

Dear Friends,

Welcome to the third edition of the newsletter for the year.

I must begin by saying a big congratulations to Sarah and her husband on the birth of their little boy last month. I am sure he will be greatly loved and be a welcome addition to the family. Well done Sarah!

A very exciting addition to the newsletter this edition is that BrainChild have taken over the writing of the “Kids Konnection” article. Brain tumours are the most common cause of death in childhood and BrainChild provides assistance and support for children and their families. In this issue, BrainChild tell us all about their foundation.

In this month’s “My Story”, Katherine tells us about the journey of her and her family. Katherine’s husband was diagnosed with an oligodendroglioma at the same time as Katherine was in the early stages of her second pregnancy and they had just paid a deposit on their first house - you can imagine the stress and financial difficulties they were facing. Thank you Katherine for taking the time and trouble to write to us with such a wonderful story - I am sure our readers will enjoy it. We do hope all goes well for you and your family in the future.

If anyone else feels like putting pen to paper, fingers to keyboard or even voice to a recorder, please try to send us your story. I know it is not easy, but you may find it rewarding and your story might help one of our readers.

We also have an article on brain scans for adult gliomas, which looks at the types of scans used and how they assist to determine tumour type, location and growth rates - all information that can assist the neuro-oncology team in the best way to treat and manage the tumour.

In this edition, we hear how Social Workers can help you during treatment for a brain tumour – thanks to Haley McNamara from CCQ for this useful information. In May this year, CCQ provided an information session about anxiety and depression after the diagnosis of a brain tumour. For those who missed out on attending, we’ve included a summary of the session in this edition of the newsletter.

Then we have an update from Dr Tamara Ownsworth on the Making Sense of Brain Tumour Project. This is a must read as it identifies some of the personal and family supports that were delivered to patients, carers and family members throughout the project.

Then of course we have all the regular inclusions, meetings, what’s happening in 2013, resources available through CCQ etc.

Happy reading! Until next time, keep smiling.

Anne.

Thought for the month:

“When we least expect it, life sets us a challenge to test our courage and willingness to change; at such a moment, there is no point in pretending that nothing has happened or in saying we are not ready. The challenge will not wait. Life does not look back. A week is more than enough time for us to decide whether or not to accept our destiny.” ~ Paul Coelho.



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

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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

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.

My Story – Katherine

Katherine spoke about her family's journey in managing a brain tumour at CCQ's Education Day for Health Professionals in May, 2013. Katherine's presentation was targeted to health professionals to help them in their efforts to better understand patients' and carers' experiences.

My name is Katherine and my husband Andrew was diagnosed with an oligodendroglioma in April 2011. This is the story of my family's journey in managing a brain tumour.

In April 2011 our family consisted of me, my husband Andrew and our 5 year old daughter Tahnee. We had just signed a contract for the purchase of our first home. I was also in the first few weeks of our much wanted second pregnancy.

Eleven days after moving into our new home we went to a shopping centre, where my husband collapsed and had a seizure. He was taken to the nearest hospital, where upon arrival he had a second seizure. A subsequent CT and MRI showed a tumour in his left frontal lobe. My husband had surgery four days later.

Post-surgery, we were taken into a little room by a neuro-surgery nurse and registrar to get the results. We were told we were lucky - that if you are going to get a brain tumour then oligodendroglioma is the one to get. With hindsight, they were totally right but at the time we didn't feel lucky. We just felt scared. Very very scared.

Most of what we were told didn't make sense to us, and to be honest, we didn't even hear a lot of what we were told by health professionals –



Left to right: Tahnee, Katherine, Andrew and baby Harry in front.

we just went numb. At the time, what would have been good for me was to have had a list of websites to look at when I got home. It's great to be able to get advice and information from doctors and the treating team, but the reality is that it wasn't always available when we needed it and most of us look on the internet anyway. And if we don't, then our friends and family do and then send us the links.

We were discharged by neurosurgery with two hours' notice. Unfortunately we hadn't met anyone from oncology and were told we would

get appointment letters through the mail. We got a leaflet for the Cancer Council Queensland and then we were on our own. Although my husband had no idea, I was scared of him coming home. I had no idea what to do if he had another seizure and this has still never been discussed with me.

I was given a lot of information about the physical care of the brain tumour scar by neurosurgery but not any information about the personality and emotional changes that can occur. It is the changes to my husband's personality and emotions

My Story – Katherine continued

that I have found most difficult to deal with. Andrew suffers far more extreme changes in emotion than he ever did before his tumour. It can be difficult to explain these changes to his treating team because they never saw him before he was sick, so they can't see the changes for themselves. I also never got to see the treatment team without my husband and that made it difficult for me to discuss these issues.

Once Andrew moved into active treatment, I also commenced my antenatal appointments. We were at the hospital on a very regular basis. Andrew started PCV chemotherapy and the vomiting was extreme – every 20 minutes for six hours. As a carer, I didn't know what to do when the anti-nausea medication failed or what I would do if his anti-seizure medication was due and he couldn't keep that down either.

Getting through the first two cycles of chemo was a real learning curve. Trying to juggle everything including appointments, medications, treatment and its effects plus organising a home and family was sometimes a real struggle.

Our small family hit a huge crisis when I was hospitalised for pregnancy-related complications at the same time my husband was due to start his third round of chemo. The hospital social worker was wonderful. She stayed with my husband for his chemo appointment because he was really anxious. Sadly at this time, we learnt that not all extended family members can or want to provide help. During this journey, I have found that health professionals can sometimes have a tendency to presume that every patient has family to provide

transport, childcare and support, when this may not actually be the case.

After five and a half weeks in hospital, I gave birth to our son two months early. My husband continued with the chemo while our son spent four weeks in the special care nursery. Some couples get matching tattoos to mark events – but we got matching cannulas! Harry finally came home just in time for Christmas.

It was great having our new baby home, but I was reaching breaking point and got to the stage where I was just surviving one day at a time. My husband was exhausted from his continuing chemo cycles and just getting out of bed was turning into a huge effort for him. I was trying to get my six year old daughter to school every day, meet my husband's needs, do the normal household stuff like groceries and also look after our newborn son. We were also in significant financial difficulties as Centrelink payments had not yet been approved. Accessing Centrelink was difficult and embarrassing – I feel like assistance from the health system to access Centrelink may have made this easier for us.

Cancer brings more challenges for the carer than just treatment issues and it is these social issues which are more difficult to sort out. For me, more assistance in managing and navigating social support systems (like Centrelink), could have made the treatment process easier for me. Most carers want to protect the patient from stress, so it is the carer who is lying awake in bed at night worrying how to pay the bills or the mortgage.

One thing we found quite awkward was that some people seemed to think they had a right to tell us how to cure cancer – be it various diets or alternative treatments. When we didn't follow their advice, some people got quite nasty, with one person asking me “so you want your husband to die then do you?” We've since gotten quite good at working out what people's views on various treatments are and how best to answer them. We have also gotten used to the phone ringing non-stop when there is a story on the news about brain cancer treatment. It is nice that people think about you, but like all brain tumour families we have normally seen the item before they have.

Our family now works in three month cycles. As we get to the MRI and result appointment dates, the stress starts to increase. My husband gets more emotional due to the worry. This peaks at the day before the follow up appointment and then slowly goes back down again.

For now, we are just in a stage of watching and waiting. Life can go back to a new normal. You gain more back which is wonderful, but you can also feel a bit lost. You've spent so long constantly at the hospital that you don't know what to do with yourself when everything slows down.

In this stage you also have to get your relationship back – for a long time during surgery and chemo you can get into a patient and carer-type relationship. Lack of energy meant Andrew struggled to deal with day to day affairs. Now this stage is over it has been important to get back to the husband and wife relationship we had before the diagnosis.

How can they help?

Social Workers

By Haley McNamara

When you are diagnosed with a brain tumour, things can seem very overwhelming and confusing. It can be difficult for a person diagnosed with a brain tumour to know how life will change for themselves and their family, how they will cope with these changes and where they can access support. A social worker can help with all of these issues and more.



Social workers are skilled at looking at an individual not only in the context of their brain tumour, but how each part of their lives impacts on the experience of having a brain tumour. Two people may have the same brain tumour diagnosis, but how each person experiences it will depend upon their unique physical, psychological, family, social, financial, spiritual, legal and personal characteristics. A social worker will assess each of these areas and then apply a variety of interventions through support, advocacy and education to help the individual and their family through the brain tumour journey.

For those who have been diagnosed with a brain tumour, you are most likely to come across a social worker in a public hospital. Social workers will be part of a multi-disciplinary care team involving doctors, nurses and other allied health staff – all of whom are working towards the best possible care for patients.

Social workers possess a Bachelor of Social Work and their conduct

is governed by the Australian Association of Social Workers' (AASW) Code of Ethics. In the hospital setting, a social worker is most likely to be involved in supporting an individual diagnosed with a brain tumour in the following ways:

- Short-term counselling.
- Support with problem solving, decision-making and adjustment to illness and/or disability.
- Advocacy for a range of services – helping to ensure your care needs are met within and outside the hospital.
- Referral to other services and agencies including medical, housing, financial, legal, transport and support services.
- Supporting patients to return home from hospital, ensuring appropriate care and support is in place.
- Providing support and information to family members.

In the public health system, you may also come across social workers in

community health centres. These social workers provide similar services including counselling, support, advocacy, referral and information. Social work services in community health centres are usually free, though there may be some criteria for accessing the service.

For more information about accessing social work support or to learn more about how a social worker can help you and your family, please contact Haley McNamara, Brisbane Cancer Support Coordinator at Cancer Council Queensland on (07) 3634 5353 or email haleymcnamara@cancerqld.org.au.

Haley is a social worker with extensive experience in cancer care in Australia and internationally. She holds a Bachelor of Social Work (Honours) and a Master of Public Health from University of Queensland, as well as a Graduate Certificate in Loss, Grief & Trauma Counselling from Flinders University.

Anxiety and depression following the diagnosis of a brain tumour

In May, 2013, Kate MacMorran, Psychologist with the Cancer Counselling Service, Cancer Council Queensland spoke at our Brain Tumour Support Service Information Session and provided us with valuable information on anxiety and depression following the diagnosis of a brain tumour. To follow is an edited summary of her presentation.

When diagnosed with a brain tumour, it is common for a range of emotional reactions to result. Cancer is a life-changing event that we perceive (either consciously or unconsciously) as a threat to our survival. Suddenly our world is changed. We may find ourselves confronting our mortality, having our expectations about our future lives thrown into disarray and experiencing our lifestyle and health as changing dramatically. What was normal to us has been turned upside down and we may find ourselves wondering what our place in the world is, how we managed to get here and realising that so much has changed for us in a relatively short period of time.

With everything so new and our health changing, one of the difficulties that we face may be figuring out exactly what is causing our symptoms – is it the brain tumour itself, treatment side-effects or an emotional response? If you are unsure how to untangle these symptoms, speak to your doctor or treating team.

Experiencing changes in your mood – whether sad, teary, depressed, anxious and/or angry (to name a few) – is a normal and common reaction to the diagnosis of a brain tumour and the rigors of treatment. However it may become problematic for us when the changes in our mood impact on our ability to engage in everyday life.

Anxiety

Anxiety is a common emotion in life. In the event of a cancer diagnosis, it is certainly reasonable to expect some feelings of anxiety. When we are feeling anxious, we may be viewing the self as vulnerable, the environment as threatening and the future as unpredictable. With this view of the self, it is not uncommon that our thoughts, feelings and behaviours would become more anxious.

Some of the common symptoms of anxiety include:

- Physical sensations of racing heart, rapid breathing, tense muscles, sweating, pupils dilate, nausea, butterflies, dry mouth and more alert.
- Thoughts such as “I can’t cope”, “I feel bad so it must be bad” or “Something terrible is going to happen”.
- Behaviour such as avoiding places, times or activities, avoiding or escaping from activities or people, freezing and being unable to speak, do things or make decisions, ruminating on thoughts and/or staying super-busy.

Depression

Having a low mood or feeling a bit down is again a common emotional

experience in life and one which is not unreasonable in the event of a cancer diagnosis. However, depression is different from feeling down, grief or sadness. People with depression find it difficult to function in everyday life and may be reluctant to participate in activities that once brought them enjoyment.

Some of the common symptoms of depression include:

- Physical sensations of tiredness, fatigue, lethargy, poor concentration and memory, sleep changes, changes in eating, changes to weight and loss of interest in hobbies, activities and sex.
- Thoughts such as “Everything is hopeless”, “Nothing can change”, “What is the point?”, “I’m useless, worthless”, “Only bad things happen to me” and “Everything goes wrong”.
- Behaviour such as withdrawing from activities, doing less of the things we used to enjoy, staying in bed, isolating ourselves, drinking more alcohol and/or taking drugs.

What can be helpful

Take control – where you can!

Problem solve to generate solutions - when you can. Not all people, events, circumstances or feelings can be

controlled, so learning to differentiate what is or isn't in your control is a key to reducing depression and anxiety and maximizing your feelings of control and stability. Attempting to control things that can't be controlled will only increase feelings of being helpless and out of control!

For example, you have no control over:

- The past.
- A cancer diagnosis.
- Other people's behaviour.
- The outcome of surgery.
- That you have symptoms and side effects from the tumour and treatment.

You do have control over:

- How you spend your future.
- Which aspects of your experience you focus on.
- Choices about your own behaviour.
- How you respond to your thoughts.
- What you do about your symptoms.

Behaviour

What you do is important to your mental health and wellbeing. Some helpful behaviours include:

- Creating a routine or structure to your day/week/month.
- Writing things down – having a “worry hour” where you write down all the things that are concerning you and when the hour is up, put those concerns aside in the journal.
- Scheduling enjoyable activities and social activities.
- Scheduling gentle and regular exercise (consistent with your doctor's advice).
- Eating healthy and nutritious food (consistent with your

doctor's or dietician's advice).

- Having a regular sleep routine.
- Gathering information on how you individually respond to anxious or depressive thoughts, feelings and behaviours. Then using that information as best you can to work out what you can manage and what are your limits.

Notice your thinking

Every single one of us has unhelpful thoughts at times. When they become more frequent in times of distress, they also become more believable because our ability to manage those unhelpful thoughts is also reduced.

What is even more problematic about unhelpful thoughts is that they aren't usually based on facts or reality, but on fear and/or speculation. Thoughts aren't facts - but how do you manage them?

Ask yourself alternate balanced statements

These are statements that explore the unhelpful thought, rather than make an assumption about the correctness of the thoughts, for example, “What am I reacting to?”, “Is this fact or opinion” “Am I being realistic here”, “What advice would I give someone else in my situation?” “Is there another way of looking at this?” or “Just because I feel bad doesn't mean it is bad”.

Communicate more openly

Talking more openly with others about your or their needs may help, particularly if you are making assumptions about someone else's thoughts or behaviours. Try to ask yourself “What do I need from that person?” or “What do they need?”. Then communicate with others about what you need from them, or what they might need from you.

Develop an action plan

Problem solving may help generate solutions and reduce distress. Grab a notebook or even talk to a friend to try and identify: the perceived problem; possible solutions; and how to implement the solutions.

Clarifying your values: what is important to you right now?

With your world changing, clarifying your values and knowing what is important to you right now can help you prioritise where you put your mental, emotional and physical energy. Prioritising your energy may assist in reducing your distress as you can dismiss what's unimportant. Some priorities for you may include (but are not limited to): partner; family; friends; social activities; parenting; work; health; treatment; spirituality; physical activity; interests or hobbies; learning/ education; and meaning/purpose.

Mindfulness

Mindfulness can briefly be described as being aware of, and paying attention to, the present moment. So not thinking about yesterday, not about tomorrow, but to what is happening right now. For most of us, this would be about getting off auto-pilot and just noticing, acknowledging and not judging what is happening to, and around us, at any given moment.

Mindfulness is a skill that we can practise, most commonly through taking a “breathing space” or meditation practice.

Getting support

Getting support is integral to overcoming cancer-related distress and suffering. For information, support and referrals to specific agencies contact our Helpline on 13 11 20.

Kids Konnection – BrainChild

The BrainChild Foundation would like to thank Cancer Council Queensland for inviting us to contribute to the Brain Tumour Support Service (BTSS) newsletter. In future issues, the BrainChild Foundation will be writing articles for the Kids Konnection section of the BTSS newsletter. For our first article we would like to share some information about the BrainChild Foundation.

What is the BrainChild Foundation?

We are a charitable organisation, established in 2010 with the aim of helping children who are affected by brain and spinal cord tumours, and their families. Please visit our website at www.BrainChild.org.au.

The Foundation is comprised of a community of medical professionals, dedicated parents and friends of children affected by tumours of the brain or spinal cord.

More information about brain and spinal cord tumours in children

Brain tumours are the second most common type of cancer in childhood, but they are the most common cause of cancer death in children. Every year in Australia approximately 200 children will be diagnosed with a brain tumour. Despite advances in surgery and medical treatment, around half of these children will ultimately die from their disease. Common brain tumours in children include medulloblastoma, ependymoma and astrocytomas.

Some tumours, for example medulloblastomas, can respond well to treatment whereas others, such as some tumours of the brainstem, are currently incurable. Treatment usually consists of surgical removal where possible, often followed by further treatment with chemotherapy or radiotherapy.

Spinal cord tumours in children are relatively uncommon, but very difficult to treat due to their location. They affect a child's ability to walk, can impair bladder and bowel function and can result in significant physical disability or even death.

Unfortunately, the consequences of these tumours and their treatments may also have wide ranging implications for a child's learning, physical and social development.

At present, our understanding of the causes and behaviour of these tumours is incomplete and we have a long, long way to go if we are to achieve better outcomes and greater rates of cure, ensuring better tomorrows for affected children.

What does the BrainChild Foundation do?

There are 5 key objectives of our Foundation, each represented by one of the stars in our logo:

The Red Star: To raise awareness of brain and spinal tumours in children and to build a community of supporters committed to finding a cure.

One objective of the BrainChild Foundation is to raise awareness of childhood brain and spinal cord tumours and the challenges and difficulties faced by families dealing with these diseases. By raising awareness of these issues the Foundation hopes to raise the funds necessary to provide the appropriate

support to diagnosed children and their families and to fund research projects which will eventually lead to better treatment and outcomes for patients.

The BrainChild Foundation hold BrainChild Awareness Day each November, where BrainChild merchandise is sold. If your school or organisation would like to support BrainChild Awareness Day please contact us for further details.

The Gold Star: Support

Every family travelling the treatment journey with their child requires some form of assistance. BrainChild Foundation offers financial support through specific financial assistance for families currently in treatment, information support through their brochures and website and family support through networking and camps. Family camps provide a time to relax and meet other families and further extend their support network. BrainChild Foundation's aim is to help make the journey easier for each family.

Following on from treatment that support must continue. The BrainChild Foundation aims to continue with care by offering education scholarships to the children and by supporting families as they transition back into the community. This support can continue up to two years from diagnosis - all applications are reviewed by the Support Committee.

If you would like to know how the

BrainChild Foundation can help you during your child's journey please access our website at www.BrainChild.org.au/contact and navigate to Support on the Contact us page.

The Yellow Star: Research

Research is essential to achieve better outcomes both in treating brain and spinal tumours in children and also in enabling a better quality of life for those who have been cured of their disease. The BrainChild Foundation aims to promote and support research into brain and spinal cord tumours of childhood, so that we may better understand the causes and behaviour of these diseases and therefore provide better treatments and a greater prospect of cure. Since being established in 2010, the BrainChild Foundation has contributed \$100,000 to research into brain tumours in children. In the 2012 - 2013 financial year, BrainChild Foundation has donated \$30,000 to the Queensland Children's Medical Research Institute (QCMRI) and \$25,000 to the Isabella and Marcus Foundation for the development of a neuro-oncology research position in Melbourne, looking particularly at DIPG tumours.

The Green Star: Treatment

The Foundation seeks to support the investigation of new and promising treatments for children with brain and spinal cord tumours. Improved treatments will not only provide a greater rate of cure for affected children, but will also reduce the side-effects that can result. We support research into better treatments for these tumours through our fundraising activities.

The Blue Star: Funding

The funds raised by the BrainChild Foundation are used to ensure our Research, Treatment and Support initiatives are fulfilled. We hold a number of fundraisers each year to enable us to reach our goals. Keep an eye on the Events page

of the BrainChild Foundation website for details about upcoming fundraising events.

Advice for newly diagnosed families

It is impossible to explain the emotions that you feel when told that your child has a brain or spinal cord tumour. We all react differently, yet we are all willing to do anything to make our child well again. This is possibly the most stressful time you will ever have to face, so don't try to do it alone. We have listed a few simple tips below to help you in the initial stages.

- Nominate one friend or family member to be your liaison. They can then disseminate information and progress reports to others via phone, email etc.
- Make notes wherever possible. Keep a diary to stay on top of appointments and write down questions and observations for the doctor.
- Support each other and ensure that you maintain a regular diet and get sleep whenever possible. You cannot help your child if you get sick.
- Be patient, hospital hours are very long! Find some good books, crosswords or take up knitting to pass the time.
- Don't be afraid to ask for help. If the lawn needs mowing or the washing is piling up, ask a family member or friend to help you out. They will be happy to do it.
- Focus on positive thoughts and surround yourselves with positive people.

How can you help?

By pledging donations, giving of your time to assist us in our fundraising or by raising awareness in your local community, you can help us to achieve our goals, to beat childhood

brain tumours and to ensure better tomorrows for affected children.

Once again, our sincere gratitude to Cancer Council Queensland for providing us with a voice through this page. If there is anything you want to know or would like us to write about please visit our webpage and leave a message.



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.

Brain Scans for adult gliomas

Reasons for doing a brain scan

All adults with astrocytomas or oligodendrogliomas will need to have brain scans (neuroimaging) during their diagnosis and treatment.

There are several reasons for doing a brain scan in a person with a brain tumour:

- To help confirm the diagnosis.
- To see where the tumour is within the brain.
- To assess what kind of tumour it is and how it is growing.
- To assess what effects the tumour is having on the surrounding brain.
- To plan biopsy, surgery or radiotherapy.
- To assess whether treatment has been successful (for example, to see how much tumour has been left behind after surgery).
- To check complications caused by treatment, such as bleeding or infection in the brain.
- To check whether the tumour has started growing again or has changed after treatment.

Brain scans are not used to look for possible brain tumours in healthy people with no symptoms (screening programs). Brain scans are used only in healthy people who are at high risk of brain tumours, such as people with neurofibromatosis and other inherited genetic conditions.

Types of brain scans

The two main types of scans used in people with brain tumours are computed tomography (CT) and magnetic resonance imaging (MRI).

Computed tomography (CT)

CT is available in most hospitals, takes less time to do and is less expensive than MRI. CT uses X-rays (ionising radiation).

When a person has symptoms that could be caused by a brain tumour, the first scan is usually done using CT. The main aim at this stage is to see whether an abnormal area of brain is visible that could possibly be a tumour. If an abnormal growth is seen, the CT scan is normally followed up with an MRI scan.

CT is also useful for:

- Identifying bleeding inside the brain.
- Assessing whether the tumour is growing into the skull.
- Identifying a build-up of calcium within a tumour (calcified tissue), which can suggest that the tumour is an oligodendroglioma.

In people who cannot have MRI scans, special CT techniques can be used instead.

Magnetic resonance imaging (MRI)

MRI is significantly more expensive than CT and is not as widely available.

MRI is more accurate and generally gives more information than CT. MRI is recommended before a brain biopsy or surgery to remove a brain tumour. The most accurate type of brain scan in a person with a suspected brain tumour is MRI performed after a dye has been injected into the person's bloodstream (contrast-enhanced MRI).

CT is useful as an extra scan for assessing tumours that have grown into the bone, or for identifying calcified tissue or bleeding.

MRI uses a powerful magnet, radio waves and a computer to make images of a 'slice' in any direction

through the head. The patient lies on a table, which slides inside a large metal cylinder. People who experience claustrophobia may need general anaesthesia or sedation so that they can keep still in the MRI machine during the scan.

MRI during surgery

Researchers are currently investigating whether using MRI during surgery might help the surgeon remove more of the tumour, and so prolong patients' survival.

So far, there is no convincing proof that this method is better than standard surgery for patients with high-grade brain tumours such as glioblastoma multiforme. Equipment for doing MRI during surgery is not yet widely available in Australia.

Safety issues for MRI

Before an MRI, all metal objects must be removed from the person's body. MRI cannot be used for people with metal inside their bodies, such as:

- Permanent clips used in surgery for aneurysm.
- Cardiac pacemakers.
- Cochlear implants.
- A tiny speck of metal inside the eyeball (e.g. due to an accident).

Nuclear medicine

Nuclear imaging (an older type of scan) is no longer used much in patients with brain tumours, because it has been replaced by CT and MRI.

Some new nuclear imaging techniques, such as neuro-SPECT¹ and neuro-PET² can be useful:

- Before biopsy, to help find the best site to target when taking the specimen.

- Before surgery, to get more information about the type of tumour (before a specimen is available).
- After surgery, to tell how far the tumour has spread.
- After radiotherapy, to tell the difference between damage caused by the radiation and malignant tumour.
- In follow-up, to detect whether a low-grade tumour has changed to become higher grade (growing more rapidly).

Brain scans after treatment for a brain tumour

After surgery

After surgery to remove a brain tumour, brain scans can be also used to look for tumour that has been left behind.

An MRI 24–48 hours after surgery helps detect changes that are due to the surgery, such as bleeding. These scans can be kept as a record so that, months or years later, the abnormal appearance caused by surgery will not be mistaken for signs that the tumour has changed to become higher grade (more rapidly growing).

Follow-up imaging

MRI is the best type of brain scan for follow-up after treatment for a brain tumour. A follow-up MRI is usually done 6–12 weeks after a person has received radiotherapy for a brain tumour, then repeated every two-to-three months. If the tumour shows no signs of growing or worsening over a long period, MRI might be repeated less often (for example every six months).

¹ Single photon emission computed tomography of the brain.

² Positron emission tomography of the brain.

Limits of brain scans

Brain scans cannot always give clear information about a tumour. For example:

- It is not possible to be sure that an abnormal area of brain seen on CT or MRI is definitely a brain tumour, even when there are also symptoms that could be due to a brain tumour.
- For an accurate diagnosis, it is usually necessary to examine a piece of tumour (collected by biopsy or surgery) under the microscope.
- CT and MRI give reliable information about some aspects of brain tumours, but do not give accurate information about the type of brain tumour.
- When changes in brain tissue are seen at follow-up after treatment for a brain tumour, it might not be possible to tell whether these are caused by treatment (such as damage caused by radiation), or by the tumour growing and worsening.

This information is an excerpt from Cancer Council Australia's resource "Adult Gliomas (astrocytomas and oligodendrogliomas): a guide for patients, their families and carers" (April 2011). This consumer guide is a derivative document complementing the Clinical Practice Guidelines for the Management of Adult Gliomas: astrocytomas and oligodendrogliomas (Aug 2009). These two guides and additional resources of the Cancer Council Australia can be found at: www.cancer.org.au.

Key points

- Brain scanning (neuroimaging) is an essential part of medical care for people with brain tumours.
- The two main types of neuroimaging used in people with brain tumours are computed tomography (CT) and magnetic resonance imaging (MRI).
- When a person has symptoms that could be caused by a brain tumour, the first scan is usually done using CT. The main aim at this stage is to see whether an abnormal area of brain is visible that could possibly be a tumour. If an abnormal growth is seen, the CT scan is normally followed up with an MRI scan.
- MRI is more accurate and generally gives more information than CT. Anyone who is about to have a brain biopsy, or surgery to remove a brain tumour, should have an MRI first.
- MRI cannot be used for people with metal inside their bodies, such as pacemakers, cochlear implants or a metal speck permanently stuck inside the eye after an accident.
- After surgery to remove a brain tumour, brain scans may be used to look for tumour that has been left behind or changes in the brain tissue caused by the surgery itself.
- MRI is the best type of brain scan for long-term follow-up after treatment for a brain tumour.
- Brain scans cannot always give reliable information about whether an abnormal area of brain is definitely a tumour, or tell the difference between types of tumours.

What's been happening...

Making Sense of Brain Tumour: A Personal and Family Support Program

The Making Sense of Brain Tumour (MSoBT) Program was developed after pilot research in 2007-2008 highlighted that the psychological support needs of people with brain tumour and their caregivers are often overlooked. The need for specialised counselling and rehabilitation was a specific recommendation out of the findings. The program involved collaboration between Griffith University, Cancer Council Queensland and BrizBrain & Spine.

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

Conducted from 2010-2013, the MSoBT program provided 10 sessions of home-based counselling and rehabilitation and aimed to improve the psychological well-being and everyday functioning of people with primary brain tumour and their family members. The final participant in the program completed therapy in June 2013. Six month follow-up assessments will continue until December 2013.

A total of 50 people with brain tumours took part in the program (27 males, and 23 females, aged 17-82 years), along with their family

members. The program supported people with any type of primary brain tumour to participate, and our clinicians provided counselling and rehabilitation to 27 people with benign tumours and 23 people with malignant tumours.

The most common treatment goals identified by participants include:

- Manage the effects of brain tumour, for example, cognitive difficulties (e.g., difficulties with memory, concentration and organisation), language impairment, loss of motivation and fatigue.
- Manage anxiety regarding lack of knowledge about brain tumour and anxiety regarding uncertainty of the future.

- Develop coping strategies for low mood, stress and anger management issues.
- Reduce social avoidance and isolation.
- Address fears /concerns of participant's children.
- Enhance preparedness for possible outcomes and end of life issues (e.g., family care plan, advanced health directive and guardianship).
- Enhance couple relationship functioning (e.g., communication, intimacy and sex-related difficulties).
- Assist with return-to-work and parenting skills.

Due to the complex cognitive and behavioural effects of brain tumour, various conventional

approaches to psychoeducation and counselling were modified to meet the needs of participants. The materials used in therapy are being collated into a specialised manual to support clinicians in the cancer and brain injury field to tailor techniques according to the goals and presenting issues of people with brain tumour and their family members.

Overall, the clinicians of the MSoBT program learnt that psychological support needs to be flexible and that it is optimal for the person with brain tumour and individual family members to have separate time to discuss their issues and concerns, as well as time together with the therapist to develop a shared perspectives on their relationship and strategies for managing the effects of brain tumour. Striking a balance between providing person-centred and family-centred support can be challenging and this needs to vary according to people's support preferences.

Evaluation of Program Outcomes

An evaluation of the program indicated that people experienced significant improvements in mental health and quality of life (e.g., depression, existential well-being and functioning in everyday roles). In contrast, people on the waiting list (a 10 week period) reported no changes in their functioning until they received the program. Furthermore, the research found that people maintained the gains in their well-being six months after the program ended. The benefits for family members will also be assessed for the 33 family members who took part and completed assessment measures.

Overall, the MSoBT program was found to be effective for improving the well-being and everyday functioning of people with brain tumour. In future, a more specific focus on evaluating support options for family members is warranted,

as they often have unique needs that vary over time. One limitation of the MSoBT program is that it was time limited for both the number of sessions and the time period in which it was provided. Many participants expressed the need for longer-term support on a flexible "as needed basis". Additionally, providing therapy in people's home, whilst greatly appreciated by the majority of participants, is not always feasible and this meant that the MSoBT program was limited to people living within one hour of Brisbane. The research team is currently exploring options for more flexible delivery modes of support, including telephone and Skype sessions.

The researchers would like to thank all participants and their families for taking part in the MSoBT program and also the dedicated clinicians including Dr Ea Stewart, Dr Katherine Horrigan, Dr Megan Broughton and Cassandra Shields.

What participants had to say about the approach used in MSoBT program:

"It was excellent. We both found it very beneficial. Learning the techniques...and understanding anxiety too – I didn't have a great deal of understanding of anxiety. It was a learning experience. (Therapist) explained why it was happening. It made us feel normal regarding the anxiety."

"Very constructive, very therapeutic. Dual reward for both me and my wife. We are very happy with the support we have received from the program"; "Very successful, it helped me achieve goals I had, and taught me strategies to address the others in the long term".

"I was quite desperate for some help, I felt very alone and I needed someone to talk to. We were lurching from one drama to another and communication between (my husband) and I wasn't very good.... We both felt supported through the program - learning a new way to communicate with each other. I've learnt how to bring up new subjects without upsetting him".



About the author:

Dr Tamara Ownsworth is an Associate Professor in the School of Applied Psychology, Griffith University. She is also the Chief Investigator in the National Health and Medical Research Council (NHMRC) Centre of Research Excellence in Brain Recovery.

Brain Tumour Information Sessions 2013

Brisbane

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

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

What's happening in 2013? Dates for your calendar...

Friday 25 and Saturday 26 October - 6th COGNO Annual Scientific Meeting, "Neuro-oncology in the Younger Adult", Sydney.

COGNO is pleased to announce the launch of the new COGNO ASM website at: www.cogno.org.au/content.aspx?page=cognoasm-home

Registration for the ASM is now open and a preliminary program is available on the COGNO website: (www.cogno.org.au/content.aspx?page=cognoasm-program).

Early registration and accommodation bookings are encouraged as there are a number of other large meetings happening in Sydney around this time (e.g. 15th World Conference on Lung Cancer commences the day following the COGNO ASM). Please note accommodation is not included in your registration and must be booked directly with the hotel of your choice. Special rates are available for delegates at the PARKROYAL hotel, details are available on the COGNO ASM website: www.cogno.org.au/content.aspx?page=cognoasm-accomm

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: Depression and anxiety after the diagnosis of a brain tumour

Presenter: Kate MacMorran, Clinical Psychologist, CCQ - May 21, 2013

Topic: Brain tumours in adolescents and young adults

Presenter: 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

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

Brain Cancer Action Week Forum 2012

Topic: Radiation therapy for brain tumours

Presenter: Dr Matthew Foote, Radiation Oncologist

Topic: Living with a brain tumour – Adjusting to your prognosis

Presenter: Associate Professor Jane Turner, Psychiatrist

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 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.

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

💻 relaxationcentreqld.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: www.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