

## Dear Friends,

**Welcome to Edition 3 of the Brain Tumour Support Service Newsletter. We have some delightful reading for you this time, in the form of personal stories which our readers all seem to enjoy.**



**Anne M. Miller,**  
*Volunteer Editor,  
Brain Tumour  
Support Service  
Newsletter.*

The first is from Nathan, an 18-year-old student, who tells us of his battle with a genetic disorder that affects the nervous system, and how at the age of five he developed a tumour of the optic nerve. This tumour did not require chemotherapy, but regular monitoring - check-ups and MRI scans. At the age of 13, when he was in Year 8, he developed headaches and nausea. An operation to relieve pressure on the brain was not successful and he needed a shunt put in, this gave him great relief but unfortunately symptoms returned and he was diagnosed with an Astrocytoma Grade 1 - this didn't need chemotherapy either.

Now, four years later, he is studying, has a part time job and is happy. What a wonderful story Nathan, you are very positive and thank you so much for taking the time to write and tell us. I hope you will soon obtain your driving licence, and your suggestion that you ask lots of questions from your medical team is great. Thank you again.

The next story is from Nathan's mother Una, who tells us her side of the story. She is full of praise for the medical team, has great support from family and friends and talks about the trip they all went on to Europe, which did them all a lot of good despite grave reservations prior to setting off. She and her husband have both now joined the Brainchild Team, and are hoping that their experience and voluntary work will help and make a difference to others. What a wonderful family, thank you so very much for your letters.

Kids Konnection tells us about Glioma, Ependymoma, Craniopharyngioma and others, where they are likely to be situated in the brain and treatment. A most interesting read.

We have an update on the fundraising of a remarkable lady, Dianne, to help promote Brain Cancer Action Week. Well done Dianne, thank you for the update.

Our Feature Article is about Reactions and Emotions to Childhood Cancer - a dreadful situation for parents. The article gives reaction of the 0-5 years, 5-12 years, teens, adolescents and young adults. All ages react differently. The article finishes with parents and other relatives' reactions while feeling completely devastated, and also gives some tips.

Finally this edition, an outline of the various titles and job descriptions of the people you may meet at the hospital. All valuable and interesting information. Then we have the usual support services, resources, phone numbers etc, plus details of a new support group which meets first Thursday of the month at CCQ.

'Till next time, keep smiling.

**Anne**

### **Thought for the day:**

*The supreme happiness of life is the conviction that we are loved; Loved for ourselves, or rather in spite of ourselves.*  
- Victor Hugo.

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## About the Brain Tumour Support Service

Information, support and referral for people who have a brain tumour, their family and friends.

### What the service provides:

- Information about benign and malignant brain tumours and treatment.
- Information about support agencies, rehabilitation services and CCQ’s Practical Support Program.
- Regular meetings that provide an opportunity to meet other group members and hear professionals discuss topics of interest.
- Regular newsletters for information and support.

For more information visit Cancer Council Queensland’s website at [www.cancerqld.org.au](http://www.cancerqld.org.au)  
Email: [helpline@cancerqld.org.au](mailto:helpline@cancerqld.org.au) or call our Helpline on 13 11 20.

## Donate now

We use your donations to help fund our research and support services for cancer patients. Thank you for your generosity.

Your tax deductible donation will contribute to vital cancer research and clinical trials, support services for patients, their families and carers, and information and public education campaigns.

*You can call our Donor Hotline on 1300 66 39 36, Monday to Friday from 8.30am to 5pm to make a one-off donation or to find out about the different donor programs that we offer.*

## Our Story – Nathan and Una

**My name is Nathan Schumacher. I am an 18-year-old man and have neurofibromatosis type one (NF1). NF1 is a genetic disorder that affects the nervous system, and one of the problems that can occur in some people with NF1 is brain and spinal cord tumours.**

When I was five I was diagnosed with an optic glioma, which is a tumour of the optic nerve and is more common in people with NF1. I was very lucky that my optic glioma did not require any chemotherapy, but I did need to have regular surveillance MRI scans to make sure that the tumour wasn't growing or causing me other problems in my brain. I did go into puberty early as a result of this tumour and had to have painful hormone injections every three weeks for years - but again no chemo!

In May 2009, when I was 13 and in Year 8 at school, I had a regular surveillance MRI scan. I had been getting some nausea and headaches. We went to see the oncologist and he told us that there was no change in my optic glioma and maybe I had a mild viral illness causing the headaches. A couple of days later he rang my parents and told them that there was a problem with the report of my MRI and we needed to come back to the hospital the next day. We had a follow up meeting with the oncologist. He told me I had a tectal plate glioma and that this was a new tumour which had not been evident on the scan done only six months ago. A decision was made to again watch and see what happened with this tumour, but to bring me back earlier to have another MRI. In the meantime I got more headaches, began vomiting occasionally (mostly in the morning) and



whenever I stood up I got a bad headache. We went back to the oncologist and he thought I had increased intracranial pressure and brought in a neurosurgeon to speak with myself and my parents, and we agreed that I needed a ventriculostomy procedure. This procedure was supposed to relieve the pressure in my brain without the need for a shunt.

I was admitted to the Royal Children's Hospital for surgery, however the ventriculostomy was not successful. After the procedure I couldn't raise my head at all and had a constant migraine for about a week. The head of the bed was raised a little bit each day, I was given very strong painkillers and after about five days I went home. The neurosurgeon explained that I did have raised intracranial pressure and would need to have a shunt, but I had to wait for some healing to occur after the ventriculostomy.

I stayed home from school for about two weeks and then was admitted again for the shunt procedure. I was concerned in case I had the same pain as after the ventriculostomy, however the minute I woke up I felt better than I had before the first surgery. I recovered at home for about a week and then went back to school.

Not long after this our family went on a holiday to Europe. Although I was feeling much better in my head I had a lot of problems with constipation from the painkillers I had used after the procedure. This affected me a great deal for quite a few weeks and it was the thing I hated the most about the whole experience.

When we came back from Europe I was a lot better and went back to school, however over the next couple of months nausea and headaches began to return. An MRI in late November showed that the tumour was growing. The neurosurgeon explained that I would need to have the tumour debulked, but he also asked if I wanted to wait until school finished. I waited until after the assessment period at school and in December, a couple of weeks before school finished, I had the tumour debulked.

I was really worried about this surgery as there was a risk that I could lose some eyesight, and movement and feeling on one side of my body. The thought of

## Our Story – Nathan and Una

losing my eyesight bothered me a great deal. The surgery was long and I woke up in ICU feeling very drowsy. At first I was a little worried as I had some problems with my eyesight. The nurses and doctors were very helpful and I had very little pain. After ICU I was sent to the ward. Mum kept making me eat and I vomited. I had a lot of visitors, including quite a few teachers from school which I thought was really nice. The one thing I didn't like was the hospital school teacher making me do school work while recovering. My mother said no to the teacher, because I was sick, and so did my school teachers but the hospital school teacher insisted I do it. My eye sight returned to normal almost as soon as I came out of ICU. I did experience some hallucinations, which I suppose was from the drugs. I do wish the

hospital was quieter and the beds were softer! I just wanted to rest but I kept getting woken up and then had trouble sleeping again because of all the noise.

We had to wait at least a week to find out what type of tumour I had. I was very lucky - it was an Astrocytoma Grade 1. The best possible outcome. This also meant that I didn't require any other treatment like chemotherapy.

It is now four and a half years since my surgery. I have regular MRI's and so far the tumour has not re-grown. I do have some other 'hot spots' on my brain MRI's but so far all is good. I am studying at TAFE and have a part-time job. I have not had any noticeable effects from my surgery other than some subtle changes to my vision which have increased my blind spots. I don't even notice them, but I have

been told to be careful to turn my head fully when crossing the road because of these blind spots. I had to seek permission from the eye specialist and the oncology team to apply for my learners driver's license, although I haven't bothered yet.

Nausea and headaches are a regular part of my life now. We don't know why this is - could be the shunt over-draining. One thing I have noticed is that I am happier and I think this is because I no longer have a feeling of pressure in my head. I am not concerned about having regular MRI's as these have been a part of my life since I was five. At least I know I am not going to go blind. If you have been diagnosed with a brain tumour I suggest that you ask a lot of questions of your medical team, but at the same time don't over-think things.

### **Our family comprises myself, Una, Ross and our two sons Dylan and Nathan. We first learned about Nathan having NF1 when he was six months old, but it didn't cause any medical problems until he was five.**

In the year leading up to the diagnosis of an optic glioma Nathan went back to having daytime naps, became more clumsy and lost a lot of weight. Nathan had a lot of procedures performed such as having his tonsils and adenoids removed, grommets inserted into his ear drums and coeliac and allergy testing, because no-one thought to check out his brain! Once he had his optic glioma diagnosed, although it was a shock it was also reassuring because at least we understood what was happening. Although children without NF1 have treatment for their optic gliomas this is not always the

case in children with NF1. By the time Nathan's optic glioma was diagnosed it had stopped growing and we began the 'watch and wait' protocol.

Nathan has already explained how his tectal glioma was diagnosed. From the outset the medical team were pretty certain it was a relatively benign glioma but unfortunately its position was problematic. Although I was sad for Nathan, I also thought he was very lucky. At least Nathan has the advantage of regular medical reviews and MRI's and his tectal glioma was detected early when it was easier to treat.

I also think we are incredibly lucky to have such high quality health care in Australia. Anytime I see reports of new research or treatment relative to Nathan's needs I discuss these at his next oncology appointment and the team are always across the information as they belong to international collegial networks. If I have a harebrained idea I think I'd like to try they usually know about those approaches as well and can point me in the right direction. There will always be the odd health care professional who doesn't provide care the way you would like, but overall we live in an amazing time and place. If Nathan

## Our Story – Nathan and Una



Una, Ross and our two sons Dylan and Nathan.

had NF1 and was born in the 1960s he would very likely not be alive today.

Along our journey there have been several times where we have been advised not look things up on the internet. I get very annoyed when people give you this pointless advice. My viewpoint is that knowledge is power. I have found out numerous helpful things on the internet. Yes, I did read some terrible things, but on balance what I gleaned helped me to process the information the doctors had provided, understand Nathan's tumour, the surgery he would likely have and how other people have coped with their diagnosis or that of their child. Each to their own though - Ross, doesn't find this approach helpful.

Our family, friends and work colleagues were very supportive and helpful when Nathan had his surgeries and during his recovery. There is always someone who has some fabulous alternative treatment that they want you to try. I have learned to thank them kindly for their advice and leave it

at that. If you express your opinion (that you're not interested or that it's a load of rubbish) then it may harm your friendship and this advice is usually offered from a place of caring. I also try very hard not to do this to others.

I was quite annoyed with Ross for pushing for us to continue with our holiday to Europe after Nathan had his shunt surgery. I thought it would be too much for Nathan and I was happy to wallow in self-pity for a little while. On reflection it was wonderful, especially as Nathan ended up having the tumour debulked not long after our return. We had been told the tumour might stay dormant for years. We were all completely distracted from the awfulness of Nathan's situation. It gave us a completely different focus and, with everything that had happened in the lead up to going, we were more mindful of each other and truly had a family holiday. Whilst I am aware that this type of holiday is not appropriate for everyone I do think that a break from the routine might be helpful

to anyone going through the surgery and chemo cycle. At the time it becomes all consuming - to the point that you can neglect the other important people in your life and lose perspective. Even a trip outside the hospital room into the fresh air can make a difference.

Since Nathan's treatment Ross and I have joined the BrainChild team. At first we felt fraudulent. Here we met parents who had lost their children to brain or spinal cord tumours, and others whose children have faced many months of treatment and who have been left severely affected by their tumour and/or treatment. I must admit that it can be quite confronting being with parents who have lost a child to cancer. I have felt guilty that my child has survived. When Nathan had his ventriculostomy he was placed in a room with a two year old boy from a regional area. His brain tumour had left him with severe effects. Separated from their young children, this family were devastated and a long way from home with no personal support systems. I was struck by their circumstances, and hoped that by volunteering with BrainChild I could make a difference. There are so many impacts from having a brain tumour diagnosis - not just the health ones but emotional, financial, educational and social. And in children the impacts span the whole family as well as school and social networks.

I will always wish that Nathan did not have NF1 or brain tumours, however I do think that his situation has made me appreciate the littlest things in every day that once upon a time I would never have noticed.

# WHEN THE PRESSURE OF HAVING A PARENT WITH CANCER BECOMES TOO MUCH

...it's time to call a **truce.**

**Canteen**  
The Australian Organisation  
for Young People Living with Cancer

## Is your family impacted by parental cancer? CanTeen has a new FREE group program called TRUCE to help young people who have a parent with cancer

Young people who have a parent diagnosed with cancer often feel distressed and isolated. CanTeen, the Australian charity for young people living with cancer, are currently offering a new program called Truce to provide coping skills to 14-22 year olds who have a parent or caregiver with cancer.

Truce helps young people deal with difficult thoughts and feelings, better communicate with others (especially family), and learn coping skills. It also helps young people feel less alone as they get a chance to meet other young people going through the same thing.

Truce is a group face-to-face program run over 7 weeks. Parents are also invited to attend one of the sessions (although this is not compulsory).

Young people who have participated in the program so far have told us that after participating in the program they can cope better, and parents felt they better understood how their children felt and had noticed positive changes in their behaviour.

**A group is to be held at the CanTeen Brisbane office (33 Vulture St, West End QLD), and at the Bloomhill Cancer Center, Sunshine Coast, starting the week of 4th August if sufficient interest is received NOW.**

For more information on Truce or to express your interest, please speak Mamta at CanTeen (1800 234 007), [truce@canteen.org.au](mailto:truce@canteen.org.au), [www.truce.org.au](http://www.truce.org.au).

## WHAT DO I DO next?

The Truce team is happy to give you more information or to answer any questions. Please feel free to call or e-mail us, or check out the website.

**T: 1800 234 007**

**E: [truce@canteen.org.au](mailto:truce@canteen.org.au)**

**W: [www.truce.org.au](http://www.truce.org.au)**

Truce is brought to you by:



SCAN HERE FOR MORE INFORMATION

**1800 234 007**  
ABN 77 052 040 516

# Update on Dianne's Fundraising

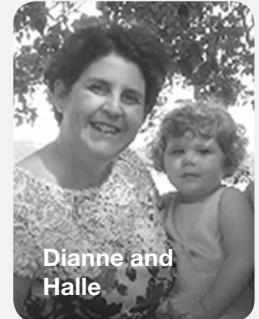
In our last newsletter Dianne shared with us her story of being diagnosed with a grade IV glioblastoma (GBM) in October 2012. Her last chemo round was taken in September 2013, and since then Dianne has been involved with Cancer Council Queensland (CCQ) as a Community Supporter in *I Can for Cancer*, working hard to promote brain tumour awareness.

To help promote Brain Cancer Action Week, Dianne organised the first ever Footprints for Brain Cancer event. This was a 4km family fun walk through the Brisbane suburb of Ashgrove. The event was designed to raise awareness and help CCQ fund research projects into brain cancer. The hugely successful event was held on Sunday 4 May and included sausage sizzles, face painting and music.

Diane did an amazing job organising this event, which raised a whopping \$12,501.63 for CCQ brain tumour research. Congratulations Dianne, you must be proud of what you have achieved and CCQ is certainly grateful for your efforts! Dianne is now looking forward to organising a bigger and better Footprints for Brain Cancer event again next year to continue to raise awareness about brain tumours and support research.

Donations to CCQ help us to provide the Brain Tumour Support Service, and for our Viertel Centre for Research in Cancer Control to fund brain cancer research projects. CCQ funding goes towards supporting cancer research throughout the state in the form of project grants, fellowships, travel/study grants and scholarships. Some recently awarded brain tumour research project grants include:

- "Understanding the function of salinomycin as a DNA damaging agent and its relevance as a potential therapeutic agent for the treatment of malignant brain tumours" Researcher: Dr Bryan Day, Queensland Institute of Medical Research Berghofer Medical Research Institute.
- "A prospective study of language function following surgical resection of left hemisphere primary brain tumours" Researcher: Associate Professor Greig de Zubicaray, University of Queensland.



- "Targeting existing therapies with innovative technology platforms to improve survival in brain cancer" Researcher: Associate Professor Jennifer Martin

For further information, or to find out about our 2015-2016 Research Project Grants, please see our website at: [www.cancerqld.org.au/page/research\\_statistics/cancer\\_research\\_project\\_grants/](http://www.cancerqld.org.au/page/research_statistics/cancer_research_project_grants/)

For more information about Footprints for Brain Cancer visit <http://www.footprintsforbraincancer.com/index.html>

# Kids Konnection BrainChild

What brain tumours are more common in children?

**More than 60% of childhood tumours are located in the back compartment of the brain, which includes the cerebellum, the brain stem and the fourth ventricle. The remaining 30 – 40% occur in one of the two cerebral hemispheres of the cerebrum or in the spinal cord.**

Some of the more common childhood tumours include:

## **Astrocytoma (also called Glioma)**

These tumours arise from star shaped neural glial cells called astrocyte. Sometimes the terms “astrocytoma” and “glioma” are used interchangeably. The World Health Organisation classifies these tumours from grade 1 through to grade 4. Grade 1 is given to the most benign tumours and grade 4 to the most malignant. Common sites in children include the cerebrum, the cerebellum and the brainstem. Low-grade astrocytomas are usually localised and grow slowly over a long period of time. High-grade tumours are much more aggressive and require very intensive therapy.

In children, more than 80% of astrocytomas are low-grade; nearly 20% are high-grade (Glioblastoma Multiforme).

## **Brainstem Gliomas**

The brainstem is located deep within the posterior part of the brain and it is here where control of our most basic functions such as breathing, heart rate and blood pressure occur. Approximately 10% to 15% of childhood brain tumours are brainstem gliomas. Their location may cause sudden dramatic symptoms such as double vision, difficulty swallowing, clumsiness and weakness. The peak age group is between five and ten years.

Those tumours localised in the midbrain/medulla have a better survival than diffuse pontine gliomas. Because of their location surgery is not an option. Patients’ symptoms often improve during or after six weeks of irradiation. Unfortunately, problems usually recur after six to nine months, and progress rapidly. Survival past 12 to 14 months is uncommon, and new approaches to treating these tumours are urgently needed.

## **Craniopharyngioma**

This slow growing tumour accounts for 5–10% of childhood brain tumours, and usually occurs in children between five and ten years of age. Craniopharyngiomas result from the growth of cells that early in foetal development have failed to migrate to their usual area just below the back of the skull. These tumours arise from cells along the pituitary stalk and may grow up and involve the hypothalamus, optic nerve pathways and the third ventricle.

At diagnosis children may have symptoms such as headache and vomiting, hormonal deficiencies (growth delay, thyroid deficiencies, delayed puberty), visual disturbances and weight gain due to hormonal disturbances.

Complete removal of this tumour is optimal if it is in a favourable location. Outcome is good, however all of these children will require long term follow-up with a team of specialists to monitor possible hormonal and visual problems.





### **Ependymoma**

This tumour accounts for up to 10% of childhood tumours and tends to occur before the age of five years. Ependymomas arise from cells lining the passageways in the brain that produce and store the cerebrospinal fluid or CSF. The tumours are most often in the back of the brain in an area called the posterior fossa. Very few ependymomas spread to other parts of the brain or to the spinal cord before they are diagnosed. Symptoms from these tumours often include headache, nausea, vomiting, visual changes and balance problems.


Surgery is utilised to remove as much of the tumour as possible depending on the tumour location. The best survival rates are from those children who have had gross total resection of their tumour. Radiation oncologists are now using focal radiation techniques after surgery with excellent long term results. Chemotherapy has also been added to recent studies.

### **Medulloblastomas (PNETs)**

These are the most common malignant childhood brain tumour occurring in 20% of children. They most often occur in the first decade of life; half occur in children younger than five to six years of age.

These tumours tend to arise in the middle of the cerebellum, interfering with CSF flow and resulting in hydrocephalus. These tumours are also referred to as primitive neuroectodermal tumour (PNET). Tumours that have the same characteristics can also arise in other parts of the brain. This tumour type has a tendency to spread to other areas of the brain and spinal cord.

Treatment by skilled neurosurgeons aims for complete resection, followed by central nervous system radiation therapy and chemotherapy. Outcome of this treatment is considered to be good.



*Cancer Council Queensland and the Brain Tumour Support Service are pleased to support the BrainChild Foundation and welcome them as our authors for the "Kids Konnection" articles in the Brain Tumour Support Service newsletter.*

*Thanks to BrainChild for working with us and sharing valuable information about services and supports for children affected by brain tumours, as well as their families.*

# Reactions and emotions to childhood cancer

**The diagnosis can come as a huge shock to everyone in the family. Each person will be trying to deal with their own feelings. These can include shock, fear, anger, sadness and disbelief.**

The effects of the child's cancer often extends to the wider community of school teachers, classmates, neighbours and other people in contact with the child and their family during this illness. Everyone involved needs the right information to support them through this difficult time.

## **A child's feelings and reactions**

No matter what age a child is, a cancer diagnosis will have a big effect on them. A child's age, level of development and personality will determine many of their reactions. However, most children will feel a mix of being anxious, afraid, angry or upset at some stage during their illness.

For most children with cancer, their life changes dramatically. Going through tests, doctor's appointments and treatment will become part of their daily life. They will have a lot to cope with and it is important they have people close by they can trust and feel loved by at all times.

Although children can show a surprising natural resilience during a serious illness, experts recognise that understanding a child's specific needs, maintaining normal routines, and providing boundaries, comfort and love, are very important to help support this resilience.

For most children their parent/s will be the main source of support during their illness. Children know a parent will be more aware than anyone else about how they cope

in unfamiliar situations, what makes them fearful, sad, happy and how to get them to relax during extra stressful moments.

Below we outline some common reactions of children with cancer, by age. Remember though, every child is unique and will react and cope in their own way.

The Cancer Council Australia booklet entitled Talking to kids about cancer has a more detailed list of children's reactions and needs at different ages. Whilst this booklet is aimed at children whose parents have cancer, the information is still relevant to children with cancer.

## **Babies and infants (0-5 years)**

Children this young worry about the 'here and now'. Their main concern will be about being away from parents. They may also be confused and upset about not being able to play and have as much fun as usual.

Very young children and babies may:

- Become very fearful of being separated from their parents – cling more than usual
- Cry, yell, scream and shout more than usual
- Become uncooperative during tests and treatment
- Become angry and upset because their usual daily routine of eating, play and intimacy with parents has been changed
- Have changes to their sleeping patterns (difficulty getting to sleep or staying asleep)

- Regress in independence, maturity or toileting habits
- Become withdrawn and not wanting to take part in things they used to enjoy.

## **Primary school age children (5-12 years)**

This age group have gained some independence. They are more aware of what is going on and although some of their reactions will be similar to an infant they may also:

- Need more emotional support than usual from their close family and friends
- Miss the interaction with school mates and other friends
- Feel uneasy and frustrated with the disruption to school work and after school activities
- Display bouts of anger and sadness about their illness and how it is causing loss of school and play time
- Withdraw from friends and reject school work as a way of protecting themselves from the disappointment of what has happened.

## **Teens**

The diagnosis of cancer in the teenage years can be very confusing and overwhelming. For some, their first reaction will be to push their family away as they try to cope with things alone. However, others will be drawn closer to their parents and siblings and rely on them more than ever. Possible reactions from



teenagers can include:

- Being angry and anxious about their body not working as it used to
- Becoming withdrawn and very low in mood (depressed)
- Pretending things are OK and make a joke of their cancer and its treatment as a way of distracting from what is happening
- Rebelling against parents, teachers and medical staff making treatment and care more difficult
- Seeking support from those outside immediate family (e.g. friends, teachers etc) more than usual
- Feeling embarrassed and upset about what has happened to them especially if treatment has

caused side effects which affect the way they look and act (hair loss, mobility problems or weight loss).

For more detailed information read:

- The USA National Cancer Institute's booklet entitled *Young people with cancer: a handbook for parents*
- Paediatric Integrated Cancer Services [PICS] website has a comprehensive list of web links for many good quality support organisations and websites relating to teenagers and young adults with cancer.

You can also call Cancer Council Helpline 13 11 20.

### **Adolescents and young adults**

A cancer diagnosis during the adolescent and young adult years

has different impacts for a young person compared to a younger child or older adult. For young people, adolescence and young adulthood are times of emerging independence physically, psychologically and socially. A cancer diagnosis and its treatment can mean negotiating this complex development as well as coping with a range of emotions which result from the stressors that cancer brings. Particular issues that young people may experience include:

- Loss of independence
- Changes to intimate, peer and family relationships
- Altered physical function, fitness, self-esteem and body image
- Questions about fertility
- Disruption to schooling and education
- Employment challenges and workplace rights
- Financial and practical concerns.

For more detailed information read:

- ONTrac at Peter Mac Victorian Adolescent & Young Adult cancer Service website: [www1.petermac.org/ontrac/](http://www1.petermac.org/ontrac/)
- Youth Cancer Services website: [www.youthcancer.com.au](http://www.youthcancer.com.au)
- Now What website: [www.nowwhat.org.au](http://www.nowwhat.org.au)

### **Siblings' feelings and reactions**

Brothers and sisters of a child with cancer have their own fears. Hospital visits, seeing their brother/sister upset, in pain or acting differently can all be very frightening to a child. They may feel they have lost the once close and fun relationship with their brother or sister. Feeling alone and lost is not uncommon.

Siblings may have feelings of anger and jealousy towards the sibling with cancer. They see them getting a lot of attention. Sadness, guilt that they were the cause of their



sibling's cancer, and anxiety are other common feelings of siblings. They may also:

- Feel shock and confusion about their sibling's illness
- Worry about what is expected of them and how they will cope
- Pretend they are OK so as not to upset their parents more than they already are
- Resent the changes their sibling's illness has brought to their life
- Get lower marks than usual at school
- Suffer behavioural changes such as fighting with friends, family and teachers.

For more information and support:

- Siblings Australia provides support to siblings of children and adults with chronic conditions including cancer
- The UK Children's Cancer and Leukaemia Group leaflet *How to Help Brothers and Sisters*
- The National Cancer Institute booklet *When Your Brother or Sister Has Cancer: A Guide for Teens*

- *Now What* has been developed by CanTeen, the Australian Organisation for Young People Living with Cancer. *Now What* has been developed by a team of people including CanTeen staff and young people whose lives have been affected by cancer.
- ONTrac at Peter Mac Victorian Adolescent & Young Adult cancer Service website: [www1.petermac.org/ontrac/](http://www1.petermac.org/ontrac/)

### Parents' feelings and reactions

Understandably, most parents who are told their child has cancer feel completely devastated. At first it can be difficult to come to terms with and try to understand how this will impact the whole family. There may be moments when people can feel numb and don't believe what is happening. Painful emotions of anger, sadness, guilt, fear and denial are all common and normal feelings of parents who have been told their child has cancer.

It may be reassuring to know that most parents get through these initial reactions and emotions by focussing on what to be done to help support their child and family through this time. Parents play a huge role in how a child copes. A

calm, loving, present and reassuring parent can help the child to cope with the treatment.

There is no right or wrong way to feel. Most parents find their emotions go up and down over the course of a child's treatment. Some days they may feel they are coping and other days may feel completely lost or out of control.

Whilst no-one can fully prepare a parent to cope with their child having cancer we hope the following tips will help:

- Find out all you can about childhood cancer, treatment and care.
- Ask your doctors where to get information on the internet. Some websites are not trustworthy and provide misleading information which can be dangerous and upsetting. For further guidance download the UK Children's Cancer and Leukaemia Groups (CCLG) leaflet *How the internet can help us?*
- Do not try to be 'brave' and cope alone. Doctors, nurses and all staff at the hospital want to help you. Talk to them, let them know how you feel and ask for help.
- Ask close family and friends for

help with home duties (cooking, washing, cleaning, shopping) and caring for your other children. They will want to help but may need guidance as to what to do. Don't be afraid to tell them!

- Look after yourself. Most parents find this the hardest thing to do, as they focus completely on their sick child's needs. But it is important to take time out for you and not feel guilty for doing this. You cannot be expected to care for your child if you are not first taking care of yourself.
- Try to talk about your feelings with those you trust. Most people say that when they share their sadness, anger or fear it helps. If you feel you may need some professional counselling ask your GP or the social worker at the hospital for a referral.
- Set up a group email or blog for people who want to know how things are going, or delegate a close friend or family member to give information to the rest of your friendship and family groups. It can be overwhelming to try and inform everyone all the time about what is happening for your child. Be careful about the information you post about your child, he or she may not want their private information in the public arena.
- Take time out to spend with your partner, family and friends. Having a child with cancer can put a lot of strain on your close relationships. It is important to maintain communication both through talking and physical intimacy where possible. You can download the fact sheet *Taking care of relationships* from the Paediatric Integrated Cancer Service (PICS) website.
- Ask for information and support from the many organisations that help children with cancer and their families.

Further information and support:

- Contact *Cancer Connect* (via Cancer Council Helpline 13 11 20) to talk to another parent who knows what it's like to have a child with cancer.

#### **Other close relatives and friends reactions**

Grandparents, aunts, uncles or other close family relatives and friends often have similar feelings to those of the parents of the child with cancer. They may find it difficult to cope with how they feel. Being given accurate and up to date information will help all of these people too.

Grandparents of a child with cancer have not only the concern for their grandchild but also for their son or daughter. Sometimes this 'double hurt' may not be appreciated by others.

Grandparents who are close to their family may find their role in the family changes when a grand child gets cancer. They can be left feeling quite lost and upset. It is important to try and make them feel part of what is going on. Allow them to take part in the child's hospital visits and care if possible. This can help everyone.

Family and friends will want to help as much as possible but they may not know what to do. There may be the odd person who reacts in a way you did not expect. Overall though, most people's intentions will be good. But parents of the sick child may need to ask and guide people to help in the most useful way. Most people will welcome being told what to do in this situation.

For more information call Cancer Council Helpline 13 11 20.

#### **Talking to children about their cancer**

It is only natural to want to protect a child and their siblings about a cancer diagnosis. However, for

most children, the regular hospital visits and tests, missing school and other activities will alert them to the fact that something is wrong. Most children pick up on their parent's feelings. How they react to upsetting news often depends on how the parents are coping with it.

We recommend being open and honest with young people about a cancer diagnosis. Reliable, age-appropriate information can help them understand and cope with changes. However, an honest discussion can be tremendously difficult, particularly when trying to cope with the diagnosis yourself.

If possible, both parents should talk to the child. This way they can support each other. It is important not to overload children with information. Throughout the conversation, clarify that the child understands what is being said. Be sure that all significant people in the child's life know what has been said. Keep things consistent and honest. It is important not to promise a child anything that adults cannot be sure of.

Letting children know how adults are feeling can will allow them to express their own feelings more easily. Reassure children that whatever they are feeling is normal and that they will be supported throughout.

For more information and support call Cancer Council Helpline on 13 11 20.

*This information is an edited extract from Cancer Council Victoria and is reprinted with their kind permission. The information in this article was reviewed by Cancer Council Victoria with assistance from The Paediatric Integrated Cancer Service (PICS), parents and staff from the Oncology units at both The Royal Children's Hospital, Melbourne & Monash Children's, Monash Health, Melbourne and ONTrac, Peter Mac Victorian Adolescent and Young Adult (AYA) Cancer Service. Sourced from: [www.cancervic.org.au/about-cancer/cancer-and-children/emotions-childhood-cancer](http://www.cancervic.org.au/about-cancer/cancer-and-children/emotions-childhood-cancer) as at 24/4/2014.*

# Glossary - People you may meet

## Medical Staff

### Consultants/Senior Staff Specialists

- Child Psychiatrist - A physician who specialises in assessment and treatment of mental health issues.
- Endocrinologist - A physician who specialises in hormonal diseases and growth problems.
- Neurologist - A physician who specialises in non-surgical diseases of the central nervous system.
- Neurosurgeon - A physician who specialises in surgery of the central nervous system. This includes both the brain and spinal cord.
- Ophthalmologist - A physician who specialises in the diagnosis and treatment of eye disorders.
- Oncologist - A physician who specialises in caring for children with cancer.
- Pathologist - A physician who specialises in analysis of samples obtained from tissue, organs, fluid and bone from the body.
- Radiologist - A physician who specialises in the reading of images such as MRI scans, CT scans and X-rays.
- Radiation Oncologist - A physician who specialises in the treatment of cancer by radiation therapy.
- Rehabilitation Consultant - A physician who specialises in the rehabilitation treatment of patients recovering from injury.

### Fellows

Fellows are senior doctors who are training to become specialist doctors in oncology (cancer). They are often very close to qualifying as specialists and therefore perform many of the roles of the consultants. Fellows generally change every 12 months.

### Registrars

Registrars are senior doctors who are in training to become specialists in caring for children; some may become specialists in cancer. These doctors work under the direction of the consultants and fellows, they change approximately every six months so they can gain experience in caring for children with different diseases.

### Residents

Residents are junior doctors in training. Resident doctors work under the direction of the registers and change approximately every three months so they can gain experience in all areas of medicine.

## Nursing Staff

### Nursing Unit Managers (NUMs)

The nurse unit manager oversees the care of all the children whilst they are within the hospital. The Nurse Unit Manager is also responsible for supervising the nursing staff who works within the ward. Any queries or concerns should be directed to the Nurse Unit Manager.

### Clinical Nurse Consultants

The clinical nurse consultant (CNC) is a senior nurse who specialises within a particular field. Within the Oncology unit you will be allocated a CNC at your child's initial hospitalisation. The CNC will then provide ongoing contact with your community including local schools and regional medical centres. Their role also includes education about your child's type of cancer and the treatment plan established by the consultants.

*List sourced from Brain Child website  
[www.brainchild.org.au/helpful-info/people-you-may-meet](http://www.brainchild.org.au/helpful-info/people-you-may-meet) as at 14/05/14.*



The Brisbane Brain Tumour Support Group is a new, peer-facilitated group for patients, carers and anyone interested in information and support for those affected by brain tumour.

**Time:** 10.00am to 12.00pm

**When:** 1st Thursday every month

**Where:** Auditorium 1, Ground Floor  
Cancer Council Queensland  
553 Gregory Terrace  
Fortitude Valley

**Parking:** Limited parking is available. Ask for details.

**Contact:** Enquiries can be directed to  
[braintsg@gmail.com](mailto:braintsg@gmail.com)

# Brain Tumour Information Sessions 2014

## Brisbane

### May

**Date:** Tuesday, May 13  
**Time:** 10.00am – 11.30am  
**Topic:** **Living Well With Seizures**

### July

**Date:** Tuesday, July 15  
**Time:** 9.30am – 11.30am  
**Topic:** **Physical activity and nutrition during and after treatment**

### September

**Date:** Tuesday, September 9  
**Time:** 10.00am – 11.30am  
**Topic:** **A couples and family guide to managing the effects of brain tumour**

### November

**Date:** Tuesday, November 18  
**Time:** 10.00am – 11.30am  
**Topic:** **Searching for meaning after a brain tumour**

*Please note: Most sessions will be held at Cancer Council Queensland (553 Gregory Terrace, Fortitude Valley). Selected sessions may be held at designated hospital seminar rooms. Light refreshments and optional group discussions will be held after the 1hr presentation. For more information & to RSVP contact the Cancer Council Helpline on 13 11 20 or email [helpline@cancerqld.org.au](mailto:helpline@cancerqld.org.au)*

Don't forget!



You can find many of our brain tumour podcasts at Cancer Council Queensland's website [www.cancerqld.org.au](http://www.cancerqld.org.au)



## Would you like to share your story with us?

Readers of our newsletter like to hear the personal stories of how others have coped with the diagnosis of a brain tumour.

If you would like to find out more about sharing your story with our readers, please contact:

**Brain Tumour Support Service**

Email: [janinerhodes@cancerqld.org.au](mailto:janinerhodes@cancerqld.org.au)

Phone: 07 3634 5307

# Services of Cancer Council Queensland

Cancer Council Queensland services are provided free. Services may vary throughout Queensland.

For further information about services in your local area please contact:

**Cancer Council Helpline 13 11 20** Monday to Friday, 8am to 6pm.  
**helpline@cancerqld.org.au** or **www.cancerqld.org.au**

## Brain Tumour Support Service

Provides support for people affected by brain tumours, their family and friends through regular newsletters and meetings that provide opportunities to meet other group members and hear health professionals discuss topics of interest. Meetings are held in Brisbane and Townsville.

## Cancer Counselling Service

A free and confidential telephone and face-to-face counselling service to help people with cancer and those close to them. The Cancer Counselling Service aims to help by providing emotional support and strategies to work through cancer-related challenges. People can be referred to the service by calling Cancer Council Helpline on 13 11 20.

## Cancer Council Helpline 13 11 20

Provides information, support and referral to support services for people affected by cancer and brain tumours. The trained staff can provide information about the various types of brain tumours and their treatments, and can send booklets, information sheets and other resources.

## Look Good... Feel Better Program

Workshops conducted by trained beauty consultants, dedicated to teaching people beauty techniques to help restore their appearance and self-image during and after treatment.

## Practical Support Program of Cancer Council Queensland

- Accommodation facilities for country patients.
- Assistance with transport costs.
- Wig and Turban Service.

## Cancer Connect

A free confidential service that puts you in touch with trained volunteers who have had a brain tumour diagnosis.



*For further information about these and other services provided by Cancer Council Queensland please call our Helpline on 13 11 20.*

*Thinking about starting your own brain tumour or cancer support group? Call Cancer Council Queensland to find out how we can support you.*



## Regional office contacts:

### **Bundaberg**

Ground floor,  
312 Bourbong Street,  
Bundaberg West  
T: 07 4150 4500  
F: 07 3259 8401

### **Cairns**

169 Aumuller Street,  
Bungalow  
T: 07 4047 5500  
F: 07 3259 8478

### **Gold Coast**

1 Short Street,  
Southport  
T: 07 5503 3700  
F: 07 3259 8457

### **Mackay**

4a, 6-8 Discovery Lane,  
North Mackay  
T: 07 4842 2000  
F: 07 3259 8371

### **Rockhampton**

43 Upper Dawson Road,  
Rockhampton  
T: 07 4932 8600  
F: 07 3259 8480

### **Sunshine Coast**

Shop 4,  
54 Baden Powell Street,  
Maroochydore  
T: 07 5451 6000  
F: 07 3259 8479

### **Toowoomba**

137 Herries Street,  
Toowoomba  
T: 07 4690 5800  
F: 07 3259 8481

### **Townsville**

24 Warburton Street,  
North Ward  
T: 07 4796 8400  
F: 07 3259 8507



# **c·vivor**

## **active cancer support**

**c-vivor is an activity-based peer support program which brings together people who have been affected by cancer to participate in a regular physical or wellness activity. The program aims to combine the benefits of physical activity with the well-known psychosocial benefits of peer support.**

If you are interested in being a c-vivor group leader or member, please contact your regional CCQ Cancer Support Coordinator via our Helpline on 13 11 20.

# Making Connections

**Talking to others who have also been affected by the diagnosis of a brain tumour can sometimes help. Depending on what suits your needs and what you're most comfortable with you can meet people over the telephone, online or face-to-face through a brain tumour support group. Some of these options are:**

## **Cancer Connect (telephone)**

Cancer Connect is a free and confidential service provided by the Cancer Council, which can put a person who has been diagnosed with a brain tumour, their partner, carer or family members in telephone contact with a support volunteer who has had a similar diagnosis. People are matched based on similar circumstances such as type of tumour, age and treatment.

Volunteers are trained to provide practical information and emotional support, complementing the care provided by the patient's health care team. They do not give medical advice or provide professional counselling.

For more information contact the Cancer Council Helpline on 13 11 20.

## **Brain Tumour Patients Telephone Support Group (telephone)**

Cancer Council New South Wales' Brain Tumour Telephone Support Group provides the opportunity for you to talk with other people living with a brain tumour. Group members range from those who are newly diagnosed, to those who have been living with a brain tumour for some time. Being telephone-based, you can join the group from anywhere in Australia. All you need is an hour, a telephone and a quiet, private space. Participation is free

and confidential. Two trained co-facilitators co-ordinate the groups, which run for one hour. Any adult who has been diagnosed with either a benign or malignant brain tumour can join.

Brain Tumour patients telephone support group meetings are held on the FIRST and THIRD Monday of each month.

For more information or to join: Free call 1300 755 632 Monday - Friday 9am - 5pm or email: [tsg@nswcc.org.au](mailto:tsg@nswcc.org.au)

## **Cancer Connections (online)**

You can talk online with other people about your experience with a brain tumour diagnosis. Cancer Connections is an online community set up by Cancer Council New South Wales that links people with cancer, their friends and families in all states. Registration is free and your contact details will remain confidential. The site is supervised and the administrator is available on-line during business hours. For more information visit website: [www.cancerconnections.com.au](http://www.cancerconnections.com.au)

## **CCQ's Brain Tumour Information Sessions (face-to-face)**

You can meet people informally at our Brain Tumour Information Sessions, which are held five times a year for patients, carers and their families in Brisbane and

Townsville. A presentation from a health professional on a brain tumour related topic is followed by a relaxed morning tea where you can meet others.

For more information call the Cancer Council Helpline on 13 11 20.

## **United Brain Tumour Support – Gold Coast support group (telephone or face-to-face)**

United Brain Tumour Support is an independent support group based on the Gold Coast. The group meets in a relaxed atmosphere and is for all brain tumour patients and their families. "We connect people together through talking, listening and understanding their day to day issues with having a brain tumour and how it affects them and their families. If you are interested in joining our group, please do not hesitate to contact us".

The group meets at Tugun Surf Life Saving Club, 29 O'Connor Street, Tugun at 10:30am on the THIRD Wednesday of each month.

For more information contact Peter 0422 784 885, visit their website at [www.braintumourhelp.com.au](http://www.braintumourhelp.com.au) or find them on Facebook.

# Support services for people affected by brain tumours

## Acquired Brain Injury Outreach Service (ABIOS)

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ABIOS is a specialist community-based rehabilitation service for people with an acquired brain injury located in the Princess Alexandra Hospital, Brisbane.

☎ (07) 3406 2311

💻 [abios@health.qld.gov.au](mailto:abios@health.qld.gov.au)

💻 [www.health.qld.gov.au/abios](http://www.health.qld.gov.au/abios)

## The Australian Pituitary Foundation Ltd

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The Australian Pituitary Foundation Ltd was founded in Sydney in 1994 by pituitary patients and family members, with the endorsement of Australian endocrinologists, neurosurgeons, radiation therapists and endocrine nurses, who saw the need to support people who have rare conditions of the pituitary gland. After five years the APF developed into a company with benevolent status, limited by guarantee.

The Mission of the Australian Pituitary Foundation is to provide support to those who have experienced pituitary gland conditions. APF promote awareness and disseminate information among the medical community, public, pituitary patients and their families.

☎ 1300 331 807 (National)

1300 307 886 (Queensland)

Sue Kozij, Director,

Australian Pituitary Foundation Ltd

💻 [qld@pituitary.asn.au](mailto:qld@pituitary.asn.au)

## Beyondblue: the national depression initiative

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Beyondblue works to raise awareness of mental health issues and produces information on depression, anxiety and related disorders.

☎ 1300 22 46 36

💻 [www.beyondblue.org.au](http://www.beyondblue.org.au)

## Carers Queensland

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Carers Queensland is a not-for-profit organisation dedicated to supporting carers through the provision of information and support including regional carer services officers and counselling.

☎ (07) 3900 8100 or toll free 1800 242 636.

💻 [www.qld.carersaustralia.com.au](http://www.qld.carersaustralia.com.au)

## CanTeen Counselling Service

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A free service for young people aged 12-24 who have cancer, have parents/siblings with cancer or parents/siblings who have died from cancer. The service offers both one-on-one and group counselling options. Counselling can be carried out face-to-face, over the phone or online.

☎ 1800 226 833

💻 [support@canteen.org.au](mailto:support@canteen.org.au)

# Support services for people affected by brain tumours continued

## Disability Information and Awareness Line (DIAL)

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DIAL is a free, state-wide information and resource service provided by Disability Services Queensland.

☎ 1800 177 120

💻 [dial@disability.qld.gov.au](mailto:dial@disability.qld.gov.au)

💻 [www.disability.qld.gov.au](http://www.disability.qld.gov.au)

## Australian Disability Parking Scheme

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Disability parking permits for eligible applicants whose ability to walk is severely restricted by a medical condition or disability.

☎ 13 74 68

💻 [www.qld.gov.au/disability/out-and-about/parking-permits/](http://www.qld.gov.au/disability/out-and-about/parking-permits/)

## Domiciliary Services

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Provide a range of home services for example nursing, physiotherapy, occupational and speech therapy, as well as equipment, respite and palliative care. Examples include Blue Care, Ozcare and St Lukes Nursing Service.

☎ For contact details of the services nearest to you, call the Cancer Council Helpline on 13 11 20 or check the White Pages

## Epilepsy Queensland Inc.

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Information and support for people with epilepsy and their family. Books and videos on epilepsy for children, teenagers and adults.

☎ 1300 852 853

💻 [epilepsy@epilepsyqueensland.com.au](mailto:epilepsy@epilepsyqueensland.com.au)

💻 [www.epilepsyqueensland.com.au](http://www.epilepsyqueensland.com.au)

## Hospitals

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Services may vary between hospitals, and may include specialists, nursing staff, social workers, welfare officers, psychologists, chaplains, occupational therapists, speech therapists and physiotherapists.

☎ Enquire at your treating hospital for information about available services.

## Lifeline

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For urgent assistance and crisis support, be sure to contact Lifeline's 24-hour telephone counselling service.

☎ 13 11 14

## Medicines Line

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The Medicines Line gives confidential information on prescription, over the counter and complementary medicines for the cost of a local call. The Medicines Line is staffed by pharmacists.

☎ 1300 888 763

## Rehability

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Rehability is a private practice offering occupational therapy, social work and case management services. They offer a multidisciplinary team approach to clinical rehabilitation for acquired brain injury and neurological conditions, in both the home and clinic environment.

Address: 161 Richmond Road, Morningside, QLD 4170.

☎ (07) 3161 2471

💻 (07) 3161 2589

💻 [www.rehabilityabiservices.com.au](http://www.rehabilityabiservices.com.au)

## Open Minds

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Offers support to people with neurological changes and supports their integration back into the community.

☎ (07) 3896 4222

💻 [www.openminds.org.au](http://www.openminds.org.au)

## Palliative Care Information Service

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Toll free contact point for both the health community and the public to obtain information about palliative care and also to refer callers to the relevant service providers.

☎ 1800 772 273

💻 [www.pcis.org.au](http://www.pcis.org.au)

## Queensland Acoustic Neuroma Association

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Self-help groups for people affected by acoustic neuromas. Support includes pamphlets, information sheets, meetings, home and hospital visits and more.

☎ (07) 3397 3291

💻 [www.qana.asn.au](http://www.qana.asn.au)

## Relaxation Centre of Queensland

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Offer courses to assist with handling stress, communication, self-esteem, coping with change, relaxation, etc. Also offers books, tapes, videos, CDs, library services and numerous seminars by local, interstate and overseas speakers.

☎ (07) 3856 3733

💻 [relaxationcentreqld.com.au](http://relaxationcentreqld.com.au)

## Self Help Queensland

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Information about self-help groups available throughout Queensland.

☎ (07) 3344 6919

💻 [info@selfhelpqld.org.au](mailto:info@selfhelpqld.org.au)

💻 [selfhelpqld.org.au](http://selfhelpqld.org.au)

## Synapse (Brain Injury Association of Queensland)

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The Brain Injury Association of Qld is now known as Synapse, a non-profit organization, dedicated to improving the quality of life of people living with and affected by Acquired Brain Injury or people whose behaviour challenges our understanding. They provide support for carers through their carers support group.

Level 1 – 262 Montague Road, West End, Brisbane Q 4101

☎ (07) 3137 7400 or toll free 1800 673 074

💻 [info@synapse.org.au](mailto:info@synapse.org.au)

💻 [www.synapse.org.au](http://www.synapse.org.au)

## Technical Aid for the Disabled Queensland (TADQ)

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TADQ provides reliable, good quality refurbished computers at very affordable prices to people with disabilities.

☎ (07) 3216 1733

## Taxi Subsidy Scheme, Queensland Transport

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The taxi subsidy scheme subsidises taxi travel for eligible applicants up to half the cost of a taxi fare (limits apply).

☎ 13 23 80

💻 [www.qld.gov.au/disability/out-and-about/taxi-subsidy/](http://www.qld.gov.au/disability/out-and-about/taxi-subsidy/)

## Useful resources

**Resources available through our Cancer Council Helpline. Call on 13 11 20 or [helpline@cancerqld.org.au](mailto:helpline@cancerqld.org.au)**

- **About Brain Tumours**  
by Cancer Council Queensland
- **Brain Tumour Support Service Newsletters**  
By Cancer Council Queensland
- **Understanding Chemotherapy**  
by Cancer Council Queensland
- **Understanding Radiation Therapy**  
by Cancer Council Queensland
- **Coping with Cancer**  
by Cancer Council Queensland
- **Understanding Nutrition**  
by Cancer Council Queensland
- **Understanding Hair Loss**  
by Cancer Council Queensland
- **Complementary and Alternative Therapies**  
by Cancer Council Queensland
- **Living Well After Cancer**  
By Cancer Council Australia
- **Caring for someone with cancer**  
By Cancer Council Australia
- **Navigating the Internet**  
by Cancer Council Queensland
- **Adult Gliomas (Astrocytomas and Oligodendrogliomas): A guide for patients, their families and carers**  
by Cancer Council Australia
- **Understanding Brain Cancer DVD: A guide for people facing a brain cancer diagnosis**  
by Cancer Council NSW & Cancer Australia
- **Brain Tumours and Driving: A guide for patients and carers**  
by Cancer Council New South Wales
- **Brain tumours, depression and anxiety disorders: factsheet 46**  
by Beyondblue & the Brain Tumour Alliance Australia (BTAA)

## Useful websites

- Cancer Council Queensland  
[www.cancerqld.org.au](http://www.cancerqld.org.au) (AUS)
- Cancer Council NSW  
[www.cancerCouncil.com.au](http://www.cancerCouncil.com.au) (AUS)
- Cancer Directory (Cancer Council Australia)  
[www.cancerdirectory.com.au](http://www.cancerdirectory.com.au) (AUS)
- Brainlink  
[www.brainlink.org.au](http://www.brainlink.org.au) (AUS)
- Brain Foundation  
[www.brainfoundation.org.au](http://www.brainfoundation.org.au) (AUS)
- Cancer Institute NSW  
[www.cancerinstitute.org.au](http://www.cancerinstitute.org.au) (AUS)
- Sydney Neuro-Oncology Group  
[www.snog.org.au](http://www.snog.org.au) (AUS)
- Brain Tumour Foundation of Canada  
[www.braintumour.ca](http://www.braintumour.ca) (CANADA)
- National Cancer Institute  
[www.cancer.gov/cancerinformation](http://www.cancer.gov/cancerinformation) (US)
- Macmillan Cancer Support  
[www.macmillan.org.uk](http://www.macmillan.org.uk) (UK)
- Pediatric Brain Tumor Foundation  
Resources about the diagnosis and treatment of children's brain tumours.  
[www.pbtfus.org](http://www.pbtfus.org)
- American Brain Tumour Association (ABTA)  
[www.abta.org](http://www.abta.org) (US)
- British Neuro-Oncology Society  
[www.bnos.org.uk](http://www.bnos.org.uk) (UK)
- Clinical trials:  
Australian New Zealand Clinical Trials Registry  
[www.anzctr.org.au](http://www.anzctr.org.au)
- National Health and Medical Research Council  
Clinical Trials Centre  
[www.ctc.usyd.edu.au](http://www.ctc.usyd.edu.au)
- The Co-operative Trials Group for Neuro-Oncology  
[www.cogno.org.au](http://www.cogno.org.au)

# About brain tumour awareness

**There are a number of organizations and not-for-profit groups that are actively working to raise awareness of brain tumours and brain cancer. Patient and/or health advocacy groups aim to support and promote the rights of patients and their carers in the health care system. Some advocacy groups consist of consumers only while others are collaborations between health professionals and consumers. Some of these groups are:**

## **Brain Tumour Alliance Australia (BTAA)**

BTAA is a national brain tumour advocacy group established in 2008 by a group of brain tumour patients and caregivers. BTAA seeks to represent the brain tumour community from the viewpoint of the patient, family and caregiver. They work closely with the International Brain Tumour Alliance (IBTA) in its promotion of their annual awareness week in November. They also provide a free copy of the American Brain Tumor Association (ABTA) resource *A Primer of Brain Tumors: Patient Reference Manual* on request.

Phone: 1800 857 221 (not to mobile)

Website: [www.btaa.org.au](http://www.btaa.org.au)

International Brain Tumour Alliance (IBTA)

Website: [www.theibta.org](http://www.theibta.org)

## **The Brainchild Foundation**

This Brisbane based charity was established in 2010 with the aim of helping children affected by brain and spinal cord tumours, and their families. The foundation is made up of a community of medical professionals, parents and friends of children affected by tumours of the brain or spinal cord. It aims to raise awareness of the challenges faced by families dealing with these diseases, to raise funds for research and provide support to families.

Website: [www.brainchild.org.au/](http://www.brainchild.org.au/)

## **Brain Cancer Action**

Brain Cancer Action is an initiative of Cancer Council NSW and the Cancer Institute NSW's Oncology Group Neuro-Oncology. They held an inaugural Brain Cancer Action Week in 2010 and collaborate with consumers in order to raise awareness around brain cancer and funds for brain tumour research. Their website has brain tumour specific information.

Website: [www.braincanceraction.com.au](http://www.braincanceraction.com.au)

## **CanSpeak Queensland**

CanSpeak Queensland is a state-based, community organisation which aims to provide a unified, independent voice for all Queenslanders affected by cancer.

By developing partnerships with cancer patients, survivors, family members and health professionals working in cancer care, CanSpeak Queensland seeks to provide a forum to share issues, experiences and ideas common to all cancer types.

The goal of CanSpeak Queensland is to promote a better quality of life for those affected by cancer.

The objectives of CanSpeak are to:

- Provide a voice for those affected by cancer in Queensland.
- Define the issues important to consumers and advocate for measures to address those issues.
- Seek greater consumer involvement in decision making at all levels in the health system to ensure policies and programs reflect consumer views.
- Develop partnerships to pursue improvements in areas of common interest or concern.
- Reduce the impact of cancer by promoting a better quality of life for those affected.
- Assist in the promotion, establishment and employment of cancer advocacy and support groups.

CanSpeak Queensland Inc.

PO Box 201, Spring Hill Qld 4004

Email: [info@canspeakqld.org.au](mailto:info@canspeakqld.org.au)

Website: [www.canspeakqld.org.au](http://www.canspeakqld.org.au)

## **Calendar 2014 – Annual Brain Tumour Awareness Events**

**March 26**  
Purple Day for Epilepsy

**April 27 - May 3**  
Brain Cancer Action Week

**October 26 - November 1**  
International Brain Tumour Awareness Week

**November 7**  
BrainChild Awareness Day



Further information and support can be provided at  
any Cancer Council Queensland office throughout Queensland  
or phone the Cancer Council Helpline 13 11 20.

[www.cancerqld.org.au](http://www.cancerqld.org.au)