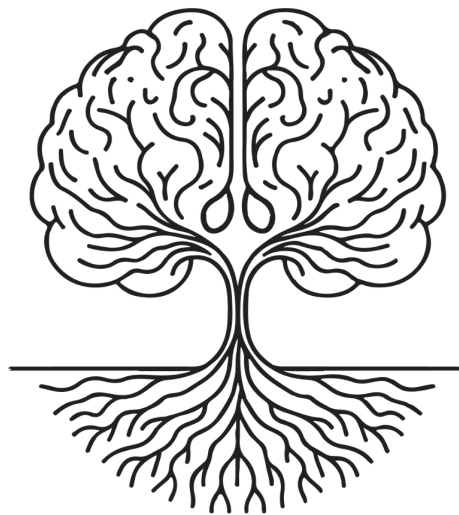


The
Australian Family Handbook



for
Childhood Brain Tumour

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Australian Family Handbook



for
Childhood Brain Tumour

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The Australian Family Handbook for Childhood Brain Tumour

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For the families whose worlds were changed in a moment,
and who face the unknown with courage, love, and hope.

*This handbook is also available online and as an audiobook.
These versions, along with other helpful resources and appendices, are
available here - www.brainchild.org.au*



*We are gathering feedback on this book to improve what's in it and how
it gets to families. Your feedback would be greatly appreciated!*

*Please go here to share your thoughts -
https://qsurvey.qut.edu.au/jfe/form/SV_73DQu9KeKTcQCKa*



*For hospitals - To order more books, please email
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Disclaimer

This handbook is intended to provide general information for families affected by childhood brain tumours. It is not a substitute for professional medical advice, diagnosis, or treatment. Always seek the guidance of qualified healthcare professionals with any questions you may have regarding your child's condition or treatment options.

While every effort has been made to ensure the accuracy and currency of the information contained in this handbook, medical knowledge and practices are continually evolving. The authors and publishers do not accept responsibility for any loss, injury, or damage incurred by use of or reliance on the information provided.

This handbook does not endorse any specific tests, treatments, procedures, or products mentioned. Inclusion of such information is for educational purposes only.

If you are experiencing a medical emergency, please contact emergency services immediately.

External Links

This resource contains links to external websites provided to help readers find additional information. These linked websites do not necessarily reflect:

- The views of the authors or affiliated organisations;
- A commitment to any particular course of action.

While we are careful in selecting the websites we link to, we are not responsible for and do not necessarily endorse the content found on these external sites. Readers are encouraged to make their own decisions as to whether the information in these websites is accurate, current, and reliable.

We acknowledge the Traditional Custodians of the many lands across Australia on which we live, learn, and care. We recognise the enduring connection of Aboriginal and Torres Strait Islander peoples to land, waters, skies, and culture, and the importance of this connection in the healthcare experience. We pay our respects to Elders past and present, who hold deep knowledge and wisdom, and extend that respect to all Aboriginal and Torres Strait Islander peoples.

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FOREWORD

You Are Not Alone

We are so glad you found this resource and so sorry you need it.

If your child has just been diagnosed with a brain tumour, you might be feeling overwhelmed and helpless. This is a new world for you and your family, and you likely have questions you never thought you would have to consider. What you are going through can be frightening, and you may feel like no one else can understand. Take a breath, and know you will not be going through this alone.

This handbook has been designed especially for you - parents, caregivers and family members of children with brain tumours in Australia. It aims to help you navigate the challenges ahead by providing information about supporting yourself and your family, what brain tumours are, how they are treated, and the available services to help. Designed with families who have gone through this journey before, we want you to know that a whole community of families, friends, and healthcare workers is in your corner.

As you start your child's treatment journey, you will meet many healthcare workers who make up your child's care team. You are an essential part of this team, too. It is important to keep communication

channels open and play an active role in your child's healthcare. It is really helpful to ask questions, speak up if something doesn't feel right, and share information about your child that is important to consider, including the values of your family. Your healthcare team should make you feel you have the power to speak up for your child and to get all your questions answered. Your team know the clinical side, but you know your child; both pieces of the puzzle are important in planning your child's healthcare journey.

While this handbook will not answer all your questions, it has been designed as a reliable source of information to guide you and help you understand your child's diagnosis and its impacts on emotions and your family. You might like to read this front to back or flip to a particular section that's relevant for you now. This book is available digitally at www.brainchild.org.au, and as an audiobook wherever you like to listen to podcasts. Alongside the information, you'll find quotes that have helped other families; we hope this is a reminder that families like yours have walked this path before you. You are not alone.



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Our deep gratitude to the families whose experiences and wisdom have shaped this book, both those who wish to remain anonymous and those who gave permission to share their names:

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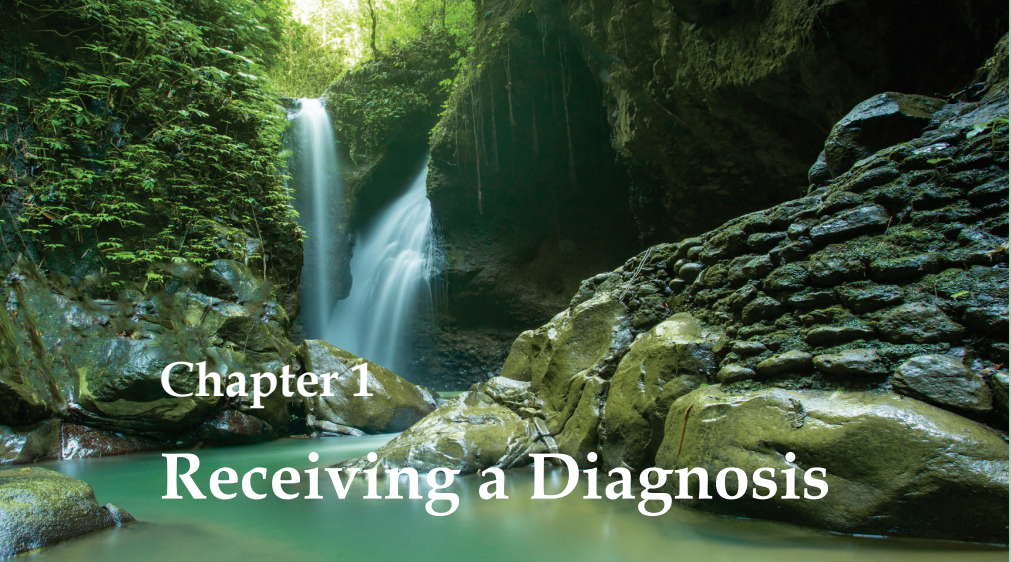
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Chapter 1

Receiving a Diagnosis

The news of your child's brain tumour diagnosis will come as a shock.

It can be difficult to process this information, and it might feel overwhelming. This section will guide you through some of the first steps after a diagnosis, such as seeking support, asking the right questions, talking to your child's teachers, and advocating for your child.

First Reactions

As you try to understand what's happening to your child, you can experience many emotions. Common reactions can include disbelief, shock, or a sense of the situation being unreal as if you are in a fog; the need to be in 'action mode', researching and creating plans; intense sadness and despair; guilt about when and how you reached out for help, or worry about the future. These reactions may come and go, and you may move between different reactions and coping methods. There is no wrong way. You might experience physical symptoms, such as 'jelly legs', trouble with sleep, a racing heart, or exhaustion. All of these are very normal, and you may experience all or none of them.

It might feel like your child's diagnosis has taken away the life you had expected you would have. The term 'grief' is usually associated with death, but humans grieve many losses. The diagnosis may come with a change in your child's opportunities, leaving you wondering what their future could look like. You may be grieving for a lost future you had imagined for your child. When your child is diagnosed with a brain tumour, you may be confronted with the possibility of their death and grieve the worry-free life you had previously.

While your focus will be on the next steps for your child's treatment, it's helpful to have some understanding of how the experience could affect the emotions and mental health of you and your family. Living through the experiences that led to your child's diagnosis, as well as receiving the diagnosis, can be traumatic. In this sense, 'trauma' is a term used to describe what happens when a distressing event is stored in a particular way in your brain and your body. This can feel like situations are 'stuck' in your head, where you replay them in your mind, or that you need to retell certain stories repeatedly. Other signs that an experience has been traumatising include avoiding reminders of the experience, trouble with sleep, and a feeling of being unable to relax. Experiencing some level of these symptoms is expected. There are things you can do to help reduce these symptoms, regardless of whether they have reached a level to be considered a problem. Things that may help to reduce these symptoms include focusing on slow and steady breathing when you are anxious, telling your story when you feel you need to, and listening to your body about what it might need. There are also specific types of therapy that help process traumatic events, which are effective and recommended by the World Health Organization (WHO). More information about emotions and support is provided in Chapter 4.

“Courage doesn’t always roar. Sometimes, courage is the little voice at the end of the day that says, I’ll try again tomorrow.”

Mary Anne Radmacher

Communication With Your Healthcare Team

Families say that there are often feelings of anxiety about placing your child’s health in the hands of a healthcare team whom you have only just met. Your healthcare providers are there to help, and most families have developed a good relationship with their team over time. Ask any questions, raise concerns, tell them if something doesn’t feel right, and share any information you think will help build this relationship.

The healthcare team is very familiar with supporting families in crisis and understands that many families struggle to hear and understand information when stressed. It is essential to understand the information as best you can, as this can help when you have to make decisions. Some strategies that families have found useful are;

Asking Questions

No question is silly. If you are thinking of a question, chances are someone else has thought about it before. Your team will be familiar with a lot of your questions and will be able to answer them. If they cannot answer straight away, they will find an answer and get back to you. It’s important to ask about any alternative or complementary medicines or therapies you are curious about or that your child is taking. Your team wants to support you in making informed decisions about what is best for your child.

Speak Up

If you are worried about something or have noticed a change, let your team know. It is better to get it checked out than regret not saying anything. You know your child best, so if something doesn't seem typical or you are worried, that is important information for your team. You are in the best position to notice things about your child.

Getting Answers in Writing

It is helpful to request information in writing. Your healthcare team may already have suitable websites for information or brochures to give you. They can also support you in sharing this information with others who need to know what is happening, such as family, school, work, and your social community.

It is common to be unable to take in all the information given to you in one appointment or discussion. This could be because the information is new and contains many unfamiliar words or because the topic is emotional, and you may be unable to focus the whole time. Your healthcare team is familiar with this and will help you understand it in whatever way you need. Don't feel silly about asking for information to be repeated or written down, asking to record notes on your phone or asking for it to be provided differently. Some families find it helpful to have a support person come to appointments who can help them take in and understand the information.

Information From the Internet

Online research is one of the first things many people do when they want to understand something. While this is very usual and can be helpful, there is a lot of unreliable information on the internet. And sometimes, too much time online can make your anxiety worse. You should always ask yourself questions when researching online, such as;

Who is the source of this information?

What evidence do they have for their position?

Is it different to other information I've heard? Why might that be?

Sorting through information can be overwhelming. It can also be easy to “fall down a rabbit hole” and read so much it becomes overwhelming. It can be useful to start by searching known reliable websites rather than general searching online. Some of these relevant to paediatric and adolescent brain tumours in Australia are;

www.childrenscancer.canceraustralia.gov.au

www.brainchild.org.au

www.canteen.org.au

www.redkite.org.au

www.campquality.org.au

www.carergateway.gov.au

Keeping a Journal

A journal can be a helpful way to track symptoms or medications and to write down questions you want to ask your healthcare team. Keeping these in one place can be helpful so that you remember what to ask. Writing questions down helps to stop them from going around in your head, meaning you can take them off the mental ‘to-do list’. There is space at the back of this manual to keep this list of questions. You could also keep your questions on your phone or email so you can add to them whenever you want. (Page 158)

Who you Might Meet in the Hospital

Your child's healthcare team will include professionals with specific knowledge about helping families with brain tumours. Below are some professions you might meet:

Medical Staff (Doctors)

Consultants/Senior Staff Specialists: Your child will have a consultant in charge of their care. A consultant has reached a high level of specialisation. When they specialise in cancer care, they are called oncologists. You may come across an oncologist who specialises in brain and central nervous system cancers, called a neuro-oncologist.



Your consultant will be in charge of your child's treatment. Often, they are the ones who tell you about the diagnosis, plan their treatment, and talk to you about test results.

Consultants are rostered on the wards at different times. If your child is admitted to the ward but your consultant is not rostered on that week, your child will be cared for by another consultant. The covering consultant will make sure your consultant is updated on any important changes.

Surgeon: Surgeons work with the consultant to perform surgery as part of the treatment plan. A surgeon who specialises in brain surgery is called a neurosurgeon.

Fellow: A fellow is a senior doctor training to become a consultant/ senior staff specialist.

Registrar: A registrar is a doctor receiving further training to become a fellow. Registrars work under the direction of consultants and fellows. Registrars rotate to different specialties every 6 months to gain experience working with other health conditions.

Resident: A resident is a qualified junior doctor. They rotate through different areas of healthcare approximately every 3 months to gain experience working with other health conditions.

Psychiatrist: A psychiatrist provides support through medication for mental health. While in the hospital, if needed, a consultation-liaison psychiatrist will partner with your healthcare team to provide medical mental health treatment for your child, like medication for mood, anxiety, sleep or behaviour.

Neuro-Ophthalmologist: When a brain tumour affects your child's sight, a neuro-ophthalmologist will assess and manage visual (seeing) difficulties. They specialise in the relationship between neurological diseases (diseases that affect the brain, like brain cancer) and visual (eye) problems.

Radiologist: A radiologist is a medical doctor who interprets scans and medical imaging results such as MRIs and CT scans to assist in making a diagnosis.

Nursing Staff

Nurse Practitioner (NP): A highly specialised nurse trained and licenced to diagnose and treat health conditions, including prescribing medicine, within their expertise.

Clinical Nurse Consultant (CNC): A specialist nurse with expertise in their chosen area. They educate you, your child, and your family, as well as providing care coordination and liaising between hospital and community-based services. In some hospitals these nurses may be called different names, including Clinical Nurse Specialist (CNS) and Cancer Care Coordinator (CCC).

Nurse Unit Manager: Often called a NUM (rhymes with ‘hum’). These nurses oversee the running of a clinical area such as a ward or outpatient department. They oversee patient care and nursing staff in their area.

Nursing Team Leaders: Responsible for coordinating care during a particular shift, so may be in charge of a ward when the NUM is not working.

Nurses: Different levels of nurses will work across wards and outpatient departments to provide the day-to-day care of your child. These include registered nurses (RNs), enrolled nurses (ENs), and assistants in nursing (AINs). Each level has particular responsibilities of care they are trained in and licenced to undertake.

Allied Health Staff

Healthcare providers who provide specialist advice but are not medical doctors or nurses are called ‘allied health’. This includes physiotherapists,

occupational therapists, social workers, nutritionists, psychologists, and many others.

These professionals will be brought in to care for your child when required. If your child needs an allied health professional, you can ask your oncologist for a referral to the service. You may also need these services when you are home in the community and can ask your hospital team for a referral to these. Some commonly used allied health services are described here.

Audiologist: Hearing loss can happen because of the location of the brain tumour or certain chemotherapy treatments. An audiologist specialises in assessing and preventing hearing disorders and helps those with hearing difficulties. They will monitor your child's hearing during treatment and offer recommendations for improving communication and hearing aids if needed. Making sure your child can hear as well as possible can help their speech development, learning, and overall quality of life.

Child Life Therapist: Some hospitals have child life therapists who use play-based methods to help children with hospital care. In some hospitals they are referred to as Play Therapists. Child Life Therapists can support your child to feel ready for procedures, cope with worries about procedures, and understand and get used to life in a hospital or treatment. In some hospitals, these tasks are undertaken by Occupational Therapists (OTs).

Dietitian: Dietitians are educated in nutrition (what we need to eat to be healthy). Children with brain tumours may experience problems eating a healthy diet. Dietitians can help address these challenges. They conduct assessments of your child's nutritional needs and provide counselling and education to address issues with their nutrition. They can develop ideas to overcome these problems and improve your child's well-being if needed.

Music Therapist: Music Therapy uses music to support emotional coping, functioning, and health. Sessions can include listening and moving to music, writing and recording songs, and music making. Music therapy is a valuable part of the overall program to support your child and is often a part of treatment that brings joy.

Occupational Therapist (OT): An OT focusses on supporting patients to undertake 'occupations' of daily life, such as play, movement, brushing teeth, or having medical procedures. They help with physical aspects, like splints or physical exercises, as well as social and emotional elements, such as training in relaxation and social skills.

Pharmacist: In the hospital, the pharmacist will manage all the medications your child needs. They will visit you in the ward to understand what medication your child has taken before and give advice. When your child is discharged, the pharmacist will make sure you have a supply of the medicines you need and a clear list of what medications your child is taking and how to take them.

Physiotherapist: Physiotherapists support the function of your child's body through movement. They can support maintaining muscle and mobility during treatment and reaching movement goals in rehabilitation when your child is home in the community.

Psychologist: Hospital-based psychologists care for your child's mental health through talking therapy. Psychological support is also available in the community for times outside of the hospital and for other family members. Psychologists can help with issues like anxiety, depression, trauma, motivation, and mood changes. Psychologists can diagnose specific mental health issues, but problems don't need to be severe to start receiving help. Neuro-psychologists specialise in supporting changes in thinking, behaviour, and emotion resulting from brain injury.

Radiation Therapist/ Radiographer: Undertakes scans and medical imaging, such as MRIs, and provides radiation therapy targeting the tumour where necessary.

Social Worker: Social workers provide individual, family, and group therapy to support children and families coping with the diagnosis and treatment of a brain tumour. They help address practical concerns, such as financial stress or employment issues, and provide counselling to assist in adjusting to the diagnosis and its impact. Social workers also connect families with community resources, support services, and educational assistance for siblings, parents, and other family members. They can help navigate the medical system and plan for hospital discharge and the resources or support you need once you're back home.

Speech Pathologist: Speech Pathologists support patients in addressing issues with speech, language, and eating. This can include temporary problems such as mouth ulcers that might interfere with eating, and long-term issues relating to changes in speech or eating from the effects of the tumour or treatment.

Welfare Officer: In some hospitals, welfare officers work with hospital Social Workers and focus on the financial aspects of treatment. They can provide support with travel arrangements, accessing Centrelink, and refer you to useful services during financial hardship.

Youth Cancer Services: If your child is aged 15- 25, in some states they can be supported by Youth Cancer Services. These services are integrated with your hospital health team and include medical, senior nursing, and allied health services that specialise in this age group.

Other Staff

Administration: 'Admin' staff are often the first people you'll meet in the hospital. They provide professional services that make your visit to

the hospital as smooth as possible, such as making sure your details are correct and your medical records get to where they need to be. They will help make appointments, contact your GP, and prepare forms for travel, consent, and insurance.

Indigenous Liaison: Aboriginal and Torres Strait Islander families can be additionally supported through an Indigenous Liaison. Ask a member of your healthcare team to be connected with this service.

Interpreter Service: If you have difficulties with English or are hearing impaired, interpreter services are available to ensure you have easy communication with your healthcare team. These can be provided face-to-face, via video conference or by phone. Ask a member of your healthcare team to be connected with this service.

Operational Staff: Food service, cleaning, and portering (moving patients around the hospital) are other important parts of your hospital stay. These staff often get to know your child and become part of the hospital community you know.

Pastoral Care Worker/Chaplain: Hospital chaplains and community clergy provide religious or spiritual care. They are specially trained to support people going through health crises and can talk to you about moral and ethical challenges that might come up during treatment. Chaplains offer spiritual and religious care within a multi-faith setting and can provide specific rituals, prayers, or celebrations upon request. Ask a member of your healthcare team to be connected with this service.

Getting a Second Opinion

Families should feel they have all the information and freedom to make informed decisions about their child's healthcare. Sometimes, this includes asking for a second opinion. If you want a second opinion, your

doctor can arrange a referral and share information with the other doctor. Your doctor will also be talking with other doctors around the country through national meetings (such as ANZCHOG and the Zero Childhood Cancer program), and may be able to share with you perspectives from those conversations. Your doctor understands how important and difficult your decisions are and that families need to ensure they have considered all options. You should not feel awkward or guilty for asking for a second opinion.

An open discussion with your doctor about this will allow them to understand your perspective, may allow them an opportunity to clarify any points where you hold different opinions, and will allow them to further explain the reasons they are recommending a particular course of action. Time may also be a factor in decision-making. If the second opinion is different from the first, both doctors should be able to explain how they have come to their recommendation. An open conversation will allow all opinions, benefits, and risks to be considered.

Talking to Your Children About the Diagnosis

This section aims to give you tools to talk with your child and their siblings about the physical and emotional things they are going through. By the time they receive a diagnosis, your child has likely been experiencing symptoms and medical tests and may know something is wrong. Their siblings are likely to have less information and understanding (although this may vary depending on how old they are and how involved they have been). Your children could be anxious or scared, and some parents worry that talking openly about the diagnosis will add to this. When children don't have all the information, they may imagine something even scarier is being kept from them. Being honest and talking openly about what is happening is vital to the health journey and can help your child feel safer. Children do not always have the language to label and

express their feelings, and so they can feel alone with their emotions. Children may express their distress in ways other than using words. It is important to understand that children will express their anxiety, stress and frustration in whatever way they can- their behaviour is another way they communicate what they are struggling with.

Children may misunderstand medical terms, and younger children may think magical forces are causing their illness. Children can worry that they did something to cause the tumour or that it is a mystical punishment for something that they have done wrong. Look out for any signs that they may be blaming themselves for the tumour or for the sadness that the family is feeling and offer reassurance that this is not their fault. You may have to do this more than once, and it is important to provide reassurance and comfort when they express this.

Where a child isn't able to express how they are feeling with words, they may be able to express where in their body they are feeling an emotion. They may have a way that their body wants to move to address the feeling, such as swaying, being rocked, running, being held tightly, hitting something, or tapping on a part of their body. Think of ways they were comforted as a baby, including music or white noise; these may also be helpful. You can also look for ways to help them express their feelings, like yelling into a pillow. Children often need a mix of comfort activities and activities to express their feelings actively.

Books and stories can help children to understand what is happening to them and their families. Redkite's book club has a range of books that can be borrowed at no cost: <https://www.redkite.org.au/service/book-club/>. The hospital occupational therapist may also be able to work with your family to create a 'social story' specific to them, which supports children to understand what is going on. You can read this story with your child whenever they want or need to, and it can also be used to educate your

children's friends or school.

If children have specific questions, try to answer them directly and clearly. If you don't know an answer, offer to talk to the healthcare team. If you tell your child that you will get back to them about a question, make sure you do; not hearing back about a question may suggest to them the answer was so terrible that you don't want to tell them. You could also try reflecting the question back to your child, asking, 'What do you think the answer is?' This can give some clues about their ideas or the things worrying them. You could also follow this up by asking what they are worrying about or what would help them feel better about what they are asking about.

Age-appropriate Communication

While parents and carers may want to shield their children from fear and difficult emotions, in most cases, even young children should be informed truthfully about their or their siblings' brain tumour diagnosis. The level of information and detail shared with a child will depend on their age and understanding. Your healthcare team can help you to plan for these conversations; just let them know you want that help. A Social Worker, Psychologist, or Occupational Therapist can all help.

Below is a general outline of how children of different ages typically understand and react to the experience of illness and some helpful communication strategies. This information is relevant for your child with a brain tumour and their siblings.

Infants & Toddlers

Understanding of Illness	Possible Reactions
- Have a limited awareness of illness - Pick up on parents' emotions, including anxiety - Fear of being separated from parents - Don't understand medical procedures or the idea of short-term pain for long-term benefit	- Increased irritability - Crying - Wanting to be close to you or seeming clingy - Changes in sleeping or eating - Colic - Mild skin rash - Going back to behaviour they had outgrown, such as thumb sucking, bedwetting, or using baby talk

Babies and toddlers need reassurance that they won't be abandoned. This is true for your child in hospital and siblings staying at home or with other carers during hospitalisation. Even though young children may not fully understand procedures or hospital visits well in advance, it is important to inform them using simple, clear, and reassuring language, usually close to the time of the event. Spend time with them, be present during procedures, and make sure someone can be with them when you need to take a break.

Pre-schoolers (3-5 years)

Understanding of Illness	Possible Reactions
- Understand sickness and wellness - May look for a cause for the brain tumour, sometimes blaming themselves - Siblings may worry about 'catching' the brain tumour - Fear of pain and injury	- Thumb sucking - Fear of darkness, monsters, animals, strangers, the unknown, or of things that they have previously grown out of - Nightmares, sleepwalking, sleep talking, bedwetting - Stuttering - Baby talk - Hyperactivity - Being emotionally distant or shut down - Fear of separation, especially during bedtime or going to preschool/ daycare - Aggression, such as hitting or biting

School-aged Children (6-12 years)

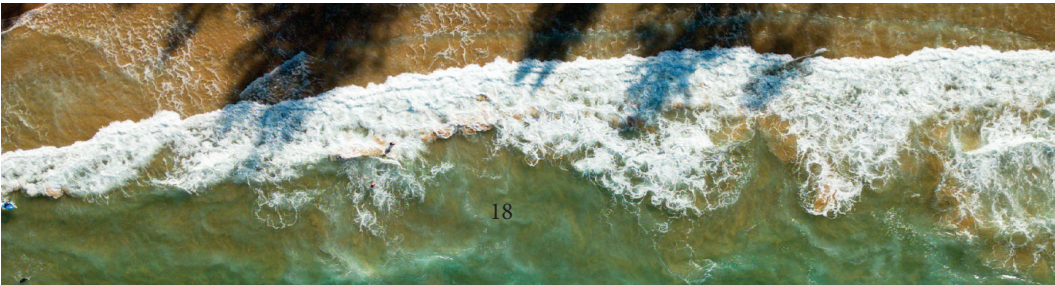
Understanding of Illness	Possible Reactions
- They are less likely to believe that they caused the brain tumour - They understand the concept of needing medication and other treatments for recovery - Fear of pain and injury is present, so it is important to be honest about tests, treatments, and pain management - They can understand a more detailed explanation of brain tumours	- Irritability - Sadness and crying - Anxiety, guilt, and jealousy - Physical complaints like headaches and stomach aches - Separation anxiety when going to school, fear of being left alone - Siblings may have hostile reactions towards their sick sibling, such as yelling or fighting - Siblings' behaviour may seem to regress (go backwards) and they may start acting younger than what they are

School-aged Children (6-12 years) continued

	- Poor concentration, daydreaming, and lack of attention - Decline in grades - Becoming withdrawn and isolated
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Teenagers (13-18 years)

Understanding of Illness	Possible Reactions
- They tend to focus on the symptoms and how the brain tumour affects their daily activities, such as school, sports, and social relationships - They can comprehend the connection between their symptoms, the brain tumour, and the role of treatment - They can handle a complex explanation of the brain tumour and may have detailed questions, showing an interest in learning more about the diagnosis - They may want to be involved in decision-making regarding their treatment - They have unique concerns about their physical appearance and fitting in with others, including worries about hair loss, weight changes, and acceptance	- Desire for more independence and to be treated like adults - Feelings of anger and rebellion - Criticism of your handling of the 'illness situation' - Experiencing depression, anxiety, or worries about being different - Displaying poor judgment - Becoming withdrawn and isolated - Not caring about things (apathy) - Physical symptoms like stomach aches, headaches, and rashes - More likely to internalise their feelings or keep them to themselves- making it harder to know how they are feeling - May argue against treatment because they want to feel 'normal'



Communication Strategies

Whatever age your child is, connection and compassion are most important. Looking after yourself is also essential to having the energy and calm to have hard conversations with your children. Some other tips to help communication and emotions in your family include:

- Offer words to recognise and label the feelings your child may be experiencing in a kind and compassionate way. You can say things like, “It sounds like you feel really anxious.” Reassure them you will be there with them and offer physical comfort.
- If your child finds it comforting, provide lots of physical contact and movement, for example, hugging, patting, swaying, swaddling and holding. You may also want to use a weighted blanket to help with this.
- Reassure them that this is not their fault and they will not be abandoned.

The first step in having a hard conversation may be to take a breath yourself. Pause. And then choose how you respond. While it’s not humanly possible to get this perfect every time, an example of this kind of conversation with a younger child could be:

“I can tell you’re so mad. You don’t want to go into hospital today. I know. You don’t want to be there. [Offer hugs and allow tears] It feels so unfair. You didn’t do anything to deserve this. I wish I could make it so we didn’t have to go either. This is so hard. I’m going to be right there with you.”

There will be times that you find that you’ve responded to your child in anger or frustration because of your own tiredness, and stress. Repairing this through an apology and comfort will still let your child know you’re on their side and that all humans make mistakes sometimes. Give yourself the kindness and forgiveness you would offer your child when they have imperfect human moments. If you catch yourself speaking unkindly to yourself about this, remind yourself you are only human and going

through a highly stressful and overwhelming experience. Recognising when you've responded out of anger and frustration and apologising, matters. It is also important to take breaks however possible to reduce the chances of this happening.

- Give them information about what to expect and what is happening in an age-appropriate way. Use pictures, dolls, or stuffed animals to discuss brain tumours for younger children. Read picture books or watch movies where families face similar challenges and talk about similarities with what your family is experiencing. For older kids, you might discuss the experiences of other children and ask if they can relate or have had a different experience. This can include practical parts of their medical care as well as fears, friendships, or other challenges your children might face.
- There may be times that your child doesn't want to do something that is part of their treatment. After you've given your child words, comfort and compassion for their feelings, look for playful ways to move toward the thing that needs to happen. For example, if a young child refuses to move somewhere, could you play some music and dance there? Have a race? Walk like an animal would? Could you blow bubbles and chase them there? Older children may benefit from the plan for something fun afterwards or having a friend come with them, for example:

"How's this? First, we do the procedure; then, we get some ice cream. We could get someone to bring up your favourite?"

Playful activities offer connection and joy, which both help to move through hard emotions and let your child know you are on their side.

- Observe your children's play for clues into their emotions.
- Keep contact with important people to promote a sense of security.
- Share your feelings and fears with people you trust.
- Follow through with what you have said you will do.

- Talk through the behaviour you see with a curious approach to help them understand how their feelings affect their behaviour.
- Teens may be more comfortable talking about their feelings with people their age. This is a usual part of adolescence for all teenagers. Encourage this and suggest ways to communicate what they need with their friends, and that it is also okay to ask for more help if needed. Connecting with other people their age who understand what they're going through can also be hugely helpful - Canteen (in-person events www.canteen.org.au) and Livewire (a safe online community www.livewire.org.au) are two ways to do this that might suit them.
- Discuss openly how the family might have to change how they do things during this time. Give as much information on what to expect as possible.
- Talk about the ways that hard times impact mental health and support that is available. That might include cancer-specific counselling through Redkite or Canteen, usual mental health professionals through your GP or headspace (www.headspace.org.au), or school or uni-based mental health professionals.

Support services relevant for your child with a brain tumour, their siblings, and yourself include Camp Quality, Redkite, and Canteen, depending on the age of your child. Registering with Cancerhub.org.au will connect you with those groups that are relevant to you. Many charities for children with cancer will also support families with benign brain tumours. It is worth asking!

Talking to Family and Friends

If, how, and when you tell the people around you about your child's diagnosis will depend on your relationships and how you usually communicate. Families who have been through this journey have found value in having a community around them but didn't realise how much work and energy it would take to keep a lot of people updated.

"I found communicating with family and friends absolutely exhausting. I really just wanted to focus on my son's well-being and what he was going through but had a constant barrage of emails and text messages from well-meaning family and friends wanting us to know they were thinking of us but also seeking updates. Very early on we set up a private Facebook group which was a lifesaver. We could share photos/videos/stories when we wanted to, friends organised meals for us through here etc. It was a lifesaver and reduced the need for lots of individual communication."

Mum of son with a brain tumour

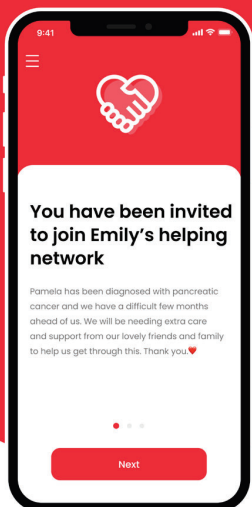


Families may not want to tell too many people because it is emotional and challenging to tell the story over and over, or they may want to keep what they are going through private. One strategy that can help is to have a trusted person take on the role of communication with a broader group of family and friends. This allows you to have someone to talk to, a wider community of supporters, and minimal obligation to keep people up to date.

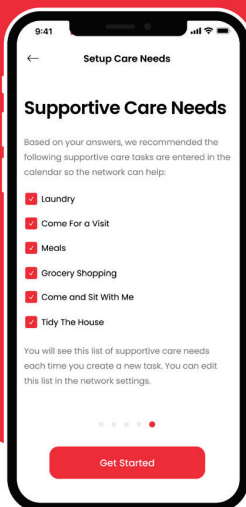
Some families find it helpful to communicate and organise practical support from their community through an app such as 'Kitecrew' (search 'KiteCrew' in Google Play or AppStore), which allows an organiser to select jobs that would be useful for other people to do for the family and can be shared with people that the organiser selects. This could also be done through social media or group chats. Try not to feel guilty about asking someone else to be your communicator. People want to help if they can, and asking someone to be the communicator may free you up to focus on your child. Practical things like getting other children to school and activities, making school lunches, or being at siblings' events when the parent has to be at the hospital can make a lot of difference to the impact on your family. This is what the Kitecrew app looks like, which can

be downloaded from Google Play or the App Store;

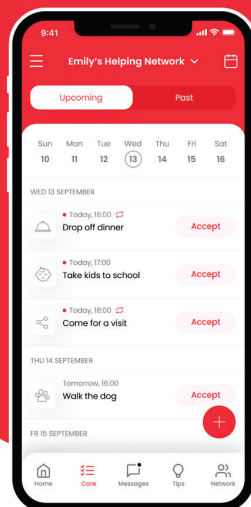
Easy invite to friends and family who have offered support



Guided questions to create a supportive care plan



Track appointments and coordinate all of your care



If you find it difficult to accept help, it might be easier to think about how you would want to help your friends or family if the situation were reversed. Also, if you need more help later, setting up a system now will mean that the support 'future you' needs will already be organised. When we feel overwhelmed or stressed, it can be hard to think about what you need, so it's better to have it sorted before you need it.

Talking to Your Child's School or Daycare

Your child will likely have to miss some schooling. For your child with a brain tumour, the treatment and side effects may impact their mood, energy and ability to focus. For siblings, stress and disruption to normal life may impact their schoolwork too. Letting the school know this as

early as possible and keeping communication open will mean that the school can best work with you to support your family.

It's likely that your child's school have not supported a family through a brain tumour before and may not understand how best to provide support. At the back of this book (Appendix B, page 147), you'll find a template for an email you can send to your school, explaining common experiences of children with brain tumours and how best to support them and their siblings through diagnosis and treatment.

The hospital school can also work with your child's school to support their education in the best way possible through their treatment. Hospital schools have teachers on-site and can work in the hospital school space or at the bedside.

You may also decide that school isn't a priority to focus on at the moment. That is okay, but it is still important for your school to know. Having school activities to do at home may be a helpful distraction for your child while they go through treatment. Going to school may help your child stay connected with their friends, but it can also tire your child. It is important to weigh what is important to your child and family.

Waiting for Answers

Families have shared that waiting for answers about their child's diagnosis, the plan ahead, and scan results can be a period of high anxiety. Having a plan makes dealing with difficult times a little easier, but during this waiting time, families can find themselves without a clear 'next step' to focus on, and a lot of uncertainty about what the next weeks, months, or years might look like. Sometimes, people can start thinking about the worst-case scenario. To help manage the anxiety and to feel some control, some families find it helpful to write down their plan for the possible

scenarios: plan A, plan B, and plan C, even when the path they take will be decided by the results or information they are waiting on. Ask your healthcare team for any information you need to know to make these plans if you think that this will help you.

Connecting With Other Families

Families often find comfort in understanding what path other families have taken on their cancer journey, and to build connections with other families further ahead of them in the brain tumour path. Connecting with others who can have the same emotions and experiences you're going through offers a different level of support than what healthcare professionals can offer. Building friendships with people who have 'been there' can bolster you through hard times, and may provide support or a listening ear when services can't.

Social media is one way of doing this, and many groups exist for this purpose. One benefit of social media is finding a community, which may include people internationally, where you might find a family with a child with a similar condition even if it is very rare. One downside is that international and interstate families will have different healthcare systems, and their experience in navigating these may not be similar to yours. Sifting through information that may be inaccurate or that does not fit your situation can be draining and may also increase your anxiety about things that you don't need to worry about. Local social media groups also exist for specific hospitals or regions, and you can ask other parents or staff at the hospital about what yours is called.

Community organisations often connect families going through similar experiences. For example, Redkite offers online groups for parents of a child who has just been diagnosed with cancer, and for parents of children

with brain tumours. Canteen, Camp Quality and Brainchild Foundation offer individual fun days and camps, which can help children, young people, siblings, and families get to know other people who understand what the journey is like.

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Chapter 2

What is a Brain Tumour?

Becoming familiar with the language used in brain tumour care and treatment can be overwhelming and time-consuming.

This section provides basic information about brain tumours and explains the process of diagnosing a brain tumour and the words you might hear.

The term ‘brain tumour’ refers to the abnormal growth of cells in or around the brain. Other terms like lesion or growth may be used. Tumours that affect other parts of the central nervous system (or ‘CNS’- your brain, eyes, and nerves that run through your spine) are usually included under the ‘brain tumour’ category. Brain tumours are classified based on where they first began growing, how they grow or change, and the cells in the brain tumour. They can be called primary or secondary, low-grade or high-grade, and categorised as benign, non-malignant, or malignant. A malignant brain tumour can also be called brain cancer. These terms are described further in the Brain Tumour Classification section on page 37.

There are many different types of brain tumours in children. Some reliable websites to research more about the particular type of brain tumour your child has include;

Country	Website	QR Code
Australia (AUS)	https://childrenscancer.canceraustralia.gov.au/types-childrens-cancers/brain-and-cns-tumours	
Australia (AUS)	https://cancerqld.org.au/get-support/cancer-information/types-of-cancer/brain-tumour/#types	
United States of America (USA)	https://www.hopkins-medicine.org/health/conditions-and-diseases/brain-tumor/pediatric-brain-tumors	
United Kingdom (UK)	https://www.cancerresearchuk.org/about-cancer/childrens-cancer/brain-tumours/types	

Symptoms of Brain Tumours

Each child with a brain tumour experiences their own symptoms and a different journey to diagnosis. While some children may not show noticeable symptoms initially, others may experience worsening symptoms over time, leading to a diagnosis. For most children, symptoms appear gradually, and it is very common for these to be mistaken for minor health or behavioural issues. Common symptoms in children are often related to increased pressure inside their skull and may include:

- Behaviour changes
- Cognitive (thinking) changes
- Dizziness or unsteadiness
- Double or blurred vision
- Frequent headaches
- Nausea and vomiting
- Seizures
- Weakness or paralysis
- Difficulty walking

Finding Brain Tumours

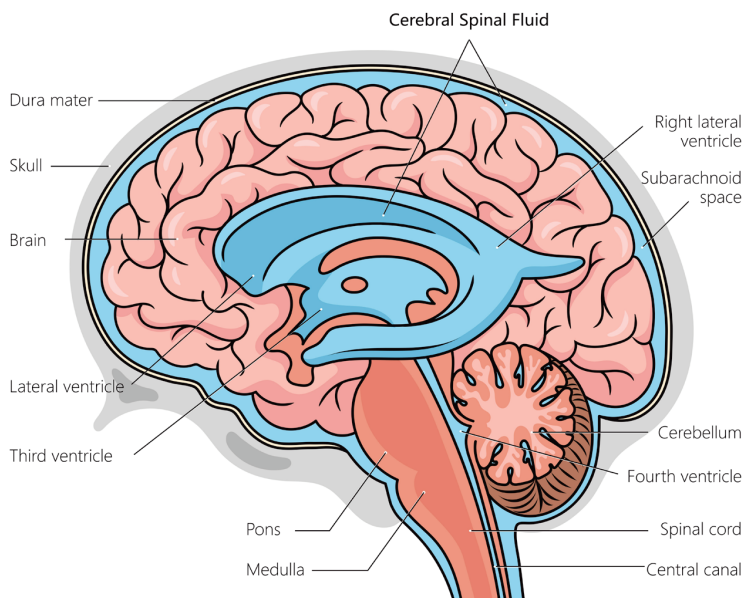
Diagnosing brain tumours in children can be challenging. Parents may not immediately seek medical attention for symptoms that seem minor, and because brain tumours in children are rare, healthcare professionals will often investigate other possible causes first.

The tumour's location in the brain affects the symptoms experienced - different parts of the brain control different bodily function. As the tumour grows and puts pressure on other brain areas, symptoms might change or develop, including difficulties with walking, balance, speech, vision, hearing, and sleep patterns.

Cerebrospinal fluid (sometimes referred to as CSF) is a clear liquid surrounding the brain and spinal cord. It acts as a cushion, protecting the brain against things like bumps on the head. Many tumours in children can block cerebrospinal fluid pathways or disrupt how it is usually absorbed, leading to the fluid building up in the skull and increasing pressure. This can result in headaches, especially during sleep or waking in the morning.

These headaches are often accompanied by nausea (feeling sick) and vomiting.

Cerebrospinal fluid



Side view of the brain, showing where the Cerebrospinal fluid sits.

Causes of Brain Tumours

The exact causes of brain tumours remain unclear. Researchers continue to explore immune system disorders and environmental and genetic factors as possible contributors. Scientists are working to identify genetic markers associated with brain tumours, aiming to make us better able to predict when someone is at risk. However, it is likely that a combination of factors causes brain tumours and are not caused by one thing. Many parents, like their children, worry that they have done something to cause a brain tumour. This is not the case.

How are Brain Tumours Diagnosed?

Diagnosing a brain tumour starts with a thorough examination of the brain and nervous system (neurological examination). This involves your child's doctor asking questions to gather a complete history of their symptoms. It may include the following assessments:

- Balance and coordination tests: walking heel-to-toe in a straight line, heel-to-shin movements, balancing with eyes closed, rapid alternating movements (e.g., touching finger-to-nose with eyes closed)
- Eye movement, pupil reaction, and reflex tests
- Facial muscle tests: smiling, grimacing
- Head movement tests
- Hearing tests
- Reflex tests using a rubber hammer
- Sensory (touch) tests using a pinpoint and cotton ball
- Tongue movement and gag reflex tests

If the results of this examination lead the doctor to suspect a brain tumour, additional tests, including scans, are usually arranged. Scans are used rather than X-rays, as X-rays cannot see tumours behind the bone. Different devices are used for brain scans. The most common ones used for diagnosis and follow-up are the Computed Tomography scan (CT/CAT scan) and Magnetic Resonance Imaging (MRI). Every child diagnosed with a brain tumour should have these scans. The following pages contain information for parents on preparing a child for a scan or procedure.

CT or CAT Scan

A CT or CAT (Computerized Axial Tomography) Scan uses a series of X-rays to create images of the body or brain. It takes a few minutes and is performed in the radiology department. Your child lies still on a table, and the table moves into a doughnut-shaped opening where the scan is completed. If your child can't lie still, they may receive medicine to sedate them for the procedure. The CT scanner rotates around their head and produces images. The technician will be in the next room and may use an intercom to reassure your child. Before the scan, sometimes a contrast agent (a type of dye) is used to help improve the visibility of the tumour. If contrast is needed, hospital staff will insert a cannula or drip (a small plastic tube) into your child's vein or use an intravenous (IV) cannula already in place.

MRI

Your child's doctors order an MRI (Magnetic Resonance Imaging) scan to get detailed pictures of the size and shape of the tumour without using radiation. It involves a magnetic field and takes approximately 30 minutes to one hour to complete. The procedure is painless and provides valuable information for diagnosis and treatment monitoring.

Preparing for an MRI

Before the MRI scan, your child should remove any metallic devices or objects, such as jewellery, wallets, pens, hairpins, or magnets, as they can interfere with the procedure. The hospital may ask your child to change into hospital pyjamas if their clothing may have metal in it. Inside the imaging department, your child will lie on a narrow bed with soft straps securing their head so they don't move during the scan. A helmet-like device may also be placed over their head, and the table will be moved to position their head within the scanner.

During the MRI scan your child lies on a table and slides into a small tunnel. A magnetic field surrounds your child's head inside the scanner while radio energy is directed to the examined area. No X-rays are used in this process. MRI imaging takes longer than a CT scan and is quite loud.



A child sliding into the MRI tunnel. Sometimes a helmet will be fitted over your child's head to keep it in the right place.

Your child must remain still during the scanning process, as any movement can affect the image quality, which could mean that the scan needs to be completed again. The scanner makes loud noises, but your child will be provided with ear protection. An MRI technologist operating a computer in another room will guide your child through an intercom, talking about the imaging process and the noise. After the scan, the bed will be moved out of the scanner, and your child can leave the room.

Sedation or Anaesthesia for MRI

Young children may need sedation or general anaesthesia to remain still during the MRI scan. If this is planned, you will receive instructions for fasting (not eating) before the procedure.

Contrast Agent Use

After routine images are taken, a contrast agent called Gadolinium may be injected into a vein in your child's arm. This contrast agent can cross the blood-brain barrier and improve the visibility of the tumour on the MRI scan. If contrast is needed, hospital staff will insert a cannula or drip into your child's vein or use an intravenous cannula (IV) already in place.

If your child has had a shunt placed to help with the pressure in their brain, it might need to be checked after the MRI scan because the magnetic field might change the shunt settings. If your child has a shunt or you are unsure, talk to your medical team before the MRI.

Image-Guided Neurosurgery: Some images from the MRI scan can assist surgeons during tumour operations, known as image-guided neurosurgery. The images are transferred to a planning system that helps the surgeon navigate the cranium (skull) and brain. Skin markers called fiducials are attached to the scalp before surgery, and a short MRI scan may be performed with the fiducials in place. Fiducials look like circular stickers and are used to help map the pathway the surgeon will take.

Other Imaging Techniques

Additional imaging techniques may be used to gather more information about a brain tumour:

- **Functional MRI Scan:** This scan helps define brain anatomy (where parts of the brain are) and locate brain function by watching the brain during specific activities.

- MRS (Magnetic Resonance Spectroscopy): MRS provides biochemical information about the brain tissue's metabolic changes.
- DTI (Diffusion Tensor Imaging): DTI visualises the brain's white matter tracts, which can be essential for surgical planning as tumours may affect or infiltrate these tracts.
- PET (Positron Emission Tomography) Scan: PET scanning measures brain activity using radioactive substances, helping to determine what the tumour is doing in response to treatment.

Brain Tumour Classification

You will hear tumours described in various ways, including low-grade and high-grade, benign, non-malignant, and malignant tumours. The World Health Organization (WHO) also uses a grading system ranging from Grade I to Grade IV to classify tumours based on their origin and behaviour. Additionally, tumours can be categorised as primary (the first to occur) or secondary (resulting from primary tumour located elsewhere).

Low-Grade Tumours

A low-grade tumour is made of slow-growing cells. If these tumours can be completely removed through surgery, they often do not recur (grow back). However, if the tumour is located near critical brain functions (like the areas that control the heart), complete removal may not be possible, and any remaining tumour can regrow. Low-grade tumours can still be life-threatening.

High-Grade Tumours

High-grade tumours are made of fast-growing cells and are often called 'aggressive'. They usually invade normal brain structures and are challenging to remove surgically. Due to their fast growth rate, high-grade tumours will cause symptoms earlier than low-grade tumours.

Benign, Non-Malignant, and Malignant Brain Tumours

The term 'benign' is sometimes used to describe tumours that are considered non-life-threatening or non-aggressive. However, in the case of brain tumours, this terminology is not entirely accurate, as benign tumours can press on brain tissue and other structures within the skull, leading to serious health complications. In recent years, there has been a shift toward using 'non-malignant' instead of 'benign' to describe tumours that are not aggressive or are low-grade.

In general:

- **Malignant Tumours:** These are cancerous and the most aggressive; they grow fast and can spread to other parts of the brain or body.
- **Non-Malignant Tumours:** These are the least aggressive, slow-growing tumours that can often be removed. They rarely invade surrounding brain tissue or other structures.



World Health Organization (WHO) Tumour Grading System

Your doctor may have explained that the WHO classifies brain tumours based on cell origin and cell behaviour, ranging from least to most aggressive. Tumour types are given a 'grade' to predict how they might grow and behave. Many non-malignant tumours are classified as Grade I or II, while malignant tumours are categorised as Grade III or IV. However, tumours can also have mixed grades.

Grade I Tumour:

- Slow-growing cells
- Under a microscope, it appears almost normal
- Least malignant
- Associated with long-term survival
- Example: juvenile pilocytic astrocytoma

Grade II Tumour:

- Fairly slow-growing cells
- Slightly abnormal appearance under a microscope
- Can invade nearby healthy tissue
- May come back as a higher-grade tumour
- Example: diffuse astrocytoma

Grade III Tumour:

- Actively reproducing abnormal cells
- Abnormal appearance under a microscope
- Affects nearby healthy tissue
- Tend to come back and progress to a higher-grade tumour
- Example: anaplastic astrocytoma

Grade IV Tumour:

- Quickly reproducing abnormal cells
- Very abnormal appearance under a microscope
- Forms new blood vessels to keep growing quickly
- Contains areas of dead cells (necrosis)
- Example: medulloblastoma

The tumour type is determined by taking a biopsy (sample of the tumour) and examining it. It usually takes around two weeks after a biopsy to receive a report on the pathology describing the tumour type. This can mean your child may be discharged from the hospital after the biopsy procedure without knowing the specific name or treatment plan for the tumour. Once the results are back your neurosurgeon or oncologist will contact you to discuss treatment plans.

Genetic Testing

Some brain tumours are associated with genetic mutations, and some can be hereditary (passed down in families through genes). Analysing the genetic makeup of a tumour can help in two different ways; planning treatment, and making decisions about other family members being tested for the tumour or gene. *Somatic genetic testing* can identify genetic changes in a tumour that may make it responsive to targeted therapies. This is sometimes called personalised medicine. *Germline genetic testing* looks at what DNA is inherited and may run in your family. Germline genetic testing can tell you if other people in your family should be tested for the tumour. There are ongoing research efforts to make genetic testing available to children and families through research and clinical trials. Speak to your oncologist or nurse if you want to find out more about genetic testing and what this involves.

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This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

A photograph of a young fern sprout growing from a mossy rock in a forest. The background is a blurred forest scene with sunlight filtering through the trees. The text 'Chapter 3' is overlaid on the left side of the image.

Chapter 3

How are Brain Tumours Treated?

Brain tumours can be treated in different ways, depending on the type and location of the tumour. Some tumours may not receive any treatment and may be monitored only. Below are descriptions of different kinds of treatment. The treatment your child needs will be discussed with you. This is a good time to ask your healthcare team any questions you have. Some types of tumour and treatment may affect your child's fertility (their ability to have children when they are older). If that is a possibility, fertility preservation will need to be discussed with your healthcare team before treatment starts.

Observation Only

Some treatment plans need observation only, meaning no treatment is necessary, useful, or possible. The reason for this will influence what other support is offered, and your healthcare team will discuss this with you. Being on an "observation protocol" can create a lot of anxiety and uncertainty around prognosis (outcomes), impacts and symptoms that are related to the tumour, and what the future will look like.

You might feel positive and negative emotions about the decision to take an observation approach. This decision is made based on what treatment is available, the associated risks, and what will lead to the best outcomes or quality of life for your child. Healthcare teams want to do their best for the families they work with, and sometimes, the best decision is only to observe.

If you need help processing these emotions, please speak to your healthcare team, register for support through community organisations (e.g., www.cancerhub.org.au), or talk to your GP about a referral to mental health support services.

Surgery

Certain tumours, like diffuse pontine gliomas, may be diagnosed with MRI scans and do not always need a biopsy. Some low-grade tumours causing no symptoms or brain pressure may be monitored without immediate surgery. Your oncologist or neurosurgeon will discuss in detail with you what surgery is recommended and the risks and benefits of alternative treatments, if available, and support you in understanding and feeling as comfortable as possible with any decisions that have to be made. Remember, you are an active member of your child's treatment team, and this is a good time to bring your list of questions.

Types of Surgery Offered:

Brain Tumour Biopsy: Taking a small amount of tumour tissue for accurate diagnosis and treatment planning. Pathologists examine the tissue under a microscope, and genetic testing may be performed.

Brain Tumour Resection: Removing as much of the tumour as safely possible to reduce symptoms and future complications. Depending on the tumour's location and risks, complete or partial resection may be attempted.

- In cases where complete removal poses risks, a biopsy or alternative techniques may be used.

Techniques for Brain Tumour Biopsy or Removal:

Stereotactic Brain Biopsy: Minimally invasive technique using computer-guided imaging for precise biopsy needle placement.

Open Brain Tumour Biopsy: Surgical removal of a small section of the skull directly above the tumour for biopsy.

Resection: Involves making an incision (cut), removing a bone flap, opening the dura mater (the protective layers outside of the brain), and carefully removing the tumour.

Craniotomy: Surgery where the bone flap is removed and then replaced

Craniectomy: Surgery where the bone flap is removed and not replaced. It may be replaced in a later surgery.

Anaesthesia Used for Brain Tumour Surgery:

General Anaesthesia: Commonly used for paediatric brain tumour surgery, carefully monitoring vital signs and blood loss. Under general anaesthesia, your child is unconscious (asleep) during the procedure.

Neuroleptic Anaesthesia: Used in older children when the tumour is located in critical brain areas, allowing brain function assessment during the procedure. Under neuroleptic anaesthesia, your child is awake but sedated during the procedure and able to respond.

Possible Side Effects of Surgery:

- Infection, bleeding, seizures, and changes to normal brain function are potential risks.
- Side effects depend on tumour location and invasion of sensitive brain areas.

- Your consultant and surgeon will discuss all risks specific to the surgery your child is having. You should feel welcome to ask any questions you have, including further information about risks and treatment options.

Radiation Therapy

Radiation therapy is a treatment that destroys tumour cells by damaging their DNA, preventing them from dividing and eventually causing tumour cells to die. This therapy uses high-energy X-rays, similar to diagnostic X-rays, but with a much higher energy. The X-rays are targeted at the



tumour using a linear accelerator. Modern radiation techniques allow for precise focusing of radiation therapy on specific areas of the brain. These techniques include 3D Radiotherapy, Stereotactic Radiation Therapy, Intensity-Modulated Radiation Therapy, Image-Guided Radiation Therapy, and Proton Therapy.

3D Radiotherapy: This technique shapes the radiation dose region around the tumour in all three dimensions.

Stereotactic Radiation Therapy: This involves using a specially made frame (a stereotactic frame) attached to the head to guide the radiation beams to the precise area of the brain requiring treatment. Because the radiation targets the tumour from different sides, the tumour receives a high dose of radiation while keeping the amount of radiation the surrounding areas receive to a minimum.

Intensity-Modulated Radiation Therapy (IMRT): This relatively new technique adjusts the intensity of each radiation beam to spare important nearby structures, such as the optic nerves, brain stem, and pituitary gland, while delivering a full dose to the tumour.

Image-Guided Radiation Therapy (IGRT): This uses imaging techniques on specialised radiation equipment (the linear accelerator) to accurately deliver daily doses of radiation to the intended areas. This involves using 2D images, optical tracking techniques, and mini-CT scans performed within the treatment unit.

Proton Therapy: Proton therapy needs highly specialised equipment and is currently not available in Australia. At time of printing there are plans to have this equipment in the next few years. Currently, if your child's treatment requires proton therapy you will be connected to international services.

In some cases, it may be difficult to tell where the exact outer edge of a tumour is due to microscopic spread into nearby brain tissue. Therefore,

a small amount of normal tissue may be included in the treatment area to ensure all tumour cells are treated. The treatment planning aims to minimise how much normal tissue falls within the radiation field.

Preparation for Radiation Therapy and Treatment Planning

After the initial visit with the radiation team, a planning appointment is scheduled. A CT or MRI scan is performed during this appointment to determine the best treatment position and precisely locate the area to be treated. The planning session typically takes about an hour. Your child needs to remain still during both the planning session and radiation treatments. They can bring a special toy or blanket with them for comfort.

A plastic mask is required for daily radiation treatments to ensure your child's head is always in the same position. This mask is custom-made by the radiation therapists on the same day as the planning session. It is made of a plastic material that becomes firm and moulds to the exact shape of your child's face and head. A CT or MRI scan of the brain is performed with the mask on for treatment planning. If your child isn't able to hold still for these sessions, they can be put under a general anaesthetic (GA). However, often having enough information to prepare and help them understand the procedure can minimise their anxiety and can mean your child is happy to stay very still, which may mean they don't need to be sedated. The radiation team and child life specialists/occupational therapists are available to assist in preparing your child for the planning and treatment sessions. In some hospitals, the mask will be decorated to look like your child's favourite character to make the process more fun.

Supporting Your Child During Radiation Treatment

During radiation treatment, parents need to accompany their child to the treatment but cannot be in the room when treatment is happening. The treatment sessions occur on an outpatient basis from Monday to Friday.

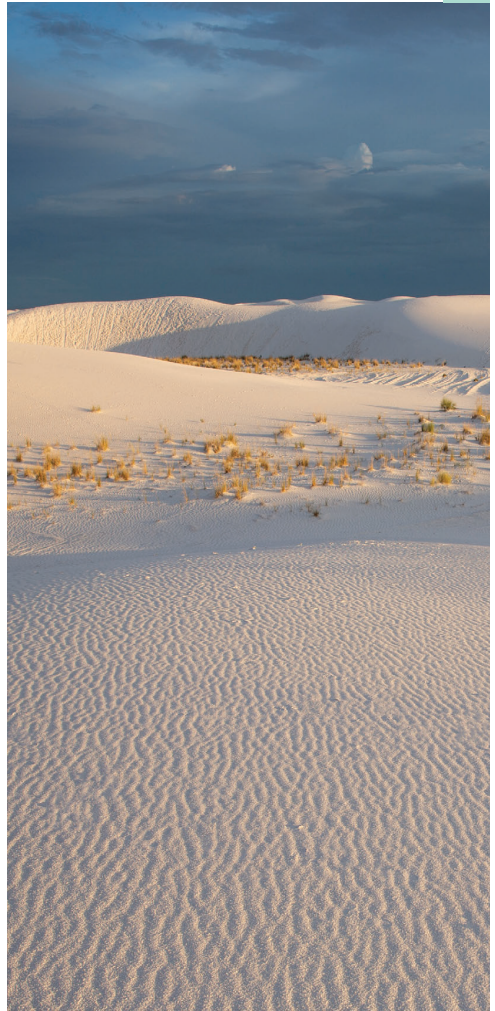
The treatment is painless and won't be felt. A barrier cream is provided to protect the skin. Your child must lie still for a few minutes while the machines make clicking or whirring noises, which are normal. Each treatment session typically lasts 15 to 45 minutes, with most of the time spent positioning your child. The actual treatment delivery takes around 5 to 10 minutes. Parents and therapists must leave the room before the machine is turned on, but will monitor your child through a video monitor and communicate through a speaker system if needed. A radiation oncologist will see your child once a week for general monitoring and to address any concerns. It is a good idea to prepare a list of questions to discuss during these appointments.

Side Effects of Radiation

Your child may experience fatigue, nausea, changes in taste, skin sensitivity, and hair loss due to the radiation. Long-term side effects will vary depending on the type and location of the tumour. The radiation team and your oncologist will discuss this with you.

Chemotherapy

Chemotherapy refers to cancer-fighting drugs. In the past, chemotherapy played a limited role in treating brain tumours compared to other cancers, as many medications couldn't cross the blood-brain barrier. However, in recent years, chemotherapy has become more critical in brain tumour



treatment, sometimes even being the only treatment option. Typically, chemotherapy is used alongside radiation therapy and surgery. In young children, where their brain is more sensitive to radiation, chemotherapy may be used instead of radiation therapy or to delay radiation until your child reaches an age when long-term risks of radiation on a growing brain are reduced.

How Does Chemotherapy Work?

Chemotherapy includes various types of drugs, which are also called agents. Traditional chemotherapy agents stop tumour cells from dividing, reducing the chances of tumour growth. Some chemotherapy drugs increase the sensitivity of tumour cells to radiation therapy. Newer chemotherapy drugs slow the growth of blood vessels into tumours, starving them of vital nutrients and oxygen, leading to tumour cell death. Other chemotherapy drugs target specific proteins or genes in tumour cells, slowing their growth or making them respond more to other treatments. Combining different chemotherapy drugs allows for multiple kinds of damage to tumour cells, improving the chances of destroying the tumour or preventing its spread. This approach also enables doctors to manage the side effects of chemotherapy more effectively.

How are Chemotherapy Drugs Administered?

Chemotherapy can be administered orally as a tablet, liquid, or intravenously (into the veins, via a drip). Chemotherapy is often given in 'cycles' where a planned combination of drugs is given over some time, often three or four weeks. After the cycle, tests may be completed to see how the tumour has responded, and the body is given time to recover before another cycle starts.

Side Effects of Chemotherapy

While some side effects are common, each drug may have specific side

effects. Your child's oncology team will discuss these in detail with you.

General side effects include:

Nausea and Vomiting: Many chemotherapy drugs can cause nausea and vomiting, either immediately or with a delay. Effective anti-nausea medications are available to reduce these symptoms. Some children may be at risk of losing too much weight, in which case supplement drinks, nasogastric feeding, which occurs through a tube entering the nose, or G-tube feeding, which occurs through a tube going directly into the stomach, can be helpful. A dietitian can provide further guidance.

Hair Loss: Certain chemotherapy drugs may cause hair loss, typically occurring two to three weeks after treatment. Hair will eventually regrow after chemotherapy; some choose to cut their hair short or shave their head to ease the transition. Cold caps, worn during chemotherapy administration, may be an option to minimise hair loss. Speak to your chemotherapy team about this option.

Myelosuppression: Chemotherapy drugs often affect the bone marrow, slowing the production of blood cells and leading to a drop in blood cell counts. This typically occurs 10 to 14 days after treatment and takes about seven days to return to normal. The three types of blood cells that may be affected are red blood cells, white blood cells, and platelets. While these are low, your child's immune system will be weaker than normal, and it will be easier for them to catch illnesses they are exposed to. They may need transfusions to replace red cells or platelets.

Sexual Function and Fertility: Some chemotherapy agents may impact fertility. Your child's healthcare team will discuss this possibility with you; this is another good time to bring any questions you have.

Long-Term Side Effects: These can happen months or years after having the chemotherapy drug. For this reason, after treatment ends, you should

make sure you have a long-term plan for monitoring, a clear list of what drugs were used, and a follow-up plan into adulthood.

Bone Marrow/Stem Cell Transplantation

Stem cells are immature blood cells in the bone marrow and can become whichever type of cell the body needs. Stem cells can be collected from blood or via a bone marrow harvest.

A stem cell transplant is where stem cells are removed from an individual before treatment and re-introduced to the patient when their immune system is low. The use of high-dose chemotherapy with stem cell transplant is often used in children three years of age and younger. It has been very valuable in treating some brain tumours. Research is investigating which tumour types best respond to stem cell treatments and the potential benefits in older children.

Following intense chemotherapy, the bone marrow takes time to recover and make new blood cells. During this time, your child is at increased risk of infection, which can be life-threatening without a functioning immune system. Introducing stem cells during this time helps to speed up bone marrow recovery and lower the risk of infections. The stem cells don't target the tumour, but help your child recover from treatment.

Immunotherapy

Immunotherapy- also known as biotherapy or targeted therapy - is a newer form of cancer therapy and is still evolving. These therapies train the body's immune system to recognise and attack cancer cells. Some immunotherapies are used to lessen the side effects of chemotherapy by helping the body to replace normal cells.

Not all types of brain tumours will have an immunotherapy that is suitable. Immunotherapy can be given in different ways, often through a drip or injection and is usually given in cycles. People can stay on immunotherapy for long periods, sometimes for years, depending on the cancer type and stage.

Preparing your Child for a Procedure or Scan

New situations often bring anxiety. When the situation may also be painful or could impact your child's health, such as a blood test, scan, or radiation treatment, it makes sense that anxiety can be quite high. If you know how best to calm yourself and your child, practice those skills and share that information with your healthcare team. Below are some suggestions on what works for a lot of people - it's ok if your situation is different!

Before the Procedure

1. Find out as much as possible about what to expect.

Some questions to ask the healthcare provider might be:

- How long the procedure usually takes.
- How your child will be positioned.
- What instruments and medications are involved.
- What support can your child have during the procedure.
- How your child is likely to feel afterwards.
- Who will be there, and if you can meet them before the procedure.
- Any choices you or your child have in how this procedure happens - having choice in situations makes the situation feel more psychologically safe and within your control. While some parts might be non-negotiable,

choosing what music plays or what toy comes in with your child might be an option.

2. Practice relaxation strategies with your child

Most children can practice relaxation strategies, such as swaying to calm music, noticing and slowing down their breathing, and age-appropriate meditations. If your child can't do this by themselves, you can support them to practice relaxation, for example by swaying them to music, or gently stroking their arm while you model slow and steady breathing.

Stanford Medicine Children's Health provide a video on youtube titled "Learning how to manage pain during medical procedures.



This video explains how the brain processes pain and strategies to help relieve pain in procedures. It may be helpful for you to plan how you will help your child get ready for the procedure, and older children (around 10+) might benefit from watching it too - <https://youtu.be/Ubk9FFoAcvs>

3. Talk to your child about the procedure

How and when you talk to your child will depend on their age, personality, and previous experience with medical procedures. In general, take a moment to calm yourself before you talk to your child about the procedure – anxiety is contagious, but so is being calm! Take deep, long breaths yourself, and then coach your child to do the same.

Give your child honest, age-appropriate information on what will happen. Some language tweaks that might be useful include saying 'poke' instead

of jab or needle and ‘pinch’ instead of pain or denying that they will feel anything. Some suggestions on when to tell your child are listed below, but trust yourself in what you think will work for your child.

Age	Timing of Discussion
Under 2 years	During the procedure - calmly explain what is happening as the procedure is occurring, provide comfort and reassurance
2-4 years	Just before the procedure - use simple language and visual explanations (eg, toys, dolls, pictures, demonstrate on a parent).
5-7 years	Up to the day before the procedure - use simple language and visual explanations (eg toys, dolls, pictures, demonstrate on a parent), you may also want to show a video or story about the procedure.
8-12 years	3-7 days before. For surgeries or procedures with significant outcomes more time - up to a month - may be useful.
Over 12 years	7 days before. For surgeries or procedures with significant outcomes more time - up to a month - may be useful.

This website has several videos of Australian children getting ready for and undertaking procedures, including surgery, scans and x-rays, audiology tests, and more. It can be helpful to watch these with your child before the procedures to help prepare them, but also so that they can ask any questions they might have.

https://www.rch.org.au/be-positive/Jazz_and_Rocco/A_child_s_guide_to_hospital/



Once you have discussed what will happen, ask your child about any relaxation or distraction they would like to have available during the procedure or as they get ready. Plan for positions that may be most comfortable for them during the procedure. The more they know the plan, the more confident they will feel when it is time.

During the Procedure

Coping strategies for you and your child will be important. The more you can genuinely express calm and confidence about the procedure, the more your child will feel this, too. Think about things that have calmed your child or held their attention in the past, and plan to use these during the preparation and the procedure. If your child is distressed, help them by naming the emotions, expressing empathy, and providing comfort. Below are some common non-medical strategies other families have found helpful during procedures. There may also be pain relief and pain disruption techniques (e.g., ‘buzzy bee’ for needles) that your nursing team can help you with.

Breathing

Breathing is one way our body communicates to our brain that we are safe. When breathing deeply and slowly, we feel calmer and give ourselves the best chance to make good decisions rather than reacting from a place of panic. And the wonderful thing about breathing is that you always have it available! You can teach your child strategies to focus on breathing, but even if all you can do is focus on slowing down and deepening your breathing, your child will start to copy the speed of your breathing without even realising it.

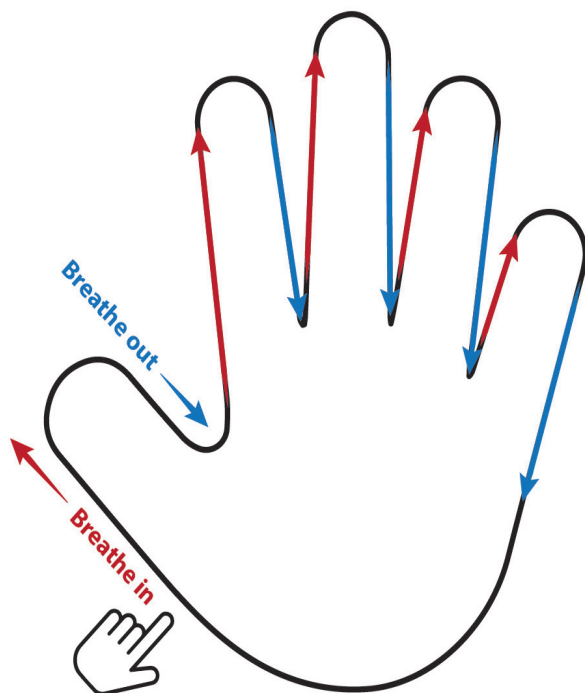
Some fun ways to focus on breathing with your child include:

Birthday Candle Breathing

Hold up your five fingers in front of your face. Take a deep breath in (to your belly if you can), and blow long and slow, aiming at one finger like it is a birthday candle. Put each finger down as the candle gets 'blown out'. Try to make each out-breath longer than the in-breath and pause before you breathe in again.

Five-Finger Breathing

Place one hand out with five fingers up and put the pointer finger of your other hand at the side of your wrist. Trace up the side of the first finger, breathing in. Trace down that finger to the webbing and breathe out. Keep doing that until you are on the other side of the hand.



Music

Think about songs your child likes to listen to that calm them down or that they find fun and engaging. Music that has a beat slower than their heart will usually have a calming effect and, depending on the procedure may be more useful than fast, happy music. Music can help set the mood, be something to dance or sing along with, and be something within your child's control when many other things are outside their control. Singing can also help with deep breathing; a steady beat can give predictability and comfort.

Distraction

Taking your child's mind off the procedure can help to interrupt anxious thoughts and decrease pain signals. Think about the things your child likes to do for fun or gets very engaged in these might be things like computer games, blowing bubbles, magic tricks, 'Where's Wally' type books, reading, talking, or crafts. For some ideas, search www.rch.org.au for 'reducing your child's discomfort during procedures' or follow the QR code.



Listening to a guided meditation can be helpful, especially if your child has practised concentrating on these. Some relaxation activities specific to children undertaking medical procedures can be found here- <https://imagination.stanford.edu/calm-during-procedures-and-pokes/>



There are a lot of other meditations for children on usual platforms like YouTube, Spotify, and Apple Music too.

After the Procedure

Acknowledge that the procedure is finished when it is over. This will allow your child to put the activity behind them mentally. Allow them to finish any activities they were involved in. It will enable them to talk through the experience if they want to. This is especially important if it has been distressing. Name the emotions you see them going through, and offer compassion and comfort to help them process the experience. Acknowledge the hard work you saw them do to get through the procedure, like trying hard to stay still or letting people know what they needed. Also, let them know if you thought they were brave or felt proud of them.



Clinical Trials:

Understanding the Options for Your Child's Treatment

Depending on your child's tumour type and currently available clinical trials, you may be offered the opportunity to participate in a clinical trial. This section outlines what these may involve and things to consider when you and your family are deciding if you would like to participate.

Understanding Clinical Trials

In cancer research, a clinical trial is a structured investigation to answer specific questions. Treatment-focused trials may explore new cancer treatments, supportive therapies, or alternative ways of giving existing treatments to improve effectiveness or quality of life. Clinical trials are often the best practice. Sometimes they are looking at making treatments more effective, and sometimes they are looking to reduce the amount of treatment and side effects.

Before testing a new treatment in humans, the treatment will go through a careful process in laboratory studies. Animal testing provides information about the treatment's effects on the body, but it cannot fully predict how effective it will be or what side effects humans will have. Participating in a clinical trial is voluntary, and your family will not be treated differently because you decided to participate or not. To make an informed decision, gathering information about the trial and other available treatment options is essential. It is okay to say no to a trial if you don't want to participate or to ask about a trial if you have heard about it.

Types of Clinical Trials

Clinical Trials can be described as Phase I (1), II (2), or III (3). Phase I studies are the first step in testing a new human treatment approach. Researchers focus on working out a safe dosage for human use and may explore the best way to give the drug. Participants start with the lowest

dose and are closely monitored for any negative effects. The dosage gradually increases until a safe and effective level is established. While Phase I trials may not produce immediate anti-cancer effects, some individuals may benefit from them over time. Once the best dosage is determined, Phase II studies evaluate the treatment's ability to shrink tumours. If a treatment is effective in shrinking a tumour in a Phase II trial, it will usually continue to a Phase III trial.

Phase III trials aim to find out if the treatment is better than the existing standard treatment for a particular type of tumour. These studies look at longer life, improved quality of life, reduced side effects, and lower cancer recurrence. Participants are randomised - randomly given either the new treatment or an alternative treatment known as a placebo or 'control', which may not be an active drug - and blinded (not told) to which condition they are in so that their expectations don't impact the outcome.

Supportive Care Studies

Some trials aim to find better ways of caring for your child with a brain tumour and their family. These trials might use drugs, for example, to treat nausea or sleeplessness, and will be given a phase number like the cancer-targeted clinical trials. Some studies examine the emotional or practical concerns associated with a brain tumour diagnosis. These studies won't have a phase number and may explore how these impacts can be reduced on the child or family.

Getting Involved in a Clinical Trial

Tumour Banks

You may be asked if you would like to donate your child's samples to a tumour bank. A tumour bank collects tumour tissue, blood, cerebrospinal fluid and bone marrow from children effected by brain tumours. These

samples are available for researchers in Australia and internationally to understand how tumours work and develop new or improved therapies.

Your treating doctor will know the clinical trials your hospital is part of. To find clinical trials in Australia search www.canceraustralia.gov.au for 'clinical trials' or follow the QR code.



Clinical trials are responsible for the advances in treatment and outcomes over the past decades, and the treatments we have today are based on the participation of people in trials. However, involvement in them is always optional; you can opt-out anytime. Before agreeing to participate, discuss the trial and other options with your treating doctor. Some questions to start the conversation might be:

- What is the purpose of the study?
- What is involved in the study? What kind of tests and treatments? How and where are they performed?
- What will happen in my child's case with or without the trial treatment? Remember in these discussions that you may be randomly assigned to the 'placebo' or fake treatment in some trials.
- What are the other options? What advantages and disadvantages are there?
- How does the trial differ from standard treatment?
- How could the study affect my child's daily life?
- What side effects could be expected from the trial drug?

- How long will the study last? What time will be required from us?
- Will my child need to be hospitalised?
- What long-term follow-up is offered after the study finishes?
- If the trial ends unexpectedly, can my child stay on the therapy?
- How is safety monitored in the study?

Deciding to participate or not participate in a study will not affect the care the hospital offers you or your relationship with your healthcare team.



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Chapter 4

Support for You, Your Child & Family

(Author - Melanie Rolfe, Researcher & Circle of Security Facilitator)

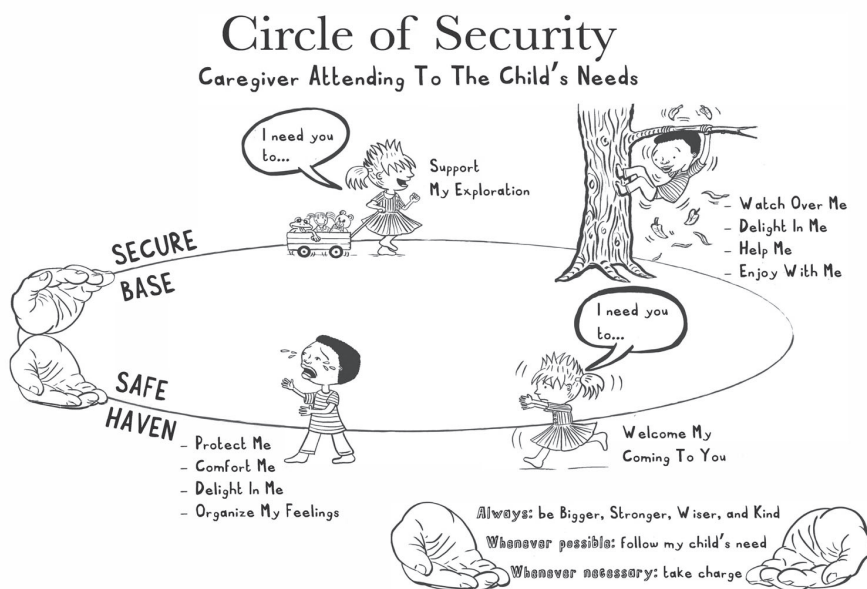
As you go forward with understanding your child's diagnosis, the effect this has on your child, yourself and your family, and processing hard feelings, it is likely you will see a difference in the way members of your family and friendship circles process and respond to this. It's important to understand that people process emotions differently. There is a wide range of 'normal' responses and ways to process emotions. Some people may not be able to support you as you expected, and others may 'step up' and provide unexpected support. This chapter aims to help you understand what your children, partner, and yourself may need now.

Parenting a Child With a Brain Tumour

A concept from a parenting approach known as the 'Circle of Security' is helpful to understand how to support your children and ensure you receive the support you need. The diagram below explains some of the theory, and there is further information in the online videos at www.circleofsecurityinternational.com.



In the circle, the hands on the left represent you. You are your child's secure base and their safe haven. Your relationship with your child is a fundamental attachment relationship (a deep emotional connection). Knowing you are there gives them the confidence to go out and explore the world (top of the circle) and come back to you for comfort (bottom of the circle). You are an essential piece of the puzzle that shapes them and how they respond to their world.



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In the top part of the circle, your child is 'going out' into the world to explore. When children are comfortable, they explore the world, and the

parent's job is to watch out for them, support them in exploring, play with them, and delight in them. 'Going out' doesn't necessarily involve physically moving and could include a child playing with others, alone, with you, or even trying new things. When your child has experienced a serious health event like a brain tumour, this part of the circle can be tricky because the child and parent may have many worries for the child's well-being and it can be difficult to let them explore and hard to find times for joy and delight.

At the bottom of the circle, the child is experiencing distress and returning to their safe haven - to you. When your child expresses distress, they must be welcomed, comforted, and helped to understand their feelings. When a brain tumour is diagnosed, there will likely be times that both your child with a brain tumour and your other children will need your support. This may not always be as clear as running to you in tears. Displays of anger, acting out, asking for your help with tasks they have previously been able to do, bed wetting, or trouble at school may all be signs that your child needs support. Your bigger, stronger, wiser and kind 'hands' to comfort them can help them make sense of what they are experiencing and feeling and can help them move from distressed to a calmer state.

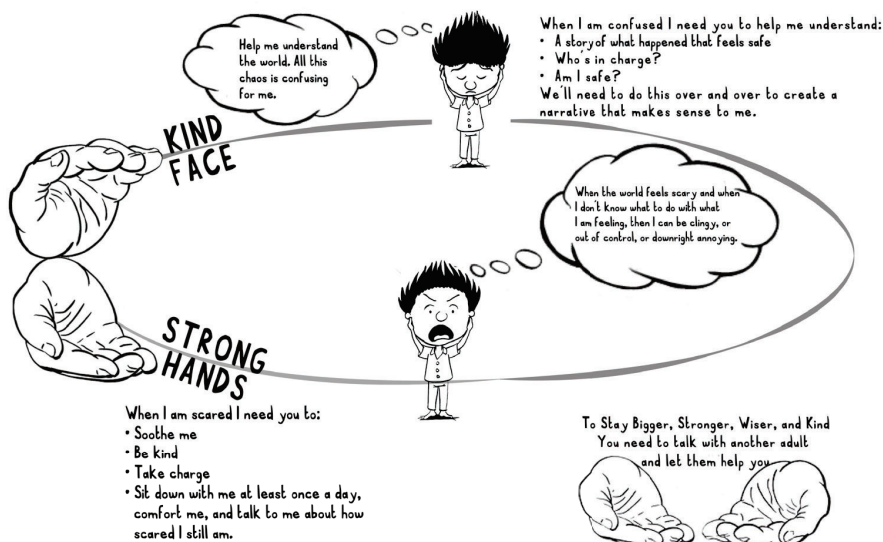
Circle of Security have specific resources aimed at helping parents understand what their children need during times of worry and upset which could be traumatising. During this time parents' role in helping their children process and understand what they are going through can help their child's coping. The Circle of Security for Traumatic Events (below) outlines this, and more info can be found online by searching for 'traumatic' on their website or following this QR Code:



Circle of Security®

Following a Traumatic Event

Helping Children Feel Safe by Being Bigger, Stronger, Wiser, and Kind



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The challenge of being the ‘hands’ for your children through hard times is that you, too, are in distress. You also need some safe hands to turn to. As your loved ones navigate their own emotions, and as your needs increase through this time, it’s possible that the people who usually support you may not be able to meet your needs. Thinking through your needs and who can provide these supports can help. And it is also important to remember that different people are good at different things. In the table below, think through the elements of the Circle of Security in the first column. In the second column, write how you would like to have these needs met; in the third column, write down a few people you can go to for these needs. There’s an example in the first row to get you started. There are also some blank rows at the bottom to add things that might not be in the Circle of Security but that you feel are important.

Circle Element	What I need	Who I can turn to
Eg. Comfort me	To be heard To be held A cup of tea To be taken care of	Friend Partner Therapist Support Group
Welcome me		
Comfort me		
Be with me		
Delight in me		
Enjoy with me		
Help me organise my feelings		
Protect me		



Doing this reflection exercise might highlight some additional support needs, such as mental health support or connections to other parents who have had a child diagnosed with a brain tumour for support. You'll find a list of services to consider at the end of this chapter (page 79).

Supporting Siblings

Siblings often take a backseat during a child's diagnosis and treatment, as the focus is on the diagnosed child. Families may need to be physically divided between locations, with a carer required at the hospital while another manages home life. Parents are stretched with pulls on their time, mental energy, and emotional capacity. Some siblings may express their distress at this situation, while some may withdraw or take on too much in an attempt to make things easier for the family.

For older children, you may be able to talk them through the exercise above and plan for times when a parent won't have the capacity to be there for a child, highlighting other people and services that can support them.

While it is important for children to feel their parents are trying to meet their needs, the concept of 'good enough' parenting is important here. Research tells us that parents who 'get it right' just 30% of the time build a secure attachment with their child - and here 'getting it right' includes where there is a breakdown in the relationship that is then repaired through apology and comfort. It is important for children to see that their parents intend to 'get it right' most of the time. For older children, it may be useful to explain how your time or energy is divided right now, so parenting them will include you being there as much as you can, and bringing in other people who can support your child. It's important not to make your child feel like they can't come to you with their needs or that they need to be there to support you. Children don't need to be your 'hands' through this. It can be a tricky balance. Circle of Security theory

says that as parents, we want our children to always feel us showing them 'I pick you, I choose you, I love you', even when life throws seasons at you when you can't be there as much as you would like.

The comfort in the "30%" idea isn't in the number itself.

It's in the message behind it:

You don't have to be perfect.

You'll miss things.

You'll lose patience.

You'll juggle more than feels possible.

But what matters is that you notice when you've missed,

That you come back.

That you keep trying.

*This is what builds trust and security
— not perfect parenting, but Good Enough.*

From www.circleofsecurityinternational.com

Some specific things that families have found useful to maintain connection and build relationships with their children during a brain tumour journey include;

- Being honest about what is occurring. Children often imagine the worst when they are not told the whole story.
- Making some connection rituals, like a goodnight video call with your favourite song or sending funny photos to each other when you are apart.
- Organising other friends and family to spend extra time with siblings when parents cannot be there.
- Including siblings in what is going on, including at the hospital when it is practical.
- Using books to talk about what is happening. Redkite has a bookclub where you can borrow books specific to families navigating childhood cancer.
- Talking to teachers to let them know the sibling may not have their usual ability to focus, time to complete homework, or emotional and behavioural self-control.
- Showing empathy and compassion for siblings' experience.
- Showing your love and appreciation for all your children through their 'love language', which may be through physical touch, words, acts of service, gifts, or time together.
- Using play for connection and distraction during particularly stressful times.
- Maintain a consistent pattern in your daily activities as much as possible. Where this isn't possible overall, you may still be able to maintain parts of it, for example, a nighttime routine of books, cuddles, and then bed.
- Practice relaxation techniques like story meditations, music, or massage.
- Encourage family members to keep up their fun and social activities where possible- these are part of feeling like 'normal' life is continuing,

and great for their mental and physical health.

- Seek help from family and friends with household tasks and childcare, and care for yourself so you have the headspace to offer your child comfort and kindness.

Partners

If you have a partner, they will likely be part of your support system. Some relationships will grow together through the challenges of this experience, and we hear many stories of partnerships where people were able to communicate, express their own needs, connect, and hold compassion for moments of pain and forgiveness for moments where people didn't get it exactly right. It is also typical for relationships to struggle through such a difficult period, and you will likely have at least some periods of disconnection, anger, and miscommunication or when you feel you are drifting apart. You will both have periods of intense emotions, fatigue, and emotional exhaustion. Now is a time to lower the pressure you put on yourselves and consider what is truly worth your energy.

Going through the Circle of Security information and completing the table with your partner will give you a common language for how you support your children and also give you language to talk about your needs with each other. For example, you might find that you have fewer moments of connection due to the pulls on your time and might need to try to schedule some time for 'enjoy with me' moments, to connect over a movie, a favourite pastime, or just a coffee. You might find it helpful to express if you are going to them for a 'comfort me' moment or let them know they can come to you for this. Disconnection can happen when someone goes to their partner for comfort but is instead offered advice or attempts to 'fix' issues. You might also talk about other supports, such as mental health services and peer support groups, that can help if you can't be the safe haven the other person needs.

Families who have been through this journey have expressed that a difficult part is the differences in coping styles that can exist. This is a time when it's important to understand that people have different coping styles, and even if you believe your partner would be better off if they adopted a different style, the middle of an emotionally challenging time is usually not the time for behaviour changes. Unless the coping style is dangerous, try to focus on asking them what they need to cope, trusting that they know what they need, expressing what you need, and forgiving each other. If their coping style is causing harm or undue distress, contact a GP or other health professional.

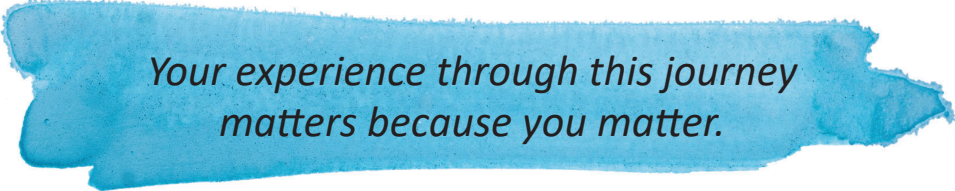
Managing Emotions

Our understanding of processing complex emotions and traumatic experiences has grown in recent years. This research indicates that our emotions are not just processed through our thoughts, and the body plays an important role. The term 'top-down' processing describes changes to emotions that occur through thinking (i.e., from the brain down to the body), while 'bottom-up' processing is used to describe changes that occur to our thoughts and emotions by moving our bodies.

If you pause to think about it, you'll probably be able to identify times when your body was telling you what it needed to manage your emotions. You might be able to think about a time when you felt restless and fidgety - a sign that your body needed movement, often rapid movement. This is a part of completing a stress response cycle. Trying to ignore this need when it is expressed in your body can lead to stress hanging around. You might be able to think of a time when you just needed a hug or to curl up under a blanket. The pressure of a hug or heavy blanket has a calming effect on your body. These are times when your body is telling you what it needs.

Another way to think about this ‘bottom-up’ processing is to think of ways to calm a newborn baby. Without language, we can make a baby feel safe and loved through calm pressure, such as being wrapped or hugged; movement, such as swaying; sound, such as white noise or music; and skin-to-skin touch, such as massage. Think about your preferences for sound, vision, touch, movement, body pressure, and even smells (these are your sensory preferences). You might be able to set up a place in your home that fills a lot of your sensory needs, or you may be bring some of these elements into the hospital. Being immersed in nature calms your nervous system and decreases the stress hormones your body produces. Going for a walk outside can be helpful. Slow, deep breathing is another way our bodies can tell our brains that we are safe.

A story or emotion that can’t be expressed can be very upsetting. Some people find it helpful to express this in words through writing or talking to someone. Some people might feel most at home when they express themselves creatively, like painting, music, or dance. When life is busy, it can be easy to write these things off as luxuries, but spending some time listening to what your emotional needs are and addressing these in a way that feels right to you will help you and the people around you to cope as well as possible through your child’s treatment.



*Your experience through this journey
matters because you matter.*

Moments where you feel under threat and out of control can be experienced as traumatic, meaning they are stored in your body and brain in a way that makes them hard to just ‘move on’ from. When a child is diagnosed with a brain tumour, the moment of diagnosis itself is

often a trauma. You might notice something has been stored as a trauma for you if you find yourself replaying it, avoiding situations or places that remind you of it, and being 'on the lookout' for other dangers like it. If you recognise these symptoms in yourself, please reach out for help. This response is very common and very treatable. The earlier you get support, the better. Therapy is one way to have a safe space to tell your story and to receive support to practice positive coping skills. Some therapies, such as EMDR (eye movement desensitisation and reprocessing), are particularly effective for processing trauma. EMDR and Trauma-focused CBT (cognitive behavioural therapy) are recommended by the World Health Organization for trauma-related distress. There is evidence that the side-to-side eye movement used in EMDR is a key component in processing trauma, and even doing everyday things that need this eye movement, such as playing Tetris and allowing your mind to wander on the distressing experience and emotions, has been shown to reduce post-traumatic stress disorder. Some apps exist to guide you through this. You'll find information on support services that may be available to you on page 80 of this booklet.

Looking After Yourself

All the people who care for you would encourage you to take care of yourself because your emotions matter. Some people find it easier to take time to look after themselves by thinking about the impact their well-being has on those around them. When you are in the best emotional place possible, you can also support those around you best. Whatever way of thinking encourages you to look after your emotions, below is an exercise to create a well-being plan to think through what you might need to best cope with the journey ahead.

Need	Me	My child	My Partner	Other	Other
Sounds, sensations, and environments that calm me					
Activities that help relieve stress					
Activities that bring joy					
Activities that help express emotions					
Activities that help process emotions					
Activities that help connect with others					
Activities that help me when I feel agitated/frustrated					



*“Rest and self-care are so important.
When you take time to replenish your spirit,
it allows you to serve from the overflow.
You cannot serve from an empty vessel.”*

Eleanor Brown

When you’ve thought through ways your emotions are best supported, you can use these steps with your children, partner, and other important people to create their well-being plan. Once you’ve thought about what you need, think about ways to build these into your life to take care of yourself through this time.

How can I build these things into my life while my family navigates hospital and treatment?

Getting Support

If you are eligible for Medicare in Australia, you can access mental health support through your GP. A GP will make a mental health care plan with you and refer you to a psychologist. If you are after a particular type of psychologist, for example, one who offers trauma-focused therapies such as EMDR, look for these online or ask your GP to refer you to one who offers this. If you are eligible for Medicare, with a mental health care plan, Medicare will cover part of the cost of the session, but there is usually still a ‘gap’ amount that you will have to pay. Some childhood cancer community groups support you with money to cover this ‘gap’- talk to your Social Worker about your eligibility for this and to receive a referral.

Families who have been through the experience of having a child with a brain tumour have expressed that it can be helpful to get emotional and

mental health support from people who have some knowledge in the area. Several community services exist that address this. Below is a list of community services that offer some emotional support across individual, group, and social activities.

Services

Your social worker can help you to connect with all of these organisations. Many will take a direct enquiry from you and then need a referral or supporting letter from a healthcare provider. Registering at www.cancerhub.org.au will connect you with all relevant services across Redkite, Canteen, and Camp Quality.

Organisation	What they offer	How to connect
Redkite	Counselling for parents, siblings, and grandparents, with a Social Worker. Financial support. Online peer support groups. Resource library, including books for siblings. Online information on childhood cancer and coping with childhood cancer.	www.redkite.org.au
Brainchild Foundation	Information specific to brain tumours in children. Emergency financial support. Therapy and tutoring to support children with brain tumours. Family camps.	www.brainchild.org.au
Canteen	Provides kids and families facing cancer with fun experiences, trusted information, specialised care, coping tools and a supportive community. They offer: recreation programs, puppet programs for schools and preschools, hospital programs, and other services.	www.canteen.org.au

Camp Quality	Provides kids and families facing cancer with fun experiences, trusted information, specialised care, coping tools and a supportive community. They offer: recreation programs, puppet programs for schools and preschools, hospital programs, and other services.	www.campquality.org.au
Children's Tumour Foundation	Support for families of children diagnosed with neurofibromatosis, through peer connections, camps, health navigation (including NDIS and transition to adult services), family education, school navigation, and a helpline. Some services not available in all states.	www.ctf.org.au

Smart Phone App Resources

What it is	Why you might like it	How to get it
EMDR App	Home-based EMDR-guided exercises which support trauma processing.	Search 'Anxiety Release based on EMDR' in Google Play or the AppStore
KiteCrew App	App to organise practical support from your social network, for example help with meals.	Search 'KiteCrew' in Google Play or the AppStore
Juiced TV App	Videos of kids and families navigating hospital and procedures. Mindfulness activities to help prep for stressful moments and procedures.	Available on tablets only (not phones) from Google Play or the AppStore

Services Outside the Hospital: NDIS

(Author - Claire Radford, Speech Pathologist)

Brain tumours and the side effects of brain tumour treatment can result in a secondary diagnosis of an Acquired Brain Injury or ABI. Depending on the severity of the impact on function and the long-term/permanent nature of these changes, your child may be eligible for support through the NDIS (National Disability Insurance Scheme). The NDIS is a government initiative that can fund reasonable and necessary supports such as equipment (assistive technology), therapy interventions in the community, and care support. Discuss your child's specific difficulties with a member of the hospital allied health team to understand whether they will meet the criteria for NDIS and the process to apply (<https://www.ndis.gov.au/>). Accessing this support as soon as possible is important as there can sometimes be waiting lists. It is best to start the process early to access support when you need it.

Community Services

I'm looking for...	What's available	How to get it
Support for my child's school	Camp Quality (for primary school children) and Canteen (12-18 year olds) offer school education programs on what cancer is and how to support someone who has it.	www.campquality.org.au 
	Ronald McDonald House offer online modules on supporting children after hospitalisation.	www.rmhc.org.au/what-we-do/learning-program/ 
	Draft email to send to school, informing them of your children's needs.	www.brainchild.org.au and QR code: 

I'm looking for...	What's available	How to get it
Education support for my child	Ronald McDonald House Tutoring.	www.rmhc.org.au/what-we-do/learning-program/ 
	Redkite - annual scholarships to support goals for 13-18 year olds.	www.redkite.org.au/service/dare-to-dream-scholarships/ 
	Brainchild - funding to support educational goals through tutoring and allied health.	www.brainchild.org.au/how-we-can-help/the-better-tomorrows-program/ 

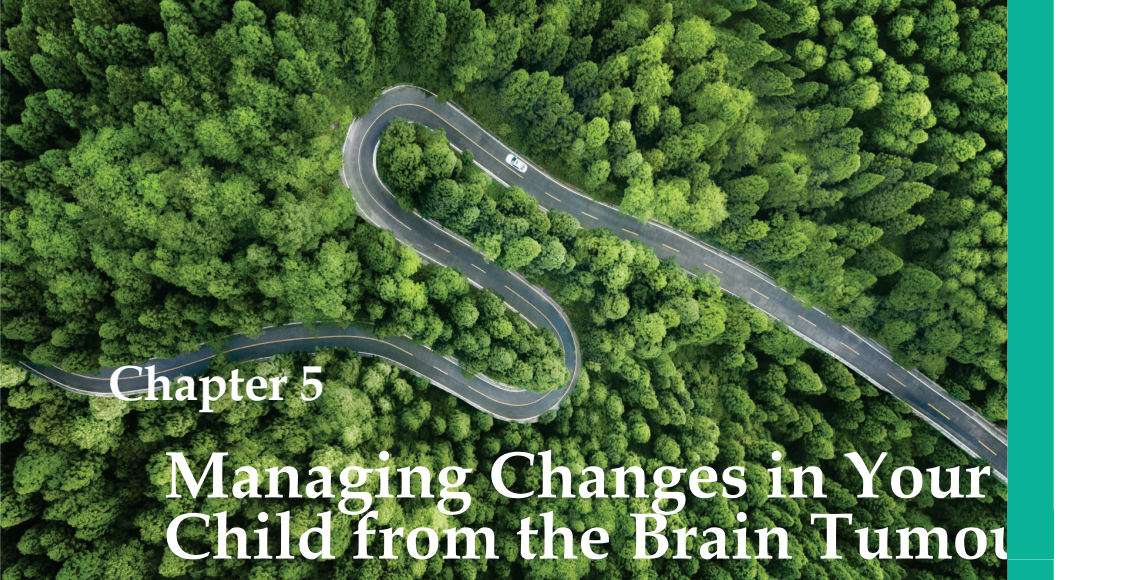
I'm looking for...	What's available	How to get it
Fun	Canteen - Day events, over-night camps, online peer support for young people 12-25 with cancer and their siblings.	www.canteen.org.au 
	Camp Quality - Day events and camps for children with cancer and their families.	www.campquality.org.au 
	Brainchild Foundation - Day events and camps for children with brain tumours and their families.	www.brainchild.org.au 
	Starlight Children's Foundation - Online community (Livewire) and wish-granting.	www.livewire.org.au  https://www.starlight.org.au/about-us/what-we-do/wishgranting/ 

Make-a-Wish- wish-granting.

<https://www.makeawish.org.au/wishes>



[illegible]

An aerial photograph of a dense, vibrant green forest. A paved road with yellow dashed lines winds through the trees in a series of loops and curves. A small white car is visible on the road. The text 'Chapter 5' is overlaid on the left side of the image.

Chapter 5

Managing Changes in Your Child from the Brain Tumour

The brain is organised into regions. Each region controls specific thinking (cognitive), physical, and emotional functions. These functions can be affected by brain tumours, hydrocephalus (pressure from the build-up of cerebral spinal fluid) and side effects of treatment. The functions that are impacted will depend on where the changes in the brain occur. In this section, you'll find information on what to expect relating to changes in your child's thinking, behaviour, communication, eating, movement, and some common side effects and symptoms. It's likely your child won't experience all of these symptoms, though it can be comforting to know what to look for.

Cognition (Thinking) and Behaviour

Many patients experience some change in their behaviour and/or thinking.

- Emotion and personality changes can include depression, anxiety, obsessive-compulsive behaviours (not being able to let things go or having to act in a certain way over and over again), changes in their ability to let thoughts go or having to act in a certain way over and over again)

behaviours, changes in their ability to manage their reactions, irritability, mood swings, withdrawal, and socially inappropriate behaviour.

- Attention and concentration changes can include confusion, being easily distracted, difficulty multitasking and planning.
- Learning and memory changes can include difficulty taking in, storing, and retrieving information, which results in short-term memory loss.
- Executive functioning changes can include being less able to reason logically or organise their thoughts, or showing impaired judgement (making bad decisions).
- Some individuals may be aware of their behaviour and thinking, while others will not.
- In some cases, changes in thinking and behaviour are so subtle that people themselves are more aware of their difficulties than those around them.

Thinking, behaviour, personality, or mood changes can be hard to accept. Some parents and caregivers feel that they have already 'lost' parts of their child as their behaviour and thinking shifted. It is normal to mourn these changes. Some people feel guilty about having such feelings and find it hard to talk about them. Know that these are normal feelings and try to find a trusted person- such as a friend or a professional - who can listen as you discuss them. Someone who has been through this journey already may be able to help you truly feel that your feelings are normal and valid.

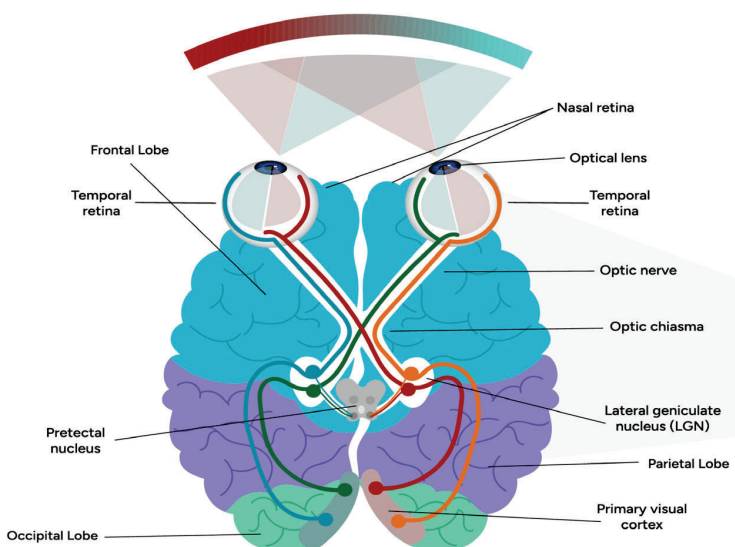
Visual Changes

If your child's vision has had changes due to a brain tumour or its treatment, it is important to understand the visual system. If your child

mentions any change in their vision or if you notice changes, discuss these with your doctor.

The Visual System

The visual system includes the eye itself and the pathways that extend from the retina at the back of the eye to the occipital lobes at the back of the brain. Visual fields refer to what can be seen in all directions while both eyes are open and looking straight ahead. Each eye has a right and left visual field, with each eye's field of vision overlapping that of the opposite eye- you can see the difference between these fields by opening one eye at a time, and switching which eye is open. The brain links these images to form one image when both eyes are open.



Optometrists and Ophthalmologists are specialists who focus on the eye and visual system. A neuro-ophthalmologist has additional knowledge of brain conditions that impact the eye and visual system.

Examining the visual system is important in your child's diagnosis and ongoing treatment of brain tumours. Regular eye examinations can help in the early detection of certain brain tumours and provide an opportunity to notice any vision changes.

Common Visual Changes and Symptoms

Papilledema: Swelling of the optic nerves, visible during eye examination, can mean increased pressure inside the skull (intracranial pressure) caused by the growing tumour or a blockage of cerebrospinal fluid. Papilledema may initially be asymptomatic (not having any noticeable symptoms), which is why thorough eye examinations are essential. Severe or persistent cases can lead to visual loss in both eyes.

Optic Disc Pallor: The visible part of the optic nerve, known as the optic disc, typically appears pink but may become yellowish or whitish in cases of optic nerve damage resulting from various optic nerve diseases.

Vision Loss to One Eye: If a tumour applies pressure to one optic nerve before it crosses the other, there may be partial vision loss in one eye. The person may notice a “missing area” or increasing blurriness in their vision. However, some people may not be aware of vision loss in one eye if they usually rely on the ‘good’ eye.

Vision Loss to Both Eyes: Problems with the visual pathways at the optic chiasm, where the two optic nerves cross, can result in vision loss in both eyes. Those affected typically experience missing vision on one side. Suppose the problem occurs directly at the chiasm area (e.g., due to a pituitary tumour). In that case, the usual symptom is vision loss on both outer sides, with a loss of vision originating from the right eye on the right side and the left eye on the left side when looking straight ahead.

Double Vision (Diplopia): Our eyes move in sync. However, a tumour, or the pressure it creates, can interfere with the nerves responsible for eye

movement. This leads to an imbalance in the action of the eye muscles. When these muscles don't move together, this can result in double vision. The third, fourth, and sixth cranial nerves are involved in diplopia. Depending on which nerve is affected, symptoms may include outward eye movement, drooping eyelid, enlarged pupil with poor light response, upward eye movement, or inward eye movement toward the bridge of the nose.

Nystagmus: The continuous movement of eyes back and forth is called Nystagmus. There are different types, depending on the speed and pattern of the eye movement. Your child may see their vision jumping because of this eye movement, but many people do not notice any changes to their vision. Nystagmus may be evident to you or may need examination by a doctor to diagnose. Your child's diagnosis can indicate what areas of the brain the tumour is impacting, usually the brainstem or cerebellum.

Impacts on Your Child's Communication

(Author - Claire Radford, Speech Pathologist)

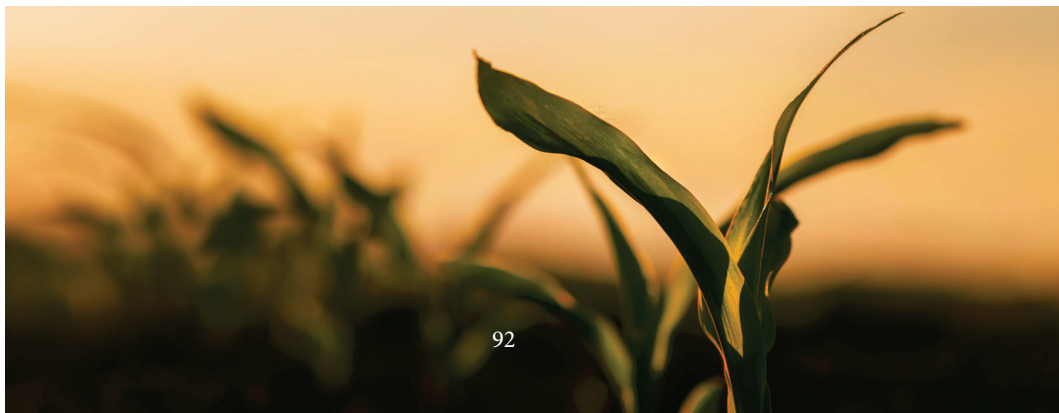
Communication is complex and includes spoken, written, or signed language, facial expression and body language. A considerable amount of communication is expressed through things other than words, like the tone of voice we use and our facial expressions.

Communication relies on several areas of the brain and can be disrupted by a brain tumour and its treatment. A brain tumour can disrupt communication by affecting the ability to understand, speak, retrieve words, form sentences, use appropriate nonverbal signals (like facial expression), consider the listener's perspective, read, or write. The disruption can occur in one or multiple areas of communication, and the type and severity of the communication problem depend on the tumour's

location and size and the treatments it needs.

If your child's communication is affected, it can be helpful to;

- Recognise that your child's ability to communicate is not the same as their intelligence.
- Meet your child where they're at. It is usual and expected that their communication may differ from what it was or from other kids their age.
- Create a relaxed communication environment.
- Communicate in a quiet setting by turning off the radio, closing doors, and limiting the number of people your child interacts with at once.
- Get your child's attention before speaking.
- Use gestures and familiar topics to help your child understand. While they are in the hospital, showing them photographs of people and family events can provide context for conversation
- Speak slightly slower at a normal volume (difficulty to understand is not the same as hearing loss, so you don't need to raise your voice).
- Offer choices when your child struggles to find words (e.g., "Do you want apple juice or water?")
- Use short, straightforward sentences with familiar words and variations to say the same thing (e.g., "Are you thirsty?" or "Would you like a drink?").



- Focus on understanding your child's message without correcting pronunciation or interrupting them.
- Be aware of your child's fatigue.
- Use technologies like speech apps to help with communication.

Impacts on Diet and Nutrition – During & After Treatment

(Author- Claire Radford, Speech Pathologist)

A brain tumour and its treatment may impact your child's eating in many ways, for example:

- Altered taste (dysgeusia) – your child may start to refuse their favourite foods because they no longer taste the same. Some children experience an unpleasant or metallic taste every time they eat. Your child may begin to prefer salty or strongly flavoured foods.
- Nausea may result in reduced appetite and weight loss.
- Fatigue can impact on your child's ability to chew foods effectively.
- Oral and jaw pain from tooth sensitivity or decay, muscle wasting (muscle atrophy), and mouth ulcers can result in avoiding food.
- Heightened gag reflex related to taste changes.
- Difficulty with the physical movement involved in eating, drinking, or breastfeeding, including in managing some textures.
- Pocketing (holding) food residue in the mouth.
- Difficulty weaning from tube feeds.
- Coughing or choking consistently when eating or drinking.
- The feeling of food getting stuck in the back of the throat.
- Excess saliva loss (drooling).
- Difficulty protecting the airway during swallowing, causing food and drink

to go down the wrong way to the lungs (aspiration).

- They may experience changes in their sense of hunger, leading them to eat more or less.

To help your child's relationship with food and nutrition during this time:

- Maintain excellent oral healthcare to reduce the risk of complications from food or drink 'going the wrong way' (aspiration).
- Avoid pressuring your child to eat/drink or force-feeding; eating and drinking need to be a positive experience to make progress, especially when your child has had lots of negative experiences around the face and mouth during treatment.
- Involve your child in mealtimes so they are still exposed to the sights and smells of foods.
- Encourage sitting at a table for family meals to model positive mealtime experiences to your child.
- Get your child to help prepare meals and snacks for the family – they can help you cut, mix, bake and cook.
- Encourage tasting during family meals.
- Get everyone in the family involved by talking about different food textures, tastes and smells to encourage interaction with food, even if your child can't or doesn't feel like eating.
- Encourage your child to play with different mealtime equipment, even if they are not eating or drinking a lot, e.g. cup play during bath time, blowing feathers through straws.
- Engage in pretend play with food toys, and equipment, or make foods out of playdough.

- Encourage food exploration play so your child can learn about different food textures and smells, even without eating them directly.
- Artificial nutrition and hydration will not treat the cancer but can provide safe ongoing nutrition.
- Take advantage of trouble-free times; offer high-calorie, high-protein foods when your child has a good appetite to compensate for poor eating during other periods.
- To boost calorie intake, add cream, butter, margarine, oil, sour cream, yoghurt, mayonnaise, ice cream, cheese, jam, jelly, marmalade, honey, syrups, sugar, and avocado.
- To boost protein, incorporate milk powder, eggs, cheese, yoghurt, peanut butter, tofu, dried peas and beans, nuts, and seeds into their diet.
- Hide extras within other foods; spaghetti bolognese, smoothies, mac n cheese, and pizza can all hide extra vegetables, protein powder, blended tofu, and other ingredients that boost their nutritional value.

Several kinds of health professionals can help with feeding and nutrition issues. Referral to a *speech pathologist* is recommended if there are concerns about swallowing related to your child's eating and drinking, sensory (relationship with the taste, smell, and feel of food), motor (movement) skills, or concerns about airway safety during mealtimes.

Referral to a dietitian is recommended if there are concerns about your child's weight, dietary variety or nutrition. A *dietitian* or medical officer should be involved in the management of tube feeding.

Impacts on Movement and Exercise - During & After Treatment

(Author - Hayley Coulson, Physiotherapist)

Physical activity and exercise improve fatigue, psychological distress, and physical function and are safe to continue during treatment. What

physical activity your child likes will be different to the next person. Your child's interests, access to facilities, and, most importantly, their current function can play a role in deciding the best way for them to move. The most appropriate physical activity can change depending on where they are in their treatment and recovery journey and their current abilities. If your child is not feeling well, then undertaking exercise may be difficult - when this happens, physical activity should be encouraged but not forced.

Below are some activities that could be recommended, but if specific information is needed, it is best to discuss this with the healthcare team, including physiotherapist and occupational therapist:

- Movements of legs and arms in bed- some movement-based video games, online yoga or dance videos can help make this more fun
- Walking to the bathroom or kitchen
- Riding a bike or scooter
- Swimming or hydrotherapy
- Age-appropriate activities such as climbing on a playground, kicking a soccer ball, dancing
- Organised sports - tennis, karate, ballet. Look for ways to adapt their existing interests wherever possible

If your child needs supportive equipment, this can be done through the Medical Aids Subsidy Scheme (MASS). Speak to your healthcare team to determine if this suits your child.

Seizures

Brain tumours can cause recurring seizures (epilepsy). Experiencing a seizure at any time can be a frightening event. Understanding different

types of seizures can help reduce some of the associated fear.

Seizures occur when cells called neurons in the brain communicate through abnormal and excessive electrical discharges. What a seizure looks and feels like depends on the specific location in the brain where the neurons misfire. Children with tumours in the cerebral hemisphere may develop seizures. Seizures can be classified into two main categories: focal seizures (partial seizures) and generalized seizures.

1. Focal (Partial) Seizures

Focal seizures start in the brain's outer layer (cerebral cortex), often on the side where the brain tumour is located.

a. Simple Partial (Focal) Seizures.

In simple partial seizures, the person remains aware during the seizure. These seizures are sometimes referred to as 'auras'. The symptoms experienced depend on the function of the affected brain region. For example, visual disturbances may occur if a brain tumour is located in the occipital lobe, which processes vision.

Symptoms of simple partial seizures may include:

- Uncontrollable twitching movements in one or more closely related body parts, which may shift from one area to another
- Numbness or tingling in a specific part of the body or spread to nearby areas
- Visual hallucinations, seeing things that are not real. Some individuals may see coloured circles
- Illusions and distortions of visual perception (e.g., curved walls)
- Imagined taste or smell, often unpleasant
- Auditory hallucinations, hearing sounds that are not present

- Mood changes, such as fear, anger, sadness, or joy
- Altered memory, such as the replaying of memories

b. Complex Partial (Focal) Seizures

Complex partial seizures involve a loss of conscious awareness without convulsions (intense body spasms). These seizures are sometimes referred to as non-convulsive seizures. Before the seizure, the individual may experience a warning sign or aura, and their awareness of the surroundings becomes impaired. During the seizure, the person may wander, stare, or perform simple movements with the mouth (e.g., chewing, lip-smacking). More complex behaviours, such as picking up and fumbling with objects or wandering, can also happen. If this happens, staying with the person and gently guiding them away from possible harm is important.

c. Partial (Focal) Seizures with Secondary Generalisation.

Partial seizures may develop into generalized tonic-clonic or grand mal seizures (see Generalised Seizures below).

2. Generalised Seizures

There are several types of generalised seizures. One common type is the generalised convulsive seizure, where there is a loss of consciousness followed by stiffness and rhythmic jerking movements. These seizures were previously referred to as grand mal seizures but are now known



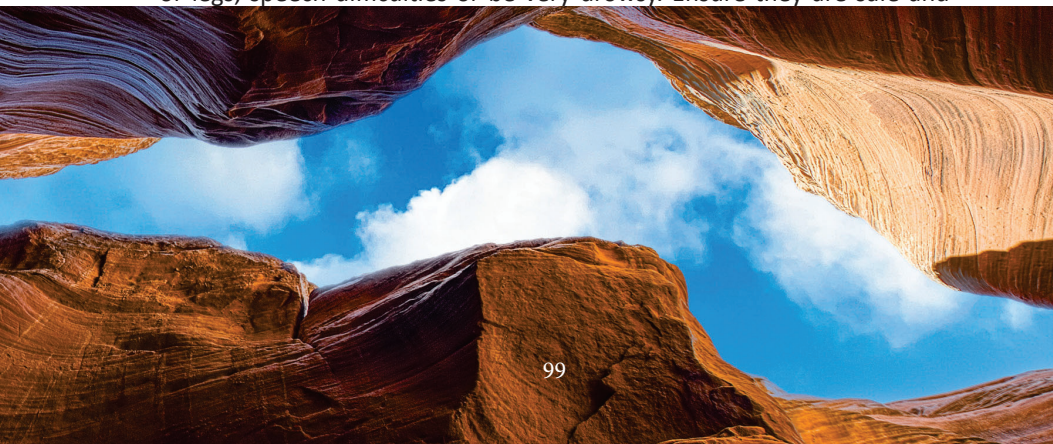
as tonic-clonic seizures, which better describe the nature of the seizure (tonic refers to stiffening, and clonic means shaking).

First Aid for a Seizure

- Don't try to restrain the person having a seizure
- Do not put anything in their mouth
- Move sharp or dangerous objects out of the way
- If on the ground, roll your child on their side and place something soft under their head to avoid banging

Call an Ambulance if:

- It is your child's first seizure
- Your child has diabetes
- Your child has a head injury
- They are in the water
- If the seizure repeats
- If the seizure lasts more than 5 minutes
- If your child is wandering, stay close and gently steer them away from danger
- When the seizure is over, your child may be confused, have weak arms or legs, speech difficulties or be very drowsy. Ensure they are safe and



stay with them until they are thinking clearly. If they continue to show these symptoms for an hour after the seizure ends, call an Ambulance.

Safety for Sports and Recreation

People experiencing uncontrolled seizures should take extra safety measures, thinking through what could happen if they had a seizure while they were doing the activity.

For example,

- Swim with constant supervision.
- Ride bicycles on paths, not roads, and always wear a helmet.
- Take extra precaution if your child is involved in sports where head injuries are likely, such as football, hockey, and soccer.
- Avoid activities where a seizure could cause significant injury, such as scuba diving and rock climbing.

Hormone, Neuroendocrine and Cardiometabolic Effects of Tumours & their Treatments

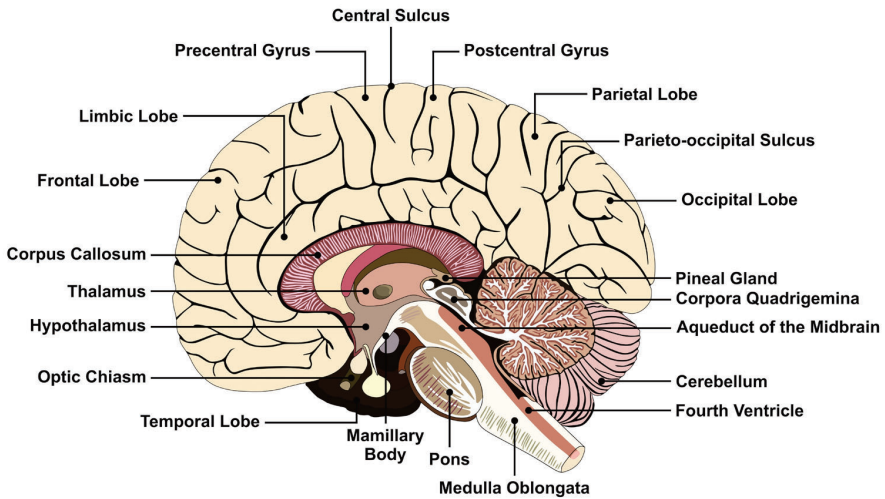
There's no way around it - there are a lot of complicated words in this section. If this section is relevant to you and your child, reading when you have the time and brain space to focus will be best.

Neuroendocrine System and Hormone Production

The neuroendocrine system creates and distributes hormones. These impact many body and brain parts, including growth, mood, and digestion.

The hypothalamus and pituitary glands in the brain are important parts of the neuroendocrine system because they start the release of hormones that impact many different functions all over the body. The

Median Section of the Brain



hypothalamus regulates essential functions like appetite, sleep, and temperature control. It also produces hormones that act on the pituitary gland, producing other hormones. These pituitary hormones regulate hormone production in target glands throughout the body. If the tumour or treatment impacts this part of the brain, it will have knock-on effects across the neuroendocrine system.

Pituitary Hormones and Their Functions

Hormones can be produced in the anterior (front) or posterior (back) pituitary gland. The anterior pituitary gland produces hormones such as luteinising hormone (LH), follicle-stimulating hormone (FSH), adrenocorticotrophic hormone (ACTH), thyrotropin-stimulating hormone (TSH), and growth hormone (GH). The posterior pituitary gland produces prolactin (PRL) and antidiuretic hormone (ADH). Each hormone has specific actions on target glands.

Treatment Effects on Neuroendocrine Function

Depending on where the tumour is located, surgery, radiotherapy, and

chemotherapy can impact the function of the hypothalamus and pituitary gland. These treatments may have acute (short-term) and long-term effects on neuroendocrine function.

Acute (Immediate) Effects: Chemotherapy or brain tumours themselves can lead to fluid balance disorders, such as excess production of antidiuretic hormone (ADH). Cortisol deficiency may also occur due to adrenal suppression from steroid therapy.

Long-term Effects: The long-term effects of brain tumours and their treatments can affect bone health, growth and height, body weight and cardiometabolic systems, puberty, sexual function and fertility, and thyroid gland function. Some may start shortly after the tumour and treatment, while others may not be obvious until years later.

Growth and height: Brain tumour survivors have a higher risk of short adult height (stature). Cranial irradiation can affect growth hormone production, leading to growth hormone deficiency. Spinal growth can also be impacted. The risk of growth hormone deficiency is influenced by factors such as radiation dose and your child's age.

Puberty: Brain tumours or their treatment can affect the production of luteinising hormone (LH) and follicle-stimulating hormone (FSH), potentially leading to early-onset puberty. Early puberty may affect predicted adult height and cause psychological issues. Delayed puberty can also occur, which may impact adult height.

Sexual Function and Fertility: Radiation therapy, especially cranial (head) or craniospinal (head and spine) irradiation, can affect the production of LH and FSH. Chemotherapy and radiation can be toxic to the gonads (ovaries and testes) and impact sexual development and fertility. The risk is determined by the type, dose, length, frequency, and treatment location. Infertility can result from an inability to produce sperm or eggs or difficulties in conception or carrying a pregnancy to term. Fertility

preservation options should be considered before treatment and can be discussed with the oncologist or fertility specialist. When treatment needs to be started urgently, there are cases where fertility preservation may not be possible.

Thyroid Damage: Cranial or craniospinal irradiation can affect the thyroid gland, which is located at the base of the neck. This can impact thyroid function, cause nodules, and cause a slight increase in the risk of future thyroid cancer. Thyroid hormone levels should be checked as part of routine follow-up.

Bone Health: As bones in children develop, treatment may affect bone metabolism, bone density, mineralisation, and the formation of new bone. Some parts of treatment that may impact this include:

- Drugs such as methotrexate and steroids
- Growth hormone deficiency
- Hypogonadism
- Poor nutrition
- Tumour infiltrating the bone
- Reduced physical activity
- Total body and craniospinal irradiation

Obesity and Cardiometabolic Effects: Brain tumour survivors are at increased risk of obesity and heart issues such as stroke, clots, lipid abnormalities, hypertension and angina-like symptoms. Some of these impacts are related to growth hormone



deficiency. Some factors that are related to the risk are:

- Age at diagnosis - younger children are at a greater risk
- Radiation to the hypothalamus
- Hormone deficiencies
- The location of the tumour, with hypothalamic tumours having a greater risk
- Gender, with girls having a higher risk
- Surgery type

Hydrocephalus and Shunts

Hydrocephalus is a condition where excess cerebrospinal fluid (CSF) builds up in the brain. This extra CSF causes increased intracranial pressure (pressure inside the skull) and various clinical symptoms like nausea and headaches. CSF, a fluid in and around the brain and spinal cord, nourishes brain cells and protects delicate structures. It circulates through channels around the spinal cord and brain, constantly absorbed and replenished. Typically, the brain maintains a balance between CSF absorption and production. However, this balance can be disrupted by a brain tumour, leading to blockages in the channels and pathways responsible for CSF circulation.

When CSF cannot circulate properly, it builds up in the brain tissue surrounding the tumour, causing an increase in intracranial pressure. This pressure causes headaches, irritability, drowsiness, and vomiting. This clinical condition resulting from the buildup of excess fluid in the brain is known as hydrocephalus. Brain tumours in the posterior fossa region of the brain, where the fourth ventricle is located, can cause blockages in CSF flow. Tumours in other brain areas can also lead to blockages or

compression of the ventricular system that circulates the CSF, contributing to hydrocephalus.

Symptoms of Hydrocephalus

The symptoms of hydrocephalus vary depending on the age of the child. Newborns and young infants may exhibit high-pitched crying, irritability, lethargy, scalp veins, seizures, bulging fontanelle, head enlargement, and vomiting. Toddlers often display similar symptoms, and losing previous skills, such as crawling instead of walking, may also occur.

Children and teenagers experience different symptoms because their skulls are no longer flexible. Common symptoms in this age group include headaches, vomiting, irritability, seizures, vision problems, coordination difficulties, and worsening cognitive (thinking) skills.

Treatment for Hydrocephalus

Sometimes, surgery to drain the fluid pathways is enough to correct the issue. If issues continue, a shunt may be necessary to be placed into the brain's ventricular system. This allows the cerebrospinal fluid (CSF) to drain away and keeps the right amount of pressure in the brain. A shunt is put in under a general anaesthetic. Most shunts need to stay in place permanently, though they may need replacing as they wear out or sometimes become blocked. Before the surgery to insert a shunt, your child will need to fast (not eat or drink), and afterwards, they may have to lie flat for around a day.

The shunt consists of a narrow, soft tube implanted through a small hole in the skull. It is tunnelled under the skin from the skull to the drainage site in the abdomen, peritoneum, lung, or heart. All shunts have a valve system that keeps CSF pressure at the right level and prevents backward flow.

Types of Shunts and Treatment Options

There are different types of shunts and placement procedures available. The ventriculoperitoneal (VP) shunt is the most commonly used shunt, with the tubing passing underneath the scalp and down the neck through small incisions. It is inserted into the peritoneum, a thin sac covering the organs in the abdomen, allowing CSF to be absorbed.

In cases where the abdomen cannot absorb the fluid, the ventriculo-pleural (VPI) shunt provides an alternative. The shunt tubing is directed to the pleural space between the ribs, where CSF is drained and reabsorbed.

Another option is the ventriculo-atrial (VA) shunt, which redirects CSF to the atrium of the heart via a vein. In the heart, CSF mixes with other body fluids and is filtered.

Endoscopic third ventriculostomy (ETV) is a surgical alternative for obstructive hydrocephalus, where the blockage to CSF flow occurs at or above the level of the fourth ventricle. This procedure involves creating a hole in the floor of the third ventricle to allow the CSF to drain into the regular fluid chambers below the base of the brain and across the brain's surface, where it will be reabsorbed. In this procedure, no hardware is left, reducing the infection risk.

Shunt Care

Damage or infection around the shunt system can mean it cannot divert enough CSF away from the brain. To care for the shunt;

- Do not put direct pressure on the shunt
- Ensure the area around the shunt remains clean
- Avoid sports that need your child to turn their head frequently, such as gymnastics and wrestling

Shunt infections are most commonly caused by your child's bacteria

entering the surgical site, not by exposure to illnesses. Signs of infection include fever, redness or swelling along the tract, and in infants, downward eye gaze. If you suspect an infection, contact your medical team immediately.

Posterior Fossa Syndrome

Posterior fossa syndrome can also be called cerebellar mutism syndrome. It happens in some children who have had surgery in the posterior fossa structures (the cerebellum and brainstem- located towards the base of the skull), though the exact reasons some children develop this syndrome are unclear. In this syndrome, children have problems with communication, motor (movement) skills, and mood. Around 25% of children who have surgery to remove medulloblastoma will develop posterior fossa syndrome. If your child develops posterior fossa syndrome they will need extra support from allied health, and a lot of patience from you, as their brain works to develop new pathways. This period can bring a lot of stress and anxiety for families. Most children will recover over a period of a few months, but some symptoms can stay for longer or become permanent.

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Chapter 6

Complementary Medicines

Parents of children diagnosed with a brain tumour face tough decisions, especially when there are multiple treatment options available. This decision-making process becomes even more complex when considering complementary medicine alongside traditional accumulated cancer treatments for their child.

A lot of research has gone into developing an ‘evidence base’ on how effective different cancer treatments are and their likely side effects. These studies use large numbers to make sure they have a good picture of what happens for a lot of different people, and they are conducted in ways that minimise potential bias. However, the scenario is different when it comes to complementary and alternative medicine, as research in this field has not been completed in the same scientific way. For example, we are only starting to understand different genetic impacts on the uptake of other vitamins. This means that the correct dose for your child is hard to determine, and the impact this may have on their treatment is hard to know. There is a lot of misunderstanding and misinformation online about complementary medicines. It is important to discuss any complementary medicines you are considering using with your healthcare team.

One way to manage these complex decisions is through shared decision-making. This process involves you, your family, and your child's healthcare provider. This process should consider the goals and values of you and your family and also take into account clinical expertise and available research. The outcome is an informed decision that brings together your family's beliefs and the best clinical recommendations.

Before deciding to use complementary therapies or consult a complementary practitioner, it is important to consider the following information:

1. Define the goals you hope to achieve by using complementary therapy. Is it symptom management? Quality of life? Assess whether the therapy has the potential to help your child with these goals. Be cautious of therapies that claim to provide a "cure" for cancer.
2. Evaluate the risks and benefits associated with the complementary therapy. Are there any known side effects? Assess the scientific evidence supporting the therapy and determine how reliable and up-to-date that information is. Striking a balance between what is known and unknown about a therapy is important. Make sure you determine the safe dosage of the therapy, as more is not necessarily better.
3. Consider potential interactions between the complementary therapy, other treatments, and your child's existing health conditions. For example, grapefruit and green tea can affect the liver's processing of chemotherapeutic drugs, leading to higher or lower drug levels in the body. Many complementary therapies can interact with each other, which may lead to unexpected outcomes.
4. Take into account any practical requirements associated with the complementary therapy. Will there be travel involved, repeat appointments, or specific procedures? Consider the costs associated with

the therapy, including financial, time, and energy expenses. Examine if these components of the therapy are in line with your goals and values.

5. Evaluate the training, credentials, and experience of the complementary medicine practitioner.

6. Explore the complementary medicine support or services available from your local cancer agency or hospital. Many conventional cancer care centres now provide mind-body and exercise therapies. If you have specific questions about your child's diet or the safety of natural health products, consider consulting a registered dietitian or pharmacist.

7. After thoroughly reviewing all the information, assess whether the complementary therapy aligns with your desired goal, does not interfere with conventional treatment, and carries acceptable risks and possible benefits for you and your child.

Once you have decided on a complementary therapy or practitioner, make sure you tell your child's oncologist and family doctor. Providing a full overview of all therapies, including complementary medicine, means your healthcare team can deliver the safest care. Having the support of your healthcare team to make decisions about complementary medicine means that you can be confident you are doing the best thing to support your child.

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Chapter 7

Long-term & Late Effects

Brain tumour survivors often experience side effects that continue from the time of treatment or develop late side effects that start weeks, months, or even years after treatment. Building a life around these impacts and new disability is often complex. Families say they don't go 'back to normal'; they must figure out how to create their 'new normal'. Many families face mental health challenges during this period as they process the enormity of what they have been through, re-establish family dynamics and routines, and understand more about what the future will hold. Being aware of this from early on can help transition to a life that factors these in and uses as many early interventions support as possible. Navigating ongoing effects is often unexpected when you need emotional support through peer support or a psychology or counselling professional. Traumatization that has happened through the diagnostic and treatment journey sometimes becomes evident during this time, in which case trauma-focused therapy, such as EMDR, should be pursued. It's important to consider the psychological well-being of all family members through this time.

*You've just come in from a rainstorm;
You can't expect to be immediately
Dry, warm, and comfortable.*

*But you can do the little things-
Take off the heavy clothing,
Turn on the coffee pot,
Wrap yourself in a blanket.*

One small thing at a time.

Healing is a process.

(Whitney Hanson)

Some everyday long-term and late effects from the brain tumour and treatment include;

Cognitive Difficulties

After brain tumour treatment, some children may experience cognitive changes to different levels. These changes can include memory, attention, concentration, retaining information, processing speed, organisation, math skills, reading, and comprehension difficulties. These cognitive changes can affect a child's performance at school, requiring additional

time, patience, and support.

Children who received high doses of cranial radiation at a young age, particularly six years or younger, are at higher risk for cognitive challenges. If your child's cognitive functions are affected, a neuropsychological assessment can provide a detailed understanding of their abilities. This assessment can guide the development of tailored recommendations and, in some cases, an Individualised Education Plan (IEP) to ensure appropriate support and accommodations at school. Obtaining a baseline assessment before treatment can be helpful, and reassessment throughout your child's development can inform future planning.

Neuropsychological/Psychological Factors

After going through the experience of brain tumour treatment, it will likely take time to get used to new disabilities and social needs. This is usual and may include a need for specialised psychology support to address the trauma of the experience. If the tumour affects the frontal lobes of the brain, it can lead to social and behavioural issues that impact the development of peer or romantic relationships. You might see some of these signs in your child:

- Less aware of social norms
- Make inappropriate social decisions
- Difficulties starting tasks
- Difficulties with emotional control and social boundaries
- Difficulties in memory, attention and concentration, anxiety issues, depression and mood changes
- Body image concerns
- Concerns with peer acceptance, confidence, and self-esteem

Encouragement and coaching may be necessary to help children develop

age-appropriate social skills, to process emotional issues, and to find alternative means of connecting with peers. Psychologists, counsellors, occupational therapists, and social workers can help navigate these social components.

Physical Side Effects

The tumour itself or its treatment can cause various physical side effects, including endocrine (hormone) problems, growth delays, kidney damage, fatigue (tiredness), and impacts on sexual development and fertility. Radiation therapy can disrupt the endocrine system, resulting in overproduction or underproduction of hormones. Growth hormone deficiency is a common effect, which can be addressed through hormone replacement therapy. Radiation to the spine may affect bone growth, which could result in shorter stature. Monitoring kidney function and addressing any issues that arise is imperative. Finally, discussions about sexual development and fertility should take place to ensure awareness of any treatment-related effects and potential interventions.

Changes in Appearance

Sometimes, children with a brain tumour may have marks on their skin, patches where their hair doesn't grow back completely after getting radiation, or they might gain a lot of weight (especially if they have hypothalamic tumours). These changes are signs of their brain tumour and



the treatments they had. Figuring out and explaining these changes to others can be a challenge. When children become teenagers, they might become very aware of these differences in their appearance and find it difficult to accept their health condition while working out who they are. Some families find it helpful to focus on what their bodies can do, how strong they are because they overcame so much, and to generally de-prioritise appearance in the family culture. Appearance is a big part of fitting in, and even with all the right family conversations, it can still be hard for children and young people to navigate. A psychologist or counsellor might be a good fit to help your child work through these issues.

Education

Cognitive abilities and social skills changes can impact a child's education. Some young adults may struggle and drop out of high school without enough support, while others may face difficulties in a TAFE or university setting. It is crucial to address these challenges early by accessing available resources and support. Teenagers nearing the end of school will often be eligible for special consideration on final examinations and entry to tertiary education. Discuss the application process and evidence required for this with your school and healthcare team. Non-government organisations such as Redkite, Ronald McDonald House, and Brainchild offer support for tutoring or pursuing special interests.

Financial and Employment Issues

Some survivors may face challenges separating from their parents or finding suitable living arrangements when their peers become more independent. Survivors with cognitive impairments may struggle with entry-level jobs in fast-paced environments such as fast food and customer service. Conducting a neuropsychological assessment can identify strengths and weaknesses, enabling career planning that aligns

with your child's strengths and maximises their chances of success in employment.

Transitioning to Adult Care

Because brain tumours and their treatment have lifelong impacts, talking to your healthcare team about what to expect when your child turns 18 is very important. Adult services usually take over care when your child turns 18, however the conversations and planning for this should start at least a year before this. You should have conversations with your paediatric team about sharing your child's information with adult services, where to go for different needs, and providing instructions to adult healthcare providers.

Doctors might still want to check your child for the tumour coming back or possible new cancers and should monitor for late effects, including hormone problems or other health issues related to the specific tumour and treatment they had. The healthcare team who cared for your child when they were younger can guide you and your young adult in getting set up for care in the adult health system and thoroughly explain what treatment was received and the ongoing monitoring required. You may need to expand to multiple services across tertiary hospitals and community specialists to receive the holistic care common in paediatrics.

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Chapter 8

Sexuality & Teen Survivors

Sexuality is an important topic for teenagers who have survived a brain tumour and an area most parents need advice on. Both the tumour itself and its treatment can affect sexual development and functioning. Sexuality is often an overlooked area when it comes to discussions between parents, teenagers, and professionals. It can be uncomfortable to address this topic, and parents' focus may be on managing various medical issues. However, as your child's medical condition stabilises, it becomes crucial to address their long-term psychosocial adjustment, which includes different aspects of sexuality, like healthy relationships, sexual safety, attraction, fertility, appearance, friendships, dating, sexual orientation, and the physical, psychological, and social changes that occur during puberty.

While many survivors of childhood brain tumour go on to have typical romantic and sexual relationships, research on psychosexual outcomes in childhood cancer survivors tells us that, on average:

- Adult survivors of childhood cancer have less sexual experience and satisfaction compared to their peers.
- They tend to have their first romantic partner and achieve sexual intimacy at an older age than their peers.

- Achieving psychosexual milestones, such as dating and masturbation, may be delayed.
- They may not feel sexually attractive or may experience less sexual attraction towards others.

Factors That Affect Psychosexual Functioning

Healthy psychosexual functioning is influenced by three main areas: medical/physical issues, neuropsychological and psychological changes, and relationship factors.

Medical/Physical Issues: The location of the tumour and the parts of the brain involved can cause hormonal changes that negatively affect sexual functioning. This can include altered sensations, changes in erectile functioning (how the penis functions), motor (physical) difficulties, difficulties in achieving orgasm and arousal, fatigue, sleep issues, fertility issues, lack of interest in sex, pain, reduced stamina and endurance, and seizures. Treatment effects, such as radiation and chemotherapy, can further impact sexual development and may lead to decreased libido (sex drive), erectile difficulties (difficulties with getting an erection), delayed puberty, fatigue, fertility issues, hair loss, precocious (early) puberty, and reduced endurance.

Medication Side Effects: Several medications, including anticonvulsants, selective serotonin reuptake inhibitors (SSRIs), and stimulants, can have sexual side effects such as decreased libido, arousal problems, erectile and ejaculatory difficulties, and difficulties achieving orgasm. It's important to discuss any concerns regarding medication side effects with your child's healthcare team or doctor. Some medications may also reduce the effectiveness of hormonal birth control methods, which should be discussed with your child's doctor or healthcare provider. Additionally,

steroids are associated with increased appetite, weight gain, and unequal distribution of body fat, which can affect body image.

Factors Affecting Healthy Relationships: Various factors can influence your child's ability to develop and maintain healthy relationships, including concerns about explaining your child's diagnosis to others, fear of relapse, fertility issues, limited opportunities for typical peer relations due to being in hospital or not being in school, increased vulnerability due to social and neurocognitive challenges, limited knowledge about the impact of brain tumours and treatments on sexual development and function, less developed social and relationship skills, and limited life and sexual experiences.

How Parents and Professionals Can Help

Young people navigating sexuality changes may not have a base understanding of what is 'normal' in sexuality or relationships. It's important to be proactive in open conversations and education so that your child can identify if they are experiencing impacts on their sexuality. Some particular areas you can support your child in include:

- Education on:
 - o Effects of brain tumour and treatment on puberty and sexual development
 - o Safe sex and sexually transmitted infections (STIs)
 - o Cyber safety, age of consent, and legal issues
 - o Talking about sexual consent
- Provide opportunities for social interaction and practising social skills.
- Preparing for social and relationship skills, such as meeting people, starting conversations, empathising, choosing friends, navigating tricky

social situations and handling rejection by practising these scenarios with them or looking at stories of these situations.

- Teaching between healthy and exploitative relationships.
- Providing opportunities, both in the home and in other settings, to build social skills such as listening, assertiveness, showing interest, giving compliments and offering opinions.



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Chapter 9

Quality of Life Care for Children with Brain Tumours

Many people don't realise that palliative care can be best described as 'Quality of Life Care'. Children with life-threatening conditions such as a brain tumour, where there is a possibility the tumour can't be cured, can benefit from palliative care even when they are likely to survive the tumour. The word 'palliative' comes from the Latin verb *palliare*, which means to 'cloak'. Palliative care aims to wrap around the patient and treat the symptoms caused by the brain tumour, not the brain tumour itself. The goal of palliative care is to promote well-being and improve the quality of life during the challenging journey of serious illness. The palliative care team support the whole family. Many families who access palliative care wish they had accepted a referral to palliative care earlier in their journey.

Paediatric Palliative Care goes beyond solely focusing on the disease process, bringing in aspects such as improving the overall quality of life, preserving dignity, and addressing the suffering of seriously ill children in a way that aligns with family values, culture, and community. Many children with brain tumours can benefit from receiving both cancer-directed treatments and palliative care services at the same time. You may be referred to the Paediatric Palliative Care Service at any time during your child's treatment to help manage symptoms.

“We wish we had understood the true and life-changing impact of paediatric palliative care earlier on in our journey. In its truest essence, paediatric palliative care is about living, supporting, empowering and embracing the child and family... Paediatric Palliative Care isn’t just about dying; it’s about living.”

Parent consumers, Paediatric Palliative Care National
Action Plan, Palliative Care Australia

Benefits of Palliative Care

Palliative care promotes care across different health professions, focussing on the whole family’s medical and emotional needs. By providing the highest quality of care, it offers assistance in various ways, including:

- Attending to social, emotional, and spiritual needs
- Alleviating physical and psychological symptoms
- Addressing grief, including anticipatory grief- the intense sadness over a possible future loss
- Accessing medical equipment
- Ensuring continuity of care regardless of the treatment location
- Assisting in making difficult decisions and care planning
- Optimising communication and coordination of services
- Supporting the whole family through the care process

Goals of Care and Making Difficult Decisions

The diagnosis of a brain tumour brings the possibility of death into people's minds. Usually, families and healthcare providers start with the hope of a cure. Adding in the support of a palliative care team does not extinguish or diminish this hope. The concept of 'parallel planning' refers to planning for a cure alongside a plan for the possibility that the tumour can't be cured. It can be helpful to have several plans. Plan A may be what you hope for your child if the best possible scenario comes true. Plan B may involve considering what is most important to your child and family if there are uncertainties about your child's condition over the next few months or weeks. You may also make plans C and D. Planning for these doesn't make any of them come true but just helps you feel better prepared.

Families often feel overwhelmed at the thought of planning for something other than the best outcome. This is when your support networks and the palliative care team can be of great comfort, helping you clarify and articulate what is important to your family. You may have goals for the care of your child and also goals for experiences in life you want your child and family to experience. Palliative care is about incorporating your goals into the treatment plan and optimising comfort and holistic quality of life.

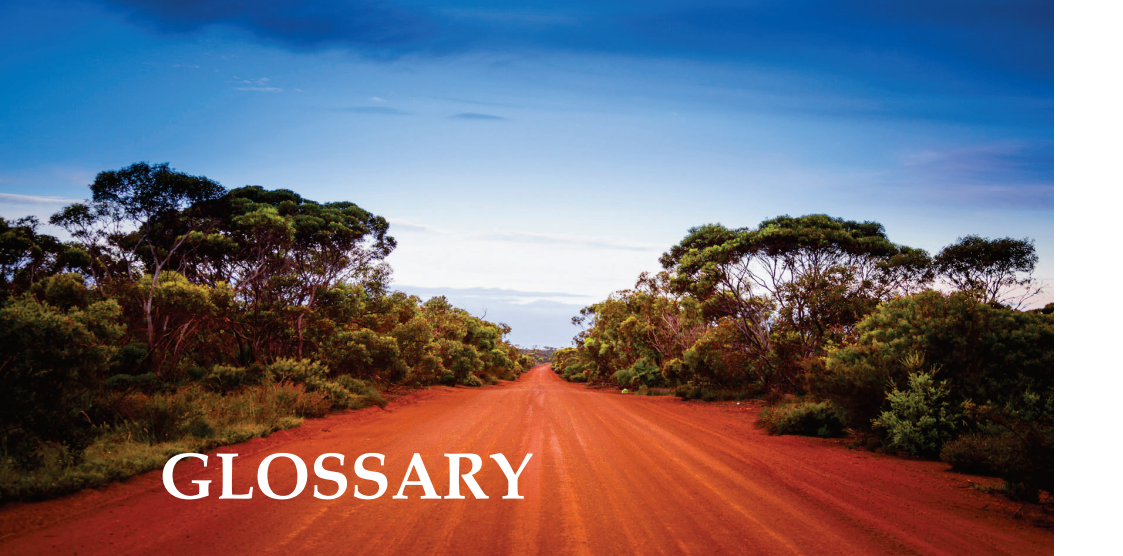
Having these goals discussed and recorded can help make treatment decisions, particularly when you feel overwhelmed. With decisions you are faced with, you can reflect on which decision is most aligned with the goals and values of your family. An example of this would be a family that chooses a comfort focus in the treatment of breathing problems, deciding that admission to an intensive care unit or being placed on a breathing machine would not be something that achieves their goals of being in their own space and together.

Advance Care Planning is the term used for planning relating to the possibility of death. These are a communication tool rather than a legal document. Specific Advance Care Planning tools exist for children ('My Wishes') and adolescents and young adults ('Voicing my Choices'). These documents discuss how your child or young person wants to be treated and can be accessed through the hospital palliative care team. This differs from an Advance Care Directive, which is a legal document that outlines medical decisions such as 'Do Not Resuscitate' (DNR) orders. These are sometimes required to ensure that children don't receive care at the end of life, which isn't in line with the family's goals and values.

Including the Palliative Care team in the care of your child, even when your child doesn't have a terminal diagnosis, can build positive relationships between your healthcare care team, you, and your family. This alliance aims to provide the best possible treatment for your child while optimising comfort and quality of life.

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GLOSSARY

Administration	'Admin' staff are often the first people you'll meet in the hospital. They provide professional services that make your visit to the hospital as smooth as possible, such as making sure your details are correct and your medical records get to where they need to be. They will help make appointments, contact the hospital and your GP, and prepare forms for travel, consent, and insurance.	Page 12
Audiologist	An audiologist specialises in as-sessing and preventing hearing disorders and helps those with hearing difficulties.	Page 9
Benign/Non-Malignant Tumours	The term 'benign' is sometimes used to describe tumours that are considered non-life-threatening or non-aggressive. However, in the case of brain tumours, this terminology is not entirely accurate, as benign tumours can press on brain tissue and other structures within the skull, leading to serious health complications. In recent years, there has been a shift toward using 'non-malignant' instead of 'benign' to describe tumours that are not aggressive or are low-grade.	Page 37
Bone Marrow/Stem Cell Transplantation	Stem cells are immature blood cells in the bone marrow and can become whichever type of cell the body needs. Stem cells can be collected from blood or via a bone marrow harvest.	Page 52
Brainstem	The brainstem, made up of the midbrain, pons, medulla oblongata, and reticular formation, is located at the base of the brain.	Page 144

Brain Tumour Biopsy	Taking a small amount of tu-mour tissue for accurate diagnosis and treatment planning. Pathologists examine the tissue under a microscope, and genetic testing may be performed.	Page 44
Brain Tumour Resection	Removing as much of the tumour as safely possible to reduce symptoms and reduce the chance of future complications. Depending on the tumour's location and risks, complete or partial resection may be attempted. In cases where complete removal poses risks, a biopsy or alternative techniques may be used.	Page 45
Cerebrospinal fluid (CSF)	A clear liquid surrounding the brain and spinal cord. It acts as a cushion, protecting the brain against things like bumps on the head.	Pages 31, 32, 100, 145
Cerebellum	The cerebellum is responsible for fine-tuning our motor activity, maintaining balance and posture, and sensing the position of our limbs.	Page 144
Cerebrum / Cerebral Hemispheres	The cerebrum, often called the entire brain, is divided into two major parts: the right and left cerebral hemispheres.	Page 144
Chemotherapy	Chemotherapy refers to cancer-fighting drugs. In the past, chemotherapy played a limited role in treating brain tumours compared to other cancers, as many medications couldn't cross the blood-brain barrier. However, in recent years, chemotherapy has become more critical in brain tumour treatment, sometimes even being the only treatment option.	Page 50
Child Life Therapist	Child Life Therapists can support your child in feeling ready for procedures, cope with worries about procedures, and understand and get used to life in a hospital or treatment. In some hospitals, these tasks are undertaken by Occupational Therapists (OTs).	Page 10
Clinical Nurse Consultant (CNC)	A specialist nurse with expertise in their chosen area.	Page 8
Clinical Trials	In cancer research, a clinical trial is a structured investigation to answer specific questions. Treatment-focused trials may explore new cancer treatments, supportive therapies, or alternative ways of giving existing treatments to improve effectiveness or quality of life.	Page 60
Consultant	A consultant has reached a high level of specialisation. When they specialise in cancer care, they are called oncologists.	Page 7
Contrast Agent	After routine images are taken, a contrast agent called Gadolinium may be injected into a vein in your child's arm. This contrast agent can cross the blood-brain barrier and improve the visibility of the tumour on the MRI scan.	Page 36

Corpus Callosum	The corpus callosum connects the cerebral hemispheres, passing messages between them.	Page 145
Cranial Nerves	The 12 cranial nerves control various functions, including smell, vision, eye movements, facial sensations, taste, swallowing, and motor control.	Page 145
Craniotomy	A surgical procedure in which a portion of the skull (called a bone flap) is temporarily removed to access the brain. The bone flap is usually replaced at the end of the procedure.	Page 45
Craniectomy	In a craniectomy, a portion of the skull is removed and not immediately replaced.	Page 45
Cranium	The cranium, also known as the skull, is the bony structure that makes up your head.	Page 145
CT (Computed Tomography) or CAT (Computerized Axial Tomography) Scan	Uses a series of X-rays to create images of the body or brain.	Page 34
Dietitian	Dietitians are educated in nutrition (what we need to eat to be healthy).	Page 10
Double Vision (Diplopia)	Our eyes move in sync. However, a tumour, or the pressure it creates, can interfere with the nerves responsible for eye movement. This leads to an imbalance in the action of the eye muscles. When these muscles don't move together, this can result in double vision.	Page 90
DTI (Diffusion Tensor Imaging)	DTI visualises the brain's white matter tracts, which can be essential for surgical planning as tumours may affect or infiltrate these tracts.	Page 36
Fellow	A fellow is a senior doctor training to become a consultant/senior staff specialist.	Page 7
Functional MRI Scan	This scan helps define brain anatomy (where parts of the brain are) and locate brain function by watching the brain during specific activities.	Page 36
General Anaesthesia (GA)	Commonly used for paediatric brain tumour surgery, carefully monitoring vital signs and blood loss. Under general anaesthesia, your child is unconscious (asleep) during the procedure.	Page 45
Genetic Testing	Genetic testing can identify genetic changes in a tumour that may make it responsive to targeted therapies. This is sometimes called personalised medicine. There are ongoing research efforts to make genetic testing available to children and families through research and clinical trials.	Page 40
Grade I Tumour	Slow-growing cells. Under a microscope, it appears almost normal. Least malignant. Associated with long-term survival. Example: juvenile pilocytic astrocytoma.	Page 39

Grade II Tumour	Fairly slow-growing cells. Slightly abnormal appearance under a microscope. Can invade nearby healthy tissue. May come back as a higher-grade tumour. Example: diffuse astrocytoma.	Page 39
Grade III Tumour	Actively reproducing abnormal cells. Abnormal appearance under a microscope. Affects nearby healthy tissue. Tend to come back and progress to a higher-grade tumour. Example: anaplastic astrocytoma.	Page 39
Grade IV Tumour	Quickly reproducing abnormal cells. Very abnormal appearance under a microscope. Forms new blood vessels to keep growing quickly. Contains areas of dead cells (necrosis). Example: medulloblastoma.	Page 39
High-Grade Tumours	High-grade tumours are made of fast-growing cells and are often called 'aggressive'. They usually invade normal brain structures and are challenging to remove surgically. Due to their fast growth rate, high-grade tumours will cause symptoms earlier than low-grade tumours.	Page 37
Hydrocephalus	a condition where excess cerebrospinal fluid (CSF) builds up in the brain.	Page 104
Hypothalamus	The hypothalamus regulates essential functions like appetite, sleep, and temperature control. It also produces hormones that act on the pituitary gland, producing other hormones.	Page 100
Image-Guided Neurosurgery	Some images from the MRI scan can assist surgeons during tumour operations, known as image-guided neurosurgery. The images are transferred to a planning system that helps the surgeon navigate the cranium (skull) and brain.	Page 36
Image-Guided Radiation Therapy (IGRT)	This uses imaging techniques on specialised radiation equipment (the linear accelerator) to accurately deliver daily doses of radiation to the intended areas. This involves using 2D images, optical tracking techniques, and mini-CT scans performed within the treatment unit.	Page 47
Immunotherapy	Also known as biotherapy or targeted therapy is a newer form of cancer therapy and is still evolving. These therapies train the body's immune system to recognise and attack cancer cells. Some immunotherapies are used to lessen the side effects of chemotherapy by helping the body to replace normal cells.	Page 53
Indigenous Liaison	Aboriginal and Torres Strait Islander families can be additionally supported through an Indigenous Liaison.	Page 12

Intensity-Modulated Radiation Therapy (IMRT)	This relatively new technique adjusts the intensity of each radiation beam to spare important nearby structures, such as the optic nerves, brain stem, and pituitary gland, while delivering a full dose to the tumour.	Page 47
Interpreter	If you have difficulties with English or are hearing impaired, interpreter services are available to ensure you have easy communication with your healthcare team.	Page 12
Lobes of the Brain	The brain's lobes are broad regions responsible for different functions.	Page 145
Low-Grade Tumours	A low-grade tumour is made of slow-growing cells. If these tumours can be completely removed through surgery, they often do not recur (grow back). However, if the tumour is located near critical brain functions (like the areas that control the heart), complete removal may not be possible, and any remaining tumour can regrow. Low-grade tumours can still be life-threatening.	Page 37
Malignant Tumour	These are cancerous and the most aggressive; they grow fast and can spread to other parts of the brain or body.	Page 38
MRI (Magnetic Resonance Imaging)	Detailed pictures of the size and shape of the tumour without using radiation. It involves a magnetic field and takes approximately 30 minutes to one hour to complete.	Page 34
MRS (Magnetic Resonance Spectroscopy)	MRS provides biochemical information about the brain tissue's metabolic changes.	Page 36
Music Therapist	Music Therapy uses music to support emotional coping, functioning, and health.	Page 10
Myelosuppression	Chemotherapy drugs often affect the bone marrow, slowing the production of blood cells and leading to a drop in blood cell counts. This typically occurs 10 to 14 days after treatment and takes about seven days to return to normal. The three types of blood cells that may be affected are red blood cells, white blood cells, and platelets. While these are low, your child's immune system will be weaker than normal, and it will be easier for them to catch illnesses they are exposed to. They may need transfusions to replace red cells or platelets.	Page 51
NDIS (National Disability Insurance Scheme)	The NDIS is a government initiative that can fund reasonable and necessary supports such as equipment (assistive technology), therapy interventions in the community, and care support.	Page 81

Neuroendocrine System	The neuroendocrine system creates and distributes hormones. These impact many body and brain parts, including growth, mood, and digestion.	Page 100
Neuroleptic Anaesthesia	Used in older children when the tumour is located in critical brain areas, allowing brain function assessment during the procedure. Under neuroleptic anaesthesia, your child is awake but sedated during the procedure and able to respond.	Page 45
Neuro-Ophthalmologist	When a brain tumour affects your child's sight, a neuro-ophthalmologist will assess and manage visual (seeing) difficulties.	Page 8
Nurse	Different levels of nurses will work across wards and outpatient departments to provide the day-to-day care of your child. These include registered nurses (RNs), enrolled nurses (ENs), and assistants in nursing (AINs). Each level has particular responsibilities of care they are trained in and licenced to undertake.	Page 9
Nurse Practitioner (NP)	A highly specialised nurse trained and licenced to diagnose and treat health conditions, including prescribing medicine, within their expertise.	Page 8
Nursing Team Leaders	Responsible for coordinating care during a particular shift, so may be in charge of a ward when the NUM is not working.	Page 9
Nurse Unit Manager (NUM)	These nurses oversee the running of a clinical area such as a ward or outpatient department.	Page 8
Nystagmus	The continuous movement of eyes back and forth is called Nystagmus. There are different types, depending on the speed and pattern of the eye move-ment.	Page 91
Occupational Therapist (OT)	OT focusses on supporting patients to undertake 'occupations' of daily life, such as play, movement, brushing teeth, or having medical procedures. They help with physical aspects, like splints or physical exercises, as well as social and emotional elements, such as training in relaxation and social skills.	Page 10
Open Brain Tumour Biopsy	Surgical removal of a small section of the skull directly above the tumour for biopsy.	Page 45
Operational Staff	Food service, cleaning, and portering (moving patients around the hospital) are other important parts of your hospital stay.	Page 12
Optometrists and Ophthalmologists	Specialists who focus on the eye and visual system. A neuro-ophthalmologist has additional knowledge of brain conditions that impact the eye and visual system.	Page 89

Optic Disc Pallor	The visible part of the optic nerve, known as the optic disc, typically appears pink but may become yellowish or whitish in cases of optic nerve damage resulting from various optic nerve diseases.	Page 90
Palliative Care	Paediatric Palliative Care goes beyond solely focusing on the disease process, bringing in aspects such as improving the overall quality of life, preserving dignity, and addressing the suffering of seriously ill children in a way that aligns with family values, culture, and community.	Page 128
Papilledema	Swelling of the optic nerves, visible during eye examination, can mean increased pressure inside the skull (intracranial pressure) caused by the growing tumour or a blockage of cerebrospinal fluid.	Page 90
Pastoral Care Worker/Chaplain	Hospital chaplains and community clergy provide religious or spiritual care. They are specially trained to support people going through health crises and can talk to you about moral and ethical challenges that might come up during treatment.	Page 12
PET (Positron Emission Tomography) Scan	PET scanning measures brain activity using radioactive substances, helping to determine what the tumour is doing in response to treatment.	Page 37
Pharmacist	In the hospital, the pharmacist will manage all the medications your child needs.	Page 10
Physiotherapist	Physiotherapists support the function of your child's body through movement. They can support maintaining muscle and mobility during treatment and reaching movement goals in rehabilitation when your child is home in the community.	Page 11
Pituitary Gland	Hormones can be produced in the anterior (front) or posterior (back) pituitary gland. The anterior pituitary gland produces hormones such as luteinising hormone (LH), follicle-stimulating hormone (FSH), adrenocorticotrophic hormone (ACTH), thyrotropin-stimulating hormone (TSH), and growth hormone (GH). The posterior pituitary gland produces prolactin (PRL) and antidiuretic hormone (ADH). Each hormone has specific actions on target glands.	Page 101
Proton Therapy	Proton therapy needs highly specialised equipment and is only available in a few hospitals in Australia.	Page 47
Psychiatrist	A psychiatrist provides support through medication for mental health.	Page 8

Psychologist	Psychologists can help with issues like anxiety, depression, trauma, motivation, and mood changes. Psychologists can diagnose specific mental health issues, but problems don't need to be severe to start receiving help.	Page 11
Radiologist	A radiologist is a medical doctor who interprets scans and medical imaging results such as MRIs and CT scans to assist in making a diagnosis.	Page 8
Radiation Therapist/ Radiographer	Undertakes scans and medical imaging, such as MRIs, and provides radiation therapy targeting the tumour where necessary.	Page 11
Radiation Therapy	A treatment that destroys tumour cells by damaging their DNA, preventing them from dividing and eventually causing tumour cells to die. This therapy uses high-energy X-rays, similar to diagnostic X-rays, but with a much higher energy. The X-rays are targeted at the tumour using a linear accelerator. Modern radiation techniques allow for precise focusing of radiation therapy on specific areas of the brain. These techniques include 3D Radiotherapy, Stereotactic Radiation Therapy, Intensity-Modulated Radiation Therapy, Image-Guided Radiation Therapy, and Proton Therapy.	Page 47
3D Radiotherapy	This technique shapes the radiation dose region around the tumour in all three dimensions.	Page 47
Registrar	A registrar is a doctor receiving further training to become a fellow. Registrars work under the direction of consultants and fellows.	Page 7
Resection	Involves making an incision (cut), removing a bone flap, opening the dura mater (the protective layers outside of the brain), and carefully removing the tumour.	Page 45
Resident	A resident is a qualified junior doctor. They rotate through different areas of healthcare approximately every 3 months to gain experience working with other health conditions.	Page 8
Seizure	Seizures occur when cells called neurons in the brain communicate through abnormal and excessive electrical discharges.	Page 96
Shunt	The shunt consists of a narrow, soft tube implanted through a small hole in the skull. All shunts have a valve system that keeps CSF pressure at the right level and prevents backward flow.	Page 104
Social Worker	Social workers provide individual, family, and group therapy to support children and families coping with the diagnosis and treatment of a brain tumour.	Page 11

Speech Pathologist	Speech Pathologists support patients in addressing issues with speech, language, and eating. This can include temporary problems such as mouth ulcers that might interfere with eating, and long-term issues relating to changes in speech or eating from the effects of the tumour or treatment.	Page 11
Stereotactic Brain Biopsy	Minimally invasive technique using computer-guided imaging for precise biopsy needle placement.	Page 47
Stereotactic Radiation Therapy	This involves using a specially made frame (a stereotactic frame) attached to the head to guide the radiation beams to the precise area of the brain requiring treatment.	Page 47
Surgeon	Surgeons work with the consultant to perform surgery as part of the treatment plan. A surgeon who specialises in brain surgery is called a neurosurgeon.	Page 7
Welfare Officer	Welfare officers work with hospital Social Workers and focus on the financial aspects of treatment. They can provide support with travel arrangements, access Centrelink, and refer people to useful services during financial hardship.	Page 12
Youth Cancer Services	If your child is aged 15-25 in some states, they can be supported by Youth Cancer Services. These services are integrated with your hospital health team and include medical, senior nursing, and allied health services that specialise in this age group.	Page 12

A large, bright yellow sunflower is the central focus, positioned slightly to the left of the center. It has a dark brown, textured center and many bright yellow petals. The background is a soft-focus field of other sunflowers and green foliage, with a clear blue sky above. The word "APPENDICES" is written in a large, white, serif font across the middle of the image.

APPENDICES

Appendix A: Overview of the Brain

The brain is the control centre for all our thoughts, actions, and emotions. It plays a crucial role in interpreting and giving meaning to the events around us. For instance, if we accidentally touch a hot stove burner, our brain receives the message from the skin sensors, recognises it as harmful, and tells us to remove our hands quickly to prevent injury. Our brain relies on stored memories to guide our actions and reactions, helping us avoid harm.

Using our senses of sight, smell, touch, taste, and hearing, the brain receives numerous messages simultaneously and selects the most relevant ones to guide our behaviour. In addition to processing sensory information (information from our senses), the brain regulates our emotions, sleeping patterns, imagination, motor functions, organ functions, endocrine system, breathing and heart rates, and responses to stressful situations.

Understanding the Nervous System

The nervous system is divided into two main parts: the central nervous system (CNS) and the peripheral nervous system (PNS). The CNS consists of the brain and spinal cord. At the same time, the PNS includes the cranial nerves (inside the brain), spinal nerves, and the autonomic nervous system (sympathetic and parasympathetic), which controls our stress response.

Brain Structures:

Cerebrum / Cerebral Hemispheres: The cerebrum, often called the entire brain, is divided into two major parts: the right and left cerebral hemispheres. Each hemisphere controls the opposite side of the body. The corpus callosum connects the hemispheres, allowing communication between them. The cerebral cortex, the cerebrum's outer layer, consists of billions of neurons (nerve cells) and glial cells and plays a role in many functions.

Brainstem: The brainstem, made up of the midbrain, pons, medulla oblongata, and reticular formation, is located at the base of the brain. It connects the cerebrum with the spinal cord and serves as a relay station, enabling communication between different parts of the body and the cerebral cortex. The pons and medulla oblongata control vital functions such as breathing, blood pressure, and heart rhythms. The reticular activating system regulates wakefulness, attention, and sleep patterns.

Cerebellum: The cerebellum is responsible for fine-tuning our motor activity, maintaining balance and posture, and sensing the position of our limbs. It enables precise movements, such as piano playing, and helps with rapid actions like typing. Damage to the cerebellum can cause coordination difficulties and unsteady movements.

Cerebrospinal Fluid (CSF): CSF is a clear fluid that surrounds and cushions the brain and spinal cord. It circulates through channels and ventricles in the brain, providing protection and nourishment. Imbalances in CSF production and absorption can lead to disruptions or blockages in the system.

Lobes of the Brain: The brain's lobes are broad regions responsible for different functions. The frontal lobes control movement and are involved in memory, intelligence, and decision-making. The parietal lobes interpret sensory signals and give meaning to objects. The occipital lobes process visual information, and the temporal lobes handle functions like hearing and memory. Each lobe can be further divided into specific areas with specialised functions.

Other Brain Structures:

Corpus Callosum: The corpus callosum connects the cerebral hemispheres, passing messages between them.

Cranial Nerves: The 12 cranial nerves control various functions, including smell, vision, eye movements, facial sensations, taste, swallowing, and motor control.

Cranium: The cranium, also known as the skull, is the bony structure that makes up your head. The neurocranium is the part that protects the brain, and the viscerocranium makes up the face structure.

Appendix B: Letter to the School at Diagnosis

This letter is a suggested template to copy and paste into a document or email to the relevant person at your child's school. It takes you through the different components of working with your child's school that families have found useful in the past.

Square brackets indicate parts you need to fill in, and curved brackets indicate areas that may or may not be relevant to your situation. You may like to include more personal information, use some sections, or tailor it so it sounds like 'you'. It's also okay if it's easiest to copy and paste, changing the parts in brackets. Use this however it is helpful for you.

A digital copy can be found here: www.brainchild.org.au



Dear [Name]

Reading this email when you have time to sit and digest it might be a good idea. I have added our details, but much of this email has been pre-written, so it might not sound like 'me'.

We have been told that [my child] has [type of brain tumour].

This brain tumour is usually treated with [surgery, radiation, chemotherapy].

In our situation, it's likely that [my child] will be away from school for [amount of time]. (We will try to come to school for periods when we can).

We want this information to be communicated to [my child's] teachers. We want other students at the school to be told [that my child has been diagnosed with a brain tumour/ general information about brain tumours but not that my child has been diagnosed with one/ just that my child will be away from school]. We prefer this information to be communicated via [individual class teachers/ school assembly/ written communication to parents/ social media]. (Please use this text to convey the message):

[Insert how you would like to word the information to the school community]

Community Support:

(For primary schools, Camp Quality may be able to support with a puppet show and education for the other students about cancer- <https://www.campquality.org.au/how-we-help/services-and-programs/cancer-education-program/>

Redkite has a list of books for different ages that can help children understand cancer and tumours, which can be borrowed from them- <https://www.redkite.org.au/service/book-club/>

Ronald McDonald House Charities provides professional development for teachers on how to best support children who have been through serious illness when they return to school- <https://rmhc.org.au/what-we-do/learning-program/>

If anyone from the school community would like to know ways they can support us, please ask them to contact [insert name and way to contact them]. They will organise a list of things we need help with and be the point of contact so that our attention can stay on our family.

While our child is in hospital, they will be supported by the Hospital School when they are well enough. The hospital school will be in touch with you to share information.

What to expect for our child:

Every child with a brain tumour will have different experiences. The impacts of the tumour will be seen on the parts of the brain it is pressing on. Sometimes, in treating the tumour, the surrounding brain tissue is impacted, and this causes further symptoms. These are some common side effects of brain tumour and its treatment, though my child may not have all of these.

- Trouble focusing & brain fog
- Mood issues
- Social issues
- Sleep disruption
- Fatigue
- Problems with gait and balance
- Nausea & trouble eating
- Headaches
- Vision problems
- Hearing problems
- Pain or numbness in extremities

Common social issues for your child with a brain tumour and their siblings include:

- Bullying relating to the illness.
- Friends not understanding the significance of what they are going through.
- Missing out on social opportunities due to being away from school.
- Friends not knowing what to say, and so avoiding them.
- For a child with a brain tumour, changes to their social skills and speed of thinking impacting relationships.
- Not knowing how to answer questions and feeling uncomfortable with these conversations.

Siblings:

Our other children are aware of the diagnosis and treatment. Issues that are common for siblings of children going through a brain tumour diagnosis and treatment include:

- Emotional ups and downs.
- Regressing to previous coping mechanisms.
- Anger, sadness, resentment, confusion, and moving quickly between usual activities and thinking about their sibling.
- Feel they need to be extra compliant so they don't add further stress to the household.
- Acting out and rebelling.
- Feeling overlooked.
- Difficulty concentrating.
- Difficulty sleeping and being tired during the day.
- Having less time at home for schoolwork due to additional factors in the household.

We ask that you support [*names of siblings*] through this time with compassion and understanding if they are operating at less than their usual level. Please let us know if you notice [*any particular areas of concern*]. The best way to contact [*me/us*] about this is [*email/phone*].

During treatment, our living situation will be different as one parent is staying at the hospital with [*our child*]. During this period [*details of any changes to the usual home situation, who to contact and how to contact them for usual schooling information, changes in who will be signing consent forms, etc.*].

I would appreciate having one person at the school who can be the contact person if we need to update you on anything about our child[*ren*]. [*Insert if you have someone in mind, or ask for someone suitable for this*].

My Child's Health Information

This section gives you space to keep all your information together. You'll find space for:

- Your child's tumour type
- Your care team's names
- Symptom tracking
- Prescribed medication
- Contact information
- Appointments
- Questions to ask your team
- Other notes

Information About My Child's Tumour

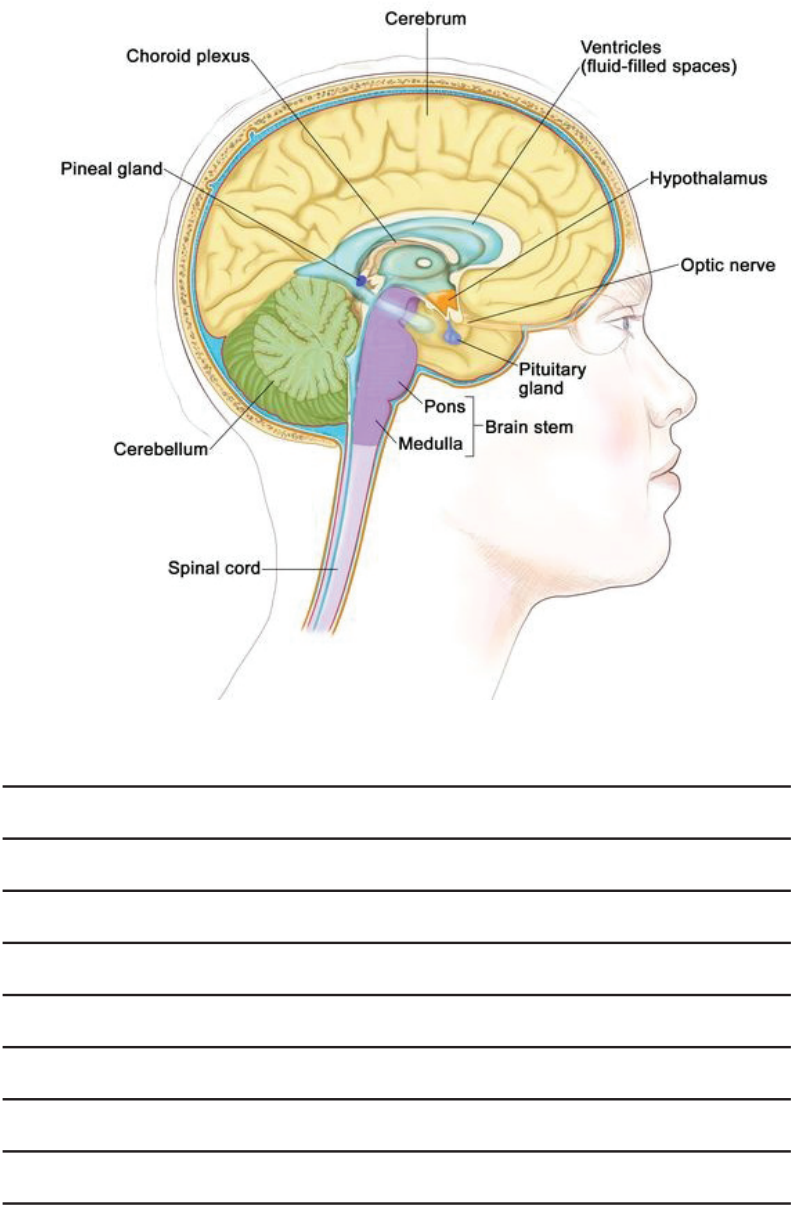
The type of tumour my child has been diagnosed with is:

The doctor's name is:

The nurse's name is:

Names of other health care providers on my child's team:

Where is my child’s brain tumour? Circle the area on the brain where the tumour is located.



Symptom Tracking Sheet - SSPedi

This checklist has been validated for use in Australian childhood cancer. You can use it to tell your care team how much each of these things are bothering your child. It is designed to be used up to a day before you see them, to help you think through what issues need to be discussed and share with them at the appointment.

	Not at all bothered	A little	Moderately	A lot	Extremely bothered
Feeling disappointed or sad	☐	☐	☐	☐	☐
Feeling scared or worried	☐	☐	☐	☐	☐
Feeling cranky or angry	☐	☐	☐	☐	☐
Problems with thinking or remembering things	☐	☐	☐	☐	☐
Changes in how your body or face look	☐	☐	☐	☐	☐
Feeling tired	☐	☐	☐	☐	☐
Sleeping more or less than you usually do	☐	☐	☐	☐	☐
Mouth sores	☐	☐	☐	☐	☐
Headache	☐	☐	☐	☐	☐
Hurt or pain (other than headache)	☐	☐	☐	☐	☐
Tingly or numb hands or feet	☐	☐	☐	☐	☐
Throwing up or feeling nausea like you may throw up	☐	☐	☐	☐	☐
Feeling more or less hungry than you usually do	☐	☐	☐	☐	☐
Changes in taste	☐	☐	☐	☐	☐
Constipation (hard to poo)	☐	☐	☐	☐	☐
Diarrhoea (watery, runny poo)	☐	☐	☐	☐	☐
Rash or itchy skin	☐	☐	☐	☐	☐
Bruising or bleeding easily	☐	☐	☐	☐	☐
Hurting to urinate (pee or wee)	☐	☐	☐	☐	☐
Changes in the way my body feels or moves	☐	☐	☐	☐	☐
Please tell us about any other things that have bothered you:					

[illegible]

Prescribed Medications

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[illegible]

[illegible]

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This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

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From the Publisher



As a publisher, author, and most importantly, a parent who has faced the devastating reality of a childhood brain tumour diagnosis, I understand firsthand the fear, uncertainty, and need for clear, compassionate guidance.

The Australian Family Handbook for Childhood Brain Tumour is an invaluable resource for families navigating this difficult journey. Developed with input from families like mine, it offers reassurance, advocacy tools, and a reminder that you have a network of support to walk through this path with you.

This book is one I wish I had when my own child was diagnosed, and I am honoured to help bring it to others who need it most.

Crystal Leonardi
Bowerbird Publishing
www.crystalleonardi.com



The Australian Family Handbook for Childhood Brain Tumour has been designed especially for you - parents, caregivers and family members of children with brain tumours. It aims to help you navigate the challenges ahead by providing information about supporting yourself and your family, what brain tumours are, how they are treated, and the available services to help. Designed with families who have gone through this journey before, we want you to know that a whole community of families, friends, and healthcare workers is in your corner.

You are not alone.

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