

Dear Friends,

Welcome to the second edition of the Brain Tumour Support Service Newsletter for 2013. Once again, we have some very interesting reading for you.



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

We hear from Karl about his experience of living with a brain tumour since the age of three. Thank you Karl for sharing your story with us – you have faced many challenges and your attitude and strength is an inspiration to us all. Then we have an article on ‘Perseveration’, which is a condition where a person keeps repeating things over and over again. Perseveration may occur in someone with a brain tumour and this article offers some strategies for patients and carers when dealing with this problem.

There is an article on ‘Temozolomide’, a chemotherapy used in brain cancer treatment to stop or slow the growth of brain cancer cells. The article looks at how it can be safely administered, some of the side-effects that people may experience and how to manage them. The ‘How can they help?’ article looks at the role of neuropsychologists, who are specially trained in the management and treatment of neurological disorders and can be involved in supporting people with brain tumours. Their specialist skills allow them to support families in several different ways, including helping them to understand the affects of a brain tumour on concentration, memory, problem solving and planning.

In Kids Konnection we’ve focussed on providing information to identify the major concerns for children making a return to school after treatment, as well as a few ideas on how parents, teachers and schools can work together to make this transition smoother.

We hear all about a Brain Tumour Education Day which was held at CCQ for health professionals caring for brain tumour patients, which sounds like it generated a lot of interest from across the state. Then there are, as usual, all the brain tumour-related support services and resources at the back of the newsletter to take a look at.

Sarah Thompson is leaving us for a time, as she is expecting a baby shortly. Congratulations, Sarah! We hope all goes well for you and your family. Very many thanks for all the hard work you have done here – we will miss you greatly. Whilst Sarah is away enjoying the new addition to her family, we welcome Janine Rhodes to the team and wish her the best of luck over the coming months.

Until next time, keep smiling.

Anne.

Thought for the day:

“The difference between school and life: In school, you’re taught a lesson and then given a test. In life, you’re given a test that teaches you a lesson.” ~ Tom Bodett.

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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 in Brisbane and Townsville 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

Email: helpline@cancerqld.org.au
or call our Helpline on 13 11 20

Raising awareness

If you know of any activities that may raise awareness around brain tumours and the support available, please let the Cancer Council Helpline know by calling 13 11 20 and ask for the brain tumour support service co-ordinator.

There may be other support services and groups available. For further information please call Cancer Council Helpline 13 11 20.

My story – Karl

Hi, my name is Karl and my journey began 23 years ago in 1988, when I was just three and a half years old. I had started vomiting, so mum took me to the doctor thinking I had a virus.

The vomiting continued randomly for months and following numerous visits to the paediatric specialist and blood tests, my parents were told the diagnosis was reflux. They became worried however, because along with the vomiting, I would occasionally stop breathing and lose consciousness. I also started losing weight and my personality was changing. Doctors said not to worry as it was just normal three-year-old behaviour. When it got to the stage where I was dry-retching all the time, our GP suggested my parents take me to a gastroenterologist.

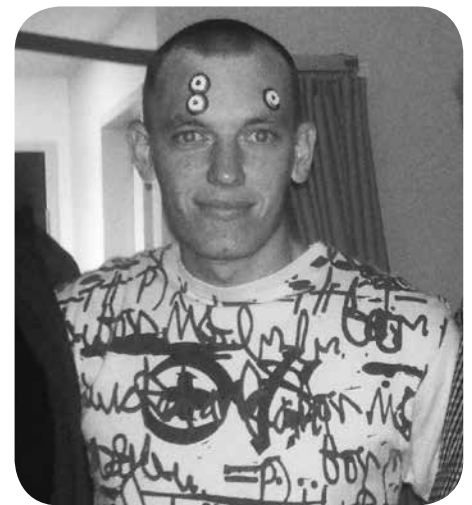
In May 1989 I had an endoscopy. The results showed that my stomach valve was not closing off properly – apparently very common for young boys – so my parents went home relieved and with medication that was said to fix the problem within a two-month period. Five days later I stopped breathing. Mum resuscitated me and I was rushed to hospital by ambulance. Results of a CT and MRI scan the following day would reveal a brain tumour in my right temporal lobe. Finally after nine months, we had answers: the vomiting was the result of partial complex seizure activity in the brain.

I had a craniotomy to have the tumour removed. My parents were informed after the surgery that the surgeon was unable to completely remove the tumour due to the risk of

permanent brain damage or death. When pathology results came back a week after surgery, the news was not good: the tumour was a grade III astrocytoma and with treatment, my parents were told, I had a five-year life expectancy of 10%. I started intensive chemotherapy treatment in July and after treatment my scans showed that my tumour had stabilised. Treatment stopped and for the next 23 years my family and I would monitor my health closely.

Epilepsy continued after surgery, so there were frequent visits to the neurologist to adjust medication. By the time I was in my late teens I was on almost 4000mg of anticonvulsants. This was difficult as it inhibited my ability to work full-time. In 2011 I started to experience double vision and had a seizure which was much worse than the partial complex seizures I had previously been experiencing. Both my eye specialist and neurologist felt the two issues were not related, but my medication doses were increased. On Boxing Day 2011, I had another tonic clonic seizure, and again my medication was increased.

I had planned a three week overseas trip in January 2012 and although hesitant to go, I decided to take the gamble. The seizures continued to worsen and became more frequent, and by the time I returned I was having tonic



clonic seizures daily. In early April 2012 I was back at the neurologist and, knowing something was seriously wrong, I requested an MRI scan. The doctor agreed we should check things out, but did not seem overly concerned. We managed to get an MRI appointment for the following day and a phone call a few days following the scan confirmed the worst – the tumour had grown back and had nearly doubled in size.

Initially I reacted quite well to this news, although once I had a minute to myself to process everything I realised the seriousness of the situation and got quite emotional. In fact, I shut myself in my room and cried. It was the unknown that I feared the most. I wondered whether I would come out of the operation the same person as I was when I

My story – Karl continued

went in. What physical or intellectual side-effects would I have as a result of the trauma? Would I become a burden on my family and friends?

My neurosurgeon was confident he could remove at least the new growth, although it would entail removing a portion of my front temporal lobe. Unfortunately, he would be away on holidays for three weeks. I elected to wait for surgery. Throughout those three weeks my seizures got dramatically worse and I needed round-the-clock care. Interestingly, there was no vomiting – the main symptom of the previous tumour. Loving friends and family were extremely helpful during this time.

I was admitted in May 2012 for an MRI stealth scan. Stealth scans take imagery of the brain from a variety of different angles and then this data is transferred onto a computer to give the surgeon a three-dimensional view of the tumour during surgery.

Technology used for surgical procedures has advanced in such a

way since my last surgery that the surgeon was able to remove both the old and new tumour growth along with a third of my right temporal lobe. Pathology testing has also evolved incredibly during the last 23 years and my results showed a low grade ganglioglioma, with no further treatment being deemed necessary.

Since surgery, I have been admitted into the neurosurgical ward via ambulance on two separate occasions because of nausea, balance issues and medication toxicity. My neurologist has since started weaning me off anticonvulsants and now, six months later, I'm down from 4500mg to 1100mg daily. Amazingly, I have not had any seizures since the surgery.

I have just had my six-month post-op check-up, and all looks good. I struggle a bit with memory loss, but this is slowly improving through brain exercises and computer programs which help to open and develop different pathways of the brain. I am very blessed to have had

such a fantastic neurosurgeon and wonderful care from the hospital nursing staff. Research into the treatment of brain tumours has developed so incredibly. Without medical science, the wonderful grace of God and the power of prayer, I surely would not be alive today. I feel truly blessed.

So now, we just watch and pray again...

Karl



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

Phone: 07 3634 5307

Perseveration

Do you repeat yourself or get stuck like a broken record?

Perseveration is getting stuck on something.

It may be an activity, word, phrase, question or movement, such as tapping, wiping, or picking that is repeated again and again even when it is not appropriate for the situation at hand. Think of children on a long journey who ask every five minutes 'Are we there yet?' Perseverating is sounding or acting 'like a broken record'.

How do I know if I have perseveration?

- You keep asking the same question over and over again even when given an answer.
- Keep saying the same phrase or word.
- Repeating the same behaviour such as tapping the foot or scratching.
- Getting stuck on one idea and not being able to shift to a different idea.
- Bringing up a topic that has already been talked about over and over again.
- Unable to change your train of thought.
- Keep eating even though you may not be hungry.
- Appear to act in a very stubborn way.

'George's' Story

Since his diagnosis 'George' talks about his tumour and other favourite

topics all the time. He seems to get 'stuck' on these topics and nothing can stop him once he starts. When someone else is talking, he does not really listen because he wants to get back to telling his story. He talks over and over about the tumour, retelling his experiences to as many people as he can. It does not matter if they have heard the story many times before. Other people find this boring but it is hard to get him to talk about other topics. His family members can be quite rude to him. They tell him to be quiet or just walk away when he starts on one of his stories. He finds this upsetting but it still does not stop his perseveration.

Strategies

For the person with a brain tumour

- Try to use lists and tick off the activities or tasks as you go.
- Set time limits for tasks to keep you on track.
- Write out tasks in steps so you don't spend too long on one task or thought.
- Try to let other people have their say when you are talking with them.

For the carer/family member

- Try gentle distraction to shift the focus away from repetition.
- Let them know that you have heard what they have been saying, and try to direct them to another task or activity that is enjoyable.
- Set up a timetable to limit the time spent on activities that get repeated over and over again.

- Try to keep your patience.
- If you start feeling stressed, walk away and give yourself a time out.
- Note the triggers that might cause an activity to be repeated and try to avoid those situations. For example, if driving past a familiar takeaway food outlet makes the person repeatedly ask for food, select another route.

Questions to ask your health professional

- What is the cause of the perseveration?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the perseveration be an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the perseveration to get better or worse over time?
- Are there any medications that can help the problem?
- Will a psychologist be able to help treat this problem?
- Are there any diet or lifestyle factors that can help with the perseveration?

This information was taken from the Cancer Institute NSW factsheet Perseveration and has been reprinted with their kind permission. More factsheets are available on their website www.cancerinstitute.org.au © Cancer Institute NSW 2008.

Temozolomide (Temodal)

If you have been diagnosed with a malignant brain tumour, your doctor may suggest a drug called temozolomide or Temodal. Temozolomide is a chemotherapy drug commonly used to stop or slow cell growth in certain types of brain tumours. Temozolomide is the generic name for the drug Temodal. The drug received its first FDA approval in 1999 to treat grade III astrocytomas, making it one of the more recent drugs to be approved as a brain tumour treatment. While it has become a standard therapy for treating persons newly diagnosed with a glioblastoma (also known as an astrocytoma grade IV), its use in other types of brain tumours and other types of cancer continues to be explored.

Studies have shown that temozolomide can stop or slow cancer cell growth, and in many instances, prolong life. It works by breaking strands of DNA - the genetic material - inside tumour cells. When DNA strands are broken, the cells are not able to reproduce as well, slowing tumour growth.

Common side effects of temozolomide include, but are not limited to, constipation, fatigue, headache, loss of appetite, low blood platelet count, nausea, vomiting, and weakness. Less common side effects include anaemia, low white blood cell count, anxiety, hair loss, back pain, rash, convulsions, diarrhoea, dizziness, itching, swelling in the arms or legs, stomach pain, difficulty sleeping, and/or a tingling or burning feeling. Many of these side effects may be preventable or manageable with help from your nurse or doctor. You should communicate with your healthcare provider if you are experiencing any negative side effects as these could be related to your treatments or related to your tumour.

How is temozolomide taken?

Temozolomide comes in a capsule, and is typically taken with water once a day (preferably at bedtime) on an empty stomach (an hour before or after any food intake). Temozolomide capsules should be swallowed whole, not chewed or opened. Because the drug is prescribed based on your body size, your daily dose may contain capsules with different strengths of temozolomide. Your treatment schedule will reflect your individual treatment plan, and depend on how well your body tolerates the treatment. Be very careful to take the medication as prescribed. It is also important to take temozolomide at the same time each day.

Can I touch the capsules?

The patient can touch the capsules. Do not remove the capsules from their package until it is time to take them. If a capsule opens or breaks, be careful not to get the drug on your skin near your eyes, nose or mouth. Breathing in the powder, or other contact with the powder, may be harmful. If the powder gets on your skin, wash the area thoroughly. Do not put temozolomide in other pill bottles or containers.

Can my caregiver touch the capsules?

Because temozolomide is a chemotherapy drug, only the patient should handle the capsules. If a caregiver helps you take your medication, you should remove the medication from the package. If a caregiver absolutely must touch the capsules for any reason, he or she should wear disposable gloves and wash their hands immediately after handling the drug.

What if I miss a dose?

It is important to follow your schedule as your doctor outlines. However, if you miss a dose take the missed medication as soon as possible and then continue on your regular schedule. If you miss a whole day of medication, DO NOT take a double dose the next day. Call your doctor or nurse.

What if I accidentally take too much temozolomide?

In case of overdose, call your local poison control centre. You also should notify the prescribing doctor as soon as possible. If you are a caregiver, and the victim has collapsed or is not breathing, call local emergency services.

Why is my temozolomide schedule different from others in my support group?

Temozolomide is available in 5 mg, 20 mg, 100 mg, 140 mg, 180 mg, and 250 mg capsules. Your healthcare provider will prescribe a dose combination that is based upon your body size and your individual treatment plan. If you have any questions about your dose or treatment schedule, call your doctor or nurse before taking the capsules.

Who should not take temozolomide?

You should not take temozolomide if you have had an allergic reaction to dacarbazine, another drug used to treat cancer, as it may cause a similar reaction. Women should not take temozolomide if they are pregnant or expect to become pregnant or are breastfeeding. You may choose to discuss with your healthcare provider the opportunity for egg harvesting if treatment initiation is not urgent. Men taking temozolomide should always wear a condom when having sexual relations with a woman of childbearing potential. Temozolomide is known to impact formation of sperm, thus men/couples interested in childbearing should discuss sperm banking before starting treatment with this chemotherapy. If you have already started taking this medication and are interested in childbearing in the future, you should discuss with your healthcare provider a time when it would be safe to sperm bank or attempt to conceive a child (likely at least 6 months after completion of temozolomide therapy). As always, read the patient information sheet that comes with

temozolomide before you start taking the drug, and every time you renew your prescription in case the information has changed.

What drug(s) may interact with temozolomide?

Other chemotherapy drugs may increase the side-effects associated with temozolomide. Before you start taking temozolomide or any other drug, always tell your doctor or pharmacist what prescription (particularly steroids or anti-seizure medications) or non-prescription medications you take – including aspirin, acetaminophen, or ibuprofen; herbal products; vitamins; and/or caffeine and alcohol. While you are taking temozolomide, do not start taking any new prescription or over the counter drugs without first consulting your healthcare provider.

Are there any side effects that I should be concerned about?

Call your doctor immediately if you experience unusual bleeding or bruising, a rash, itching, difficulty breathing or swallowing, seizures or infections.

Can anything be done about nausea?

Drugs to prevent nausea and vomiting can be taken before and/or after administration of temozolomide. Some – but not all – people taking temozolomide experience nausea. If you do, please tell your nurse or doctor right way as these symptoms could be related to your treatments or may be related to your tumour. Drugs to treat nausea and/or vomiting may be used alone or in combinations for symptoms

that are not controlled with one medication. Communicate early with your healthcare provider if you are not feeling well. The sooner you notify your care team about negative symptoms, the faster you can access medications to provide symptom relief.

How can I learn more about temozolomide?

Your doctor, nurse, or pharmacist can provide you with print information about temozolomide, instruction sheets for taking the drug, and tips for managing its side effects. Call your doctor's office and ask for the information if you do not receive it. A consumer information sheet on temozolomide is available.

What can I do with unused temozolomide?

Call your pharmacist for help if you have unused supplies of any prescription drug, including temozolomide. Your pharmacist can advise you based on your state laws for disposal of chemotherapy drugs.

This information is not intended as a substitute for professional medical advice and does not provide advice on treatments or conditions for individual patients. All health and treatment decisions must be made in consultation with your physician (s), utilizing your specific medical information.

This information is reprinted with permission from Temozolamide fact sheet, © 2012 American Brain Tumor Association (ABTA). To access more information on brain tumor treatment and managing side effects visit the ABTA website at www.abta.org.

Neuropsychologists

Neuropsychologists are psychologists who are specifically trained in the assessment and management of neurological disorders. These professionals have at least six years of university-based training, including a master's degree or doctoral degree. Unlike psychiatrists and neurologists, neuropsychologists are not medically trained, but have particular skills in identifying how damage to the brain affects everyday functioning (e.g., thinking abilities, behaviour and emotional well-being).

**By Dr Tamara Ownsworth,
Neuropsychologist Griffith
University**

Neuropsychologists may be involved in supporting people with a brain tumour in a number of ways. Firstly, they may conduct a neuropsychological assessment and then provide feedback to assist people's understanding of the effects of the tumour on their cognitive or thinking abilities. Secondly, they typically assess a person's emotional functioning or psychological well-being through questionnaires and an interview. During the interview, it is helpful for people to describe the changes they have noticed in their everyday functioning since the tumour and its treatment, as well as how they were functioning prior to their illness.

A third and very important role that neuropsychologists have is to provide feedback on the assessment and to summarise this in a report. Their recommendations and ongoing support may entail the following:

- Tailored education or information regarding the brain and the effects of the tumour on everyday living;
- Rehabilitation strategies for managing these effects (e.g.,

strategies to enhance memory and attention);

- Counselling and psychological therapy to support the individual's emotional adjustment (e.g., to manage depression, anxiety or anger) as well as family members' well-being; and
- Referral to other health professionals and support services.

What is neuropsychological assessment?

A neuropsychological assessment is designed to assess an individual's abilities across a wide range of cognitive functions including concentration, memory, problem-solving, language, perception and planning and organisation. This is achieved by giving the person a number of tasks and comparing his/her performance with individuals their own age. Neuropsychologists are also interested in identifying a person's strengths or weaknesses relative to their own abilities. This information may be used to guide various decisions in everyday life (e.g., return to work plans) and how to pursue many other valued activities and roles.

The length of the assessment will vary depending on the reason for the assessment. Generally, the time involved ranges from five to eight hours (including the interview), and this may be conducted over a number of sessions. Some people may have more than one neuropsychological assessment following diagnosis of a brain tumour, in order to monitor changes in their cognitive functioning over time.

Access to Neuropsychology Services and Costs

Major hospitals in Queensland that have a neurosurgery department or brain injury rehabilitation unit typically have a neuropsychologist on staff (or at least a consultant). Therefore, individuals may be referred to a neuropsychologist as part of their hospital care prior to, or following discharge. For those going through the public system there is no charge. However, not everyone treated in the public system will be referred to a neuropsychologist. Individuals can discuss this with their treating doctor and ask for a referral, although there may be a considerable waiting period to access this service.



People who have a case manager after hospital, for example through the Acquired Brain Injury Outreach Service or Commonwealth Rehabilitation Services, may have a neuropsychological assessment organised as part of their rehabilitation program. If this is not the case, other options include a private neuropsychologist (self-referred or through your general practitioner) or university-based psychology clinics who have post-graduate psychology interns who are being supervised by a fully qualified neuropsychologist. The University of

Queensland and Griffith University both offer this service with reduced fees (cost likely to be \$250-\$400 for an assessment and report).

The fees for private neuropsychologists can vary considerably, with some offering reduced fees for individuals with financial difficulties. As a general guide, private neuropsychologists are likely to charge anywhere between a few hundred dollars and a few thousand dollars, although a more precise indication can be obtained by contacting these

professionals. Unfortunately, there is no Medicare rebate for neuropsychological assessments. Some private health insurers may contribute to some or all of the costs, however, people need to check this with their own insurer.

Neuropsychologists specialise in the assessment and management of neurological disorders and can greatly assist individuals and family members to better understand the effects of brain tumour and to manage the implications in everyday life.



Kids Konnection

Returning to school after treatment

The transition from completion of treatment to a return to usual daily activities may be a difficult time for children and their families. Cancer is a major life changing experience, particularly in the case of childhood cancer, and the child and the family will need time to adjust to the physical and emotional effects of the illness.

Children are encouraged to return to school once the initial phase of treatment is over, as maintaining as normal a lifestyle as possible is essential to the child's adjustment to living with cancer. A return to school gives children the message that they are able to continue with life and gain mastery over their environment. School is part of normal life for all children and participation helps children to cope with the impact of cancer.

In most instances the hospital providing the child's treatment will have support services available to assist in the return to school. The hospital school teachers and oncology liaison nurses are available to assist the child and family in making the transition from hospital to home, and then back to school. Oncology liaison nurses will contact the school shortly after the initial diagnosis and, with the parents'

consent, can provide information about the disease and treatment. School visits to talk to teachers and/or students can often be arranged, even for rural patients.

Younger children

For younger children, Camp Quality provides a unique puppet show which provides education for children about cancer. It addresses important issues such as cancer not being contagious and the need for children to help the classmate undergoing treatment. Parents can discuss having Camp Quality come to their child's school with the teacher or school. Please contact Camp Quality for further details on telephone 07 3216 0299 or visit their website at www.campquality.org.au.

Children may initially return to school on a part-time basis. They may be feeling anxious about coping and seeing friends again. Children may feel anxious about being able to keep up with their work, about their fear of teasing, about rejection, about side-effects from their illness, about tiredness and about their physical changes including altered appearance. It is important for the class to make the child feel welcome back at school. Parents and teachers working together with the child and their peers can assist in an easier transition to school life.

Teenagers

High school students with cancer may be reluctant to return to school as they may be self conscious, be uncertain about the reaction of the school community and may have fears about their ability to keep up with the program. Some adolescents are reluctant to let their peers know much about their disease. Adolescents may find it helpful if parents can work with the school and teachers to ensure that the privacy of students is respected and that the school has someone who will act as an advocate for the student and include them in any decisions about subjects or workloads.

Peers should be encouraged and supported to maintain normal interactions with the sick teenager. They need the opportunity to discuss their feelings about cancer, their relationships, and to be reassured that their friendship is a valuable support to the recovery of their friend.

Adolescents may need assistance in setting realistic academic goals and support to help them to reach their potential. Special measures may need to be put in place to assist them to meet formal academic assessment requirements, especially in the higher grades. This is best achieved through parents, adolescents, teachers and the school working together to provide appropriate modifications and support.

Specific needs of children with brain tumours

Children with brain tumours may have more complex education needs than children with other types of cancer as a result of the effects of the tumour and the effects of treatment upon brain function.

There is a limited amount of space inside the skull and the growth of the tumour may cause changes in brain function. The tumour may damage brain tissue and cause pressure effects on other parts of the brain. This damage may be transient or permanent.

The severity and types of problems children exhibit will depend on the location of the tumour in the brain. Tumours arising from the frontal lobe may be the cause of behavioural problems and memory loss, while tumours in the occipital lobe may create visual disturbances. Epilepsy may also occur and the child may be taking medications to control seizures. This medication may also decrease alertness and interfere with learning.

Children who have a brain tumour may need to have their school program modified to suit their education, behavioural and physical needs. Advice and assistance for teachers can be obtained from

the Advisory Visiting Teacher at the hospital where the child is undergoing treatment. Community organisations and the Cancer Council Queensland may be able to offer more specific resource materials for parents, teachers, schools and children. Please contact the Cancer Council Helpline on 13 11 20.

Tips for schools

- Establish and maintain contact with the child and family.
- Educate the school community about childhood cancer and prepare classmates for the child's return to school.
- Be aware of and make allowances for side-effects and specific medical conditions.
- Treat the child normally - be positive and encouraging, sensitive and realistic.
- Remain aware of the needs of siblings.
- Communicate with health and other teaching professionals if required for further support.
- Advocate for the child with respect to formal education requirements. This may mean allowing extra time for examinations or assignment deadlines, so that the student's true abilities in subject areas can be recognised.

Support from community organisations

Cancer Council Queensland

P: 13 11 20
www.cancerqld.org.au

CanTeen

P: 07 3252 9262
www.canteen.org.au

Camp Quality

P: 07 3216 0299
www.campquality.org.au

Redkite

P: 1300 722 644
www.redkite.org.au

Childhood Cancer Support, Inc

P: 07 3252 4719
www.clcs.org.au

Reference

Material for this article has been extracted from "Understanding Childhood Cancer: a handbook for all teachers" produced by the Cancer Council Queensland and available from our webpage www.cancerqld.org.au or by contacting the Cancer Helpline on 13 11 20.

What's been happening...

A Brain Tumour Clinical Education Day for health professionals

A free Education Day was held at Cancer Council Queensland in Brisbane on Friday, 3 May during Brain Cancer Action Week (28 April – 4 May).

The day was for health professionals caring for people affected by brain tumours and, from all accounts, was a great success. It was attended by over 100 health professionals from a wide range of disciplines, including doctors, nurses, social workers, occupational therapists, physiotherapists, psychologists from oncology and neurosurgical areas, as well as radiation therapists and academics. Many travelled from areas outside of Brisbane, including Gold Coast, Sunshine Coast, Toowoomba, Warwick and Rockhampton. CCQ also gave out three travel grants to assist health professionals from regional areas to attend the day – with successful applicants coming from Townsville and Bundaberg.

We were fortunate to have radiation oncologist and neuro-oncology specialist, Dr Eng-Siew Koh from Liverpool Hospital in Sydney as a special guest on the day. Dr Koh's research interests in neuro-oncology include clinical and supportive care, care coordination for brain tumour patients, quality of life and late effects, and she provided an excellent insight into what is happening around the country in this challenging area.

The opening session involved a panel of local neuro-oncology experts presenting three case

studies outlining the clinical care for different types of brain tumours. Neurosurgeons, Dr David Walker and Dr Christian Schwindack, medical oncologist Dr Po-Ling Inglis, radiation oncologist, Dr Andrew Pullar, and neuro-oncology nurse practitioner, Vivien Biggs participated in a lively discussion outlining the care of a brain tumour patient from their different perspectives.

Neuropsychologist, Dr Gail Robinson presented on 'managing changes to thinking and behaviour' and discussed the prevalence of cognitive impairment in patients with primary brain tumours, outlining the importance of cognitive assessments. She discussed some of the challenges around accessing these specialist services, and ways for health professionals to assist families in this area.

We heard about the support services available to brain tumour patients and their families in the community, and, most importantly, from a patient and carer perspective. Andrew Hamilton was diagnosed with a glioblastoma multiforme in 2008, and Katherine Landers, whose husband was diagnosed with an oligodendroglioma in 2011, both provided excellent insights into their brain tumour experience. This session was aimed at allowing health professionals to

reflect on the care they provide, and to improve their understanding of their patients' and carers' needs. It certainly made an impact on us all.

Radiation oncologist, Dr Michael Fay outlined the challenges to neuro-oncology in regional areas, particularly Rockhampton. For example, he explained the difficulties faced by patients and their families when they are required to travel for treatment or to visit specialists when they are unable to drive and there is insufficient public transport. Other difficulties discussed were the absence of a multi-disciplinary team, fewer support services, the cost of equipment, clinical trial availability and cost. Dr Fay also looked at ideas to improve expertise related to brain tumour treatment in regional areas and discussed the improvements they were making.

Dr Eng-Siew Koh provided an excellent presentation on the need for effective care coordination of brain tumour patients. She highlighted the need for increased communication between treatment teams and the importance of linking services, and also identified the increased need for effective coordination in rural areas.

Last, but certainly not least, we heard from palliative care consultant, Dr



Left to right: David Walker, Christian Schwindack, Vivien Biggs, Andrew Pullar, Po-Ling Inglis and Eng-siew Ko

Mark Deuble on end of life issues for patients and families. He provided an overview of the role and goals of palliative care and highlighted the need to improve communication in order to provide effective support and care to patients and families.

The event concluded after workshops which allowed those in attendance to share their valuable experience and

knowledge and to reflect on what they had gained from the day. We are grateful to all those who attended and participated. Such a great response demonstrates the commitment and enthusiasm that those working in this challenging area of neuro-oncology have to improve supportive care outcomes for their patients and families.

Kerrin Gregory, Cancer Care Coordinator from Townsville Hospital, who received one of CCQ's Travel Grants, said:

'I thoroughly enjoyed the education day and am grateful for the opportunity to attend. It enabled me to network with other health professionals and gather valuable information. I was also able to obtain some valuable resources – written, DVD, CD – that I can use to provide better information to colleagues, patients and carers.'

'The presentations were very relevant and informative. They helped validate the care we provide here in Townsville, but also highlighted areas in my practice and our service that I can look at improving upon, such as attempting to meet patients early, i.e. post-surgery and prior to discharge, and looking closely at the information I provide to patients and carers. I also plan to increase referrals to allied health and look into specialist services for cognitive testing.'



Dr Eng-Siew Koh presents on the need for effective care coordination of brain tumour patients.

Brain Tumour Information Sessions 2013

Brisbane

July

Date: Tuesday, July 2
Time: 10.00am – 11.30
Topic: **Returning to work after treatment for a brain tumour**
Venue: Cancer Council Queensland

September

Date: Tuesday, September 3
Time: 10.00am – 11.30
Topic: **Using complementary & alternative therapies for brain tumours – how do you know what is safe?**
Venue: Cancer Council Queensland

October

Date: Tuesday, October 29
Time: 9.00am – 11.30
Topic: **When your child has a brain tumour – support for parents**
Venue: Cancer Council Queensland

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

Townsville

June

Date: Monday, June 17
Time: 5.30 – 7.30pm
Topic: **Adjustment to illness: the impact on families and supports available**

September

Date: Monday, September 16
Time: 5.30 – 7.30pm
Topic: **Understanding brain cancer: coping with depression, anxiety and memory loss.**

December

Date: Monday, December 9 – Christmas party
Time: 5.30 – 7.30pm
Topic: **Maintaining wellbeing while living with uncertainty**

Please join us for the information sessions, which are held at Cancer Council Queensland in Townsville, 24 Warburton Street, North Ward. The sessions are followed by light refreshments with all invited to stay for an informal group discussion. For more information & to RSVP contact Kate McInnes on (07) 4796 8405 or email KateMcInnes@cancerqld.org.au

c-vivor

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.



What's happening in 2013?

Dates for your calendar...

Saturday, November 2 – A Brain Tumour Forum for patients and carers

This all-day forum will focus on providing information and support to brain tumour patients and their carers. It will include presentations from neuro-oncology clinicians and patient perspectives, as well as aiming to provide an opportunity to meet others dealing with a brain tumour diagnosis.

Please note: This event will be held at Cancer Council Queensland's Brisbane Office, 553 Gregory Terrace, Fortitude Valley. RSVP's are essential as seating is limited, and more information will be made available closer to the date. Pod-casts of selected presentations will be made available after the events at CCQ's website www.cancerqld.org.au.

Listen to podcasts

You can find our brain tumour pod-casts at Cancer Council Queensland's website www.cancerqld.org.au. The podcasts listed here were audio-recorded at Information Sessions & Forums held in Brisbane.

Brain Tumour Information Sessions

Topic: Brain tumours in adolescents and young adults
Presenters: Dr Sarah Olson, Neurosurgeon

Dr Melissa Jessop, Paediatric/AYA Oncologist – March 26, 2013

Topic: Managing fatigue related to a brain tumour

Presenters: Jodie Nixon, Occupational Therapist & Elizabeth Pinkham, Physiotherapist – October 30, 2012

Topic: Managing changes in thinking, emotions, and behaviour following diagnosis of a brain tumour

Presenters: Joanne Oram and Helen Tinson, Neuropsychologists – July 3, 2012

Topic: When a parent has a brain tumour – how to talk to your kids

Presenter: Assoc. Professor Jane Turner, Psychiatrist – May 29, 2012

Topic: Clinical trials in brain tumours

Presenter: Dr Zarnie Lwin, Medical Oncologist – November 1, 2011

Topic: Low grade gliomas

Presenter: Dr Lindy Jeffree, Neurosurgeon – September 13, 2011

Topic: Complementary and alternative therapies for brain tumours

Presenter: Christine Carrington, Pharmacist – May 31, 2011

Topic: High grade gliomas – diagnosis, surgery and latest treatment

Presenter: Dr Sarah Olson, Neurosurgeon – March 29, 2011

Brain Tumour Forums

Brain Tumour Clinical Education Day held at CCQ in Brisbane - May 3, 2013

CCQ held a free Education Day for health professionals working in the area on neuro-oncology during Brain Cancer Action Week 28 April – 4 May, 2013.

The focus of the day was on improving the information and support provided to brain tumour patients and carers.

Topic: Strategies to improve care coordination for brain tumour patients and carers

Presenter: Dr Kiew Soh

Topic: End of life issues for patients and families

Presenter: Dr Mark Deuble

The Brain Tumour Alliance Australia (BTAA) Forum held at CCQ in Brisbane – August 11, 2012

Topic: A patient perspective

Presenter: Ms Renee Hindson

Topic: The views of a Neuropsychologist

Presenter: Dr Gail Robinson, Neuropsychologist

Topic: Current and promising therapies for adult brain tumours

Presenter: Professor Susan Chang, Neuro-oncologist

Topic: Living with a brain tumour: patient and caregiver needs

Presenter: Professor Susan Chang, Neuro-oncologist

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 Cancer Council, which can put a person who has been diagnosed with a brain tumour 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

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

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 on 0422 784 885 or visit their website: www.braintumourhelp.com.au

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 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 the 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.

Support services for people affected by brain tumours

Acquired Brain Injury Outreach Service (ABIOS)

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

🌐 www.health.qld.gov.au/abios

The Australian Pituitary Foundation Ltd

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

Beyondblue: the national depression initiative

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

Carers Queensland

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

CanTeen Counselling Service

A free service for young people aged 12-25 who have a parent with cancer or a parent who has 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

Disability Information and Awareness Line (DIAL)

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

☎ 1800 177 120

💻 dial@disability.qld.gov.au

💻 www.disability.qld.gov.au

Australian Disability Parking Scheme

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/

Domiciliary Services

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.

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

💻 www.epilepsyqueensland.com.au

Hospitals

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

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

☎ 13 11 14

Medicines Line

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

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

Support services for people affected by brain tumours continued

Open Minds

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

☎ (07) 3896 4222

💻 www.openminds.org.au

Palliative Care Information Service

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

Queensland Acoustic Neuroma Association

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

Relaxation Centre of Queensland

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

💻 relaxationcentreqlld.com.au

Self Help Queensland

Information about self-help groups available throughout Queensland.

☎ (07) 3344 6919

💻 info@selfhelpqld.org.au

💻 selfhelpqld.org.au

Synapse (Brain Injury Association of Queensland)

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

💻 www.synapse.org.au

Technical Aid for the Disabled Queensland (TADQ)

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

☎ (07) 3216 1733

Taxi Subsidy Scheme, Queensland Transport

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/

Resources available through our Cancer Council Helpline

A variety of information booklets and brochures are available to assist people who are affected by brain tumours.

To receive a copy of any of these resources, or to have information from the internet printed and mailed out to you please contact the Cancer Council Helpline by phone 13 11 20 or emailing 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)

Resources available online

Brain Tumour specific resources are available online at:

Cancer Council Queensland
www.cancerqld.org.au (AUS)

Cancer Council NSW
www.cancercouncil.com.au (AUS)

Cancer Directory (Cancer Council NSW)
www.cancerdirectory.com.au (AUS)

Brainlink
www.brainlink.org.au (AUS)

Brain Foundation
www.brainfoundation.org.au (AUS)

Cancer Institute NSW
www.cancerinstitute.org.au (AUS)

Sydney Neuro-Oncology Group
www.snog.org.au (AUS)

Brain Tumour Foundation of Canada
www.braintumour.ca (CANADA)

National Cancer Institute
www.cancer.gov/cancerinformation (US)

Macmillan Cancer Support
www.macmillan.org.uk (UK)

Pediatric Brain Tumor Foundation
Resources about the diagnosis and treatment of children's brain tumours.
www.pbtfus.org

American Brain Tumour Association (ABTA)
www.abta.org (US)

British Neuro-Oncology Society
www.bnos.org.uk (UK)

Resources listed below are available in PDF format on the ABTA website
www.abta.org

- *A Primer of Brain Tumors – A Patients Reference Manual*
- *About Ependymoma*
- *About Medulloblastoma*
- *About Pituitary Tumors*
- *Focusing on Treatment – Radiation Therapy*
- *Focusing on Treatment – Steroids*
- *Focusing on Treatment – Stereotactic Radiosurgery*
- *Focusing on Treatment – Surgery*
- *Focusing on Tumors – Ependymoma*
- *Focusing on Tumors – Glioblastoma Multiforme and Anaplastic Astrocytoma*
- *Focusing on Tumors – Meningioma*
- *Focusing on Tumors – Metastatic Brain Tumors*
- *Focusing on Tumors – Oligodendroglioma and Oligoastrocytoma*
- *Focusing on Treatment – Chemotherapy*

Clinical trials:

Australian New Zealand Clinical Trials Registry
www.anzctr.org.au

National Health and Medical Research Council
Clinical Trials Centre
www.ctc.usyd.edu.au

The Co-operative Trials Group for Neuro-Oncology
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

International Brain Tumour Alliance (IBTA)
Website: 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/

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

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
Website: canspeakqld.org.au

Calendar 2013 – Annual Brain Tumour Awareness Events

March 26
Purple Day for Epilepsy

April 28 - May 4
Brain Cancer Action Week

October 27 - November 2
International Brain Tumour Awareness Week

November 1
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