called the pituitary stalk. This stalk allows the two organs to communicate.

Cells in the hypothalamus are responsible for regulation of several essential functions including appetite, sleep and temperature control. In addition, some cells produce hormones that act on the pituitary gland cells, which in turn produce other hormones. Pituitary hormones then act on target glands in the body to regulate the production of hormones from those glands.

Hormones can be produced in either the front (anterior) or the back (posterior) of the pituitary gland. Cells of the anterior pituitary gland respond to hypothalamic factors to produce hormones (Table 1). The two hormones of the posterior pituitary gland include prolactin, which is released under influence of hypothalamic dopamine, and anti-diuretic hormone, which is mainly produced in the hypothalamus and is deposited in the posterior pituitary gland and released when needed. The hormones produced by the pituitary gland and their functions are summarized 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 boys and estrogen in girls
Follicle-Stimulating Hormone (FSH)	Production of sperm from testicles and eggs from ovaries
Adrenocorticotrophic hormone (ACTH)	Production of cortisol from adrenal glands that helps 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

Neuroendocrine function may be impacted by effects of a brain tumour or its treatment. If your child develops symptoms of neuroendocrine dysfunction, she may be seen by the pediatric endocrinology team at diagnosis, during treatment or after the completion of treatment, to address any ongoing issues.

Tumour Effects

Tumours that arise within the pituitary gland may lead to excess production of one of the above hormones and this can cause varying effects, depending on the hormone produced.

Other pituitary tumours may not produce hormones but cause pressure on other cells, or invade parts of the gland leading to reduced production of one or more pituitary hormones.

Tumours outside the pituitary gland may press on the pituitary stalk, affecting the communication between the hypothalamus and pituitary gland.

Treatment Effects

Surgery, radiotherapy and chemotherapy can all affect hypothalamic-pituitary function. The effects of brain tumours and their treatment(s) on neuroendocrine function can have acute and late effects.

Acute Effects

Fluid balance disorders:

- Excess anti-diuretic hormone (ADH) production: This syndrome can occur as a result of chemotherapy, including treatment with vinca alkaloids. It may also be caused by the brain tumour, the body responding to the tumour, or sometimes following surgery.

Cortisol (steroid) deficiency:

- Adrenal suppression secondary to steroid therapy

Late Effects

The most common late effects of a tumour and its treatment may involve:

- Bone health
- Growth and stature
- Obesity and cardiometabolic problems
- Puberty
- Sexual function and fertility
- Thyroid gland damage

Growth and Stature

Survivors of brain tumours have a greater chance of short adult stature. Your child's final height could be affected in several ways. For example, cranial irradiation can affect growth hormone production, resulting in growth hormone deficiency. This is the most common hormonal deficiency resulting from cranial irradiation. Spinal growth can also be affected by cranial irradiation.

Both craniospinal irradiation (CSI) and cranial irradiation (CI) can affect the proportions of spine to limb length.

While the development of growth hormone deficiency is dependent on the dose of radiation, the dose threshold at which the deficiency develops is unknown. Age does appear to be a factor, as younger children appear more sensitive to the effects of radiation than older children or adults.

When chemotherapy and radiotherapy are both given, there may be an increased risk for growth hormone deficiency. Why this happens is not fully understood. Other pituitary hormone deficiencies, such as thyroid-stimulating hormone (TSH), adrenocorticotrophic hormone (ACTH) and gonadotropins may also impact your child's growth.

Treatment for growth hormone deficiency involves administering growth hormone. In some cases, growth hormone is used with other types of treatment to prevent early puberty. Testing for growth hormone deficiency as well as its treatment and monitoring, are done by the pediatric endocrinology team.

Puberty

In some cases, a brain tumour or its treatment may affect the production of luteinizing hormone (LH) and follicle-stimulating hormone (FSH). This can lead to the early onset of puberty and a possible reduction in predicted adult height. Additionally, children who experience early puberty may also develop associated psychological issues and may benefit from counselling.

Delayed puberty caused by hypogonadism may lead to a delayed growth spurt, which may or may not impact your child's adult height.

Hypogonadism is 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.



Sexual Function and Fertility

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 boys are more resistant to radiation than sperm-producing cells; small doses of radiation can affect sperm production. The impact of treatment depends on your child's gender, age the dose and type of drug, and radiation he receives. The more modern treatments aim to reduce the exposure to pituitary gland and gonads, thereby reduce the risk for adverse health effects immediately and in the future.

If you have a teenager who is sexually mature and who will be undergoing treatment for a brain tumour that could adversely affect her fertility or his virility, 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 treatment of your child's tumour is possible. There are also legal and ethical issues involved and young people – youth and teenagers – should be counselled regarding fertility preservation prior to treatment.

*For information on sexuality and teens please turn to the **Sexuality & Teen Survivors of Brain Tumours** section on **Page 215**.*

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 males, 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 females, 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 child's fertility will be compromised. The first step is to inform your physician(s) and oncology professionals of your wish to preserve your child's fertility. Options are available for patients beginning treatment and for those who have already started or completed treatment.

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

Many young Canadians are leading 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 child's oncologist or fertility specialist to determine the likelihood of infertility associated with your child's course of treatment.

Thyroid Damage

The thyroid gland is located at the base of the neck and can be affected by cranial irradiation or craniospinal irradiation. This exposure leads to abnormal thyroid function, the development of thyroid nodules and a small risk of future thyroid cancer. Thyroid hormone levels should be checked.

Bone Health

The possible mechanisms that can affect bone health in children with brain tumours include:

- Drugs including methotrexate and steroids
- Growth hormone deficiency
- Hypogonadism
- Inadequate nutrition
- Malignant infiltration to the bones including vertebrae
- Reduced physical activity
- Total body and craniospinal irradiation

An altered bone metabolism, a reduction in the formation of new bone, and a reduction in bone volume can all result from treatment and may affect your child's developing bone mass. Bone mineralization defects can be addressed medically through lifestyle modifications and by treating any growth hormone or gonadotropin deficiencies.

Obesity and Cardiometabolic Effects

Children who survive brain tumours can be at risk for obesity. Some of the factors that predict that risk include:

- Age at diagnosis, with younger children being at greater risk.
- Radiation to the hypothalamus, with higher doses of radiation having a greater adverse effect.
- Hormonal deficiencies including growth hormone deficiency and hypogonadism.
- The location of the tumour: hypothalamic tumours pose a greater risk.
- Gender – girls may be at higher risk.
- The type of surgical intervention your child undergoes.

With or without the presence of obesity, there may also be an increased risk of stroke, clots, lipid abnormalities, hypertension and angina-like symptoms in adult survivors of childhood brain tumours. Some of these effects, including lipid problems or being overweight, may be related to growth hormone deficiency.

Imaging

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Imaging

Your child's doctors will order imaging of a specific part of his body so they can get detailed pictures of the size and shape of the tumour. The information from the pictures will be used to plan your child's treatment.

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

MRI (Magnetic Resonance Imaging) Scan

An MRI scan uses a magnetic field instead of X-rays to take pictures of your child's 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 useful in monitoring your child's treatment response.



What Does an MRI Involve?

When you and your child arrive at the diagnostic imaging department, an MRI technologist will meet you. She will want to know if your child has had previous surgery involving metallic devices (e.g., pacemakers, port catheters, shunts, aneurysm clips). The MRI technologist will also ask your child to remove any metals 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. During a head or spine MRI, your child needs to lie on a flat, narrow bed. His head will be secured with soft Velcro® straps. In addition to the straps, a window device, like a helmet, may also be placed over his head. The table is then moved so that your child's head lies within a tube-like or doughnut-shaped structure.

If your child is not having sedation or general anesthetic, he may be able to watch a DVD or listen to music, so bring along a favourite movie or cd to help soften the noise and provide a distraction.

Once the scanning process begins, your child 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 your child will be given ear protectors to minimize any discomfort. The MRI technologist is in another room operating a computer. She will tell your child, via an intercom, when she 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 your child can get up and leave the room.

What Happens if Your Child Needs Sedation or Anesthesia?

Sedation or general anesthesia is administered to young children to ensure they lie very still in the MRI machine. In most situations you will know in advance if this is planned, so your child can stop eating and drinking beforehand. It is important to follow the fasting instructions correctly.

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 child's 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 (BBB). However, because tumour blood vessels are abnormal they allow substances, such as the contrast agent, to cross the BBB. The contrast agent can be seen on the MRI scan and is known as contrast enhancement. The contrast enhancement of the tumour is helpful for further characterization of the mass.

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 of a hospital. Your child will be placed on a narrow table and may have to wear straps across his body to maintain position. The table will be moved so that the part of his 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. In most hospitals you can be with your child in the room provided you wear a gown for protection from radiation. The technician will be in the next room and will be able to offer reassurance, if necessary, via intercom.

Pregnant mothers are not permitted in the CT room.

Using computers, the CT scanner takes a series of pictures that are be used to make a diagnosis. In the situation where a brain tumour is detected on a CT scan, a radiologist may require an MRI scan of your child's brain for further assessment of the tumour.

CT is an excellent technique for assessment of calcification that is present in certain tumours. Many times a radiologist will require a CT after MRI to confirm the presence of calcifications. There are many brain tumours that commonly have calcifications, such as craniopharingiomas. Calcifications are calcium deposits that are of high density in nature (white) on a CT scan.

Other Imaging Techniques

Other types of imaging techniques may be used to obtain further information about a brain 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 your child counts out loud, repeatedly moves some muscles, or looks at certain objects (while in the MRI scanner), specific areas of your child's 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 specific to those brain regions. This technique may be helpful in showing where the speech and motor centres are located in relationship to the tumour, and this information can be useful to the neurosurgeon.

MRS (Magnetic Resonance Spectroscopy)

MRS is a type of magnetic resonance sequence that enables the radiologist to assess the metabolic changes in your child's brain tissue. It provides complementary biochemical information to structural imaging, and sometimes can 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 (NAA), 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 infiltrate 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.

PET scanning is still under investigation for pediatric brain tumours and are not the standard of care.

Surgery



Surgery

What Are the Goals of Surgery for a Child with a Brain Tumour?

The goals of surgery for a child with a brain tumour are:

- To obtain a sample of the tumour in order to establish the tumour type through a biopsy. This will guide further treatment.
- To remove the entire tumour, or as much as can be done safely. This is called de-bulking.
- To reduce any of the symptoms being caused by the tumour, through decompression of the tumour mass and relieving pressure on the brain.

How Is Surgery Different in Children?

Brain tumours in children are different from those in adults, both in their location and the tumour types. Unlike adults, most pediatric brain tumours are located in the posterior fossa. This is the area of the skull that contains the cerebellum and brain stem. In addition, brain tumours that are common in children, such as a juvenile pilocytic astrocytoma, medulloblastoma and ependymoma, occur less frequently in adults.

Surgery for brain tumours in children poses a unique set of challenges for the neurosurgeon. Because of their size, children (especially young children and infants) have a smaller volume of blood. Blood loss during brain surgery in children can be a more serious concern than in adults, and children are more likely to need a blood transfusion during or after surgery.

Because of the location of most pediatric brain tumours, children are also more likely to have hydrocephalus or a build-up of cerebrospinal fluid (CSF) in the brain. This may need to be treated with a shunt (known as a VP shunt) or an endoscopic third ventriculostomy.

*For more information on **Hydrocephalus and Shunts**, please turn to **Page 97**.*

Do All Children with a Brain Tumour Require Surgery?

Certain types of tumours located in the brain stem (known as diffuse pontine gliomas) can be diagnosed with an MRI scan and do not need to be biopsied. In addition, some low-grade tumours which are not causing any symptoms or pressure on the brain may be monitored with repeat neuro-imaging and clinical examinations. Most children with a brain tumour do eventually require surgery, although your neurosurgeon may recommend observation and repeat imaging, depending on the location and other characteristics of the tumour.

What Types of Surgery Might Be Offered?

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

Brain Tumour Biopsy

The goal of a brain tumour biopsy is to obtain a small amount of the brain tumour tissue in order to determine the tumour type. This is necessary because the doctor that reads CT scans and MRI scans (called a neuroradiologist) cannot determine with complete confidence what type of brain tumour a child has by just looking at scans. It is important to know with certainty the type of brain tumour, in order to determine the timing, order and appropriateness of the planned treatments. For example, a suprasellar teratoma would require gross total surgical resection whereas a suprasellar germinoma is optimally treated with chemotherapy and radiation, not surgical resection. A diagnosis of the tumour type can be made by a pathologist or neuropathologist, a specialist 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 a tumour as is safely possible. When the tumour exerts pressure on the surrounding brain, it can cause symptoms. Removing all (gross total) or part (sub-total) of the tumour may help to reduce any symptoms by reducing pressure on the areas surrounding the tumour. This is called decompression. Resection might 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.

If a tumour is located in a part of the brain where attempts to remove the tumour will cause serious side effects, your neurosurgeon may only recommend a tumour biopsy. Certain rare types of brain pediatric tumours, known as germ cell tumours, can often be diagnosed with a blood test or a spinal tap and may not need a biopsy. In general, if a tumour is causing symptoms and it is felt that it can be removed safely, an attempt is made to completely remove it. If a tumour is located deep in a sensitive part of the brain, a biopsy can be done using special techniques such as an image guidance system. This technique is minimally invasive: it involves the use of specialized equipment that allows the neurosurgeon to accurately biopsy the tumour through a very small opening in the skull.

For some types of tumours (such as a craniopharyngioma), which have a large cystic component, the surgeon may insert a catheter or tube into the tumour cyst, so it can be drained.

How Is a Brain Tumour Biopsied or Removed?

The approach your child's neurosurgeon uses to remove a tumour depends on where it is located in the brain. The shortest path to the tumour that involves going through the smallest amount of normal brain tissue is usually the safest. Once the tumour is identified, the surgeon carefully goes around the tumour, sometimes removing the inside of the tumour as he goes. Special equipment such as a Cavitron® ultrasound machine is often used to break up and help remove the tumour. The surgeon may use a special operating microscope to help see the tumour, and may monitor different brain functions during surgery.

Stereotactic Brain Biopsy

Many brain tumour biopsies (especially those involving deep or otherwise inaccessible tumours) can be performed through a burr hole, using a biopsy needle guided by computer images that have mapped the location of the tumour in three dimensions (also known as neuro-navigation systems). This technology functions as a GPS for the brain, allowing neurosurgeons to perform minimally invasive biopsies to obtain brain tumour samples for diagnosis.

Open Brain Tumour Biopsy

Sometimes the neurosurgeon will perform what is called an open brain tumour biopsy, which is usually performed with 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 tumour by directly seeing it. 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



How Is a Resection Performed?

Since the goal of a brain tumour resection is to remove as much of a brain tumour as is safely possible, the operation is usually more involved and takes longer than a brain tumour biopsy.

During the operation, an incision is made in the skin, and 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 neuro-pathologist for identification. The dura matter 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 / 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 de-bulking, 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 Type of Anesthesia Is Used for Brain Tumour Surgery?

General Anesthesia

When general anesthesia is performed, your child is unconscious for the surgery. Most brain tumour operations are done using this type of anesthesia. Pediatric anesthesiologists administer the anesthetic, and perform an intubation once your child is asleep. 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. Your child is then placed in the position required for surgery. Pediatric anesthesiologists are experts in childhood physiology, and carefully monitor and correct all of the previously described features during the course of the operation. Any blood lost during surgery will be replaced by blood products during the surgery.

Neuroleptic Anesthesia

In some cases, such as neuroleptic anesthesia, your child is “awake” for the surgery. This form of anesthesia may be used in older children. Although your child is “awake” during the procedure, appropriate intravenous sedation with a local anesthetic makes him 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, your child remains awake during the operation in order to help the surgeon in assessing these functions as the tumour is removed. Your child’s function is assessed continually during surgery.

What Are the Possible Side Effects of Surgery?

Surgery to remove a brain tumour in a child 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 child's neurosurgeon will explain the risks of surgery to you before proceeding.

Is Stereotactic Radiosurgery Ever Used in Children?

Stereotactic radiosurgery is a form of treatment using focused beams of radiation on the scalp. No incision is made. The two most common ways of delivering radiosurgery are with a linear accelerator, shortened to LINAC, or with a Gamma Knife®. Stereotactic radiosurgery can be used in children for specific types of tumours, such as an acoustic neuroma (also known as a vestibular schwannoma) or small parts of other types of tumours that could not be removed through open surgery.



Photo courtesy of Elekta Canada Inc.

Radiation is administered by way of high energy X-rays or gamma rays. The surgeon can focus the X-rays on the brain tumour, minimizing the chance of injury to the surrounding brain tissue.

A Gamma Knife® machine is used almost exclusively to treat brain lesions like tumours, whereas linear accelerators are used to treat tumours in other locations of the body.



Photo courtesy of Elekta Canada Inc.

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

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 providing a protective barrier to 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.

In children, brain tumours usually occur in the back of the brain – the posterior fossa region. As a tumour grows and fills or compresses the fourth ventricle, a blockage of the CSF can occur. 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, requiring treatment. Symptoms to watch out for will vary, depending on the age of your child, but the signs to be aware of are detailed below.

In newborns and young infants:

- High-pitched crying
- Irritability
- Lethargy
- Scalp veins
- Seizures
- The fontanelle (the soft spot on the baby's head) may bulge because the bones in the skull have not solidified and will expand due to the increased pressure
- The head may enlarge
- Vomiting

Toddlers often have the same symptoms that show in newborns and young children. Another sign to look for in this age group is a loss of their previous abilities, such as reverting to crawling when the child has already learned to walk.

Children and young adults may exhibit different symptoms, as their skulls cannot expand to accommodate the build-up of CSF. Headaches, vomiting, and irritability are common symptoms. Seizures are an immediate indication that medical attention is required. Problems with vision, loss of coordination, and a decline in academic performance are also symptoms in this age group.

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 ventricle (right) but at times, depending on the location of the tumour, other ventricles may require shunting. 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), which is surgically implanted into the ventricle through a small hole made in the skull (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 or administering drug therapy.

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 your child has, as this could be important information if your child runs into difficulty 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 also has good capacity to absorb 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 in children; that is, the type of hydrocephalus where the blockage to CSF flow is at or above the level of the fourth ventricle. The surgery 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. Sports that require your child to turn her head frequently, such as gymnastics and wrestling, should be avoided, as the excess movement can damage 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 the shunt is infected, your child will 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 a child's own bacterial organisms and is not acquired from exposure to other children or adults who are ill.

Signs that an infection is present vary, depending on the age of your child. The symptoms are similar to those mentioned in the Symptoms of Hydrocephalus section, but will characteristically include classical signs of infection such as fever and redness or swelling along the tract of the shunt. In infants, downward deviation of the eyes may also occur. If these symptoms develop, contact your child's medical team immediately.

Clinical Trials

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Clinical Trials

As part of your child's treatment, the neurosurgeon or oncologist may present you with the option of having your child participate in a clinical trial. For this reason it is important to know what a clinical trial is, what it means to be part of one, and what your rights and responsibilities are if you choose to participate.

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 already used in cancer treatment.

Clinical trials can also compare the best known and routinely used standard therapies with newer therapies to see if one produces more cures or remissions with fewer side effects. 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 or may not yield favourable results, but with each trial important questions may be answered, and the understanding of the disease or how the drug works advanced.

A rigorous process ensures that before a new treatment is tested in humans, 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 pre-clinical studies 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.

Treatments now being used (standard treatments) are the base for building new, hopefully better, 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 your child is offered the opportunity to take part in a clinical trial, know that your child's involvement in them is completely voluntary and that her treatment will not be affected regardless of your decision about her potential participation.

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 prevention, detection, diagnostic, treatment, and maintenance, all of which aim to improve a person'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 study 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 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 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, study 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 drug is built. Participants 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 the tumour type 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 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, ensuring accurate results.

The results seen in the experimental group are compared to those seen in the control group. The majority of studies available to children with brain tumours are Phase III, which are offered at all Canadian Pediatric Brain Tumour Consortium (CPBTC) centres.

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 the families cope with the illness of a loved one.

How to Find Out About Clinical Trials

The CPBTC is a group of tertiary care centres in pediatric neuro-oncology in Canada that are involved in the treatment of children with central nervous system tumours. These centres recruit for clinical trials and your child may be offered a place in an open trial. Multiple studies have demonstrated a survival advantage in children treated in a clinical trial compared to children treated as per an individualized or institutional protocol. Children involved in trials are closely monitored.

Important Questions to Ask About Clinical Trials

If you are thinking about having your child take part 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? (Find out what is done and how it is done.)
- What is likely to happen in my child's case 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 child's tumour, and how does the study compare the standard treatment to the new treatment?
- How could the study affect my child's daily life?
- 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 my child have to be hospitalized? If so, how often and for how long?
- What type of long-term follow-up care is part of the study?

- If the clinical trial ends earlier than planned, can my child remain on the therapy after the trial closes?
- How is safety monitored in the study?

Participation in clinical trials is always voluntary. If you choose not to enrol your child in a clinical trial, the standard of care your child receives will not be affected.

*For more information on **Clinical Trials**, please visit www.BrainTumour.ca/clinicaltrials.*

Chemotherapy



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 are 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 such a disease. More typically, however, it is used in combination with radiation therapy and surgery. In young children, chemotherapy is often used either in place of radiation therapy or to delay it until the child reaches an age where the risk for long-term damage is reduced.

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), starving tumours of nutrients and oxygen, and causing the tumour cells to die. Other newer agents target specific proteins or genes in the tumour cells, slowing down their growth, or making them more susceptible to other drugs 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 is given either as pills or capsules to be swallowed. Most chemotherapy is given intravenously (into a vein).

What Side Effects Are Associated with Chemotherapy?

Many share some general side effects, but there are also side effects specific to each individual drug. Your child's oncology team will discuss in detail with you, any potential side effects.

The oncologist will give you detailed information about your child's chemotherapy treatment. Your physician and pharmacist are also able to answer any questions you may have about the drugs being used, Handouts are usually available and information can also be found on the Internet – you can ask your health care team for assistance with this.

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 child's health and medical care, such as hearing loss or kidney impairment.

General Side Effects

Nausea and Vomiting

Many chemotherapy drugs may cause nausea and vomiting. This may happen immediately (as the drugs are given), or delayed (several days later). There are many effective anti-nausea medications which stop or reduce nausea and vomiting. Occasionally, some children may have anticipatory nausea where they get sick at the thought of coming into the hospital for treatment.

Some children may need help with maintaining their weight as they may not be able to eat properly. Helpful items can include supplement drinks, nasogastric feeding or G-tube feeding. Your child's dietitian will discuss this with you further.

Hair Loss

Some chemotherapy drugs may cause hair loss. 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. Hair will grow back once 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, your child 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 child's 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 your child develops neutropenia, antibiotics will likely be required. If your child develops a fever or becomes sick after chemotherapy, you should contact the hospital and have your child examined immediately.
- **Platelets** are small cells which stick together and help the blood to clot when you cut yourself. If the platelet count becomes low, there is a 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 the platelet count.

Sexual Function and Fertility

Some chemotherapeutic agents may affect fertility. Your child's health care team will discuss this possibility with you; depending on the drugs your child will be given.

*For more information on how chemotherapy and radiation can affect fertility and sexual function please turn to the **Sexuality and Teen Survivors of Brain Tumours** section on **Page 215**.*

Stem Cell Transplantation

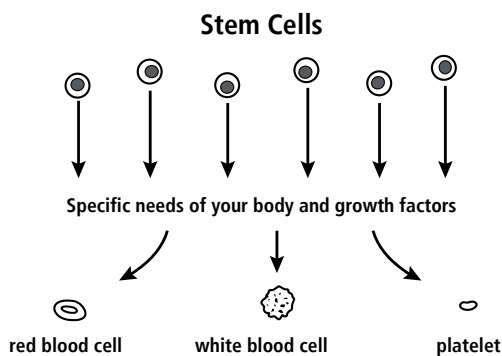
The treatment for brain tumours has improved over the decades to include many different modes of therapy including chemotherapy and stem cell support. In young children, chemotherapy and surgery have become the mainstays of therapy with the treatment designed to maximize chemotherapy and avoid or delay radiation. Part of this approach may involve high dose chemotherapy with the support of stem cells. The use of stem cells allows for very high-doses of chemotherapy to be given for the purpose of improving cure rates in young children, especially those who are too young for radiation.

What Does Stem Cell Transplantation Do?

After high doses of chemotherapy, the bone marrow takes some time to recover and make new blood cells. This puts children at risk for life-threatening infections. Introducing stem cells into the blood after high dose chemotherapy can speed up bone marrow recovery and thereby reduce the risk for infection by creating new blood cells to replace those that have died.

What Are Stem Cells?

Stem cells are immature blood cells. They form in the bone marrow and as they mature they develop into red blood cells, white blood cells, or platelets depending on what the body needs at any given time. Stem cells can be collected from your blood using a procedure called peripheral blood stem cell collection (PBSC). They can also be collected from the bone marrow via a bone marrow harvest.



What Is a Peripheral Blood Stem Cell (PBSC) Collection?

PBSC is the most common type of stem cell transplant. The procedure involves separating and collecting one type of white blood cell, called a mononuclear cell, from your blood. These white cells are important because the stem cells separate out along with them. The separation and collection are done by the cell-separator machine. Except for a small number of red blood cells, the machine returns all the blood to the donor.

When Is PBSC Collection Done?

Peripheral blood stem cell collection is performed usually after 2 to 4 cycles of chemotherapy. Standard treatment will include injections of a substance (growth factor) Undogranulocyte colony-stimulating factor (G-CSF or GCSF), following chemotherapy. G-CSF encourages the bone marrow to make stem cells, and moves the cells into the blood stream from the bone marrow. G-CSF is given daily until the number of these stem cells in the blood reaches its peak. It usually takes 10 to 14 days after chemotherapy to achieve the peak level. This peak period lasts only 24 to 48 hours and is the best time for stem cell collection.

How is a PBSC Collection Done?

The cell separator machine is set up, and your child is connected to the machine:

- With a special venous catheter, usually set into a big vein in the groin area (femoral line). The catheter is typically put in place while your child is under sedation in the intensive care unit, the day before or on the day of collection; or your child may have a special central venous catheter (MedComp®) in place that allows for stem cell collection.
- Collection is rarely done using needles and tubing to access a vein in the arm, although in older children this may be an option.
- Collection of stem cells usually takes about 2 to 3 hours. Your child will need to stay in bed but can read, watch videos or do other passive activities to help pass the time. Your child can also eat, sleep, or visit with friends and family during the stem cell collection procedure. Often, the slight humming sound of the machine puts children to sleep.

PBSC collection is not a painful procedure, especially when using a special venous catheter – the preferred method in toddlers. However, the insertion of needles may cause some discomfort.

PBSC collection is safe for children, and kids in general tolerate the procedure very well. Successful collections can be done in one day.

After the collection, your child may feel tired and need rest. He may require a platelet transfusion after the procedure and, if a femoral line was used, it will likely be removed two hours after the procedure and once there is confirmation of a successful collection.

Are There Any Side Effects?

Side effects are rare but the anti-coagulant used to keep your child's blood from clotting in the machine may lower the amount of calcium in his blood. Low blood calcium can be prevented through the use of milk, naso-gastric feeds, or oral calcium given to him during the stem cell collection.

What Happens After the Stem Cell Collection?

Peripheral blood stem cells are cryopreserved and frozen after collection, and stored until needed. When your child's treatment protocol calls for high-dose chemotherapy, the stem cells are thawed and re-infused into your child's blood stream.

Re-infusion is done through a central venous catheter or port and takes only a few minutes. Generally, it takes 9 to 14 days for the stem cells to germinate and grow. Recovery of the white cell count is known as engraftment. During the germination period, blood products, antibiotics and pain support may be needed and G-CSF is used to help bring about engraftment.

The use of high doses of chemotherapy with stem cell rescue is a helpful treatment option that is being used in children three years of age and younger. It has been shown to be very valuable in the treatment of certain types of brain tumours, especially the desmoplastic nodular subtype of medulloblastoma (infratentorial PNET). Current research is looking at identifying all the tumour types that respond best to this approach, and whether there is a role for this in children over the age of three.

Radiation Therapy



Radiation Therapy

Radiation therapy destroys the tumour cells by inducing damage to their inner structure (DNA), stopping their ability to divide. When exposed to radiation, the cells eventually die when they try to reproduce, and are absorbed into the body. The amount of radiation used is similar to that of diagnostic X-rays (e.g., chest X-ray) but of a much higher energy, and cannot be seen or felt. Radiation therapy involves aiming the X-rays at the tumour using a linear accelerator.



Modern radiation techniques allow doctors to accurately focus radiation therapy to the area(s) of the brain requiring treatment. 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 exclude important parts of the brain (such as optic nerves, the brain stem, and the pituitary gland that are near the tumour, and yet still give a full dose to the tumour.
- Image-guided radiation therapy (IGRT) refers to the use of some form of 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.

Occasionally, even with the best available technology, it is impossible to determine the exact outer edge of a tumour because of possible microscopic spread of the tumour into adjacent brain tissue.

Therefore, some normal tissue may need to be included in the treatment area to make sure all the tumour cells are treated. Fortunately, most normal cells are less sensitive to the effects of radiation, compared with tumour cells, and can recover more easily from radiation damage. Through precise planning of the treatment, the amount of normal tissue within the treatment field is kept to a minimum.

Radiation is generally given in many small doses (fractions) over a period of several weeks. Depending on the type of tumour and its location in the brain, the daily amount of radiation and the length of treatment will vary and will be determined by your child's radiation oncologist.

Preparation for Radiation Therapy and Treatment Planning

After the initial visit with the radiation team, your child will be booked for a planning appointment. As part of this appointment, a CT or MRI scan must be done at the radiation centre in order to plan the radiation treatment. Its purpose is to determine the best treatment position and to locate precisely the area to be treated. The planning session can take about one hour to complete. Your child will be expected to remain still during the planning session and during her radiation treatments. This can be very challenging for some children. In order to help your child through this time, feel free to bring a special toy or blanket with you to the appointment.

Your child will need a plastic mask to wear for daily radiation treatments. The mask will be made the same day as the planning session by the radiation therapists. The mask is used to keep your child's head in the same position during each treatment. This mask is made of a plastic material that is firm at room temperature, but is quite soft and able to be fitted to the exact shape of your child's face and head when the material is placed in warm water. Your child will have to lie still for a few minutes while the plastic mold cools down to room temperature and becomes firm again. Once the mask is made, she will undergo a CT or MRI scan of the brain for treatment planning purposes.

Your child may anticipate and fear the unknown of yet another new procedure, which may make her cooperation difficult, especially if she is very young. In these situations it may be necessary for her to be sedated for the planning session and daily treatments. However, if she is adequately prepared for what to expect during the planning and treatment appointments, it will help in gaining her cooperation and, with older children, may eliminate the need for sedation. Your radiation team, together with the child life specialists are valuable resources in preparing your child for radiation planning and treatments.

*For more information on **Your Child's Health Care Team**, please turn to **Page 175**.*

Radiation Treatment

It will be necessary for you to attend your child's treatment sessions. Treatment takes place in an outpatient setting, Monday through Friday.

Receiving radiation is like having an X-ray taken: while there is no pain or sensation, your child must lie still for a few minutes. Although she will not see or feel anything during the treatment, the machines may make clicking or whirring noises, which is normal.

During treatment, your child will spend 15 to 45 minutes each day in the treatment room. Most of this time is spent positioning your child for her treatment. The actual treatment takes approximately 5 to 10 minutes. Parents and therapists must leave the room prior to turning the machine on. You and the therapists are able to watch your child on a video monitor and interact with her through a speaker system, if needed.

A radiation oncologist will see your child once a week for general monitoring and to discuss any concerns you may have. It may help you to write down your questions and bring the list with you to appointments. The radiation nurse coordinator and radiation therapists will be available daily to address any of your concerns or questions.

Physical Side Effects of Radiation Therapy

Many children who undergo radiation treatment do not experience any side effects. Whether or not your child will experience side effects depends on a number of factors including the particular area of the body being treated, the amount of radiation prescribed and the size of the area being treated. At your initial visit, the radiation oncologist will discuss with you, in detail, the expected short and long-term side effects specific to your child's treatment.

Potential Side Effects During Treatment (*Acute Side Effects or Short-Term Side Effects*)

Acute or short-term side effects can result from radiation therapy. Typically, they will disappear within weeks of finishing treatment.

Skin Reactions

Some children will experience radiation skin reactions in the area exposed to treatment. After 2 to 3 weeks of treatment these areas may become red, itchy, warm and sensitive, like a sunburn.

The following are guidelines for the care of your child's skin in the treated area:

- Gently clean the area with mild soap and lukewarm water, and pat the skin dry.
- Do not apply any ointments, creams or powders to the treatment area.
- If the skin becomes dry and itchy, try not to let your child scratch. Please advise your radiation team and they will provide or prescribe a cream.
- Do not expose the treated area to extreme hot or cold, such as a hot bath or shower.
- Keep the affected area protected from the sun by using a brimmed hat.

The skin changes mentioned above will subside gradually within 2 to 6 weeks of completing treatment. Once the treatment has finished, you may continue applying cream in the affected area to help with healing. In time, the treated skin can become darker or appear tanned, but will gradually return to normal.

Hair Loss

Hair roots are sensitive to radiation and hair in the treatment area will most likely fall out in the second to third week of treatment. In most cases, the hair will start to regrow within 2 to 3 months. However, higher doses of radiation in certain areas may cause permanent hair loss.

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

Fatigue

The stress of coping with a serious illness, the trips made for treatment, and the effects of radiation can all cause fatigue. Other treatments such as surgery or chemotherapy may also have an effect. Fatigue can be worsened due to loss of appetite, lack of sleep, decreased physical activity and low red blood cell count.

To ease the effects of fatigue:

- Plan your child's activities, if possible, to allow for rest and relaxation.
- If they need to nap, let them.
- Encourage your child to eat a well-balanced diet.

Lack of Appetite or Nausea

Some radiation treatments may cause loss of appetite, nausea and vomiting. If this occurs here are some suggestions to help:

- If your child feels sick or is vomiting, the doctor can prescribe medications to help.
- Give your child small meals or healthy snacks throughout the day.
- Encourage your child to drink lots of fluids.
- Try to have her maintain a balanced, healthy diet.

Headaches

Because radiation may cause some swelling (edema) around the tumour site, she may experience some degree of headache or nausea after the first few treatments. These symptoms do not always occur, but when they do they usually settle down within a few days. If your child is experiencing headaches, let the radiation team know. They may recommend observation or medication.

Potential Side Effects in the Months Following Radiation

Somnolence Syndrome

Somnolence syndrome is described as a transient period of increased sleepiness and/or decreased appetite. It can occur between 1 to 2 months after radiation treatment. Your child may feel like sleeping more often during the day and longer hours overnight. This will resolve gradually over several weeks. If you are concerned about the symptoms, contact your health care team.

Potential Effects in the Years After Radiation Therapy (Late Effects or Long-Term Side Effects)

The integration of surgery, radiation therapy and chemotherapy over the last several decades has significantly improved the cure rate in children with brain tumours. Because children still have some significant growth ahead of them at the time of treatment, radiation therapy can be associated with some additional, possible late effects. Many of these radiation late effects are not only related to the radiation therapy itself, but also are often related to tumour effects and the effects of surgery and chemotherapy.

Radiation therapy to the brain of a young child may produce cognitive effects that can impair learning and your child's success at school over the months and years following treatment.

Factors associated with a greater degree of impairment are: younger age at treatment; location of the tumour in your child's brain; larger volume of brain receiving treatment; and increased radiation dose.

Radiation is always considered very carefully for children under three years of age. The connections of the brain are developing very rapidly up to the age of three, and may be impaired by the radiation. An endocrine and neuropsychological assessment will be done in appropriate circumstances.

Radiation therapy to any part of the body may be associated with growth effects in that particular area. Factors that predict a greater impact on growth include the volume of tissue being treated, age at treatment and the specific area being treated. More specifically, for children with a brain tumour requiring cranio-spinal irradiation, treatment to the spine, radiation can impair growth by a direct effect on the bones of the spine.

Radiation of the brain can impact hormonal function as well. This relates to the fact that the four main hormonal systems are all centrally controlled by the hypothalamus / pituitary complex in the brain. Radiation to the pituitary or hypothalamic area may sometimes be associated with a decrease in hormone production lasting from a few months to a few years later. Growth hormone and thyroid hormone are the most frequently



affected and are very important for your child's growth. Both of these hormones can be replaced by medication, should their production be adversely affected by treatment. The hormones associated with sexual development and stress are far more resistant to radiation, and are far less frequently affected by treatment.

Lastly, as with the use of radiation in any part of the body, radiation to the brain can be associated with the development of new tumours in a small proportion of children. This may occur many years later after successful treatment of the initial tumour. The radiation team will discuss all of these details with you in further detail, and reading materials will also be provided.

It is important to remember that the risk of radiation is very low, and the benefit associated with it in terms of curing the current disease always significantly outweighs the risk of a second tumour in the future.

Supportive Medications



Supportive Medications

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

Listed below is a table containing some support medications commonly used in managing side effects associated with cancer treatment. Your physician and pharmacist will discuss with you in detail, any medications prescribed for your child.

Consult with your child's doctor or pharmacist before giving your child other medications, including over-the-counter products, herbal or alternative medications.

Anticonvulsants / Anti-Epileptics

Medication Anticonvulsants / Anti-Epileptics	Potential Side Effects
Carbamazepine (Tegretol®)	When your child begins taking this medication, he may experience some dizziness, drowsiness, headache, double vision, weight gain and nausea. These effects usually wear off after a few days of treatment. If your child develops a fever, skin reaction or rash, inform your doctor right away. Occasionally, decreased blood cell counts may occur while on this medication. The levels of this drug in your child's blood may be increased or decreased by other medications. This medication can be taken with food to prevent stomach upset.

Clobazam (Frisium®)	Clobazam is currently used only in combination with other anticonvulsant medications for refractory seizures. Inform your doctor if your child is on any other anticonvulsants. Common side effects include drowsiness, dizziness and fatigue. Allergic skin reactions may also occur. Tolerance may develop over time and some patients may cease to respond to this medication. Clobazam can be taken with food to prevent an upset stomach.
Divalproex Sodium (Epival®)	Divalproex sodium is another form of valproic acid. Please refer to section for valproic acid for potential side effects.
Gabapentin (Neurontin®)	This medication is generally well tolerated. If side effects do occur, the most common include headache, fatigue, nausea, drowsiness and blurred vision. This medication can be taken safely with other anticonvulsants without risk of interactions. Morphine may increase levels of gabapentin in the blood, if taken at the same time.
Lamotrigine (Lamictal®)	This medication is generally well tolerated. Potential side effects include headache, fatigue, dizziness, drowsiness, double or blurred vision, nausea and nasal congestion. A skin rash may develop within the first six weeks of taking lamotrigine. If your child develops a rash, inform your doctor immediately.

Levetiracetam (Keppra®)	This medication is generally well tolerated. The most frequently observed side effects are drowsiness, dizziness, weakness and infection (such as the common cold). Occasionally, decreased red blood cell counts can be seen.
Oxcarbazepine (Trileptal®)	This medication can be used on its own or in combination with other anticonvulsants. The most common side effects include dizziness, fatigue, drowsiness, headache, nausea and double vision. These effects usually occur at the start of treatment and normally wear off with time. Trileptal can also cause sodium blood levels to drop. If your child is at risk, his doctor will have his sodium blood levels monitored closely on regular basis. The levels of this drug in your child's blood may be increased or decreased by other medications.
Phenobarbital (Phenobarbital®)	Common side effects may include drowsiness, headache, depression, insomnia, confusion, shortness of breath and high blood pressure. If your child develops a skin reaction or rash, inform your doctor right away. The levels of this drug in your child's blood may be increased or decreased by other medications.

Phenytoin (Dilantin®)	Common side effects of phenytoin include drowsiness, dizziness, slurred speech, difficulty sleeping, headache, constipation, nausea, vomiting and weight gain. Irritation of gums may occur. This medication can be taken with food to prevent an upset stomach. Personal dental care is important as well as regular supervision by a dentist. Children on steroids may require a higher phenytoin dose. The levels of this drug in your child's blood may be increased or decreased by other medications. Dietary supplements, enteral feeding preparations and nutritional drinks may interfere with absorption of the medication and decrease its effectiveness.
Valproic Acid (Depakene®)	Common side effects include drowsiness, dizziness, headache, nausea, vomiting, indigestion, diarrhea, constipation, weight gain and tremors. Occasionally, valproic acid may reduce the number of platelets in the blood, leading to bruising and bleeding. Liver failure has occurred in children under two years of age. Cases of life-threatening inflammation of the pancreas have also been reported in children. Some drugs may produce side effects when used in combination with valproic acid.

Anti-emetic / Antinauseants

Brain tumour treatments may cause nausea and/or vomiting in some children that can range from mild to severe. This is a frequently reported side effect that can significantly impact daily functioning and quality of life. Medications called anti-emetics are often given to prevent or minimize this side effect and control nausea. These medications can be given before or after treatment.

There are several anti-emetics available in Canada and your child’s doctor will assess which medication or combination of medications may be most appropriate. Some common anti-emetics used in children with brain tumours include Ondansetron (Zofran®), Granisetron (Kytril®) and Dimenhydrinate (Gravol®).

Side effects of the following medications:

Medication Anti-emetic / Anti-nauseants	Potential Side Effects
Dimenhydrinate (Gravol®)	Available as a pill or as an injection for IV use. Tablets can be taken with or without food. Common side effects include drowsiness, dizziness, dry mouth, excitement (especially in children).
Ondansetron (Zofran®) and Granisetron (Kytril®)	These medications are available as a pill or as an injection for IV use. Tablets can be taken with or without food. They are generally well tolerated. Possible side effects include headaches, flushing, dizziness and constipation. Less commonly, these medications may cause irregular heartbeats (fast or slow heart rate), low blood pressure and chest pain (more likely with ondansetron).

Chemotherapeutic Agents

There are many different types of chemotherapeutic drugs that are given to children with brain tumours. The chart below is not a complete listing of all possible chemotherapy medications, but will provide general information about some that are available in Canada.

*For complete information about these medications, it is important to talk to your child’s doctor and your pharmacist. For more information, please turn to the **Chemotherapy** section on **Page 113**.*

Medication Chemotherapy Agent	Potential Side Effects
Carboplatin (Carboplatin®)	This drug is given by injection into a vein. Carboplatin may cause low platelets (bruising, bleeding) and white blood cell counts (increased risk of infection). Common side effects include nausea and vomiting, diarrhea, constipation, hair loss, decreased appetite, and weight loss. Also reported:impaired kidney function, high-frequency hearing loss and allergic reactions.
Carmustine (BiCNU®)	This drug is given by injection into a vein. Nausea and vomiting are common side effects, but usually only last 4 to 6 hours. This medication may cause low platelets (bruising, bleeding) and white blood cell counts (increased risk of infection). Less common side effects include decreased liver function, breathing problems, loss of appetite and hair loss.

Cisplatin (Cisplatin®)	This drug is given by injection into a vein. Nausea and vomiting are common side effects and may be severe, they can last for several days. Cisplatin may cause low platelets (bruising, bleeding) and white blood cell counts (increased risk of infection). Other common side effects include impaired kidney function, high frequency hearing loss, tingling and numbness in toes and fingers, loss of appetite, hair loss and low magnesium blood levels. Allergic reactions have also been reported.
Etoposide (VP-16, Vepesid®)	Etoposide can be administered orally in a capsule form or by injection into a vein. Etoposide may cause nausea and vomiting, hair loss, decreased appetite, weight loss, and diarrhea. This medication may also lower platelet (bruising, bleeding) and white blood cell counts (increased risk of infection). Allergic reactions have also been reported. Blood pressure monitoring is required during intravenous infusions as the medication can lower blood pressure and cause dizziness.

Ifosfamide (Ifex®)	This medication is administered by injection into a vein. Common side effects include nausea and vomiting, hair loss, decreased appetite, weight loss, low magnesium, potassium and phosphate levels in the blood. Ifosfamide may lower platelet (bruising, bleeding) and white blood cell counts (increased risk of infection). This medication requires intravenous hydration to prevent decreased kidney function and damage to the bladder that could cause blood in the urine; another medication (Mesna) is given with ifosfamide to prevent bladder problems.
Lomustine (CeeNU®, CCNU)	Lomustine is an oral medication in capsule form. It should be taken on an empty stomach with a glass of water at bedtime. Common side effects include nausea and vomiting, decreased appetite and weight loss. This medication may lower platelet (bruising, bleeding) and white blood cell counts (increased risk of infection).

Procarbazine (Matulane®)	Procarbazine is an oral medication in capsule form. It should be taken with a full glass of water. Certain foods that contain tyramine should be avoided, while taking procarbazine. Ask your pharmacist for a detailed list of restricted food items. Common side effects include nausea and vomiting; sensitivity to sunlight; dry and itchy skin or rash; mouth sores; flu-like symptoms such as fever or chills; tingling and numbness in toes and fingers; weakness; insomnia; and nightmares. This medication may lower platelets (bruising, bleeding) and white blood cell counts (increased risk of infection).
Temozolomide (Temodal®)	Temozolomide is an oral medication in capsule form. It should be taken with a glass of water on an empty stomach. Taking it at bedtime may reduce nausea and vomiting. Other common side effects include fatigue, decreased appetite, weight loss, headache, and low platelet count (bruising, bleeding). Less commonly, this medication may lower white blood cells (increased risk of infection).
Vincristine (Vincristine®)	Vincristine is given by injection into a vein. Common side effects include hair loss, constipation, jaw pain, tingling or numbness in toes and fingers. Nausea and vomiting are less common.

Vinblastine (Velbe®)	Vinblastine is given by injection into a vein. This medication can cause nausea and vomiting; stomach cramps; hair loss; decreased appetite; hair loss; constipation; mouth sores; fatigue, and mild joint or muscle pain. It may lower platelets (bruising, bleeding) and white blood cell counts (increased risk of infection). Vinblastine may also cause tingling and numbness in toes and fingers.
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Chemotherapy drugs may interact with other medications which could reduce the effectiveness of the medication, or cause severe side effects. Inform your child’s doctor and pharmacist of all changes to his medications, including prescription and non-prescription drugs, vitamins and natural products.

*It’s important to have an open dialogue with your physician or nurse about any and all natural products that your child may take. Turn to the **Complementary and Alternative Medicines** section on **Page 169** for more tips and information.*

Steroids

Steroids, also called corticosteroids, are frequently prescribed when a person is diagnosed with a brain tumour, or before or after surgery, and during radiation therapy, because they reduce swelling. Brain tumours can cause tumour associated edema or brain swelling in the normal tissue surrounding them. Edema is the accumulation of fluid in the tissue around the tumour and is very common with brain tumours.

Steroids reduce the swelling 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, and may also improve neurological function. The full effect of the steroids in reducing swelling becomes evident between 24 to 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.

*Never discontinue steroid medication abruptly.
Always consult your child's doctor.*

Your child's doctor will give instructions to gradually reduce the dosage over a period of time. This is called "tapering" and it will prevent the development of steroid withdrawal syndrome.

Discuss any questions about these medications with your doctor and pharmacist. If your child is having surgery, it is important to mention that he has been or is currently on steroids.

Side Effects of Corticosteroids:

- Steroids can increase risk of infection by suppressing the immune system.
- Mood swings, personality changes, mild depression and irritability are common.
- Appetite is often increased with steroid use, which can lead to weight gain.
- Facial swelling (“moon face”) and flushing can occur.
- Sleep disturbances may be minimized by giving most of the daily dose in the morning and avoiding any doses after dinner time.
- Adolescents may experience an increase in acne.
- Long-term use has been associated with a risk of cataracts, osteoporosis, muscle weakness and diabetes.
- Steroids can alter the gastric lining of the stomach causing stomach pain and irritation; this can be prevented by taking medications with milk or food; antacids (e.g., ranitidine, Zantac®) may help prevent or reduce this irritation.
- Steroids interact with some anti-epileptic medications which may lead to decreased effectiveness of the steroid.

Communication and Your Child



Communication and Your Child

Communication involves the exchange of ideas using speech, language and non-verbal signals. Effective communication involves accurately receiving messages (hearing, understanding and interpreting) and sending messages (sounds, words, thoughts). In addition, both the listener and the speaker understand the “rules” of conversation, including turn-taking, shared background knowledge and the use of nonverbal signals (facial expressions, body posture, tone of voice, gestures). Communication can involve using spoken, signed or written information.

A brain tumour can disrupt communication at any level – the ability to understand, speak, retrieve words, produce sentences, use appropriate nonverbal signals, take into account the listener’s perspective, or to read or write.

Breakdown can occur in one or many areas of communication. If your child isn’t speaking or is speaking less, it doesn’t necessarily mean he doesn’t understand what is being communicated to him. The type and extent of the communication problem depends on the tumour location and size.

Not all brain tumours result in a communication problem.

In general, ways that you, your family and your health care team can support your child’s communication include:

- Realizing that the ability to communicate is not the same as intelligence.
- Treating your child according to his developmental age.
- Providing a relaxed communication setting.
- Communicating in a quiet environment – turn off the radio, close the door, limit the number of people your child talks to at one time.
- Ensuring your child is paying attention before speaking.

- Using gestures and familiar topics to help your child understand. While he is in the hospital, show him photographs of people and family events can help to provide context for conversation.
- Speaking slightly slower, and at a normal level of loudness. (Difficulty in understanding is not the same as hearing loss).
- Providing choices, if your child has difficulty finding words, (e.g., "Do you want apple juice or water?").
- Using short, straightforward sentences with familiar words and different, but related words to say the same thing (e.g., "Are you thirsty?" or "Do you want a drink?").
- Concentrating on understanding your child's message; don't correct pronunciation or interrupt him.
- Being aware of your child's fatigue.

Nutrition



Nutrition – During and After Treatment

Good nutrition is important for children diagnosed with a brain tumour. Your child will need adequate nutritional stores to fight her tumour in addition to his normal requirements for growth and development. You can play a significant role in your child's care by understanding the importance of good nutrition, and encouraging her to eat of a wide variety of healthy foods.

Many parents feel empowered and able to participate more actively in their child's treatment plan when they understand the important role nutrition plays.

A well-nourished child is better able to:

- Withstand the effects of the brain tumour, as well as treatments such as chemotherapy, radiation or surgery
- Fight off infections
- Avoid weight loss / excessive weight gain
- Repair cells and heal wounds by building new tissues
- Achieve normal growth and development

Good Nutrition

Protein, carbohydrates and fat provide us with energy. They also provide the building blocks that help your child grow, heal and stay healthy. While vitamins, minerals and water help the body use energy from these nutrients, they do not provide energy themselves. And, no single food can provide all the essential nutrients. It is important to eat 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 <i>Servings Per Day</i> Children 2-3 years: 3 Children 4-8 years: 4 Children 9-13 years: 6 Teens 14-18 years: 6-7	1 Serving 1 slice of bread $\frac{3}{4}$ cup hot cereal $\frac{1}{2}$ bagel 30 g cold cereal $\frac{1}{2}$ pita or tortilla $\frac{1}{2}$ cup cooked pasta $\frac{1}{2}$ cup cooked rice
Vegetables & Fruits <i>Servings Per Day</i> Children 2-3 years: 4 Children 4-8 years: 5 Children 9-13 years: 6 Teens 14-18 years: 7-8	1 Serving $\frac{1}{2}$ cup fresh, frozen or canned vegetables $\frac{1}{2}$ cup cooked leafy vegetables 1 cup raw leafy vegetables $\frac{1}{2}$ cup fresh, frozen or canned fruits $\frac{1}{2}$ cup 100% juice
Milk Products <i>Servings Per Day</i> Children 2-3 years: 2 Children 4-8 years: 2 Children 9-13 years: 3-4 Teens 14-18 years: 3-4	1 Serving 1 cup milk $\frac{1}{2}$ cup canned milk 1 cup fortified soy beverage $\frac{3}{4}$ cup yogurt $\frac{3}{4}$ cup kefir 50 g cheese

Meat & Alternatives <i>Servings Per Day</i>	1 Serving
Children 2-3 years: 1	½ cup cooked fish, shellfish, poultry, lean meat
Children 4-8 years: 1	¾ cup cooked legumes
Children 9-13 years: 1-2	¾ cup tofu
Teens 14-18 years: 2-3	2 eggs
	2 Tbsp peanut or nut butters
	¼ cup shelled nuts and seeds

Source: Canada's Food Guide, Health Canada

Strategies To Encourage Eating

Be Adaptable and Creative

- Avoid getting angry or stressed if your child won't eat. She can pick up on these feelings and become upset as well.
- Be flexible and supportive.
- Make foods more appealing. For example, use cookie cutters to make different shapes of cheese and bread.
- Praise your child when she is eating well, and for trying new things.
- Understand that food cravings and aversions are common.

Let Children Participate

Children love to be involved. Encourage your child to participate in planning and the preparation of meals and snacks.

Take Advantage of Trouble-Free Times

Take advantage of foods high in calories, protein and nutrients when your child's appetite is good to make up for nutritional losses during periods when her eating is poor.

Make Every Bite Count

When your child's nutritional intake is poor, try adding calorie and protein rich foods to her diet.

Calorie Booster Guide

Add	To
Cream - 10% or 18%	Soups, cereals, milkshakes, puddings
Whipping cream	Custards, fruit, cakes, pie, Jello®
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
Avocado	Sandwiches, salads, as a topping for burgers, or as a dip

Protein Booster Guide

Add	To
Skim milk powder (30ml or 2 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 your child increase her calorie and protein intake include:

If your child is unable to maintain proper nutrition, her 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 sandwiches
- Peanut butter cookies
- Peanut butter or oatmeal cookies
- Trail mix*
- Yogurt

*Choking hazard in children less than four years of age

Possible Treatment Side Effects Affecting Nutrition

Brain tumour treatments may cause significant changes in your child's ability to eat. Some children experience side effects that impact their digestive system, such as vomiting or diarrhea. Side effects vary from child to child, and depend on the type and duration of treatment. Understanding why changes in your child's eating habits occur will help you overcome these barriers to good nutrition.

Chemotherapy may affect normal, healthy cells as well as destroying tumour cells. This can cause:

- Abdominal cramps
- Changed sense of taste or smell
- Constipation or diarrhea
- Mouth sores
- Nausea and vomiting
- Loss of appetite
- Sore mouth and throat

Radiation therapy may damage normal cells in the body at the site where treatment is/was administered. This may cause:

- Nausea and vomiting
- Loss of appetite
- Changed sense of taste or smell
- Dry mouth
- Difficulty swallowing
- Feeling of fullness
- Pain in the jaw
- Headache
- Diarrhea

Overcoming Side Effects

The following suggestions may help your child overcome some common side effects of treatment. If you need more information, please talk to your child's doctor, dietitian or nurse.

Loss of Appetite – “I don't feel hungry”

It is extremely common for children to lose their appetites because they feel sick from treatments. Short periods of appetite loss are acceptable, but if prolonged, can pose a problem (e.g., weight loss, poor tolerance to treatment).

Try the following until you find what works best for your child:

- Offer smaller meals and snacks more often during the day.
- Have nourishing snacks handy for nibbling.
- Serve favourite foods: macaroni and cheese, mashed potatoes with butter, spaghetti, cheese and crackers, etc. (unless your child is very nauseous and is vomiting)
- Add eye appeal to meals by serving a variety of colourful foods.
- Try to increase calories and protein without increasing the amount of food to be eaten (See suggestions on **Page 156**).
- Light or moderate activity may stimulate your child's appetite.

Nausea

Nausea, or the feeling of the need to throw up, is one of the most common side effects of chemotherapy and radiation. Nausea can be short in duration, lasting just a few hours, or can continue for several days. Some children, especially older children and adolescents, may experience symptoms of nausea just thinking about treatment or trips to the hospital. This is called anticipatory nausea. Other children will feel nauseous but never throw up, and others may experience both nausea and vomiting.

While some foods can help children with nausea feel better, it is best to treat nausea when it's mild, or before it even happens. Your child may be prescribed anti-emetic (anti-nausea) medications that help control or avoid

nausea. Talking to your child's medical team about the best way to use these medicines is important, as is communicating with her team, if you feel that the medicines aren't working as well as you'd like. Each child is different, and some may need various combinations of anti-emetic drugs to achieve good control of their nausea.

Here are some other suggestions that might help your child if she feels nauseous:

- An empty stomach may make your child feel more nauseous due to the presence of stomach acid. Encouraging her to nibble on foods through the day can help her body to absorb this acid and help her feel better.
- Never give your child her favourite food, if she is very nauseous or vomiting. If she vomits her favourite food, she may never eat it again and then you've lost a good source of calories or a meal she will reliably eat.
- Offer plain, bland, starchy foods like dry toast or crackers, plain cereal, breadsticks, pretzels and arrowroot cookies.
- Offer other easy-to-digest foods such as broth, white rice, Jello® and clear liquids like juices or ginger ale.
- Some children find plain, salty food like saltine crackers helpful.
- Avoid foods that are spicy, greasy, acidic or strong-smelling as these can make nausea worse.
- If your child feels more nauseous with the smell of food, keep her away from the kitchen when you're cooking, and serve meals cold or at room temperature.
- Ensure that your child drinks through the day to avoid becoming dehydrated. Water, diluted juice, ginger ale, and electrolyte drinks (e.g., sports drinks or special electrolyte drinks made for children) may be helpful. Children tend to prefer their drinks cool or cold when they feel nauseous.

- Older children and adolescents may find foods with ginger or peppermint helpful. They may also find that sucking on a hard candy helps their nausea.

This tip is not appropriate for younger children, when choking is a hazard.

- Encourage your child to keep her mouth clean to get rid of bad tastes that may linger. Good dental hygiene and the use of baking soda mouthwashes can be very helpful (your medical team can give you a recipe).

Vomiting

Many children will vomit with their treatment, especially if they feel nauseous. For some children this can be very upsetting, so trying to control the need to vomit is important. Anti-emetic medication may be very helpful in avoiding or controlling vomiting. Many of the above tips for controlling nausea are just as helpful if your child is vomiting.

If your child vomits large amounts throughout the day, she is at risk of becoming dehydrated, so encouraging her to drink (water, diluted juice, sports or electrolyte drinks, ginger ale) is very important. Your child may tolerate sipping drinks throughout the day better than drinking large amounts at one time. If you are unable to control your child's vomiting for a period of 24 hours using anti-emetic medicines or the tips above, speak to your medical team.

Taste Changes – “My food tastes funny”

Foods that once were loved by some children may no longer taste the way they expect. Your child may not want certain protein such as red meats or sweet foods.

- Serve foods chilled.
- Avoid extremely sweet foods, such as candy, jams and honey.
- Try ketchup or applesauce for dipping protein foods, this can change the taste (e.g., chicken fingers and ketchup, pork chops and applesauce).

Diarrhea

Your child may experience diarrhea or loose, watery stool as a result of her treatment. If her diarrhea continues for more than 1 to 2 days, it can lead to dehydration. It is important to let your medical team know so they can help. Here are some suggestions to help manage diarrhea:

- Limit foods high in insoluble fibre (or foods containing roughage), as they can make the diarrhea worse. Examples of insoluble fibre foods are whole grain breads and cereals, most raw fruits and vegetables (especially fruit or vegetables with skin, berries and citrus fruits). Choose canned or cooked fruit or vegetables instead of raw fruits and vegetables.
- Foods that are high in soluble fibre can help improve diarrhea as they make stool more solid. Some examples are oats / oatmeal, rice, potatoes, bananas and applesauce.
- Avoid giving your child dried fruit and foods that cause gas, like beans, broccoli, cabbage and cauliflower, as well as chewing gum and soda pop.
- Avoid giving your child food and drinks that are high in sugar (e.g., like candy, juice, soda pop, iced tea or fruit punch), as they can make diarrhea worse.
- Avoid giving your child high-fat and deep-fried foods.
- Some children will not tolerate dairy products like milk, milkshakes, cheese or ice cream when they have diarrhea. You can avoid these foods, if this is the case, but yogurt is a good food to give your child as it contains "good bacteria" that can help improve your child's digestion.
- If your child has persistent diarrhea, consider giving her foods high in salt and potassium, as these minerals can be lost in her stool. (e.g., soup broths, electrolyte drinks, potatoes and bananas).
- Remember to give your child lots of fluids as tolerated, to avoid dehydration. Encouraging her to sip on fluids throughout the day.

Constipation (problems with regular bowel movements) that results from chemotherapy, radiation or pain medication is common in children being treated for cancer. Children with decreased activity and inadequate fluid intake are also at risk of becoming constipated. Constipation can be very uncomfortable, and can cause stomach pain and reduced appetite.

Below are some tips to help you manage constipation in your child. If she is constipated, she may need medications that help soften her stool or improve her regularity. Talk to your medical team about this.

- Encourage your child to eat high-fibre foods like whole-grain breads, pastas and cereals, brown rice, fruits and vegetables (especially dried fruit, berries and citrus fruits, corn, broccoli, carrots and leafy greens), beans and lentils.
- Encourage your child to drink more fluid, like water, milk or juice. Prune juice may be helpful in small amounts.
- Try to add extra fruit and vegetables to your child's diet, by using them in sauces, soups, sandwiches, smoothies, in yogurt, ice cream, cereal and pancakes.
- Try adding a small amount of bran or ground flax to your child's cereal, or mix it into pasta sauces. Start with a very small amount (such as 1 to 2 teaspoons / day) and gradually increase it to a maximum of two tablespoons per day.
- If possible, encourage your child to be more active. This can be as simple as getting out of bed and going for a short walk, or just playing a little bit around the home.

Infants Have Special Needs

The weight of an infant should be monitored carefully to determine growth and make sure she is gaining weight. Feeding amounts and schedules may need to be very flexible and the needs of each infant assessed individually.

Because infants grow and develop quickly, it is extremely important to ensure they receive all the nutrition they require to grow and develop. Brain growth and development is rapid in the first two years of life, so proper nutrition is essential.

Your infant's weight should be monitored carefully to make sure she is gaining weight. And your baby's length should be measured monthly to monitor her growth. Your infant's medical team will assess her needs on an ongoing basis, as different treatment regimens may require flexible feeding amounts and schedules. Some infants will consume less milk and solid foods because their treatment makes them feel unwell. Your dietitian can help you modify the diet to make sure your child gets all the nutrition she needs to grow.

In some cases, infants and young children require tube feeding to help ensure their nutritional needs are met. Many parents feel stressed about feeding their children and, if other methods of feeding don't work, having a tube to provide nutrition can be a great stress-reducer.

Swallowing Difficulties

Swallowing difficulties in this age group more commonly occurs in the oral and or pharyngeal stage of the swallow.

The Oral Stage

During the oral stage, your child may have difficulty moving food or liquid from her mouth to her throat. This may happen, for instance, if she has mucositis, reduced sensation, or reduced strength and movement of the cheeks, tongue or lips.

If your child develops difficulties swallowing, either the Speech Language Pathologist or the Occupational Therapist on your child's health care team will provide techniques to help your child swallow safely. Who on your child's team provides this function will vary from hospital to hospital.

Signs of difficulty in the oral stage include:

- Difficulties with chewing
- Food or liquid escaping from the lips
- Food pocketing, where food becomes stuck in the cheeks
- Increased or decreased duration of food or liquid in the mouth

The Pharyngeal Stage

During the pharyngeal stage, your child may experience difficulties when beginning to swallow, so the food or liquid in her mouth may stay in her mouth or travel too quickly into her unprotected airway.

Signs of swallowing difficulties in the pharyngeal stage include:

- Coughing
- Regurgitation of food
- Throat clearing
- Vomiting
- Wet-sounding voice

If your child develops difficulties swallowing food or liquids, the designated therapist on your team will assess the problem and advise the team of the food or liquid textures that would be safe for your child to swallow. The therapist may also create a program to maximize your child's independence during meals.

If your child is experiencing substantial difficulties with swallowing, leading to persistent lung infections or the inability to maintain her nutritional requirements or weight, a tube may be placed through the nose into the stomach called a nasogastric tube (NG) tube. This tube is used for feeding.

If her difficulties with swallowing last for several months or swallowing difficulties are anticipated, a gastric feeding tube may be placed directly into the stomach through the skin on the abdomen (a G-tube). If necessary, your child can be fed through this tube indefinitely.

If your child's swallowing difficulties improve, the feeding tube can be removed easily and will leave a small scar.

If appropriate, it is possible to feed your child by mouth with the tube in place, and there can be a gradual return to normal eating. Your swallowing therapist and a clinical dietitian will stay in close contact with you and your child to help with this transition. If necessary, you will be taught to feed your child with both an NG tube or a G-tube.

Decisions About Complementary and Alternative Medicine (CAM)

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

Parents of children living with a brain tumour face many tough decisions. Often there are multiple treatment options that each have their own benefits and risks. Making treatment decisions can be particularly challenging when parents also consider adding CAM to their child's cancer 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 will likely hear about the research and evidence that exists for the use of conventional cancer treatments. The evidence lays out what is known about the treatment and what the expected benefits are, as well as any known 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 child's unique situation. How can you make an informed decision about including CAM in your child's treatment when there is little credible human evidence regarding the risks and benefits of CAM therapies? It can be hard to know where to begin.

Making Safe CAM Decisions

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

If you choose to use a CAM therapy or a CAM practitioner in conjunction with your child's hospital treatment plan, it is important to tell your child's oncologist and family doctor. Knowing all the therapies your child is 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 CAM therapy. Does the therapy have the potential to help your child achieve these goals? Remember that goals may be physical, emotional and/or spiritual. Be cautious of therapies that claim to "cure" the cancer.
- 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 determine what dose of the therapy is safe. More is not always better.
- Will the CAM therapy interact with other treatments or health conditions your child 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 of drug in the body. As well, many CAM therapies can interact with each other, creating unexpected results.

- Consider what logistical requirements may be involved if your child uses 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 child can afford the financial, time and energy costs of using the CAM therapy.
- What CAM support or services can you get from your local cancer agency or hospital? Many conventional cancer care centres now offer mind-body and exercise therapies. Ask to see a registered dietitian or pharmacist if you have special questions about your child's 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 acceptable risks to you and your child.

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

CAM therapies may be an important part of your child's overall experience with cancer. Make sure you have the support and information you need to make an informed decision for your child.

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

Your Child's Health Care Team

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Your Child's Health Care Team

Audiologist

Hearing loss is a possible side effect of either the brain tumour itself, or some types of chemotherapy used in treatment. An audiologist is a professional specializing in the assessment and prevention of hearing disorders and in helping those who are deaf or hard of hearing. The audiologist will monitor your child's hearing so that you and your child's medical team can be advised of any changes in his hearing status during treatment. The techniques used in the hearing assessment are painless, and a child of any age can be tested.

In cases where significant hearing loss has occurred, the audiologist will make recommendations around improving communication, and may also recommend hearing aids. Optimizing your child's hearing abilities will help him with speech development, learning, and quality-of-life by making it easier to communicate with friends and family.

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 have received special training to provide support and assistance to people facing a health crisis in a clinical setting. Community religious leaders are well-versed in their respective traditions and ceremonies.

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.

The illness of a child raises many questions and concerns in the minds of family members. There are moral and ethical challenges that may emerge during protocols and treatments. You may want to contact pastoral care services directly or with the assistance of your doctor or nurse.

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

Child Life Specialist

Child life specialists are trained to assess and understand children's reactions to stressful situations including diagnosis, hospitalization and day-to-day treatment. They offer services to help your child or teenager cope with these and other stresses.

A child life specialist will learn about your child through you and by spending time with your child, listening to what your child says and by the changes in behaviour that you and the medical team notice.

Child life specialists can help by:

- Encourage children and youth to express themselves through play and activities such as health care play, art, music and photo-journaling.
- Encourage social connections with friends and classmates.
- Ensure that play and leisure are part of your child's healing process.
- Help siblings to understand what is happening and to express their feelings about the situation.
- Help to keep your child on track physically, socially and emotionally during treatment.
- Help with challenging behaviour (e.g., refusing to take pills, temper tantrums).
- Help you to help your child during painful procedures.
- Help you understand your child's reactions and behaviour.
- Teach and prepare your child for medical procedures and surgeries to help reduce the fear of the unknown.
- Use play and activities to help your child understand and cope with his diagnosis, treatment and other health care experiences.

The goal of therapy is to keep life as normal as possible for your child during these challenging times.

Child life specialists advocate for a family-centred approach to your child's care. Most large hospitals have Child Life Services. If a child life specialist is not available, be sure to ask who is responsible for this important component of your child's care.

Clinical Dietitian

A child living with a brain tumour and the associated treatments can experience a variety of nutritional challenges. Some children have difficulty eating and may lose weight due to a loss of appetite, nausea, vomiting or dry mouth. Other children may gain too much weight and need strategies during and post-treatment to avoid the complications of obesity. A consultation with a clinical dietitian can be very helpful. These members of the allied health care team have extensive post-secondary education in nutrition and can help children and families to overcome some of the problems and live with others.

A thorough nutritional assessment involves the review of current and past treatments and medications, as well as a review of your child's weight and diet history. Following the assessment, your child and family will receive nutritional counselling in order to address the area(s) of concern. Most children's hospitals will have the services of a clinical dietitian. Ask your health care team for guidance if your child has difficulty eating or experiences weight loss.

Hospital Social Worker

Hospital social workers are members of the health care team and are professionally trained in providing individual, family and group therapy. They are trained to meet various support needs of children and families, from practical concerns to immediate and ongoing coping with the diagnosis of a brain tumour, for children, their siblings, parents and other caregivers.

The onset of illness frequently disrupts personal and family lifestyles and can bring changes that result from new or unexpected stress and the demands of treatment. Hospital social workers are available to

assist children and their families with difficulties that may arise from hospitalization or adjustment to the diagnosis, treatment and living with a brain tumour. They often work with families throughout the journey of treatment and beyond – during both in and outpatient visits to the hospital. Many are trained in crisis, adjustment, grief, loss, resource, relationship and medically related counselling.

Social workers can help by:

- Addressing sources of stress and conflict, such as relationship stress, conflict with the health care team, financial stress and parenting challenges.
- Assisting families with finances or other practical issues, such as dealing with parental / caregiver employment issues.
- Counselling your child and your family in adjusting to the diagnosis, treatment, outcome and living with a brain tumour diagnosis.
- Developing strategies for coping with and communicating about the illness, its treatment and its impact within the family.
- Linking to government support and community resources, schools, and additional support for siblings.
- Making or facilitating connections to support services in the hospital and community.
- Managing the medical experience, such as navigating the medical system, preparing for admission to hospital, or outpatient procedures.
- Support in planning hospital discharge, or meeting resource needs after discharge.

Social workers are available to assist you and your family cope with the diagnosis, treatment, impact and longer term effects of your child's brain tumour.

Your entire family may consider counselling to assist in managing the diagnosis and to prepare for living with the impact of a brain tumour, both in the short and long-term. Please do not wait until symptoms of stress appear. Any member of the health care team can assist you in contacting the social worker.

Interlink Nurse

The Pediatric Interlink Program is an Ontario-based community nursing service program of the Pediatric Oncology Group of Ontario (POGO), funded by the Ministry of Health and Long-Term Care.

The Interlink Nurse coordinates care to meet the needs of children with cancer and their families throughout the cancer journey, from diagnosis to end of therapy or bereavement. The Interlink Nurse is a member of the hospital team and works together with health care staff both in the hospital and the community through hospital visits, home visits and telephone calls.

In Ontario, ask your nurse case manager, oncologist or nurse practitioner for your local Interlink Nurse information. Other provinces may have similar health care roles – please check with your health care team.

An Interlink Nurse can help your child and family members adjust to the challenge of living with a brain tumour by:

- Arranging supports and services.
- Helping plan for your child's treatment.
- Linking your family with government or private financial supports.
- Making referrals to community organizations.
- Offering support to your child's siblings.
- Providing education and support to schools, through classroom visits, meetings with teachers, arranging home schooling, and helping your child return to school.
- Reviewing your child's diagnosis and treatment plan with family and caregivers.

Anyone can make a referral to Interlink. The program offers support to children and youth under the age of 19 years who are receiving treatment at a hospital centre in Ontario. There is no charge for Interlink services during the course of your child's illness.

Neuro-Ophthalmologist

Your child may experience visual difficulties resulting from tumour involvement in the areas of the brain that control vision. In this case, your child 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 child's records and scans from previous evaluations, and will 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 your child has difficulty moving his eyes or experiences double vision, appropriate treatment may improve or resolve the symptoms.

Neuro-Oncologist

A neuro-oncologist is an oncologist with a specific interest, training and expertise in the management of brain tumours. There are adult neuro-oncologists, pediatric neuro-oncologists and neuro-oncologists who are involved in the care of both children and adults with brain tumours.

The role of the neuro-oncologist may vary among centres. In some health care teams their role is limited to the administration of chemotherapy. However, many neuro-oncologists are part of a multidisciplinary program and are involved in all decisions regarding a child's care, such as at the time of diagnosis and before surgery: they will discuss the treatment plan and the rational for and importance of surgery.

After surgery, the neuro-oncologist is involved in reviewing the pathological diagnosis resulting from the surgery, and is involved in the discussion and decision regarding your child's post-operative management: this can

vary from follow-up to radiation and chemotherapy. During post-surgical treatment the neuro-oncologist supervises the care of your child, does follow-up assessments in the clinic, reviews the scans, and addresses all issues that can affect the daily life of your child. Most neuro-oncologists are also very involved in palliative care.

Neuropsychologist

Neuropsychology is the study of the relationships between behaviour and the brain. A neuropsychologist observes and measures different areas of functioning as they relate to the workings of the brain. These areas may include:

- Intellectual and other cognitive functions, such as attention, memory and comprehension, and how these relate to how information is processed
- Behaviour and emotions

A neuropsychologist assesses the different areas of cognitive and behavioural functioning, and determines whether the results of the assessment are consistent with your child's disease process.

Following a brain tumour diagnosis, your child may be referred for a neuropsychological assessment. The assessment will answer specific questions (e.g., is memory impaired?), and will establish a baseline of your child's functioning. The assessment will also determine the impact of future treatments on your child's cognition, and can be used to plan for a return to school following surgery or treatments.

The assessment can take several hours to complete, and you and your child's teachers will likely be asked for information about your child's daily functioning, as this information forms part of the assessment.

If your child has received or will receive radiation treatment, a neuropsychological assessment has particular importance. Radiation, although necessary to treat the tumour, can permanently affect the functioning of the brain: many children experience attention, learning and thinking difficulties following radiation treatment.

Neuropsychological assessment can help determine if or how your child might be affected. The neuropsychologist may recommend specific strategies or educational programs to help your child maximize his learning capacity, as well as make suggestions as to how you and your child can adjust to deficits or changes in cognitive or behavioural functioning. The neuropsychological assessment may also indicate that your child is eligible for special education services at school.

Periodic re-assessment will be necessary to track your child's recovery and any possible late effects of radiation.

Neurosurgeon

Neurosurgery is a branch of medicine specializing in the anatomy, function and diseases of the brain and spinal cord. A pediatric neurosurgeon specializes in the diagnosis and management of any problems related to diseases of the brain, spinal cord and peripheral nerves, in children 0 to 17 years old. In particular, a neurosurgeon will perform surgical procedures that aim to relieve the pressure of a tumour on the brain or spinal cord, while at the same time obtain tissue for diagnosis. Neurosurgeons will 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 your child through regular clinic visits and neuro-imaging studies (usually MRI scans). The doctor will review all of your child's 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 (NP)

NPs are nurses with additional education and training that enables them to work with your physician and other health care members to manage your child and family's 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 your child before and after the operation. An NP who works in oncology may do special procedures or assess how well your child is 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 child's illness or treatment. An NP can help manage your child's symptoms, arrange referral to other specialists and help to navigate or coordinate your child's care following discharge from hospital. NPs may assist with the transition to adult follow-up care once your child is over 18 years of age.

Occupational Therapist

The occupational therapist will evaluate your child's performance in activities of daily living by taking into account your child's movement, thinking and sensory abilities. The occupational therapist will help you to make the most of your child's strengths and maximize his independence through different types of activities.

Occupational therapists may help with:

- Self-care evaluation and training
- Selection and training with assistive devices and other equipment such as wheelchairs
- Swallowing difficulties and feeding skills
- Energy conservation
- Splinting of limbs, if necessary, to help maintain movement of joints
- Home evaluation and adaptation
- A return to meaningful activities in areas of self-care, school and play

If your child develops difficulties swallowing, either the speech language pathologist or the occupational therapist on your child's health care team will provide techniques to help your child swallow safely. Who on your child's team provides this function will vary from hospital to hospital.

During rehabilitation, the occupational therapist will continue to reevaluate what your child can do as his independence increases. Often the speech pathologist, physiotherapist and occupational therapist work together as a team. Upon discharge from the hospital, the occupational therapist will organize follow-up outpatient therapy for your child, if necessary.

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 children to assist in balance or eliminate double vision. The optometrist may work in partnership with the neuro-ophthalmologist.

Pediatric Endocrinologist

A pediatric endocrinologist is a sub-specialist who deals with disorders of endocrine glands including diabetes, growth and puberty problems. A pediatric endocrinologist may be involved in caring for a child with a brain tumour at diagnosis, and during and after cancer treatment, to screen for and treat hormonal problems that may arise due to the tumour or its treatment.

Pharmacist

The hospital pharmacist is an important member of your child's 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 child's health care team to provide comprehensive drug therapy management including drug selection, monitoring for side effects and drug interactions, as well as assessing outcomes of drug therapy.

Hospital pharmacists work directly with patients to identify their medication needs. They will provide you with information about your child's medications so that you are aware of the benefits and risks of each drug. Additionally, pharmacists provide discharge counseling when it is time for your child to go home, instructing you on how to administer the medications. Pharmacists also welcome any questions you may have about your child's drug therapy.

Hospital pharmacists can 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. Your child's nurse or your community pharmacist can also be a valuable resource.

Physiotherapist

A physiotherapist or physical therapist is a health professional that assesses and treats movement problems caused by disease or injury.

A physiotherapist will look at and treat your child if your child's motor function changes (e.g., the way your child moves), as a result of the tumour and/or its treatment.

In the early stages after surgery, the physiotherapist may:

- Help your child keep his joints and muscles moving
- Help with treatment to clear your child's lungs of mucous (mucous is a clear, thick liquid made by the lining of the lungs)
- Help with movements like sitting, standing, walking and climbing stairs
- Provide child and family education

In the later stages, during or after treatment, the physiotherapist may:

- Help with improving your child's strength, flexibility, coordination and balance
- Help him become as active as possible
- Arrange for community services for your child, if needed
- Provide ongoing education for all members of the family
- Assist with maximizing independent function and encouraging an active lifestyle

Radiation Therapist

Radiation therapists are specifically trained in planning and giving radiation treatment. They work closely with the radiation oncologist and physicians to design, plan, prepare and administer the radiation treatment. You will meet the radiation therapist at the first planning session. They are also responsible for the actual delivery of radiation therapy on a daily basis.

The therapists can answer many questions about radiation therapy, its side effects and how to manage them. In addition, they are a good link to other members of the health care team. In particular, they are instrumental in alerting the radiation oncologist about any concerns you may have, or if they feel that something has changed that requires immediate medical attention.

Pediatric Radiation Oncologist

The pediatric radiation oncologist is a doctor specially trained in the use of radiation therapy as treatment for your child. The radiation oncologist will collaborate with the oncology doctors in the overall management of your child's disease, and will meet with the team to discuss your child's treatment and potential use of the radiation therapy.

The radiation oncologist is responsible for prescribing the radiation, supervising treatment, and assessing your child during treatment, and will continue to see your child in follow-up and aftercare in long-term clinics.

Once it is determined that your child requires radiation therapy, an appointment will be arranged for you and your child to meet with the radiation oncologist to discuss benefits and potential side effects of the recommended treatment.

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

Pediatric Radiation Nurse or Radiation Therapist (RT) Coordinator

The pediatric radiation nurse, or RT coordinator, is responsible for the coordination of your child's radiation treatment. The RT coordinator provides daily supervision of your child's care during therapy and is available to provide you with information regarding any general concerns you may have, and to support you and your child throughout treatment. You and your child will have daily contact with your RT coordinator and you should feel free to ask her any questions you may have.

Successful Academic and Vocational Transition Initiative (SAVTI) Counsellor (Ontario)

Another member of your child or youth's health care team is the SAVTI Counsellor. Her role is to support the education and vocational goals of youth 16 and over. The SAVTI Counsellor will ensure that accommodations are provided to youth dealing with late effects in high school, college, university and/or work environments. The SAVTI Counsellor can be very helpful in your teenagers return to high school after treatment ends.

The SAVTI Counsellor is also involved in transition planning from high school to college or university and/or employment or life skills programs.

In Ontario, ask your nurse case manager, oncologist or nurse practitioner for your local SAVTI Counsellor's contact information. Other provinces may have similar health care roles – please check with your health care team.

Speech Language Pathologist (SLP)

The value and complexity of communication often becomes apparent when a child's ability to communicate changes as a result of a brain tumour. Consequently, your child may be referred to an SLP while in hospital or upon discharge.

The SLP will evaluate your child's communication functioning using a variety of informal activities, standardized tests and behavioural observations. Assessment methods are normally tailored to the needs of each child. The SLP may target any of the following areas:

- Oral motor functioning and articulation (coordination of speech muscles for talking)
- Swallowing ability
- Language comprehension and production (ability to understand or express ideas)
- Reading and writing
- Thinking skills (memory, problem solving and reasoning)
- Social interaction skills
- Voice, fluency (smooth vs. bumpy speech) and resonance (oral and nasal airflow during speech)

The SLP will provide consultation, education and strategies to help improve your child's speech and language difficulties as well as maximize his communication strengths.

Upon discharge from the hospital, the SLP will make the appropriate community referrals for ongoing intervention, if necessary.

If your child develops difficulties swallowing, either the SLP or the occupational therapist on your child's health care team will provide techniques that enable your child to swallow food safely. It is up to the individual hospital to determine who on your child's team provides this function.

Leaving the Hospital



Leaving the Hospital

Going home can be exciting and joyous for the whole family. It can also be a hectic, fearful and anxiety-filled period. Both you and your child may feel apprehensive when leaving the security of familiar doctors and nurses, even though they are only a phone call away. All of these emotions are normal responses to being discharged from the hospital.

If home care or services are needed, advance co-ordination can ease the transition from hospital to home. If there is any medical equipment your child will need, the social worker or nursing staff will make the arrangements. They will also help you navigate the system regarding referrals for the appropriate community resources and programs.

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

After your child's treatment comes to an end, your family will want to try to restore life to a "new" normal. With the understanding that there are going to be some changes both large and small, you can seek out any support you may need. It is advisable to familiarize yourself with any issues that may arise and what, if any, services are available should they be required. Your child's health care team will assist you in organizing the transition home by making appropriate referrals. Your child may have already begun a rehabilitation program before leaving the hospital.

It is often difficult to predict exactly how your child and your family will manage in your home setting. Maintaining daily routines and keeping up with the outside world as much as possible is important as it helps ease the transition for everyone.

Treating your child as if she is fragile might keep him away from situations that provide opportunities to grow and develop normally. Your encouragement and support in re-establishing normal daily routines will help. Over-protecting your child might send her a message that you think she cannot handle a normal routine, whether emotionally or physically, and this can create more distress in the long run.

Sometimes, when a family is going through such a stressful situation, parents may find it difficult to determine what information or emotional support their child needs. Trying to find the right balance between protecting children and sharing information can be particularly tricky.

Your child will continue to have ongoing assessments with the treating physicians after her release from hospital. For example, she will likely have regular CT or MRI scans, frequently at first, and then once or twice a year thereafter. Periodic blood work may also be required. Keeping a journal of your child's progress and writing down any questions that arise can be very helpful. Taking the journal to each doctor's appointment will help you remember to ask the doctor about any new or ongoing concerns you may have.

When to Contact Your Child's Physician or Specialist

Before leaving the hospital:

- It will help if you discuss, ahead of time, with your child's doctors (and write down in your journal) what signs and symptoms you might normally expect to see during your child's recovery period.
- Ask the doctor what complications may occur.
- Discuss ahead of time what constitutes an emergency and where to take your child if an emergency occurs.

When at home, if your child experiences any of the following symptoms, seek medical attention:

- A seizure
- 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 the body
- Contact with a communicable disease (e.g., chicken pox), if receiving chemotherapy
- Decreased consciousness (confusion, drowsiness)

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

Remember...

- Put aside such considerations as not wanting to bother the doctor, thinking your problem may have no urgency or waiting until morning.
- A parent's intuition is wonderfully reliable, so call the doctor if you sense that your child's condition has changed or taken a turn for the worse; some situations can be life threatening.
- Report any obvious physical or behavioural changes, even if the symptoms don't match any that have been highlighted previously by your child's medical team.
- You know your child best, so don't hesitate to call medical professionals when you need answers or notice an unexpected symptom.

Clarify in advance how you can reach your child's physician and members of her health care team during non-working hours. It may be useful to keep individual phone numbers at the back of this handbook, as well as by the telephone, for quick reference.

*Please turn to **Appendix I: Health Care Team Contact Information** on **Page 274** to list contact names and phone numbers of your child's health care team.*

Some physicians may have you call them directly, while others may ask you to call their residents (doctors in training to become specialists) or other team members who will then notify your physician. Ask each professional that you deal with what to do when you have an urgent problem and then record each suggestion for future reference.

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.

Dealing with one pharmacy is recommended, so that your family pharmacist can keep records of your child's 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 your child has 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 your child, 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 child's health and drug therapy.

Many parents have questions about their child's 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 give the drug to your child, common side effects your child 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 child's 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 child's 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.

Your Family Physician or Pediatrician

Your family's physician or your child's pediatrician plays an important role in your child's care. Maintain regular contact with this health care professional and kept up-to-date. Ask all of the specialists involved in your child's care to send a copy of each report to your family physician regarding diagnosis, treatment and prognosis. Check to make sure that these reports are being received. Good communication is necessary between all of your child's health care professionals. Anything unusual should be reported to all members of the health care team.

Your child's physician has access to many support services in the community to aid you and your family. Many of those services require a physician's signature on medical assistance forms. Your child's physician can also provide the necessary drug information and prescription renewals.

Even though specialists for the brain tumour are treating your child, your child's physician is still her primary doctor for general health care.

Treatment-Related Fatigue

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

Experiencing fatigue can keep your child from wanting to take part in normal activities and adversely affect her quality of life.

Signs that your child is experiencing fatigue include:

- Difficulty concentrating
- Exhaustion, even after a good night's sleep
- Irritability
- Tiring quickly during any physical activities

Fatigue is a common side effect in those 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 a frequently reported side effect of chemotherapy. Each child will experience a different level of fatigue.

There are several ways to help your child manage fatigue. Educating yourself and incorporating lifestyle changes will help.

Rest

Incorporate short periods of quiet rest and relaxation into your child's day, especially when she begins to feel tired. This allows the body to recuperate, decreases stress, and improves energy levels. If your child has returned to school, talk to her teacher about a quiet place she can go to when she needs to rest.

Eat Healthy

Eating nutritious foods and drinking plenty of liquids will help to increase your child's energy levels. By eating a well-balanced diet, your child's body will be able to withstand the effects of treatment, including fatigue, fighting off infections, avoid weight loss and repair cells. Eating foods that are high in carbohydrates and protein gives the body a quick boost of energy. If you are unsure about what dietary needs your child may have after treatment, talk to a dietitian at your child's hospital.

Stay Active

It is important that your child stays active on a regular basis. Research has shown that regular exercise during the treatment phase can reduce fatigue. Walking short distances several times a week may help. Make staying active a family activity and find fun things to do in your area or right in your own backyard.

Self-Image and Hair Loss

After your child has returned from the hospital and has completed treatment, self-esteem and self-image may come into play. This is especially true if any physical changes are apparent. A scar from the incision, hair loss, change in weight or a physical deficit from the tumour or treatment can be difficult for a child to cope with.

During this time it is important to support your child and help her find ways to cope with these changes. For example, if an incision scar or hair loss is worrying your child, help her find some fun hats or colourful scarves to make the scar or hair loss less visible. Wigs may also be an alternative for children with hair loss.

Immunization and Communicable Diseases

While your child is receiving treatment for her brain tumour, it is very important that she not receive any immunizations without first consulting your physician, as the immunizations can be dangerous for your child. Depending on the treatment needed, your child's immune system may be affected. Your child's body may not be protected in the usual way that makes immunizations safe for other children. Some vaccinations contain live viruses. Normally, the body reacts through the immune system to develop antibodies (protective mechanisms which help to avoid an infection if your child comes in contact with the virus again). If this system is altered by medications given to treat the brain tumour, your child is defenseless against the live virus and can become seriously ill.

Once treatment has stopped, it will take a period of time before the immune system is back to its normal fighting strength (approximately 3 to 6 months). Consequently, it is essential that you contact the physician, neurosurgeon or oncologist prior to your child receiving any vaccine.

Avoiding communicable diseases, such as chicken pox, is important while your child's immune system is affected by treatment. Communicable diseases spread readily from one child to another through direct contact. Because your child's immune system will be compromised during treatment, special precautions should be taken to ensure contact is not made. Your child may not be able to fight off the virus and may become quite ill, requiring hospitalization. Ask your health care team for further information.

Tips for avoiding communicable diseases:

- Avoid touching your eyes, nose and mouth. Germs spread this way.
- Throw the tissue in the trash after you use it.
- Try to avoid close contact with sick people.
- Wash your hands often with soap and water.

If soap and water are not available, use an alcohol-based sanitizer.

Difficulty Sleeping

Many children with brain tumours appear to have some difficulty with sleep patterns. The most common complaint seems to be that the child falls asleep easily, but awakens two to four hours later. Some children 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. It is important to know that this is natural, and in many cases it is the body's way of telling your child that she needs time to heal. 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.

Sleep is necessary for healing and should be encouraged when possible.

Children require different amounts of sleep depending on their age. Younger children require more hours of sleep each night. Monitor your child's sleeping habits. If your child is up several times throughout the night, short naps during the day may help until her sleep rhythms return to normal. Having your child go to bed at the same time each night might help train her body to recognize that it is time to sleep.

Doing relaxing activities before bed may also help to induce sleep. A cup of hot milk, reading a storybook, and talking to your child in a soft, soothing voice while tucking her into bed can all help him or her relax.

Making the Transition: Your Child's Return to School

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Making the Transition: Your Child's Return to School

School is a big part of a child's life and plays an important part in returning to a normal routine during and after brain tumour treatment. Attending school can help children feel good about themselves and hopeful for the future.

Some children with brain tumours may find it difficult to go back to school, especially if they have experienced bodily changes, such as hair loss, weight loss or gain, or changes in mobility. Also, frequent or long absences from the classroom can interrupt the learning process: a child with a brain tumour may face an additional challenge with learning, due to physical changes in the structure of his brain. To help with the transition back to school, one key thing to remember is to have information available for school staff. Your child may be the first student with a brain tumour to attend their school, and staff will appreciate any information that can help them support your child. Here are a few more suggestions to help prepare for the transition:

- Ask your clinic nurse or physician for a letter with details about your child's medical condition and any valuable information that is important for educators to know (e.g., physical problems / mobility issues, medications). Be sure to make enough copies for all the school staff involved in your child's well-being (principal, teachers and school nurses). Offer to meet with your child's school team to answer any questions they may have.

- If your child has had a neuropsychological assessment, consider giving a copy to his educators. A neuropsychological evaluation measures cognitive (memory, learning, attention, language), motor and social skills. Once a child's educational needs have been identified, educators can create a plan, known as an Individualized Educational Plan (IEP), to ensure these needs are met. The IEP highlights specific teaching and environmental adaptations and strategies that use your child's strengths and support his weaknesses. For example, some children with brain tumours struggle to concentrate with the noises that are part of a classroom, and they may need extra support. Having your child sit at the front of the classroom may be beneficial.
- Once your child has returned to school, keep in touch with his teacher to monitor his school performance and social well-being. Some children may be more emotional than before their diagnosis, while others may become more quiet and withdrawn.
- Before your child returns to class, encourage teachers and your child's classmates to discuss ways to support your child upon his return. Children who feel they have more support from classmates are less likely to feel sad or worried.

Your child's classmates can also benefit from any relevant information. An information session can teach them about brain tumours and help create a supportive environment. During sessions like this, classmates can learn about your child's condition and ask any questions. Some hospitals have a school liaison nurse or social worker who can come and meet with school staff and classmates.

Together, parents, educators and classmates can help your child find his place back to his second home: his school.

Potential Long-Term and Late Side Effects



Potential Long-Term and Late Side Effects

Children and young adults who survive a brain tumour and are now carrying on with their lives may have side effects that remain with them over the long-term. Or they may develop late side effects that manifest weeks, months or years after treatment. As your child begins to move on, you may find that some side effects persist. Helping your child learn how to live with these changes will be essential to his quality of life and independence.

*Research shows that brain fitness helps with cognitive difficulties such as memory and retention. For more information on **Brain Fitness**, visit www.BrainTumour.ca/brainfitness.*

Cognitive Difficulties

Some children experience varying levels of change in their cognitive abilities after brain tumour treatment. Common changes include having difficulty with memory, retention, attention and concentration, and processing speed for new information. Other abilities that might be impacted include organization, math skills, and reading and comprehension. Children who survive a brain tumour often have some level of difficulty at school due to these changes in cognition, and may require more time, patience and support.

Depending on the tumour type, size and location, as well as the treatment, these cognitive changes will be unique in each child. Children who underwent high doses of cranial radiation to the whole brain at a young age (e.g., six years or less) are at particularly high risk for cognitive changes.

If your child's cognitive functions are affected, a neuropsychologist can perform a neuropsychological assessment to provide an in-depth understanding of your child's cognitive function.

A neuropsychological assessment should be done for all children after treatment.

Recommendations can then be made that are tailored to your child's needs. Neuropsychological assessment results are important for your child's teachers and, in some cases, an Individualized Education Plan (IEP) will be developed to ensure that your child has the help and support at school she needs to cope. A baseline assessment (before treatment) is not always done, but in some cases it may be helpful. Ask for a copy of the neuropsychological report as it will outline your child's strengths and weaknesses. One advantage of follow-up care is that as your child reaches adulthood, a neuropsychological test can be administered again if the last one is outdated and your child's abilities have changed. The results of this assessment will allow you and your family to better plan for the future.

Education

Your child's education can be affected if she experiences changes in her cognitive abilities. Some young adults who do not get the help they need may struggle and drop out of high school, while others may complete high school but have difficulty in a university or college setting.

Financial and Employment Issues

Investigating how your child can live independently as she gets older should be done early on to determine what support systems are available in your community. Some children who survive brain tumours have issues with separating from parents, or difficulties with living arrangements at an age when other children are becoming more independent.

*For more information on **Financial Resources**, visit www.BrainTumour.ca/finances.*

In some cases, when children have finished school, they are no longer eligible for health benefits under their parents' health benefits plan. If this is the case, other financial resources need to be investigated early on to ensure that resources are available to fall back on when parental benefits run out.

Employment may also present some issues survivors whose cognitive abilities have been affected. Often, entry-level jobs, such as working in a fast-food restaurant or a retail store, may not be appropriate as they can be fast-paced environments. These young adults may not succeed because it is not the right environment for them. A neuropsychological assessment will examine your child's strengths and weaknesses, and by determining these far enough in advance, career planning can be done to make sure that the right job and environment are found to help your child succeed in her employment.

Social and Behavioural Skills

Following treatment, some children may have an altered way of thinking, or their behaviour may be different. Some may demonstrate very low focus and motivation, while others may become intensely focused and feel most comfortable with structure. This may also be true for relationships with peers in that some children may become isolated and have a difficult time developing peer groups. On the other hand, others may develop intense attachments in their relationships, which their peers may find difficult to understand.

Neuropsychological assessment can determine in which areas your child is lacking the necessary skills and a neuropsychologist can work with your child to find strategies that may help her overcome these barriers.

If the tumour was located in the area of the brain that plays a role in understanding social situations, your child may come across as socially awkward. The ability to read non-verbal cues from other people may be affected. Changes in speech, language abilities and emotional control may also affect a child's social interactions.

It is very common for children with serious medical conditions and long hospitalizations to become more comfortable interacting with adults rather than other children of their own age. They often require encouragement and coaching to gain skills in interacting with same-aged peers. Some brain tumour survivors who have lasting changes in physical function and

mobility may have difficulties keeping up physically with classmates (e.g., running around) due to fatigue, balance or gross motor difficulties, and will need to develop other means of interacting with their peers.

Physical Side Effects

There are different physical side effects that may occur as a result of the tumour or its treatment including endocrine problems, growth delays and kidney damage. Sexual development and fertility may be impacted as well.

Hormone deficiencies can occur when the endocrine system is compromised from a tumour or its treatment – especially radiation therapy. If the pituitary gland and/or the hypothalamus are affected, it may cause either an overproduction or underproduction of certain hormones. Growth hormone is commonly affected and when an inadequate amount is produced it causes a slowing of growth and an inability to reach full height potential. If a deficiency of growth hormone is detected in your child, she can undergo hormone replacement which involves giving synthetic growth hormone by injection.

Radiation therapy given to the spine can also impact growth in children, as the radiation can directly affect the growing bones of the spine. If your child had a tumour in the spine, there may be a possibility that she may not grow as tall as originally expected.

Additionally, there are several chemotherapy drugs that may affect the kidneys. Usually, the effects are not severe. Problems are typically detected by a blood or urine test. A specialized diet may be suggested or a referral to a nephrologist.

Sexual development and fertility are topics that may be uncomfortable for parents to discuss openly with their kids or may not think to discuss. Puberty may occur early or late in children as a result of treatment. When puberty starts earlier than usual, it is referred to as precocious puberty. This means that sexual development (e.g., body hair, breast development, menstruation, enlargement of scrotum) begins at an unusually early age. Fertility should be discussed with young adults as some brain tumour

treatments can have an impact. Any potential effects of treatment on your child's fertility and sexual health should be discussed with the medical team in advance.

*For more information, please visit the **Fertility** section on **Page 74**.*

Changes in Appearance

Some children who are brain tumour survivors have scars, areas where their hair does not fully grow back following radiation treatment, or have experienced significant weight gain (hypothalamic tumours). For these children, there are visible signs of their brain tumour and its treatment that they must adjust to and may have to explain to others. As they enter their teenage years, they may become particularly aware of these changes in appearance and struggle to accept their medical condition as they form their self-concept and identity.

Transition Into Adulthood

As your child gets older, it is important to ask her pediatric team what to expect when she turns 18. As your child becomes an adult, care will need to be moved into an adult medical setting. Doctors may still want to monitor your child for relapses of the brain tumour, potential secondary cancers, follow up MRI or CT scans, endocrine issues or other medical issues. Your child may also continue to require academic support, and social supports to develop skills to move into the workplace. The pediatric oncology team can help you and your young adult navigate the system when the time comes for this change.

As your child and family begin to reclaim your lives, long-term effects from the tumour and treatment may continue. Determining in advance what these side effects may be will allow you to incorporate the necessary changes into your family's life, so you may successfully manage and promote your child's transition into adulthood.

Sexuality and Teen Survivors of Brain Tumours

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Sexuality and Teen Survivors of Brain Tumours

Sexuality in teens who have survived a brain tumour is an important topic for several reasons. First, sexuality changes are common after brain tumours, because of the tumour itself or because of the treatment, which can affect sexual development and functioning.

Second, sexuality is a topic that is often not addressed in people with brain tumours, and an area that may be uncomfortable for parents and teens to openly discuss with one another and with professionals – parents may not view this as a priority given the array of medical issues that they have to manage.

As your child's medical issues stabilize, the focus on transitioning back into the home, school and community becomes important. Given increased survival rates for children with brain tumours, it becomes essential to address their long-term psychosocial adjustment, which involves:

- Developing healthy romantic and sexual relationships
- Ensuring sexual safety
- Feelings of attraction
- Fertility and reproduction
- Focus on appearance
- Friendships and dating
- Increased awareness of sexual orientation
- Interest in opposite sex
- Physical, psychological and social changes with puberty
- Questions about sex

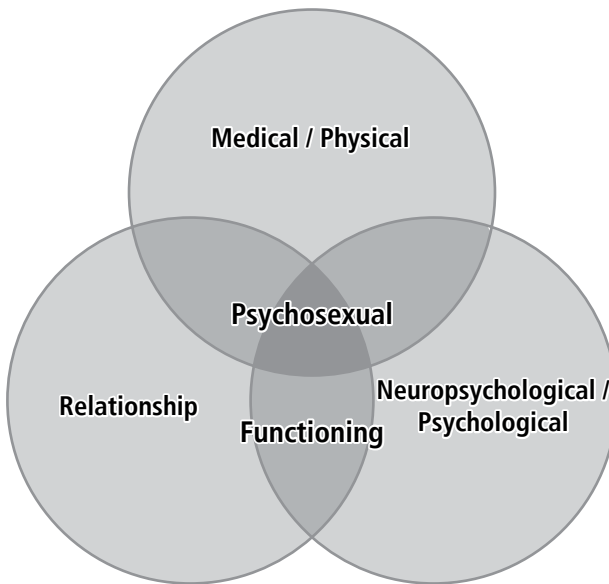
Research on psychosexual outcomes in survivors of childhood cancer shows:

- Adult survivors of childhood cancer have less experience with sexual intercourse and are less satisfied with their sexual lives.
- They are often older than their peers when they get their first boyfriend or girlfriend.

- They are often older than their peers when they achieve sexual intimacy.
- They have fewer friends.
- There is a reduced likelihood of getting married.
- There may be delays in achieving psychosexual milestones (e.g., dating, masturbation).
- They may not feel sexually attractive towards others.
- They may feel less sexual attraction towards others.

Factors That Affect Psychosexual Functioning

Healthy psychosexual functioning involves an interaction between three areas: medical / physical issues, neuropsychological and psychological changes, and relationship factors. Each of these areas is addressed below.



Medical / Physical Issues

Depending on where your child's tumour was or is located, and the brain structures involved, there can be hormonal changes and negative effects on sexual functioning. This may include:

- Altered sensations – hypersensitivity or hyposensitivity
- Changes in erectile functioning
- Changes in gross or fine motor functioning
- Difficulties in achieving orgasm
- Difficulties with arousal
- Fatigue and sleep issues
- Fertility issues
- Lack of interest in sex
- Pain
- Reduced stamina and endurance
- Seizures

Additionally, there can be effects of treatment, such as the impact of radiation and chemotherapy on sexual development, which can include:

- Decreased libido, erectile difficulties, vaginal dryness
- Delayed puberty (delayed onset of development of sexual characteristics), delayed menstruation, lack of pubic hair
- Fatigue
- Fertility issues
- Hair loss
- Precocious puberty (puberty starts earlier than usual): body hair, breast development, early menstruation, enlargement of scrotum
- Reduced endurance

Medication Side Effects

Many medications (e.g., anticonvulsants, selective serotonin reuptake inhibitors (SSRIs), stimulants) have sexual side effects, such as decreased libido, arousal problems, erectile and ejaculatory problems, and difficulties with orgasm. It will be important to discuss any concerns you may have regarding potential side effects with your child's health care team or doctor.

Some medications may also reduce the effectiveness of hormonal birth control methods so it is important to discuss this with your child's doctor or health care provider. Additionally, steroids are often associated with increased appetite and weight gain and unequal distribution of body fat, all of which can affect your child's body image.

Neuropsychological / Psychological Factors

If your child's tumour affects the frontal lobes of the brain, there may be social and behavioural issues which can impact the development of peer or romantic relationships. These might include:

- Alterations in social judgment, social awareness, and ability to respond to social cues
- Apathy or initiation difficulties
- Behavioural disinhibition
- Changes in memory, attention and concentration, which can impact on social conversations
- Difficulties with irritability or emotional control
- Difficulties with social boundaries
- Personality changes
- Poor impulse control

There are also psychosocial adjustments which can impact your child's social relationships. These involve:

- Anxiety issues
- Body image: hair loss, scars, change in weight, physical changes, shortened stature

- Depression and mood changes
- Peer acceptance
- Reduced confidence
- Self esteem

Factors that can affect your child's ability to develop or maintain healthy relationships include:

- Concerns around how to explain the diagnosis to others
- Concerns around relapse
- Fertility issues
- Fewer opportunities to develop normal peer relations
- Increased vulnerability due to social and neurocognitive challenges
- Lack of knowledge around the impact of brain tumours and treatments on sexual development and function
- Less developed social and relationship skills
- Limited life and sexual experience

How Parents and Professionals Can Help

Provide opportunities for discussion, maintain open lines of communication and a non-judgmental viewpoint, so that your teen will feel comfortable raising whatever concerns or questions she may have.

In helping your child or teenager in her journey to good health and sexuality it is important not to assume that she understands what normal sexuality is, or about healthy boundaries and relationships. Things you can do to help your child include:

- Being proactive – providing information and education about puberty, effects of brain tumours and treatments on sexual development, maintaining safety with respect to sexually transmitted infections (STIs), cyber safety, age of consent and legal issues.

- Providing opportunities for social interaction and practicing of social skills.
- Fostering relationship skills (e.g., meeting people, starting conversations, learning empathy, choosing friends, handling rejection).
- Teaching safety skills and the difference between healthy versus unhealthy relationships, so your child can avoid exploitive relationships.
- Providing opportunities to build social competence: listening, assertiveness, being positive, showing interest, giving compliments, offering opinions.
- Remembering that the ultimate goal is to optimize your child's quality of life now and for the future.

Pediatric Palliative Care

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Pediatric Palliative Care

Children with high-risk or progressive brain tumours often benefit by receiving concurrent cancer-directed treatments and palliative care services. The aim of palliative care is to promote well-being and optimize quality of life during this journey with serious illness. The aims are not limited to only the disease process, but also to improving quality of life, maintaining dignity, and attending to the suffering of seriously ill or dying children in ways that are appropriate to their upbringing, culture and community.

Palliative care promotes interdisciplinary care and collaboration focused on addressing the family's medical and psycho-emotional needs, in order to provide the highest quality of care. This care can help you in:

- Addressing grief and bereavement issues.
- Addressing social, emotional and spiritual needs.
- Attending to suffering from physical or psychological symptoms,
- Being a point of continuity no matter where your child is receiving care.
- Making difficult decisions and in planning care.
- Optimizing communication and coordination of services.
- Providing the highest quality hospice and end-of-life care.

Integrating palliative care into your overall care plan helps establish a therapeutic alliance between the primary care team, your child and your family, in order to provide the best possible treatment for your child while optimizing comfort and quality of life.

Communicating Your Needs and Perspectives

Communication with your child's physician and other members of the team is very important. Tell your medical care team as much about your child and family as possible. Do not hesitate to bring your child's and family's needs to the attention of your care team – they cannot address your needs if they do not know what your concerns are or what is most important to you.

The better the team knows you and your child, the better able you and your team are to make an individualized plan of care.

You may not automatically know what information is important to share and this is okay. It will be helpful for the team to be able to gauge your level of understanding of the prognosis, goals and treatment options as treatment begins and at other key points in time, if the illness progresses. It will also be very helpful, for example, to hear about who your child is, how your family is doing, and what the brain tumour experience has been like for each of you.

The diagnosis of a brain tumour is overwhelming for all families. The way you look at the tumour and its impact on your child and family is likely to change as time goes by and as symptoms resolve or progress.

The chart below is designed to help you communicate with your child's health care team at key points during that journey, such as:

- At the beginning of treatment.
- At the end of radiation therapy.
- Immediately following diagnosis.
- Upon returning for the first MRI scan following radiation.

Other times to consider these questions might be:

- If your child's condition is deteriorating.
- The symptoms are continuing to progress or worsen.
- Upon confirmation on imaging that the tumour has progressed.
- When symptoms seem to be returning.

Your family’s level of understanding is likely to shift during any and all of these events, and your goals of care for your child and family may change as well. The medical team will not be aware of these changes unless you help them understand your evolving thoughts and goals. Be sure to inform the care team if any changes occur when you reconsider these questions.

Category	Questions to consider
Understanding your perspective	What does good quality of life mean for you and your child? 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 most concerned about? What is your definition of being a good parent to your child?
Information and decision-making	What information do you or your child need right now? How do you like information to be delivered / handled? How much does your child want to participate in decision making and conversations about his diagnosis, prognosis and treatment?
Symptoms	What are your child’s most concerning or distressing symptoms that interfere with good quality of life? Are you fearful about your child experiencing any specific symptoms?

Spiritual	Are you or your child experiencing spiritual distress? Is this illness impacting your spiritual or religious beliefs? Are you searching for meaning in your current circumstances?
Emotional	Do you feel abandoned or angry? Is anyone in your family experiencing emotional distress that is interfering with good quality of life?
Social	Are there any family needs that, if left unaddressed, could lead to increased distress? Are there any sibling needs that are currently not being addressed? Are there family or friends that are impacted by your child's illness who you feel require resources, information or support? Is your child's school, your community or other groups providing you with support? Do they require any resources?
Chance for treatment success (Prognosis)	What is your family's understanding of your child's chance for recovery and for overall life expectancy?
Goals	What are your goals for treatment? What other goals do you have for your family and your child?
Treatment options	What is your understanding of the availability of cancer-directed treatment options? Are there treatment options aimed at enhancing your child's quality of life?

Establishing Goals of Care and Making Difficult Decisions

Most families start with the hope of attaining a cure for their child. Your hopes may change as the possibility of a cure becomes less likely. While maintaining hope for the best possible outcome, it is helpful to reflect on all potential outcomes, including the possibility that the tumour will continue to grow in size despite everyone's best efforts. Parents often wonder how they can possibly prepare for such an overwhelming and difficult situation. One approach is to develop a care plan that considers possible outcomes, and the approach in care that you and your child would desire.

Having hope is very important: it sustains your child and your family and caregivers during very difficult times.

In these difficult situations, parents start to think about what is most important for the child and family. Based on what is happening with the tumour, its treatment and the child's experience, families are able to think about what their most important goals are in the care of their child. Some families may also have important life goals that they would like to accomplish with their child. These goals are critical and should be taken as seriously by the health care team as evaluating blood levels or assessing for side effects of medications. Every attempt should be made to integrate these goals into the overall plan of care for a child with a brain tumour as a way to balance medical interventions with comfort and the best possible quality of life.

If or when the tumour begins to grow, despite the treatment, you may realize with greater certainty that the tumour is incurable. During this time it is appropriate to continue to hope for the best possible outcome. If you come to recognize that your child has a disease that cannot be cured, it is also critical to work on determining the goals you would like to achieve for your child and your family. You may want to think about what is most important to you and your family, and how you would like to spend the remaining time you have with your child. You will once again face many difficult decisions.

It may be easier for you to make decisions at this time if you think about whether or not the possible treatment choices presented to you will help you achieve the goals you have identified for your child and family. Parents report that the most difficult decisions they have to make for their child happen at this stage, decisions such as whether or not to stop fighting the tumour and stop cancer treatment or enrol their child in a clinical trial.

Parents may also choose not to pursue certain treatments that will not achieve their primary goals of care. An example of this would be a family that chooses to pursue a comfort focus in the treatment of breathing problems, deciding that an admission to an intensive care unit or being placed on a breathing machine would not be something that achieves their goals. Other important decisions to consider include:

- Whether or not to enrol your child in hospice.
- Whether or not to speak to your child about the fact that the disease is worsening or that he may be dying.
- Choosing a location in which your child would like to die.
- Whether an autopsy should be performed.

Other goals to consider at this stage may include whether or not your child should continue to go to school or take a holiday.

While these are some of the most difficult decisions your family will ever have to make, the specific goals of care you and your family have made for your child and yourselves will help minimize distress and ensure your child's comfort. Your health care team can help guide your family as you make these decisions. The key to establishing goals of care remains open communication between your child, yourself and the primary health care team. Some examples of goals of care include:

- Curing the disease
- Prolonging life with the best quality of life possible
- Providing comfort
- Maintaining or improving your child's ability to perform activities of daily living
- Attaining specific life goals (e.g., going to graduation, camp, wish trip)

- Support for family and loved ones
- Advancing medical knowledge (helping contribute to a cure)
- “Knowing we did all we could” (that we did not give up)
- “Being the best parent that I can be” (making the best decisions for my child)

These goals are not necessarily mutually exclusive. Many 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. When making these decisions, think to 10 years down the road and how you will feel about the choices that they are making today. The aim is to feel that there will be no future regrets about these trying decisions.

Some Things to Consider When Making Difficult Decisions

Every decision and situation is unique. However, some things that parents think about include:

- What does my child want?
- What are health care team members recommending?
- What am I feeling? What does it mean to parent my child who is ill?
- What are our beliefs as a family? How are these beliefs impacting our decisions?
- How will these decisions affect our family? Do I want to involve our family in making these decisions?

When children are involved in end-of-life decision-making, some reasons they provide for making the choices they make include:

- Wanting to avoid treatment that will make them feel worse, cause pain or other symptoms.
- The desire to achieve specific life goals (e.g., going to graduation, prom, camp, on a trip).
- Pursuing comfort when cure is no longer an option.

- Wanting specific, care-directed goals, which include not continuing therapy.
- Seeing how other children around them have approached decisions and end-of-life issues.
- Not wanting to give up, and therefore pursuing any treatment options provided to them.
- Pursuing experimental treatments in order to help other children who may be diagnosed with their illness.
- Evaluating and taking into consideration the desires of their family.

Who Can Help Make Difficult Decisions?

Your primary health care team is generally looked to for the most support. Many families also ask for help from other staff, family, friends, and spiritual leaders. Other families who you have come to know through the brain tumour journey may have helpful insights as well.

It is important to recognize that these decisions are understandably very difficult, and because they are so trying, it is important to recognize when you need help in making decisions. You may require assistance in obtaining information or communicating with others who have more experience in this process. Any time you recognize that you need help in making these decisions, ask your health care team for assistance.

Recalling your specific goals of care will be helpful in directing these decisions. Once you have identified those goals, share them with your team regularly so they can maintain your goals as they suggest a course of action for your child.

Ongoing communication is key in every aspect of the palliative care process.

Depending on your child's age and situation, it may be appropriate to discuss your decisions with your child. They may bring insight and revelation that the team can draw on in making decisions. If you have doubts about whether or not to discuss these decisions with your child, ask for help in determining if it would be appropriate or beneficial.

Where Should Your Child Receive the Remainder of His Care?

Discuss the location of care that you feel is best for your child, and be aware of the necessary support that you will require in that setting. Your child will continue to receive care to address any pain and other symptoms. Choosing to continue to receive cancer-directed therapies on a study may limit your location options, such as your ability to return home. This must be considered in the context of overall goals of care.

If being at home is important to your child and family, advance planning and coordination of resources are important. Every effort will be made to facilitate coordination of your child's and family's goals of care throughout the treatment course.

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

Your child's and family's desired location of care may change based on disease status, symptom control and your family's comfort level in providing care. Home care is often chosen by families as they feel that their children are most comfortable in their own home. If this is the best option for your family, you will need to ensure you have the appropriate medical equipment and medications for your child. Discuss what support you can receive in your home, if this is the option for you. For those families that feel home care is not the best option, other locations of care may include hospitals, a hospice or a long-term care facility.

What Is a “Do Not Attempt Resuscitation” Order

A “Do Not Attempt Resuscitation” (DNAR) order is a request to allow a natural death for your child rather than performing cardiopulmonary resuscitation (CPR) if your child's heart or breathing stops.

You and your child's primary health team will consider putting a DNAR in place according to the goals of care for your child. It is best to make this decision when the goals of care are transitioning, rather than during a time of crisis. If you decide a DNAR is appropriate for your child, the order is put

in his medical record by your primary medical team. A DNAR order is most appropriate when medicines or procedures to restart your child's heart or breathing (aggressive resuscitative measures) are unlikely to benefit him, and when such measures may actually be harmful. This is usually the case when your child's physical decline is due to the growth of the tumour.

As children go home to receive care, many will have an out-of-hospital DNAR in place. It is best to plan for these events in advance. Unless a DNAR is in place, emergency medical staff will attempt to resuscitate all children whose heart or breathing has stopped.

How Much Should You Involve Your Child in Discussion About His Care?

Every situation is different and the level of understanding for children varies greatly. Research and experience of families point toward early disclosure as being most helpful. You know your child best and over the course of your child's illness you will have learned how much he wants to know and how he handles information.

Children 10 years of age, or even younger in some cases, understand complex situations and can help in making difficult end-of-life decisions. Some families regret not speaking to their child about these issues, especially if they feel their child knows or wants to discuss things further. Studies have shown that parents who have discussed death and dying with their child do not report any regrets about doing so. On the other hand, some parents who did not discuss these issues with their children report wishing they had. If you desire some guidance around these discussions, your health care team can be a valuable resource.

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

Grief and Bereavement

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Grief and Bereavement

The death of a child seems so unimaginable and unfair. This is a reality that some families eventually face. When a child is lost after the diagnosis of a brain tumour, families may feel intense emotional pain, loneliness and a loss of purpose.

Grieving after the loss of a child is a natural part of the healing process. The feelings of disbelief, sorrow, anger and guilt that can be part of this grief are often overwhelming, and recovery – coming to terms with your loss – can take time.

The way an individual grieves will depend on their relationship with the person who has passed away, their personality, 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 to grieve will also be unique. As a parent, your grieving process will be very different from that of a remaining sibling. Siblings may be faced with emotions that are difficult for them to talk about and express to their parents.

Grief and bereavement support will be helpful during this time of sadness and exists in many centres across Canada. Family bereavement support groups are available through many hospitals and cancer care facilities, and can be accessed through the social work department, pastoral care department or your family physician. Individual bereavement counselling is also available. You can also contact your local hospice for bereavement support.

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

Appendices

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 of 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

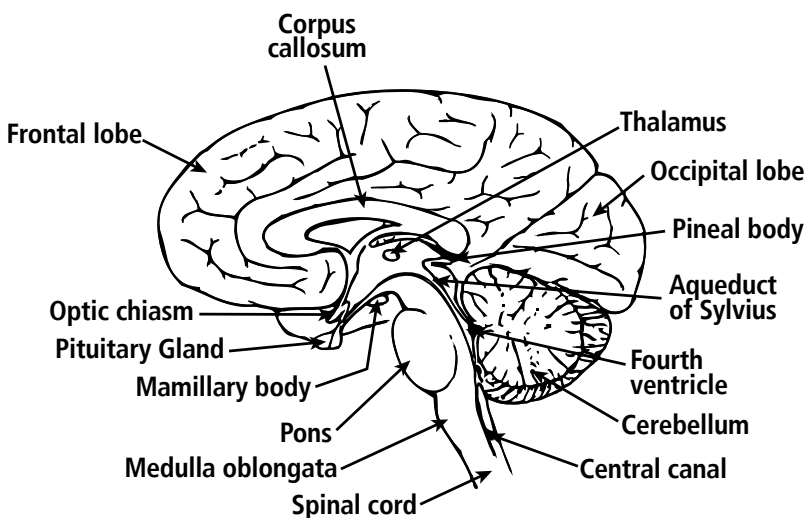
The term cerebrum is often used to describe the entire brain. It forms the bulk of the brain and is divided into two major parts: the right and left cerebral hemispheres. Generally speaking, the left side of the brain controls the right side of the body and the right side of the brain controls the left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

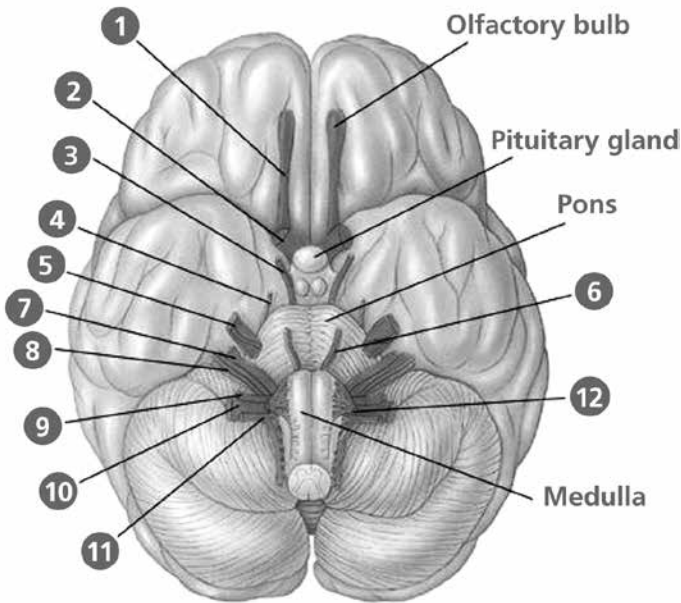
The corpus callosum connects the two halves of the brain and delivers messages between them.

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).

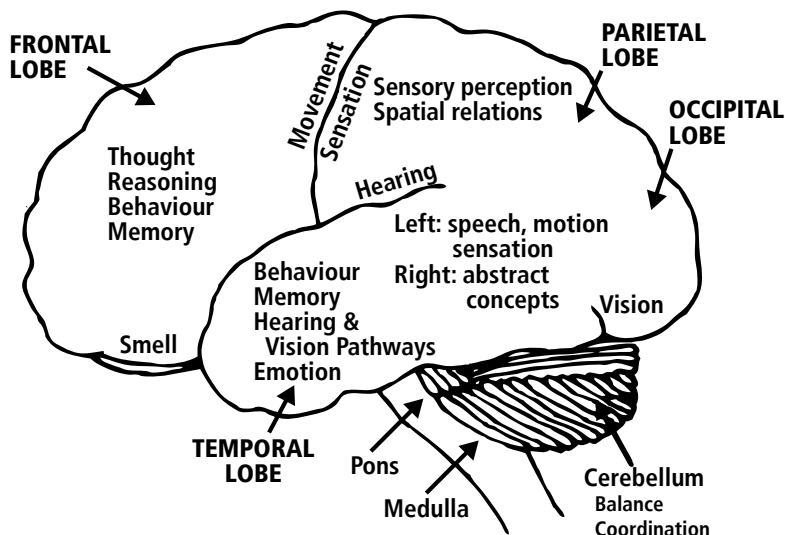
Lobes of the Brain

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*

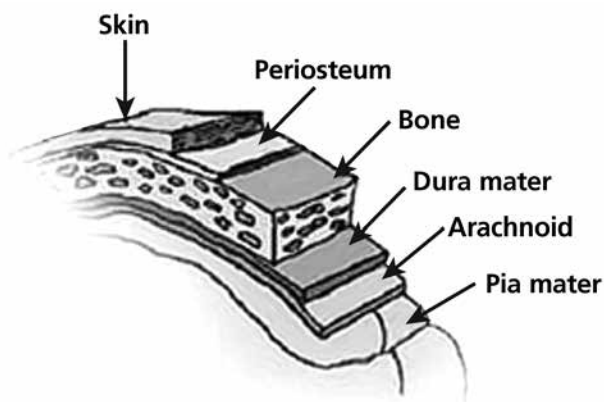
Medulla Oblongata

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.

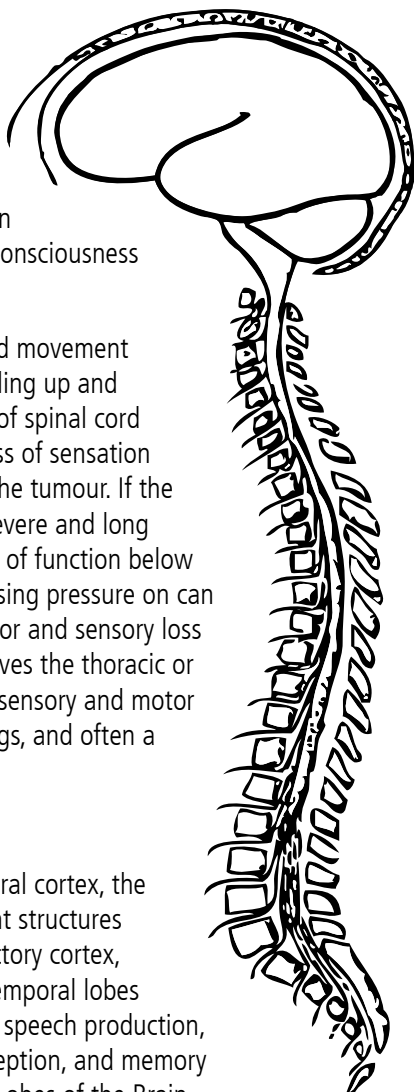
Bladder functions, sensory functions and movement are all dependent on information travelling up and down the spinal cord. Any interruption of spinal cord function by a tumour may result in a loss of sensation and motor function below the level of the tumour. If the pressure on the normal spinal cord 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

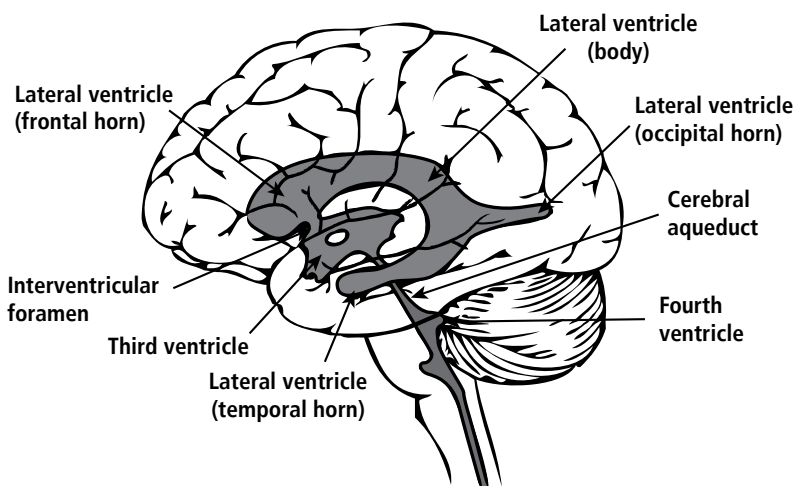
The thalamus serves as a relay station for almost all information that comes and goes to the cortex. It plays a role in pain sensation, attention and alertness. It surrounds the third ventricle.



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 your child is feeling the effects of “chemo brain” or experiencing difficulties with concentration and recall due to a benign brain tumour, there are some brain fitness tips that may help her in coping with memory or cognitive changes.

Brain Fitness Tips

- Encourage your child to play 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 your child on track, make lists or use a chart board / wipe board in your kitchen or in his bedroom to develop a system of reminders.
- “Neurobics”: Encourage your child to use his brain in non-routine ways. For example, if he is right-handed, try brushing his teeth with his left hand every morning.
- Understand what influences memory problems: Schedule difficult tasks when your child feels her 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 child’s program.

Here are some examples of brain fitness activities that you and your child can work on together.

Word Search:

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

BRAIN

MEDICATION

TESTS

BRAINWAVE

NURSE

TREATMENT

DOCTOR

RADIATION

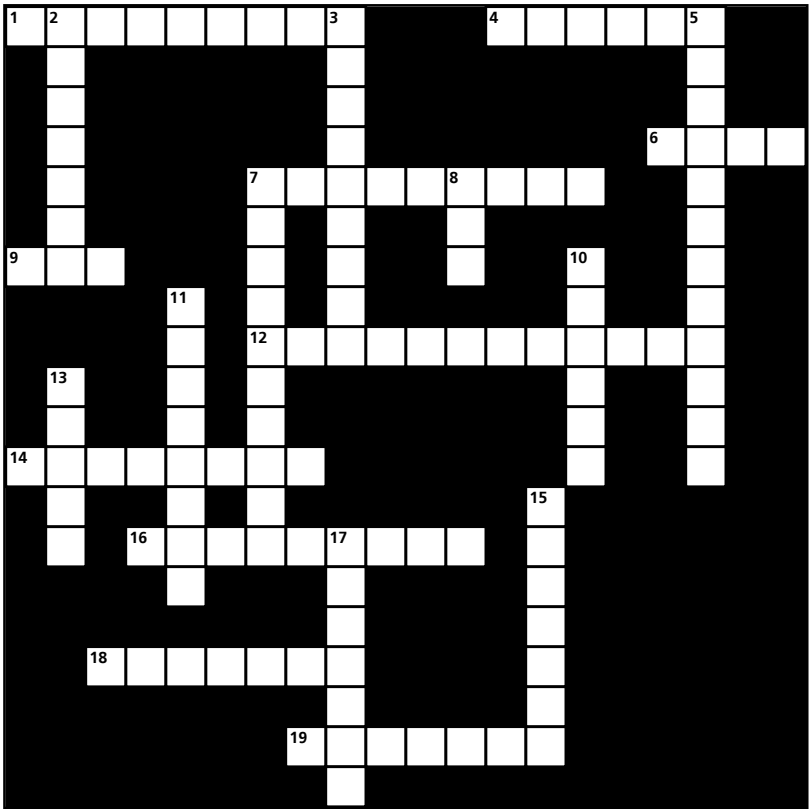
TUMOUR

HOPE

SURGERY

VOLUNTEER

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 310** of the handbook for the answers to the crossword puzzle.*

Appendix C: Pediatric Brain Tumour Types

This section provides the names of many different types of pediatric brain tumours. General information about these tumours is provided to help you in learning more about your child's 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

High grade astrocytic tumours are less common in children. They can occur anywhere in the brain.

Anaplastic ependymoma

WHO Grade III

See Ependymoma

Atypical teratoid / Rhabdoid tumour (ATRT)

WHO Grade IV

ATRT is a very aggressive tumour seen in infants and young children. The tumour is characterized through a mutation of the tumour suppressor gene INI1, so germline testing for patients and parents is warranted.

Central neurocytoma

WHO Grade II

Very rare tumour in children.

Choriocarcinoma

See Germ cell tumours.

Choroid plexus carcinoma

WHO Grade III

This tumour affects the choroid plexus tissue (the tissue responsible for the production of cerebrospinal fluid or CSF). This tumour is key for a pre-cancer syndrome and genetic testing is warranted. Ten per cent of choroid plexus tumours are choroid plexus carcinomas, which are malignant. This tumour occurs most often in children.

Choroid plexus papilloma

WHO Grade I

This tumour affects the choroid plexus tissue (the tissue responsible for the production of cerebrospinal fluid or CSF). About 90% of choroid plexus tumours are papillomas, which are slow-growing and non-malignant.

CNS primitive neuroectodermal tumour (PNET)

WHO Grade IV

PNET are less frequent, but highly aggressive tumours located anywhere in the CNS besides the posterior fossa.

Craniopharyngioma

WHO Grade I

A tumour that usually develops near the pituitary gland (a small endocrine gland at the base of the brain). Craniopharyngiomas are intracranial tumours that consist of a cystic and solid component. Craniopharyngiomas are often not discovered until they press on important structures around them.

Diffuse astrocytoma

WHO Grade II

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

Dysembryoblastic neuroepithelial tumour (DNT or DNET)

WHO Grade I

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

Embryonal carcinoma

See Germ cell tumours.

Ependymoma

WHO Grade I (Myxopapillary ependymoma)

WHO Grade II (Ependymoma)

WHO Grade III (Anaplastic ependymoma)

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

Ganglioglioma

WHO Grade I

This is a rare tumour type which can be localized throughout 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 region of the brain. They present in adolescents. Incidence rates are much higher in Asia compared to North America and Europe. GCTs can show leptomeningeal spread. Tumour markers (alpha 1-fetoprotein AFP and human chorionic gonadotropin HCG) should be obtained in the serum as well as in the cerebrospinal fluid and if significantly positive, no histological confirmation is needed. The majority of intracranial GCTs are pure germinomas.

Germinoma

See Germ cell tumours

Glioblastoma multiforme (GBM)

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.

Gliomatosis cerebri (GC)

WHO Grade III

GC is defined as a high-grade astrocytic tumour which infiltrates more than one part of the brain.

Juvenile pilocytic astrocytoma (JPA)

WHO Grade I

JPA is the most common pathological subtype of a low grade glioma characterized through Rosenthal fibers. The most common locations are the posterior fossa and the optic pathway.

Medulloblastoma (MB)

WHO Grade IV

MB is the most common high grade central nervous system (CNS) tumour in children. The primary tumour location is in the posterior fossa / cerebellum but metastases within the CNS at the time of diagnosis are quite common (around 30%). MB can also metastasize outside the CNS, within the bone marrow or bones.

Mixed germ cell tumour

See Germ cell tumours

Myxopapillary ependymoma

See Ependymoma tumours

Pilomyxoid astrocytoma (PMA)

WHO Grade II

PMA is often found in the hypothalamic / chiasmatic region and affects infants and young children predominantly.

Pineoblastoma

WHO Grade IV

Pineoblastoma is a central nervous system Primitive neuroectodermal tumour (PNETs) localized in the pineal region.

Pleomorphic xanthoastrocytoma (PXA)

WHO Grade II

PXA are rare and occur in older children.

Subependymal giant cell astrocytoma (SEGA)

WHO Grade I

SEGA is the main tumour type in children with underlying tuberous sclerosis.

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 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 oligodendroglioma			*	
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 neurocytoma		*		
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 Syndromes

The following are examples of multi-system genetic disorders:

Tuberous Sclerosis Complex (TSC)

Tuberous Sclerosis can cause tumours in all organs of the body. TSC can cause tumours in all organs of the body. In some cases, it can cause neurological damage resulting in severe seizures, developmental delays and autism. Subependymal giant cell astrocytoma (SEGA) is the brain tumour type typically associated with TSC. Subependymal Giant Cell Astrocytoma (SEGA) is the brain tumour type typically associated with Tuberous Sclerosis.

Neurofibromatosis Type 1

This autosomal dominant disorder is passed from one generation to the next in 50% of cases, however in the other 50% it is a spontaneous new mutation. Classical skin changes include cafe-au-lait spots, freckling and cutaneous neurofibromas. Learning disabilities and attention deficit hyperactivity disorder occur frequently in affected individuals. Many types of brain tumours are associated with neurofibromatosis, with the most common being optic pathway tumours and focal areas of signal intensity (FASL).

Neurofibromatosis Type 2

This autosomal dominant disorder is passed from one generation in roughly 50% of patients and is a spontaneous new mutation in the other 50% of cases. Neurofibromatosis Type 2 is usually diagnosed by the presence of acoustic neuromas (schwannomas) on the vestibule-cochlear nerves on both sides of the brain, and often presents as deafness. The most common other brain tumour is meningioma.

Appendix E: Information About My Child's Brain Tumour

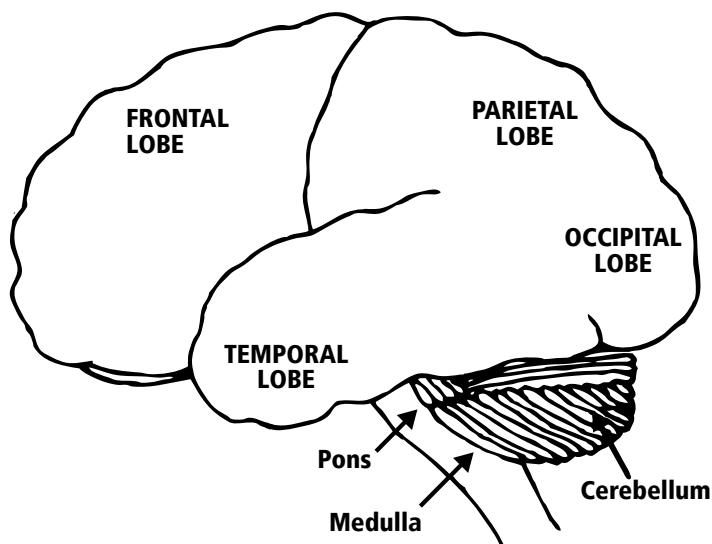
The type of tumour my child has been diagnosed with is: _____

The doctor's name is: _____

The nurse's name is: _____

Name of other health care providers on my child's 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 our next appointment? With whom? _____

Other comments: _____

Appendix F: Questions to Ask the Doctor

Having open communication with your child's health care team is important to make informed decisions about their health. 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 appointment. Consequently, it is a good idea to take a family member or friend with you to your medical appointments to take notes. The following questions are suggested for you and your family to think about and discuss with various members of your child's medical team, as well as any other questions you think are important.

What type of brain tumour does my child have? What is its most common name? _____

Is the tumour malignant / high-grade or non-malignant / low-grade? _____

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 child's prognosis? _____

What is the goal of this treatment plan? _____

What are the expected benefits of this treatment? _____

What are the possible risks or side effects of each treatment, both in the short term and the 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 my child? _____

What clinical trials are available for my child? Can my child be treated following a clinical trial even if they are not registered or enrolled on study?

Who will be coordinating the overall treatment and follow-up care for my child? _____

What support services from the clinic, hospital and/or the community are available to my child? 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 the treatment of my child (e.g., travel or lodging costs) who can help me with these concerns?

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

Appendix G: Symptom Tracking Sheet

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

What in your child's body feels bad or seems different? _____

When did it start? _____

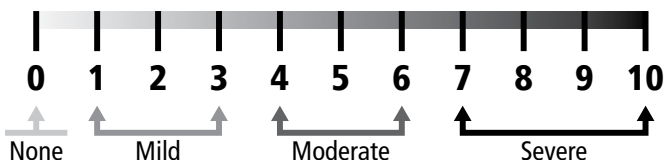
What time of day does it happen? _____

How long does it last? _____

How often does it happen? _____

If he has pain, describe it. Is it sharp, dull, shooting, aching? _____

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



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

Is there anything he cannot do because of how he feels? _____

Appendix H: Prescribed Medications

Medication	Instructions / Dose	Date		Prescribing Doctor
		Started	Stopped	

* It is strongly recommended that you take all of your child’s 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

Appendix K: Helping Children Understand a Diagnosis

Although parents want to protect their children from fear and other difficult feelings, experts agree that children as young as three or four years old should be told the truth about their brain tumour diagnosis. The amount of information and detail that you share with your child about his brain tumour will depend on his age and what you think he can understand. Try to keep the lines of communication open, as you will likely need to have several conversations with him throughout the treatment process.

The following suggestions are for all the children in your family, to help them cope with their sibling's diagnosis.

Newborns / Infants / Toddlers

Children's Understanding of Illness

- They have little awareness of illness.
- Infants are aware of feelings their parents show, including anxiety.
- Children are most afraid of being separated from their parents and of medical procedures they cannot understand.
- Children need to be reassured that they will not be abandoned by their parents at the hospital.
- Although young children have no way of anticipating or understanding a procedure or trip to the hospital far in advance, they should still be told of upcoming events in simple, clear, and reassuring language.

Your Children's Possible Reactions

- Fussy and cranky
- Crying
- Clinging
- Changes in sleeping or eating habits
- Colic

- Slight skin rash
- Toddlers: tantrums, more negativity
- Return to thumb sucking, bedwetting, baby talk

Your Possible Responses

- Provide consistent caretaking by maintaining your baby's schedule.
- Ask family members and friends to help with household tasks and care.
- Give plenty of physical contact like patting, hugging and holding.
- Observe your children's play for clues to their feelings.
- Provide daily contact to help your children feel secure.
- Express your feelings and fears with others.
- Use relaxation tapes, music or baby massage.

Preschoolers (3-5 years)

Children's Understanding of Illness

- They have a beginning level of understanding about illness.
- They look for a specific cause for their brain tumour, such as something they did or thought.
- They need to be reassured that they did not cause their brain tumour.
- They need reassurance that you will not abandon them.
- A sibling may think they can catch the brain tumour.
- They are afraid of pain and of being hurt.

Your Children's Possible Reactions

- Thumb sucking
- Fear of the dark, monsters, animals, darkness, strangers and the unknown
- Nightmares
- Sleepwalking

- Sleep talking
- Bedwetting
- Stuttering
- Baby talk
- Hyperactivity
- Apathy
- Fear of separation from significant others (especially at bedtime or going to preschool)
- Aggression (e.g., hitting, biting)

Your Possible Responses

- Talk about brain tumours with pictures, dolls or stuffed animals. Read a picture book about brain tumours.
- Read a story about nightmares or other problems your children may be experiencing.
- Explain what to expect; describe how things may change regarding routines, activities and schedules.
- Reassure your child that he will be taken care of and will not be forgotten.
- Provide brief and simple explanations. Repeat explanations when necessary.
- Encourage your children to have fun.
- Show emotion with some caution.
- Assure them that they have not caused the brain tumour by their behaviour or thoughts.
- Paraphrase for children what their behaviour might mean.
- Continue usual discipline.
- Reassure your child's siblings, when talking about the brain tumour, that they cannot "catch it."
- Be honest with them about tests and procedures that may hurt, but also explain that the treatment is being done to help make them better. You may also explain that doctors have ways of making the pain go away.

School-Age Children (6-12 years)

Children's Understanding of Illness

- They are less likely to believe that their brain tumour was caused by something they did.
- They are more likely to understand that they will need to take medicine and undergo other treatments to get better.
- They are afraid of pain and of being hurt; therefore, be honest with them about tests, treatments, and pain control.
- They are capable of understanding a more detailed explanation of brain tumours.

Your Children's Possible Reactions

- Irritability
- Sadness, crying
- Anxiety, guilt, jealousy
- Physical complaints such as headaches, stomach aches
- Separation anxiety when going to school or away to camp
- Hostile reactions toward their sick sibling, like yelling or fighting
- Poor concentration, day-dreaming, lack of attention
- Poor grades
- Withdrawal

Your Possible Responses

- Use books to explain illness, treatment, and potential outcomes
- Assure them that they did not cause the illness by their behaviours or thoughts.
- Reassure them about their care and schedule.
- Take time to listen and let them know you care about their feelings.

Teenagers (13-18 years)

Children's Understanding of Illness

- They are most likely to think about their brain tumour in terms of its symptoms and its effects on their daily activities, such as school, sports, and relationships with friends.
- They are capable of understanding the relationship between their symptoms and the brain tumour and the role of treatment.
- They can understand a complex explanation of the brain tumour and may have many detailed questions. They may be interested in learning more about their diagnosis.
- They may want to be involved in making decisions about their treatment.
- They have a unique set of concerns surrounding their physical appearance and their ability to fit in with others. They may be concerned about losing their hair and gaining or losing a lot of weight.

Your Children's Possible Reactions

- They want to be more independent and treated like adults.
- They experience feelings of anger and rebellion.
- They may criticize how you handle the "illness situation."
- They may experience depression, or anxiety, or worry about being different.
- They may show poor judgment.
- They may withdraw.
- They may demonstrate apathy.
- They may experience physical symptoms such as stomach aches, headaches and rashes.
- They may be more likely to turn their feelings inward (so you are less likely to see their reactions).

Your Possible Responses

- Encourage them to talk about their feelings, but realize they may find it easier to confide in friends, teachers, or other people they trust.
- Provide plenty of physical and verbal expressions of love.
- Talk about role changes in your family.
- Provide privacy as needed.
- Encourage them to maintain activities and peer relationships.
- If problems are noted, provide opportunities for counselling.
- Set appropriate limits.
- Provide resources for learning more about the disease and getting support.
- Talk honestly with them about the possibility of side effects.

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 be 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 percent 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 Scan (Computerized Axial Tomography): 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 benign 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.

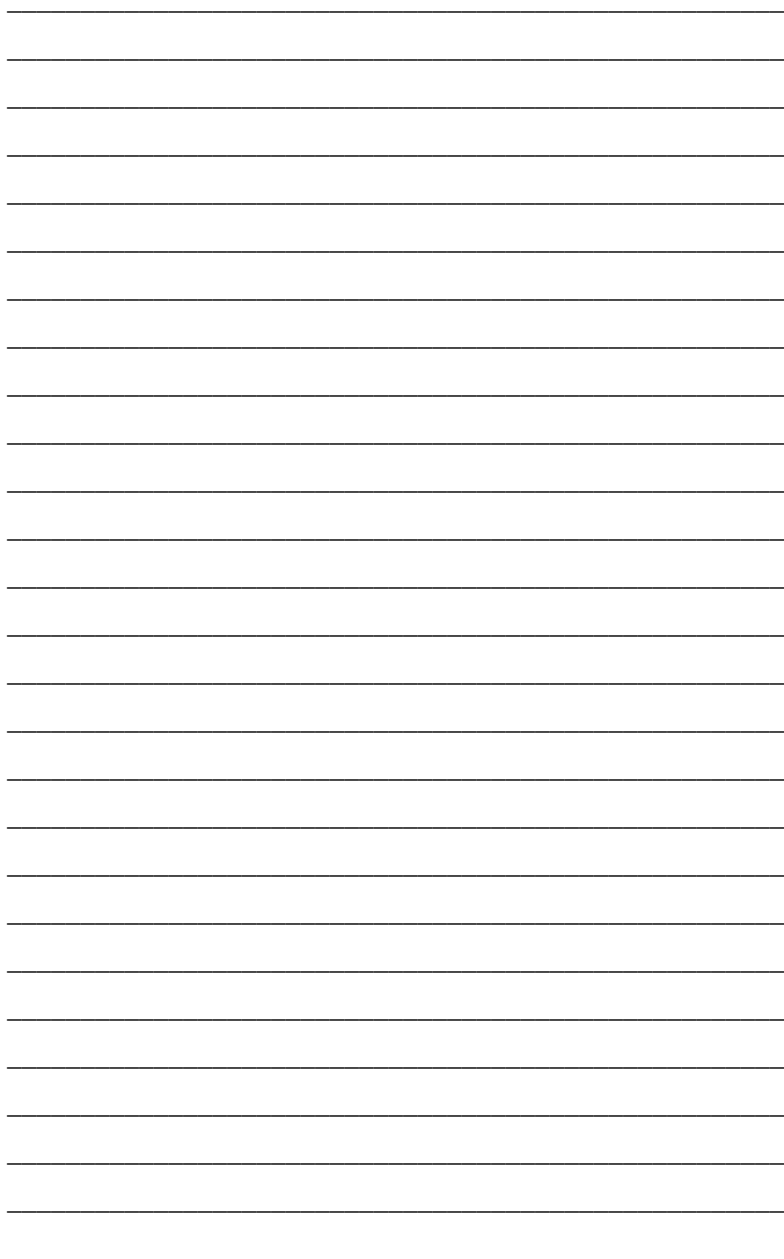
VP Shunt and VA shunt: A plastic catheter with a reservoir used to divert cerebrospinal fluid from the ventricles of the brain to the abdominal cavity or the heart.

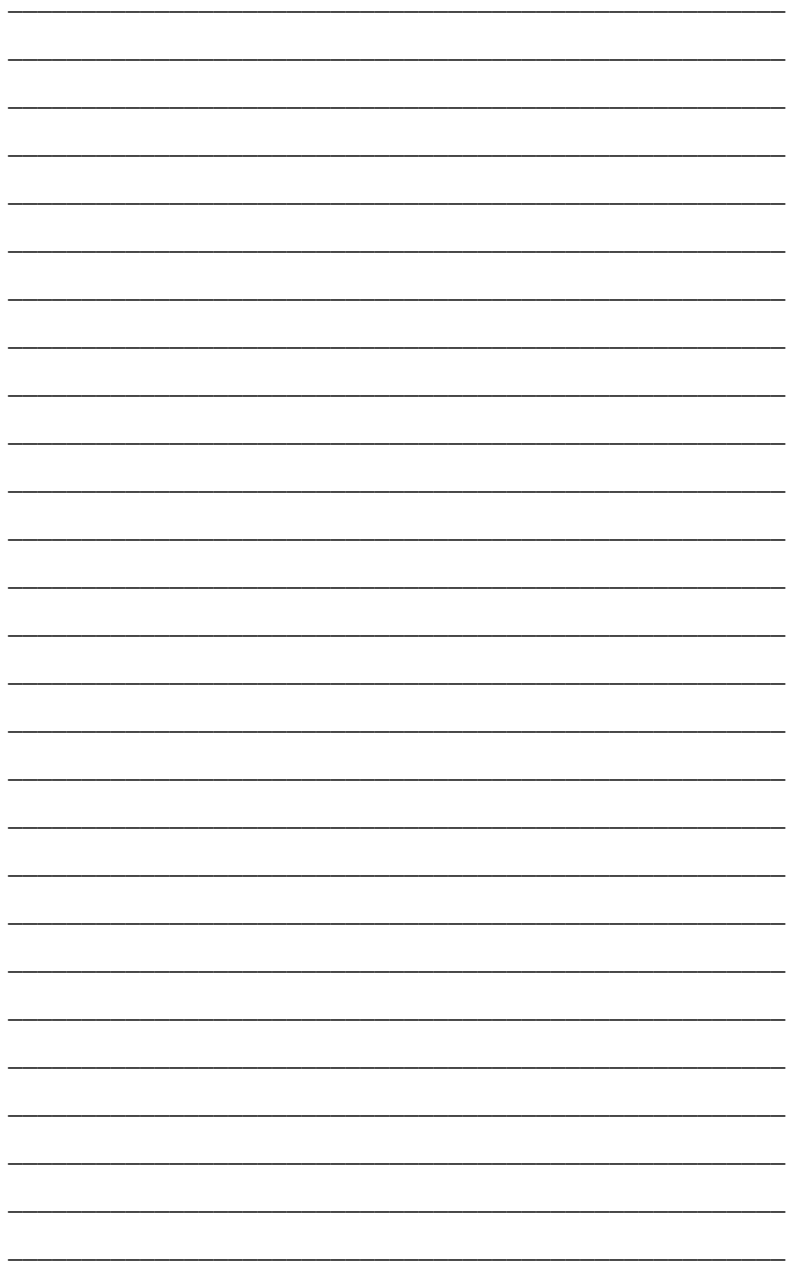
Wernicke's area: Part of the temporal lobe that surrounds the auditory cortex. It is thought to be essential for understanding and formulating speech. Damage in Wernicke's area causes deficits in understanding spoken language.

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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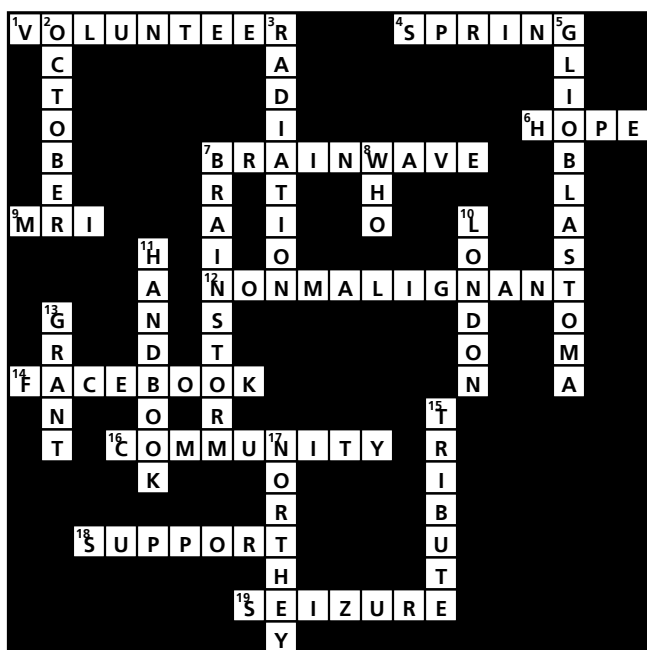
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Answers to Crossword Puzzle





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