

He waka
eke noa

**brain
tumour
support**NZ
In it together



Supporting students with brain tumours

A GUIDE FOR NEW ZEALAND TEACHERS AND FAMILIES
HE KETE ĀWHINA MO NGĀ KAIKO ME NGĀ WHĀNAU

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Ngā tino whakaaturanga

Mā ngā pukupuku roro e whakarerekē ai ngā ao. Me uaua te kite, ā, he tino rerekē ngā āhuatanga me ngā pānga ki te tangata.

I te wā o te maimoatanga ā-hōhipera tuatahi ka tautohu te whānau me ngā kaiwhakaako i ngā tino hoapā, ka whakaae ki tētahi mahere tohatoha pārongo, ā, he riterite te whakapānga atu a ngā kaiwhakaako.

Ko te whakamahere i tētahi whakawhitinga pai ki te pokapū, ki te kura rānei whai muri i te maimoatanga e hāpaitia ana e te kaiako o te Kura Hauora ā-Rohe i te nuinga o te wā.

Ko ētahi take hauora e hiahia ana ki ngā mahere tiaki motuhake mā ngā pokapū me ngā kura. He mea waiwai te tohatoha pārongo e pā ana ki te maimoatanga.

He mea hirahira te mahi a te kaiako. Kei roto ko te aronga ki ngā kaha, ki te kauawhi pāpori, otirā ki ngā urutaunga ki ngā wero.

Ko tā te whānau he mahi matua hei kaikōkiri i roto i te mahi tahi haere tonu me te ākongā me ngā kaiwhakaako.

Ko ngā putanga o ngā pukupuku me ngā maimoatanga ko te whānuitanga o te pānga ā-tinana, ā-pāpori, kāre ā-roto, ā-hinengaro anō hoki ka hiahiatia ngā rautaki mātauranga me te tautoko i hangaia mā ia akonga. Ka puta mai pea ētahi pānga whai muri i te maimoatanga, i tētahi wā roa rānei ā muri ake.

Ko te ruhi tētahi o ngā pānga uaua e tino kitea whānuitia ana. Me aroturuki, me whakaiti te nui o te mahi, me whakarato tautoko me te "whakatā mā te roro".

Kei roto i ngā ripanga he taipitopito kōrero e tautohu ana i ngā pānga pea o ngā pukupuku/maimoatanga me ngā rautaki e hāngai ana ki te mātauranga.

Key points

Childhood brain tumours change lives. They are rare and their characteristics and impact vary widely.

During initial hospital treatment the family/whānau and educators identify key contacts, agree a plan for sharing information, and educators keep in touch.

Planning a successful transition back to the centre or school after treatment is usually assisted by the Regional Health School teacher.

Some health issues require specific care plans for centres and schools. Sharing of important treatment information is essential.

The teacher's role is key. It includes a focus on strengths and social inclusion as well as adaptations for challenges.

Family/whānau have a vital role as advocates in ongoing teamwork with the student and educators.

Tumours and treatments can cause a range of physical, social, emotional and cognitive effects that require individualised education strategies and support. Some effects may emerge after treatment or even a long time later.

Fatigue is one of the most common and difficult effects. It requires monitoring, reducing workload, providing support and "brain rest".

Detailed tables identify possible tumour/treatment effects and associated strategies for education.

Why is this guide important?

A childhood brain tumour can be a devastating diagnosis that changes the lives of students and their families with major impacts on how a person feels, learns, and interacts with the world. Our brain is central to our identity - it controls what we do, think and feel. The brain is also the only vital organ with core functions that continue to develop right through to adulthood.

For Māori, the head is also the most tapu/sacred part of the body.

A brain tumour, treatment effects, and prolonged absence from school and peers, can all cause a range of significant effects. While returning to education after treatment is an important milestone in the quest for a return to a normal life, changes may make it hard to always know how best to provide support. It takes effort for a teacher to understand the educational, practical, and social impacts this can have for a particular student.

This guide provides key information and links to further resources for teachers and family/whānau to increase their knowledge and understanding of how to support students with brain tumours.

It is written for school and early childhood leaders, specialist teachers, teachers and support staff, along with the student and their family/whānau.



Childhood brain tumours

In Aotearoa New Zealand only about 32 children are diagnosed each year with tumours of the central nervous system (the brain, its coverings and the spinal cord) and there are many different types of primary brain tumours. Brain tumours in children tend to be different from adult brain tumours, and often have a better outlook.

Brain tumours differ in where they are located in the brain, the cells they originate from, and the associated effects and treatment options. Gliomas and medulloblastomas are the most common types of childhood brain tumours. Current options for treating a brain tumour include surgery, radiotherapy and chemotherapy. Many people have a combination of treatments. The choice of treatment depends on several factors including:



Tumour Location



Tumour Size



Age of Patient



General Health



Tumour Type / Grade

(Adapted from littlebrainstrust)

The family/whānau will have information about the student’s particular tumour and treatment from specialist reports.

Detailed information on specific brain tumour characteristics, effects and treatments is available at thebraintumourcharity.org/brain-tumour-diagnosis-treatment/



Initial specialist treatment

Multidisciplinary hospital team

Children with brain tumours receive specialist assessment, diagnosis, treatment, and follow-up from a multidisciplinary team at either Starship Children's Hospital or Christchurch Hospital. Oncologists (specialist doctors for cancer) and surgeons lead the critical medical treatments of surgery, radiation, and chemotherapy.

Nurses, doctors, social workers, play specialists, physiotherapists, occupational therapists, pharmacists, kaiatawhai (Māori support liaison), Pacific Island support workers, child psychologists, and/or psychiatrists may be involved depending on the impact.

For children and families from outside Christchurch or Auckland, a close relationship is maintained, and care is shared, with their local hospital.

Neuropsychologist assessment

Brain tumours affect many children's educational achievement and social functioning. Depending on the level of need, a brief screening or a more comprehensive neuropsychologist assessment from a specialist psychologist will be provided.

Through this assessment process strengths and weaknesses, as well as how they can affect daily functioning, are identified. Report recommendations can help teachers understand how to build on strengths and address any issues with learning, thinking, and behaviour. The report with recommendations will be provided to families (and schools, with the family/whānau's consent) and sometimes follow up contact between the psychologist and teachers will take place by phone. For students with the most significant effects, psychologists will continue to provide annual reviews with educational recommendations.





Regional Health School teacher

A specialist teacher from the Regional Health School will become involved with school-aged students receiving treatment for brain tumours while they are in hospital. The teacher will coordinate the initial educational programme and ensure suitable resources are put in place. Depending on the extent of the student's particular needs, this could include a learning programme from Te Aho o Te Kura Pounamu (Te Kura – The Correspondence School).

The Regional Health School teacher in the student's home community will work with the student, family/whānau, and school staff when the student is admitted to their regional hospital or at home. They will also assist in planning a successful transition back to school when the time comes. This transition is carefully managed, with the student usually attending part-time to begin with. The Regional Health School teacher can remain involved until school attendance becomes more frequent.

The Regional Health School teacher may also support the student's school in an application to either the School High Health Needs fund or the Physical Disability Service for the student to receive a period of support to help them attend school safely.

Information on the funding schemes and services available, as well as other learning support specialists, is provided in the "Learning Support Areas" section on this website: education.govt.nz/quick-links/learning-support/.



Providing support at diagnosis

Agree on a key education contact

When a student is first diagnosed, the family/whānau is shocked. They may not be thinking a lot about education or want to share much with their child's centre/school at such an early stage.

Parents often say that the number of people they are dealing with and the information they are receiving at the time of diagnosis is overwhelming. Therefore, the centre/school needs to agree on one main contact person - **a person the family/whānau is happy with**, e.g. the centre head teacher, primary school principal, teacher, SENCO, or learning support coordinator; or in a secondary school, perhaps the form teacher, dean, learning support teacher, or counsellor.

Keep in touch

The key contact person lets the family/whānau know that the centre/school is there to provide support.

The contact person needs to follow the lead from the family/whānau and student about contact. It is very important to **find out what contact the family/whānau wants** at this stage, and **what information they agree can be shared, and with whom**.

Even when they are not available for direct contact, most students with brain tumours and their families want to feel supported and connected. There are lots of ways that friends and classmates can **keep in touch regularly** including through cards, pictures, and messages of support. If students aren't well enough to talk on the phone and direct contact is not a family/whānau priority right now, it does not usually mean they want to be left alone. Possibilities for contact include sending texts or using other private social media to message, and sending newsletters and use of your usual communication platforms (such as Seesaw) for other news from the centre/school.



“

After my brain tumour diagnosis I felt isolated and far away from my friends, however the daily messages of love and support gave me the strength I needed on the really hard days”. Kate NZ

Make a plan for sharing information

The centre or school contact person should prepare a plan for sharing information about the student with other staff and students based on the family/whānau and student's agreement about what information can be passed on, who it is to be shared with, and by whom. The hospital social worker is usually the primary adviser and a family support coordinator from Child Cancer Foundation may also assist.

Remember that the student's siblings, classmates, other students, and centre/school staff also need to be thought about in the plan. If a student is very seriously ill a number of people may be upset and/or need support. In traumatic circumstances a centre or school can also contact their local Ministry of Education office for advice.

Some students find it empowering to tell their own story or participate in the discussion. There is no one right way - some students have used a photo story or slides or a blog, others have presented with a principal, teacher or parent. In other circumstances a parent or teacher may be the best person to talk to staff and classmates about the student's tumour and treatment before the student's return.

The discussion may include explaining why the student was absent, the agreed information about brain tumours and the treatment, effects including any changes to the way they look and feel, why they may need extra help now, and how the class might help their peer. Classmates can be encouraged not to treat the student differently and to recognise "I'm still me".

Care is needed not to give out more information than the family wants shared or the child knows. Encourage students to ask questions and respond calmly to concerns that peers bring up. Answering questions honestly, and providing reassurance can help create a supportive environment in which classmates appreciate that regardless of the diagnosis the student is still their friend.

Young children aged 3-5 may have a very simple understanding of what this means. Use simple language and possibly picture books and toys to help explain what's going on. Talk about feelings and what they can do when they feel a particular way.

Children between six and twelve have increasing understanding of illness and the potential implications. They can understand what a brain tumour is. Books and animations can be useful as aids.

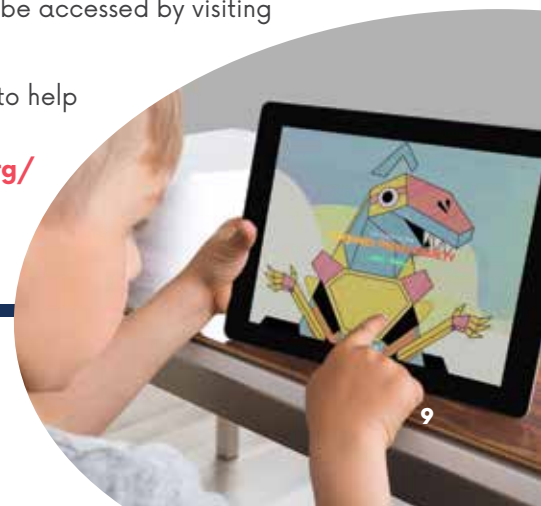
Teenagers understand and talk in more depth about brain tumours and can be given basic medical information.

Useful explanations

Short, animated films have been developed to help children and young people understand a range of topics about brain tumours and their treatments.

Imaginary Friend Society is a series developed on behalf of the Pediatric Brain Tumor Foundation (USA) that explains complicated cancer topics in a way that children can understand and that takes "the scare out of cancer care". These can be accessed by visiting this website: imaginaryfriendsociety.com/

The Brain Tumour Charity (UK) has also published several animations to help children understand a range of topics about brain tumours and their treatments. Refer to this link to view these: thebraintumourcharity.org/living-with-a-brain-tumour/get-support/children-and-families-service/support-families/animations-explaining-brain-tumours/



Returning to school or early childhood education

In early childhood, play-based learning, fewer programme or social demands, and family/whānau participation all make a return to education easier. Also the hospital play therapist may have provided the child with opportunities to play through their experiences of the hospital treatment during their hospital stay.

School aged students usually consider returning to school to be an important part of getting back to their normal life as much as possible, and they are often particularly motivated by the social contacts and friendships. However, the process of reintegrating is not always easy and may take some time and effort from the student supported by their family, teachers and peers. Students' resilience, feelings about learning difficulties, and support will vary and may also change over time.

Plan the return

The key contact person from the school or centre works with the student, family/whānau, and the student's team to plan the return. The team may include the Regional Health School teacher, the hospital social worker and, if families request, a family support coordinator from CCF.

The teacher's role

A teacher's role in supporting students to return, participate, maintain friendships, and learn successfully following a brain tumour diagnosis is really important. It requires a collaborative approach with the student and family/whānau and other supports, planning, gathering important information, sensitive observation and ongoing checking in and adaptation. Teachers can also support the child by mobilising other support people such as a teacher aide or peer.

The student and family/whānau

The student needs to be at the centre. Ask the student what they think about going back and continue to check in with them. Family/whānau are key team members and while family members may still be adjusting and learning themselves, they are key partners who have been with their child since the brain tumour diagnosis and throughout treatment (including being connected with specialists).

The student and their family/whānau will have already been through a lot and returning to school or an early childhood centre setting may be a particularly stressful time.



It is critical that children and young people gradually ease back into activity and learning in a planned way."

Ministry of Education Guide to Acquired Brain Injury





There was lots of noise in the classroom, I found it difficult sometimes.”

Vanclooster et al, p5

If possible, teachers meet the family/whānau early and listen carefully to their suggestions, fears, and concerns about returning. Teachers should not assume to know what is right for the family/whānau – what families want and how they deal with this experience is influenced by a range of factors including beliefs, culture, and family/whānau circumstances. Similarly, students will have different perspectives – some students appreciate help and want to share information themselves; others do not want extra attention.

When talking with the family/whānau, it is important that teachers show empathy and are encouraging, working to create an atmosphere of support where issues can be discussed and strategies revisited. All team members need to be proactive, give feedback, and don't always wait for scheduled meetings. Getting to shared understandings, expectations, and goals between home and school will help the student's readjustment.

Peer support

The role of peers is also important. Because social contacts and friendships are often a high priority for the student, sensitive use of peer support can be really helpful. For example, an older buddy could be assigned who the student can go to and who regularly checks in or a classmate could be a buddy who helps the student return to the classroom and assists with particular challenges that arise in the class.

Letter to other families

If the student has had chemotherapy, the centre/school needs to have a plan about how to protect the student's immunity after chemotherapy and report any exposure in the centre/school community to measles and chickenpox. Measles and chickenpox can be very dangerous to children going through chemotherapy as it suppresses the immune system. The KidsHealth website has a letter to families that schools and centres can use as part of the plan to protect students with cancer from measles and chickenpox: kidshealth.org.nz/letter-let-other-parents-know-about-your-students-cancer.

Gather important treatment information

Starship Hospital and the Paediatric Society recommend that the early childhood centre/school should ask the family/whānau for the following basic information:

- What treatment the student (has and) will receive
- Possible physical and emotional side effects
- What the student knows about the brain tumour
- Any medication they need and when they should take it
- A rough schedule of treatment, procedures, or tests which may result in your student's absence from school

Families receive copies of medical letters which they may choose to share with the school.





You need to go at the child's pace rather than race to get back to normal and have it all go to custard." *NZ parent.*

Adapt the programme

Teachers may be able to meet the student's needs without ongoing outside help if the difficulties are mild, there is good information, and planning occurs together with the family/whānau. However, difficulties may be masked because of good oral language, or they may seem like behavioural issues. Such difficulties may also become evident or increase over time, in which case, it is appropriate to seek advice and extra support.

Care Plans and Individual Education Plans

Students with brain tumours may have health needs that require a detailed plan. This will usually be developed by a health professional with the student and their whānau, along with the early childhood service or school. This link provides more information and a care plan template: education.govt.nz/school/health-safety-and-wellbeing/student-and-staff-health/health-conditions-in-education-settings-supporting-children-and-young-people-2/.

If the student has high ongoing health needs that require a support person, with support from the relevant professionals, the school can make an application for support from the School High Health Needs Fund. See Regional Health School teacher above, and refer to this link: education.govt.nz/school/student-support/special-education/school-high-health-needs-fund/.

If the student has significant needs for ongoing programme adaptation, the school or centre can develop an Individual Education Plan (IEP) with the family/whānau and other team members and meet regularly to update this plan. An IEP is a written plan developed by the teacher, whānau, student and wider team together that sets out goals, how and when they will be reached, and who provides support. IEPs can also be designed to support the transition back to school. The Ministry of Education has several resources to help teachers develop an IEP: seonline.tki.org.nz/Media/Files/A-K/IEP-Online/Collaboration-for-Success-Individual-Education-Plans, and inclusive.tki.org.nz/guides/collaborative-planning-for-learning/.



I was so sad that I couldn't participate with the others, because I have problems with my leg. It has improved, but sometimes I still cannot do the things I want and then, I don't want to be there."

Vancloster et al, p5

Specialist support

Some school students with brain tumours receive extra education support from within their school. Others may receive Resource Teacher of Learning and Behaviour (RTLB) In Class Support. Students with the highest needs for education support may be eligible for specialist support from the Ministry of Education and other agencies as outlined in the following links:

education.govt.nz/quick-links/learning-support/

kidshealth.org.nz/specialist-support-available-schools-help-student-cancer

In early childhood education early intervention teachers can sometimes be part of the team supporting a young student back to early learning. There may also be possible support from education support workers. This is managed through the local Ministry of Education office.

Emerging challenges

Today, most children diagnosed with brain tumours become long term survivors. Unfortunately, the treatments that are effective in treating the brain tumour can contribute to health problems that become evident after treatment or even a long time later. They affect some children more than others, depending on factors like the age of the child, the tumour location, and the kind of treatment the child has received.

These challenges are often called “late effects”. In New Zealand, a child will receive long term follow up care that is often referred to as the Late Effects Assessment Programme (LEAP). Regular assessment and monitoring for all survivors of childhood cancer throughout New Zealand occurs. A child with a brain tumour and their family/whānau may visit a dedicated LEAP clinic at Starship, Wellington or Christchurch Hospital, or see a specialist at a local hospital.

Effects that may become evident after treatment include cognitive skill gaps, impacts on physical functions, growth and development changes and emotional and social impacts.

Transitions

Transitions such as changing class, school, or moving from primary to secondary school are major changes that require the same careful planning as the student’s initial transition back to education after treatment. It is crucial that there is an effective, comprehensive transfer of information and strategies when students change class or school. In particular, the move to secondary school, with many teachers, new classmates, and multiple demands from the secondary programme, will need particularly careful planning. This includes planning ahead of time and involving the student and their team, as well as teachers from the new school meeting together. A written transition plan can be tailored to the student’s strengths, as well as their needs for programme and timetable adaptation and extra support. Refer to: inclusive.tki.org.nz/guides/transitions-managing-times-of-change/



Now, I like to learn new things in class and my teacher is so nice to me. In the beginning I didn't like anything, I didn't want to do anything."

Vancloster et al, p5



Effects of brain tumours and strategies to help

Every student's experience will be unique

The effects of a brain tumour vary widely depending on the tumour and its treatment. Personal, environmental, and family/whānau factors can also have an impact. Strategies suggested will need individual adaptation.

Effective, inclusive teaching

A teacher's sensitive observation at school will provide vital information to guide the adaptation of the student's programme. **Regularly checking in with the student** and the family/whānau and **problem solving together** to refine strategies for new challenges are all good practices that are essential for students affected by brain tumours. Similarly while the strategies below may be essential for the child with the brain tumour, many will also be beneficial for **all students**.

Build on strengths

Find and focus on the student's strengths. Sometimes new strengths have emerged through the intense experience of diagnosis and treatment.

A student with a brain tumour might now be a supportive and caring peer, a fabulous fund raiser, a supportive advocate. Think carefully about how the student can contribute to their community.

It is crucial that strengths and inclusion are emphasised, and adaptations made do not cause the student to be defined by need and difference. A key strategy for resilience building is also noticing the positives - a strengths based approach also helps supports resilience.



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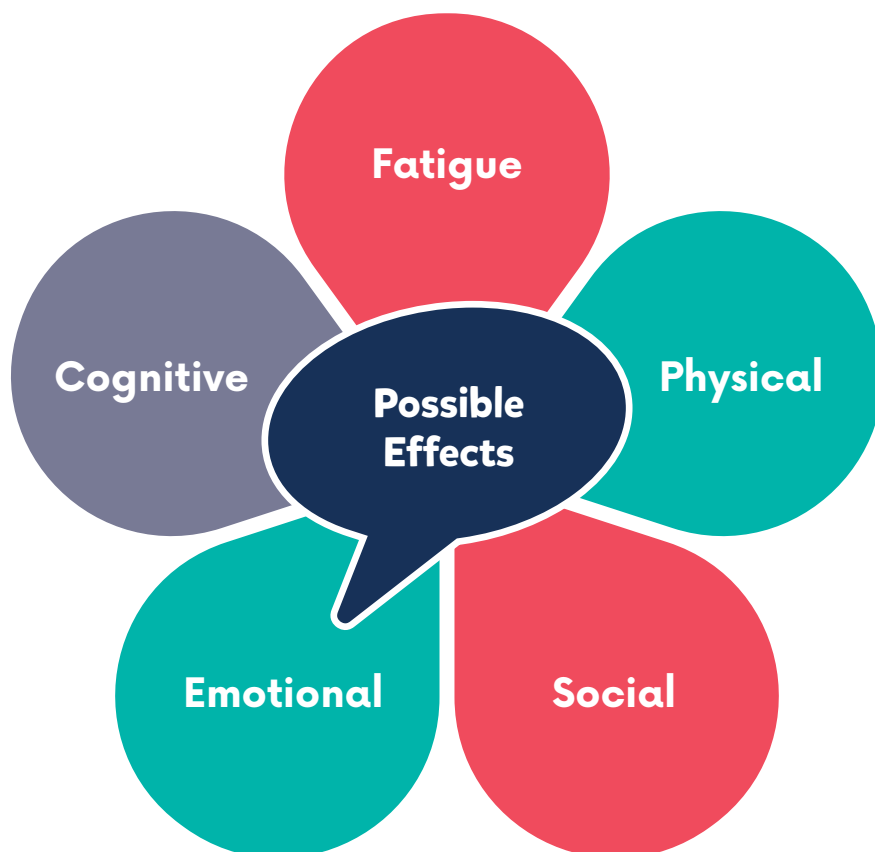
You find inner strength you never thought you had – you find out pretty quickly that it's sink or swim so you learn to be like Dory and just keep swimming." *Kate*





His resilience is astounding. You know he did have trouble with that beforehand sometimes. Now he's much more determined to make things work for himself - to get through the obstacles".

Parent NZ



Note:

Many of the effects listed do not apply to everyone. Whānau may want to choose if or when to read on from here. Your health team will discuss the specific effects that do apply to your child.



Physical effects and strategies

Possible Physical Effects	Examples of Strategies
<p>Fatigue</p> <p>Fatigue is one of the most common and difficult effects of a brain tumour and its treatment. Fatigue is a form of physical, emotional, and/or mental tiredness that may never completely go away. It can last for years and be overwhelming. Therefore, it is very important to reduce the student's overall workload (rather than just providing more time for the same work).</p> <p>Having a tired brain may not look like fatigue from the outside. For example, a student may be impulsive, restless, distracted, or more easily emotional. The student may be more easily tired, particularly in afternoons, later in the school week, or after noisy or lengthy activities. Fatigue can accumulate, and the recovery time can be days not hours.</p>	<p>Monitor fatigue.</p> <p>Schedule activities that need concentration or energy early in the day.</p> <p>Reduce the workload in both daily activities and homework and consider whether part time attendance is needed.</p> <p>Provide support:</p> <ul style="list-style-type: none"> • Arrange some one-on-one time with a teacher or buddy. • In a secondary school, have a key worker the student can go to (and have a back-up if that person is not available). <p>Provide extra "brain rest" time in a quiet place without iPads or other devices. Screen time is not restful as it is very stimulating for the brain.</p> <p>Slow down the pace:</p> <ul style="list-style-type: none"> • Allow the student more time to complete tasks. (NB: NZQA special assessment conditions for older students include extra time.) • Allow a student to come in early from play to conserve energy. <p>Refer to: kidshealth.org.nz/brain-injury-mental-fatigue</p>



Now, with the all-clear, I've got things to look forward to. The biggest change I've had to get used to is the fatigue. You don't really understand how much it affects you, until you've got it. It stops you from doing the things you want to do. It makes me frustrated, when I can't do things or when I'm just so tired that I can't do any school work.... And just going out – I always feel very tired if I go out."

From Brain Tumour Charity Losing My Place: The Reality of Childhood with a Brain Tumour | Page 8

Possible Physical Effects	Examples of Strategies
<p>Visual impairment</p> <p>Both tumours and treatment can affect vision and alter the way the brain makes sense of visual information. Effects can include partial vision, visual field impairment, and uncontrolled eye movements.</p>	<p>For significant vision impairment, refer to specialist reports and contact your Resource Teacher: Vision at BLENZ for specialist education support and individual education strategies. See: inclusive.tki.org.nz/guides/low-vision-and-learning/</p>
<p>Auditory issues</p> <p>Some children with brain tumours are left with partial hearing loss or deafness.</p> <p>Noisy environments can make hearing and listening difficult for these students. This means such environments can be very tiring.</p> <p>Some students will no longer be able to tolerate loud noises.</p>	<p>For significant hearing loss, refer to the resource teachers of the deaf or advisers on deaf children for support and individual strategies. Refer to your regional Ministry of Education office. See: inclusive.tki.org.nz/guides/deaf-or-hard-of-hearing-students-and-learning/</p> <p>For students with difficulties tolerating noise, several possible strategies may help:</p> <ul style="list-style-type: none"> • Use a noise thermometer to help the whole class to stay within a noise limit. • Provide a quiet place for schoolwork and a quiet place away from crowds for break times (perhaps with one or two peers). • Supply noise reducing headphones for noise and work to lower noise levels in the classroom.
<p>Balance and motor skills</p> <p>A student's difficulties with balance may cause unsteadiness during walking, biking etc. This means that a range of physical education activities may be difficult.</p> <p>There may also be difficulties with activities such as carrying bags or moving around the class or school. Going to the toilet and dressing may be more difficult.</p> <p>The student may experience writing and co-ordination difficulties.</p>	<p>Consult the Ministry of Education if a student's physical disability is preventing them from participating and learning. This may include significant balance, coordination, and mobility issues. Physical adaptations to the student's environment may be needed to enable learning.</p> <p>Allow the student more time to change locations at school, e.g. by letting them leave the class 5 minutes early. It may also be beneficial for a buddy to help them, e.g. by carrying heavy bags.</p> <p>The student may need help and an agreed plan for emergency evacuations.</p> <p>Provide easy access to a close toilet as assistance may be needed. Possibly work with whānau to know which days include physical education so the student can come dressed appropriately.</p> <p>Explore providing the student with greater access to tools such as tablets, laptops, or voice recorders. Consider special assessment conditions for tests and examinations (such as writer or extra time). For information relating to secondary school assessments, see: education.govt.nz/school/student-support/special-education/special-assessment-conditions/</p> <p>Simplify tasks that require co-ordination and allow a student to learn the steps one at a time.</p>

<p>Seizures</p> <p>Seizures are one of the most common symptoms of childhood brain tumours and their treatment.</p> <p>Ways in which seizures can present in students include:</p> <ul style="list-style-type: none"> • ‘Absences’ where a child appears to briefly ‘zone out’ • Twitching muscles • Making unusual noises • Temporary impairment of consciousness with visual or auditory hallucinations • Loss of consciousness and convulsing 	<p>Find out as much as possible from the whānau about the type of seizures the child has, how long they last, what they look like, and any triggers. Find out what medication, first aid and care is (or would be) needed. Also record what constitutes an emergency and what the emergency plan is.</p> <p>Epilepsy NZ has support specialists and resources to help teachers. They recommend seizure management plans that have been signed off by a medical practitioner. See: epilepsy.org.nz/understanding-epilepsy/epilepsy-and-seizure-management-tools/epilepsy-plans/</p> <p>The student may need a written care plan. The Ministry of Education has guidance available here: education.govt.nz/school/health-safety-and-wellbeing/student-and-staff-health/health-conditions-in-education-settings-supporting-children-and-young-people-2/#health-plan</p>
<p>Changes in appearance</p> <p>Changes in appearance are common effects that can have a major impact on students socially and emotionally. These changes may include treatment effects such as loss of hair and weight loss or gain. Fluid retention, slow growth, and delayed puberty may also be visible effects for some children. Students may also have surgical scars, tubes that stay in place during chemotherapy, or a shunt that removes excess fluid from the brain.</p>	<p>Refer to guidance in emotional effects section over the page. After a student’s hair loss, relax school rules on wearing caps or other headwear and inform all teachers.</p> <p>Provide privacy for changing rooms.</p> <p>Ensure tubes are not knocked. Seek advice regarding tubes and shunts, how to recognise signs and symptoms of a medical complication, and who to tell. Document this information in the student’s individual care plan. Refer to: education.govt.nz/school/health-safety-and-wellbeing/student-and-staff-health/health-conditions-in-education-settings-supporting-children-and-young-people-2/#health-plan</p>
<p>Growth and development changes</p> <p>Endocrine issues (including hormonal imbalances) can lead to tiredness, feeling hungry all the time, impaired growth, and delayed or early puberty.</p>	<p>Request any specialist advice the whānau has received that relates to school management. If specific school strategies or medication are required, include them in the care plan or IEP.</p>
<p>Nerve damage/pain</p> <p>Treatments can sometimes cause nerve damage in hands and feet, which can cause pain in extreme weather. Difficulty regulating temperature may make it hard for a student to tolerate cold conditions.</p>	<p>Ask the whānau for information about any possible nerve damage and medication.</p> <p>Ask the child what helps – possibilities may include moving around, taking off shoes, putting on gloves, or soaking hands in warm water.</p> <p>Let the student stay inside in cold weather and relax school uniform policies.</p>
<p>Toileting</p> <p>Chemotherapy can sometimes cause diarrhoea or constipation.</p>	<p>Provide the student with easy, immediate access to a private toilet that cannot be overheard. Keep spare clothes at the centre/school.</p>

Emotional/social effects and strategies

After a brain tumour, many students face major readjustments. Stress levels often increase from dealing with a range of changes, which may include fatigue, memory difficulties, appearance, friendships, being seen as disabled by others, and living with the fear of relapse. For some students, this is really disheartening. It can be a painful process moving from grief/sadness to a gradual acceptance of a new identity.

Teachers may see a range of behaviours associated with emotional difficulties and adjustments. Examples include:

Anxiety, worry, agitation (about friendships and schoolwork), fear of the cancer returning including 'scanxiety' while waiting for scan results, and depression

Loss of confidence, lower self-esteem, increased dependence, mood swings, and tearfulness

Frustration, irritability, anger, and aggression

Attention seeking behaviour or disinhibition, difficulty identifying emotions in others, and reduced voice control leading to shouting

Unexplained physical symptoms and complex regional pain

Social effects can also be wide-ranging, including:

Feeling isolated from friends and withdrawing

Being bullied

Feeling different after their experiences and finding previous networks for interaction harder to maintain



I hope they don't find me weird, just because I have been sick. If I would lose my friends because of this, that would be terrible."

Vancloster et al, p6



Every day I put on a face so that my loved ones don't see how shit I feel, emotionally and physically.... I put on a face for friends and family, making sure my make-up hides how tired I look".



From Brain Tumour Charity Losing My Place: The Reality of Childhood with a Brain Tumour | Page 12

Practical approaches to help with social and emotional issues are described in:
inclusive.tki.org.nz/guides/behaviour-and-learning/

For students with brain tumours, the following are often important:

Building a relationship and developing their strengths and interests

Reducing the educational demands and variables at school associated with stress

Providing additional support and a quiet go-to space

The student may prefer or need more adult or peer support, including support with play/social interaction to ensure integration with peers

Scheduling enjoyable activities with a partner or small supportive group

Planning trips and extracurricular activities ahead of time to ensure inclusion

Seeking help

For serious need, with parent/guardian consent, refer to the student's health team, or seek specialist support from education services such as Resource Teacher Learning and Behaviour (RTLB), school guidance counsellor, community services such as the Child Cancer Foundation counsellors, or health services such as the Infant, Child and Adolescent Mental Health Service (ICAMHS).

Cognitive effects and strategies



They couldn't seem to understand how I was disabled and that I needed things to be explained a number of times, as I forgot what I was meant to be doing. I have a really short attention and concentration span, which infuriated my teacher, thinking I was just being rude. I needed them to slow things down, as I can't process information at a 'normal' rate."

From Brain Tumour Charity Losing My Place: The Reality of Childhood with a Brain Tumour | Page 17

For cognitive and academic difficulties, the major interventions in the literature include adapting the learning programme, providing supports, and ongoing monitoring (sometimes led by a neuropsychologist). In Aotearoa, many teachers are skilled in inclusive practices. Good information, teamwork, and relevant strategies will support teachers to promote engagement and learning for the student with a brain tumour.

Collaborative teamwork between the student and their family/whānau, the school, and in some cases specialists is really important. By working together, the team will be able to identify learning needs, plan so that the teaching and learning environment reflect the student's needs, ensure ongoing communication, and have regular reviews to note any progress and/or changes in the student's learning and wellbeing at school.

A focus on ensuring participation and belonging is also important. This includes adaptations that will enable students to work with and alongside their peers in the everyday activities and routines of the classroom.

Cognitive and language-based abilities may be affected. Following a brain tumour, some students may develop skills and learning at a slower rate than other students. The most common cognitive effects reported are attention, learning and remembering, and processing speed changes.



Concentrating, learning and remembering

Attention and concentration difficulties are common. These difficulties are typically exacerbated by fatigue and can easily be mistaken for a poor attitude. The student may be easily distracted and find it hard to finish tasks. Therefore, retaining concentration in a noisy or distracting environment will be even harder for these students.

Learning and remembering new things, particularly school learning tasks, may also be harder after a brain tumour. There may be increased difficulty keeping information in mind, which can affect a student's ability to follow multi-step instructions or do complex tasks, such as re-telling, doing mental activities with several steps, spelling, etc.

Strategies to help the student attend, learn, and remember include:

Setting achievable goals and rewarding achievement

Seating the student where they consider it easiest to focus

Getting the student's attention when giving directions

Reducing requests and checking that the student has understood what the task is

Breaking tasks down into smaller, less complicated chunks and assisting with the organisation of these

Reducing distractions, e.g. by allowing the student to work in a quiet area and/or with a smaller group

Providing breaks and a rest area (some students need opportunities to move around)

Utilising memory aids such as lists, charts, calculators, mind maps, mobile phones or assistive technology for photos, audio recordings, etc.

Encouraging the student to ask for help from teacher or an assigned buddy

Processing speed

Slower processing speed is very common in students who have had brain tumours. Processing speed is sometimes described as a foundational capacity for other complex abilities. It includes the processing of visual and/or verbal information.

The student may need sufficient time to read or complete tasks and homework at their own pace. They may have difficulty following multi-step tasks, making quick decisions, starting a new task, staying focussed, or keeping up with conversations.

For students with slower processing speed, slow down and adapt instructions:

Provide enough time to understand and respond

Give time to read things more than once

Provide opportunities to practise tasks

Reduce complexity and time constraints including in assessments

Provide instructions in smaller chunks

Include written, visual, or taped instructions where needed

Clearly list what is required for each task

Give an outline of lesson or notes for older students

Provide extra support to the student by ensuring that they feel comfortable asking questions, giving them a buddy, and, for older students, allowing them to email questions after the lesson.

Planning and organising

The high-level processes necessary for self-regulation and self-management of thinking, emotions, and behaviour are collectively known as executive functioning. These processes include important planning and organising skills. After a brain tumour, a student may find it difficult to organise their day, e.g., by having the right equipment and being in the right place. Starting a task and planning what needs to be done when, keeping time, reorganising when change is needed, multi-tasking, and sequencing may all be more challenging.

Strategies to support planning and organising include:

Use of post it notes to organise ideas

Utilisation of visual prompts, pictures, and mind maps for new material

Teaching self-talk, e.g., asking “what’s the next thing I need to do?”

Use of checklists, planners, calendars, and alarms or reminders (with timers for younger students or phone apps for older students)

Regularly reviewing and checking in with the student



My teacher told me that I can always come and talk to her when I need it, and about everything I want. I have already talked about my time at home. Then, she always says something sweet.”

Vanclooster et al, p7



Reasoning and problem solving

This is central to most school learning. A student may struggle to apply previous learning to solving new problems. They may find it hard to weigh up information and reach conclusions, continue with a plan that is not working, or appear to make impulsive decisions.

Strategies that may assist students with their reasoning and problem solving include:

Teaching, practising, and commending use of problem-solving strategies

Explaining the reasons for changing course on a task

Asking questions and talking through steps

Regularly prompting the student to evaluate progress

Noting and praising success

Planning and using strategies that enable the transfer of learning from one task or situation to another (generalisation)

Communication difficulties

The student's tumour and any associated surgery can sometimes affect speech and language. Resulting difficulties can be temporary or longer term and can have a significant emotional effect.

Aphasia is the most common communication difficulty experienced by people with brain tumours. It is an impairment of language caused by damage to the brain and can affect both speaking and understanding language. This can result in issues such as not being able to find the right word or having words not come out in the right order. Difficulty may also be evident in reading, writing, speaking, or understanding what has been said or written. After a brain tumour some people may also have difficulty knowing when to talk and when to listen in conversation. Speech difficulties including slurred speech and changes in intonation or volume may also occur in some students affected by a brain tumour.

For major communication difficulties in education settings, refer to speech language therapists from the Ministry of Education. The student may also have access to a speech language therapist from the hospital providing support.

Final comments – communication is key

What happens at the centre or school makes a real difference to the impact a brain tumour has on a student's learning and wellbeing. It takes effective teamwork - understanding the impact, brainstorming, planning, monitoring, and revising strategies. Central to this is effective ongoing communication.



Explaining what's happened is a moment for the student, peers and a teacher to share learning about empathy and compassion too - you know that's a really good teachable moment." *Parent NZ*



My friends know, but they don't really know-they haven't processed it and need reminding." *Student NZ*



You know the tumour is identified but some of the ongoing effects are harder to convey to teachers in a way that's digestible. For my son that's the visual impairment – where he sits in the classroom and how things are written on the board matter." *Parent NZ*



A couple of my teachers checked in with me every now and then. They would ask how I was doing and how things were going. That was really good. I had extensions without asking for them which was also really nice." *Student NZ*

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NB: "Returning to School: A Teacher's Guide for Pupils with Brain Tumours, During and After Treatment" by Edwards, Marshall & Haeems is particularly relevant to secondary pupils.



**A special
thank you**

Special thanks to the individuals with brain tumours, families, and staff from the Ministry of Education, Northern Health School, Child Cancer Foundation, and Starship and Christchurch hospitals for the information shared.

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