Brain Tumour Support Service

Edition 1, 2013

Dear Friends,

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

Welcome to the first edition of our Newsletter for 2013. We hope you have all fully recovered from the Christmas and New Year celebrations. What a start to the year it has been: first the heat, then we were blown away and swamped by Cyclone Oswald. I feel for the many people in Bundaberg and other areas who lost their houses, which must have been so dreadful.

We were very lucky here with no power cuts, only the terrific wind which blew several trees down in the grounds. It sounded just like an express train coming through and was very frightening. My family were on their way back from Tamworth and had to stop in Warwick for two nights as the roads were all closed.

Just before Christmas I was invited to Cancer Council Queensland's annual awards ceremony and high tea at the Victoria Park Golf Club. It was beautiful and we all enjoyed ourselves. I was presented with my twenty years' service award, which was very nice. I can't believe I have been writing the editorial for this newsletter for so long!

We have some good reading for you in this first issue. Juan has written a most interesting story about his long battle with a brain tumour. Thank you Juan, it sounds as though you are truly living your life to the full and are an inspiration to us all.

You may wonder about psychologists and how they can help you. Our article on psychologists explains a little about their role and how you can access them. Then there is an article on disorientation, which can sometimes be caused or exacerbated by a brain tumour. The article offers some useful strategies to help you cope should this happen to you or your loved one.

There is also a piece on Meningiomas, a type of primary brain tumour, mostly benign, which arise from the meninges covering the brain.

This is a great overview, looking at the different types of tumours, their incidence, and symptoms which may arise.

Kids Konnection tells the interesting story of Nathan, a teenage boy who loved his sports and was stopped in his tracks by the diagnosis of a tumour on his pituitary gland. Thank you, and well done, Nathan, for taking the trouble to write such a brave and honest account of your experience.

Finally, we provide some useful information on making a Will, why it is important for everyone, and how to go about it.

As usual we have the dates of upcoming brain tumour Information Sessions which are to be held in Brisbane and Townsville throughout the year, and all the usual support services and resources available. We hope that you will be able to come along and join us sometime this year, at one of our Information Sessions, or at the all-day Forum which we are planning to hold in November during Brain Tumour Awareness Week.

That's all for now, so till next time, keep smiling and happy reading.

Anne.

Thought for the day:

"There is a crack, a crack in everything
That's how the light gets in"
~ Leonard Cohen lyric

Index

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 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 – Juan

My story starts in 2002 when, at the age of 22, I started to experience absence seizures. They were obviously happening without me knowing it, only the people around me noticed it. I was told that I acted very strangely and was sometimes unresponsive.

I felt like I was under some type of spell, a little light-headed, slight vertigo, and shortness of breath, and that was how my absence seizures began to take place in my life. Since I never really felt sick or broke things, I chose to ignore them.

That was until 2003. I was at work in the kitchen, and during service I dropped some plates that I had in my hand, and I acted as if there was no one inside me. I'm told I became completely unresponsive. My chef forbade me to work until I had a medical certificate, so I went to the Doctor, who then sent me to see a neurologist. I was sent for an MRI and that's when cancer began to play a major role in my life. I was diagnosed with a glioma in the middle of my head. Initially, I was told that it was too small to operate on and that because of its location it would be too risky to have a biopsy. The neurosurgeon told me we should monitor it until any change happened. So, we watched and waited until 2005, when it suddenly tripled in size, and we had no other choice but to have it operated on immediately.

I was operated on, but only 80% of the tumour was able to be removed as the rest of it was attached to the basal ganglia, and could not be touched. To treat the rest I had three years of chemotherapy and 20 sessions of radiotherapy. And here I am, telling my story seven years after having a malignant oligoastrocytoma the size of a golf ball removed from my head.

My will to live and love for life was too great for cancer to stop me from continuing to enjoy my life. So, since that moment on, I have said to myself that I am in control of how I live my life and nothing is going to stop me from living it to the fullest.

I like to think that after all this time, and my close encounter with death, I have been doing just that. I try to do everything that I think is worthwhile, that is exciting and adventurous, reminding myself that I only live once. I feel that if I don't take advantage of every second that goes by I will lose it, and it will never come back.

I take every opportunity I have to play golf – which is my passion in life – even if it´s raining. Every time I have the chance to go rock climbing – my second passion – I do that too. These are the two things that I enjoy doing the most and keep me motivated. I try to pass on this message to the people I meet, live strong and live well, and as if every opportunity was your last.

Apart from the two sports I just mentioned, I also love to listen to music, which takes me to a different world and inspires me. It gives me something to reflect on, and time to remember all that I've been through and those people that have touched my life in one way or another, many of whom have helped me to get to where I am today. It makes me cry sometimes, it makes me smile, it inspires me, it motivates me, but above all it makes me feel very alive.

I have to thank my mother more than anyone else. She was my carer and pillar of strength, and never skipped any moment of this whole battle. Thanks mum, for all your support and for never doubting my recovery.

My story – Juan continued

My friends are also really important to me and their support has provided me with the strength and confidence to overcome many of the challenges I've faced.

When I was first diagnosed with a brain tumour the hardest part was to think that I might never have a family and that there would be so many experiences and great moments that I would miss out on with my family. I really have to thank God for giving me another chance in life, and for allowing me to continue with a normal life. I feel fortunate as my experience with brain tumour has allowed me to never take anything for granted and to enjoy every second and every experience. I continue to work as a chef, and my biggest joy, and the thing that my wife and I look forward to more than anything, is the arrival of the baby we are expecting.

I know that everyone's experience will be different. I am fortunate that my cancer experience has never pulled me down, and that my faith in life and in God has remained strong. I hope you, too, will be able to find some positives in the sometimes overwhelming challenges of a brain tumour, and that my story has helped you in some way, and perhaps encouraged you to share your own story.

Juan David Lucio

Mindfulness courses

The aim of the Living Mindfully course is to increase a person's ability to manage difficult feelings and to help people to live more fully in the present moment.

Through mindfulness meditation practice and guided group discussion, participants learn to:

- focus and calm the mind
- ground attention and awareness in the present moment
- have more choice about how they respond to life's challenges

What does the course involve?

The Living Mindfully course is open to patients and/or carers and runs over 8 weeks.

Each session lasts for about 2 hours with a limited number of participants.

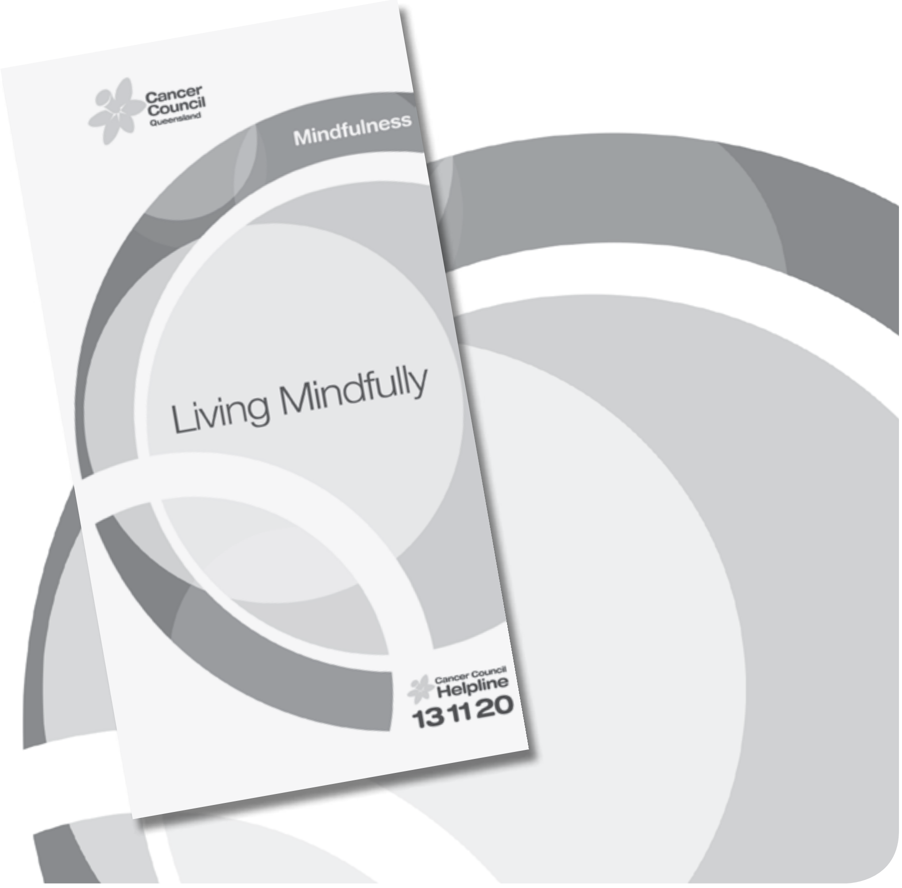
Sessions involve meditation practice and led group discussion.

Regular practise of meditation at home is an important part of the program to ensure you get the most from the course.

In 2013 courses commence:
May and June

Locations: Brisbane, Gold Coast, Sunshine Coast, Townsvillle, Rockhampton & Bundaberg

For more information contact the Cancer Council Helpline on ph:13 11 20 or email livingmindfully@cancerqld.org.au



How can they help?
Psychologists –

Following diagnosis of a brain tumour it can feel as if your world has fallen apart. Many people struggle with upsetting thoughts like "Will I survive?" "How do I tell family and friends?" "What does my future hold?". It is common at this time to feel depressed and fearful and on edge. For many people difficult thoughts and feelings get less over time. Other people continue to struggle and can find themselves feeling overwhelmed.

A psychologist can help you to cope with difficult thoughts and feelings soon after diagnosis or down the track during and after treatment. They provide an opportunity to talk about things that may be worrying or confusing and help you with different ways to understand your cancer problems or situation. Examples of things they may help you with include relationship troubles, loss and grief, concerns about work, how to talk to children and family, anxiety or depression problems and dealing with the difficulties of diagnosis and treatment. Some people see a psychologist just to build their confidence to deal with brain tumour challenges that might come up in the future.

People who might benefit from seeing a psychologist after a brain tumour diagnosis include the person with the tumour or their close family or friends. Many couples and families find it helpful to see a psychologist together to work on their problems as a team. The sorts of things that might be taught in sessions include:

1. education about normal thoughts and feelings following a brain tumour diagnosis
2. communication and partner support strategies
3. ways to manage child behaviour
4. relaxation and other ways to manage stress
5. challenging of unhelpful negative thoughts
6. sleep management techniques
7. increasing pleasant and rewarding activities
8. goal setting.

Registered psychologists in Queensland must have undertaken an approved psychology degree AND have undertaken a minimum of 2 years of supervised practice or a (minimum) 2 year postgraduate course.

Clinical neuropsychologists are a type of psychologist who have undertaken further training in the assessment and treatment of thinking and behaviour problems following brain injury. Although most psychologists will be able to help people deal with the emotional upheaval and adjustment to a brain tumour diagnosis, only a neuropsychologist has specialist training in the assessment of cognitive, behavioural and emotional problems that might arise directly from damage to the brain.

You can find psychologists in many of the public hospitals, in some non-government organisations and in private practice. Private health funds may rebate part of the cost of a private psychologist and some people are eligible for a medicare rebate if they are referred by their general practitioner. The Cancer Council Queensland – Cancer Counselling Service offers up to five (telephone or face to face) sessions with a psychologist experienced in helping people cope with cancer. You can find a psychologist by talking to your GP or treatment team, by calling the Cancer Council Helpline on 13 11 20 or by contacting the Australian Psychological Society (APS) Psychologist Referral System on 1800 333 497.

by Samantha Clutton
Clinical Psychologist
Cancer Council Queensland's
Cancer Counselling Service

Meningiomas

Although meningiomas are considered a type of primary brain tumour, they do not grow from brain tissue itself, but instead arise from the meninges, three thin layers of tissue covering the brain and spinal cord. These tumours most commonly grow inward causing pressure on the brain or spinal cord, but they may also grow outward toward the skull, causing it to thicken. Most meningiomas are benign, slow-growing tumours. Some contain cysts (sacs of fluid), calcifications (mineral deposits), or tightly packed bunches of blood vessels. There are several systems used to name, or group, these tumours. One system names meningiomas by the type of cells in the tumour. Syncytial (or meningothelial) meningiomas are the most common and feature unusually plump cells. Fibroblastic meningiomas feature long, thin shaped cells. Transitional meningiomas contain both types of cells.

Another system uses the terms benign, atypical and malignant (or anaplastic) to describe the overall grade of meningiomas. In this system, benign meningiomas contain easily recognized, well-differentiated (resembling normal) cell types which tend to grow slowly. Atypical tumours represent 10–20% of meningiomas. They contain proliferating cells that may be faster growing and more likely to grow back after treatment, even after seemingly complete resection (surgical removal). Therefore, these tumours must be followed carefully for early signs of recurrence. Malignant or “anaplastic” tumours are poorly differentiated forms that often recur rapidly. Although they are quite rare (1–3%), malignant meningiomas can be highly aggressive and difficult to treat. Another common practice is to attach the location of the tumour to its name. For example, a parasagittal meningioma is located near the sagittal sinus, a major blood vessel at the top of the cerebral hemispheres. A sphenoid ridge meningioma is found along the ridge of bone behind the eyes and nose. Some meningiomas can cause problems despite their benign nature, because they are difficult to remove when they are located in functionally sensitive or hard to reach areas. Depending on the situation, stereotactic radiotherapy or radiosurgery may be particularly helpful in some of these cases.

Incidence

Meningiomas account for about 34% of all primary brain tumours. They are most likely to be diagnosed in adults older than 60 years of age, and the incidence appears to increase with age. Meningiomas are rarely found in children. They occur about twice as often in women as in men.

Cause

Researchers are studying several theories about the possible origins of meningiomas. Between 40% and 80% of meningiomas contain an abnormal chromosome 22. This chromosome is normally involved in suppressing tumour growth. The cause of this abnormality is not known. Meningiomas also frequently have extra copies of the platelet-derived growth factor (PDFGR) and epidermal growth factor receptors (EGFR), which may contribute to the growth of these tumours. Previous radiation to the head, a history of breast cancer, or neurofibromatosis type 2 may be risk factors for developing meningioma. Multiple meningiomas occur in 5–15% of patients, particularly those with neurofibromatosis type 2.

Some meningiomas have receptors that interact with the sex hormones such as progesterone, androgen and less commonly, oestrogen. The expression of progesterone receptor is seen most often in benign meningiomas, both in men and women. The function of these receptors is not fully understood, and thus, it is often challenging for doctors to advise their female patients about the use of hormones if they have a history of a meningioma. Although the exact role of hormones in the growth of meningiomas has not been determined, researchers have observed that occasionally meningiomas may grow faster during pregnancy.

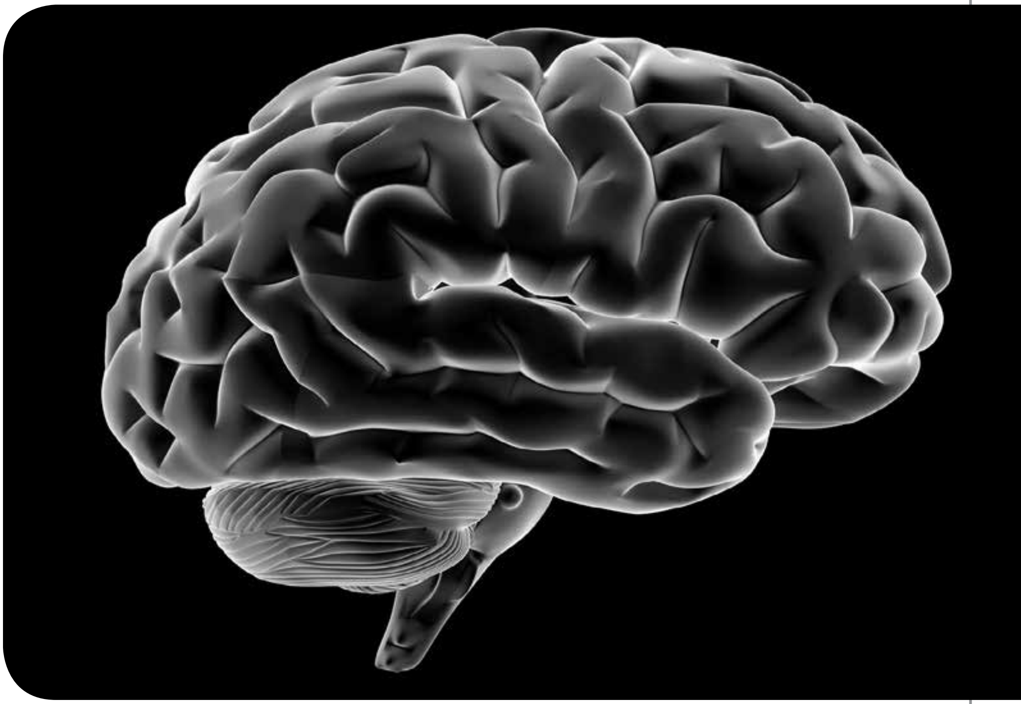
Symptoms

Meningiomas are usually slow growing and, therefore, may grow to a large size before causing symptoms. These tumours are most often found in the coverings of the parasagittal/falcine region (near the top of the brain) and the convexity (the outer curve) of the brain. Other common sites include the sphenoid ridge at the bottom of the brain, called the skull base. As the tumour grows, it may interfere with the normal functions of the brain. The symptoms will depend on the location of the tumour. The first symptoms are usually due to increased pressure on the brain caused by the growing tumour. Headache and weakness in an arm or leg are the most common, although seizures, personality change or visual problems may also occur.Pain and loss of sensation or weakness in the arms or legs are the most common symptoms of spinal cord meningioma.

Diagnosis

Your doctor will begin with a neurological examination, followed by an MRI and/or a CT scan.

MR angiography (a MRI scan of the blood vessels) or an arteriogram (a blood vessel X ray) may be performed to help the doctors plan an embolization, a procedure to block the blood vessels in the tumour. Used for tumours that have an extensive blood supply, embolization may help reduce bleeding during surgery. If you have a tumour, these tests help your doctor determine the location, size and probable type of tumour. However, only an examination of a sample of tumour tissue under a microscope confirms the exact diagnosis. Such a tissue sample can only be obtained through a surgical biopsy or excision.



Treatment

Options include;

- Watchful waiting
- Surgery
- Radiation Therapy

There are also several drugs used to treat the symptoms of a brain tumour. Steroids are used to decrease swelling, or edema, around the tumour. Anti-seizure drugs control seizures. Anti-nausea drugs prevent vomiting and help control nausea.

Clinical Trials

Some treatments are offered in organized research studies called clinical trials. These are generally used for recurrent or inoperable tumours resistant to radiation. Your doctor can determine if you are a candidate for treatment in one of these trials.

Several other treatment approaches have or are being explored:

- Hydroxyurea (used as a radiosensitizing drug in the treatment of other types of tumours)
- Progesterone receptor inhibitors
- Somatostatin analogs (hormones that prevent the release of growth hormones)
- Targeted molecular agents
- Epidermal growth factor receptor (EGFR) inhibitors
- Platelet-derived growth factor receptor (PDGFR) inhibitors
- Vascular endothelial growth factors (VEGF) inhibitors
- Immunotherapy or the use of biological agents to stimulate the immune system

This information is reprinted with permission from Meningioma, © 2012 American Brain Tumor Association (ABTA). To access the entire publication for more information on treatment and managing side effects visit the ABTA website at www.abta.org.

Kids Konnection

Nathan's Story

My name is Nathan Hodge, and up until 2009 I was a fairly normal teenage boy. I was a sports freak; everything I did had to have some sort of physical activity in it. Then I began to drink a lot, like I'm talking up to 14 to 15 *litres* of water a day! Mum took me to the hospital and they gave me an immediate MRI scan. The scan showed a growth on the pituitary gland but at this time it was not cancerous. Over the next few months I had a couple more MRIs and the hormone levels in my body began to fade and then my pituitary gland started losing its function.

Before treatment

It was about 18 months after this first happened that I was diagnosed with an inter-cranial germ cell tumour on the stalk of my pituitary gland, which at the time meant absolutely nothing to me. It was like they were speaking another language. The pituitary gland is smack bang in the middle of my brain and we were told that operating to remove the tumour was off the cards, due to the risk of damaging my eyesight. So it was decided that I would have six cycles of chemotherapy followed by radiation therapy treatment.

Mum and I had to pack up and leave our family and friends behind and travel 2-3 hours up to Brisbane to begin treatment. The hospital said that we needed to stay 10 minutes from the hospital. We had no family in Brisbane and were unable to get into a charity house at such short notice. The closest we could get to the hospital was my uncle's house out near Ipswich. Although the hospital was not happy with us being that far away, we didn't have a choice. My uncle and aunt had six children but still managed to take us in and provide a roof over our heads. This was not ideal because of the infections I was exposed to, but it's all we had and I'll be forever grateful to them for what they did for us.

When I started treatment I didn't tell anyone that I had cancer. This is because I still had my hair, I was feeling well, I had no central lines, and most of all I didn't feel sick. I felt like these kids around me had it so much worse than I'd ever known. It may sound silly but I felt that I didn't belong there. I also had no idea what I was in for.

The cancer journey is tough enough to break any relationship, and powerful enough to form life-long friendships. My family tried to hide the fact that we were struggling to pay the bills and the mortgage on the house, because they always told me their sole focus was on me getting better. But I knew something was up, and being my usual nagging self, repeatedly asked what was wrong. I was told in classic Aussie style that "she'll be right" and that there was no need to worry. I later learned that we would have to sell our home. I have two sisters, and my dad Glenn had to stay at home to look after them, and, to continue to work, and mum had to stay with me. This separation ended up tearing our family apart, with my dad walking out on us a week after I had gone home for good – the week after Christmas. Not a great year for me and my family.

Although my family told me that I was wrong, I was convinced that losing our

house and my family splitting up was my fault. I could not have stopped what happened, but I believe that my illness was a major contributor.

Going back to school was scary and overwhelming. I didn't receive the welcome back that I'd expected, and although I think I gained some respect from my peers, after they found out what I'd been through, everyone was extra cautious around me.

My appearance had changed a lot. When I had left school I had long black hair, was extremely fit and even had a six pack! When I returned seven months later I had put on 35kg. I had no hair and still had a steroid face with many battle scars.

One day I was sitting in class. My hair had only started to grow at the sides, which left a great big bald patch right on the top of my head. A casual teacher walked straight up to me and said, "yeah digging the reverse Mohawk dude" and I casually replied ", yeah I had cancer". He almost fell over and was very embarrassed. I just took it as a compliment and laughed it off.

As we all know kids can be cruel. I knew people were talking about me and putting me down, but I had a great group of friends that would walk into the middle of someone's conversation and tell them to get a life. But really, I tried to ignore those people. It's easy to say now but it was hard to deal with and it did upset and frustrate me until I began to think that if these people have a problem with me, then it's their problem, not mine, so why fret over it.

Almost two years later here we are. Although I am fine on the outside I still have problems on the inside, dealing with day-to-day life. I try to see my cup as half-full most of the time, although sometimes it seems half-empty. Like on those days when I get tired, and sometimes even thinking of past friends. I have had a few friends that have passed away from cancer. Every day I think of them, and ask myself "why them, why not me?." I sometimes believe that I have survivor's guilt. I will be forever grateful that I have survived my cancer, even though I have life-long medical conditions. I wear these medical conditions as my battle scars and even as my badges of honour. I have a real sense of achievement, and being elected school captain and successfully getting my L-plate licence are among my best achievements so far.

After treatment

I want to thank everyone that helped me during my journey, especially my family, and wish the best for anyone about to go through what I've been through.

Finally, I'd like to leave you with the wise words of Sir Albus Dumbledore:

"Happiness can be found in the darkest of times, if one only remembers to turn on the light."

Thank you

Nathan spoke at our Brain Tumours in Childhood Forum held at CCQ on November 2, 2012. Pod-cast of this speech is available at our webpage www.cancerqld.org.au

Seize the Day study awards

Grants for young people affected by cancer

www.cancerqld.org.au

Cancer Council Queensland

Cancer Council Queensland recognises the significant challenges that cancer raises for young people, and that these challenges often occur at a crucial time of change and growth in their lives. The **Seize the Day Study Awards** provide an opportunity for young people to share their cancer experience and how this experience has impacted their educational and life goals. Each year, Cancer Council Queensland allocates $50,000 towards the Seize the Day Study Awards.

What?

Cancer Council Queensland's Seize the Day Study Awards are financial grants of $300 to $,2500 to help with the costs of post-secondary education.

Who?

You can apply for Seize the Day if you are a Queensland resident aged between 16 and 21 years who is planning to commence or continue post-secondary education next year and have experienced cancer personally or with a close family member.

How?

Applications are open from April to July each year, with recipients announced in December. To apply or for more information, visit www.cancerqld.org.au or call the Cancer Council Helpline on 13 11 20

Closing date for the return of applications to Cancer Council Queensland is the last Friday in July.

Grants for young people affected by cancer

What?

Cancer Council Queensland's Seize the Day Study Awards are financial grants of $200 to $2500 to help with the costs of post-secondary education.

Who?

You can apply for Seize the Day if you are a Queensland resident aged between 16 and 21 years who is planning to commence or continue post-secondary education next year and have experienced cancer personally or with a close family member.

How?

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Cancer Council Queensland

Seize the Day
study awards

Disorientation/appearing confused

Feeling lost, not knowing where you are…?

What is disorientation?

Disorientation is a state in which a person may not know where they are, who they are, or what day it is. People may look dazed or have a lack of clarity in their thoughts. It can be hard for them to make sense of what is happening around them. Some people may appear confused and unclear about things.

Key facts

A survey of people with a brain tumour found that

- 37% frequently became confused
- 13% were frequently or almost always disorganised

How can I detect confusion or disorientation?

- Not knowing what day, date or time it is.
- Uncertain about where you are.
- Not sure of who you are.
- A lack of attention.
- Disorganised thinking.
- Lower level of consciousness, for example seeming very drowsy.
- A lack of clear thinking or behaviour.
- Feeling bewildered, overwhelmed or puzzled.
- Getting lost easily.
- Losing your train of thought.
- Feeling uncertain of how to do things or get places.

'Alan's' Story

'Alan' is a man in his early sixties diagnosed with a Glioblastoma (high grade tumour) in his left parietal lobe. He is very unwell and has undergone several courses of cancer treatment. 'Alan' has been showing some confusion in that he will stop in the middle of a speech, appearing to lose his train of thought. He has difficulty keeping track of the days and sometimes gets confused about what month it is. 'Alan' often appears aimless at home as he gets up out of his chair and wanders into the kitchen without any plan of what he is doing. He needs help all the time when he goes out, as he is likely to get lost and no longer feels safe outside his home. His wife has now left work to be his full time carer and has to give him daily support and comfort.

Strategies

For the person with a brain tumour

- Use a whiteboard or timetable to write out your daily and weekly routine
- Use lists to outline tasks that you need to do and tick off each task when it is done.
- Cross off days on a calendar to identify the day and date.
- Ask someone to come with you when you go to appointments.

For the carer or family member

- Maintain a regular routine.
- Label rooms or objects with names or symbols.
- Use a wall calendar and cross off the days with your family member.
- Let the person know daily, what day it is and the date.
- Give reassurance and reminders of where they are and where they are going.
- Give them help in making decisions.
- Try to give them only one piece of information at a time.
- Limit the number of people in the room at any one time.
- Keep noise levels as low as possible.
- Lay clothes out for the day if they are having difficulty working out what to wear.
- Try to only give simple, single step instructions and repeat them if needed.
- Make sure they feel safe and keep an eye on them to give any help they need.

Questions to ask your health professional

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

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

Have you made a Will?

Why it's important

A Will is a legal document that specifies how you want your assets to be distributed when you die.

Making a Will is the only way that you can make sure that your assets are protected and that your estate is distributed as you wish. If you die without a Will, you will not be able to say who oversees the distribution of your estate or who is to receive a share in it. It will be divided and distributed by a legal formula, and may not be as you expect or want it to be. If you die without a Will, your estate will go to your nearest next of kin. In short, if you have a spouse and no children, your estate will go to your spouse. If you have a spouse and children, your chattels (personal belongings) and your estate to the value of $100,000 will go to your spouse. The rest will be divided among your children. If you have no spouse or children, then your estate will go to your parents. If they are no longer living, then it will go to your brothers and sisters. If they are no longer living, it will go to your nieces and nephews. It can be complicated for people with little family. Sometimes an organisation like the State Trustees must search to find someone's next of kin. This is time-consuming and expensive. Anyone who thinks that they should have been included in the Will could challenge it.

Before you make a Will

Make a list of everything you own. Include all real estate, furniture, bank accounts, shares, money on term deposit, business holdings, insurance policies, collectables, interest in a trust or deceased estate, cars or any other item you may want to leave to a specific person or

charity. Give some thought to who you want to benefit from your assets (the beneficiaries) and who you will appoint to administer your estate (the executor).

Making your Will

Your Will must be in writing. It must signed by you in the presence of two witnesses (who are both present at the same time), and it must be dated at the time it is signed. You must be at least 18 years of age to make a Will (unless you are married or have obtained a court order).At the time you make or change your Will, you must have the mental capacity to understand what you are doing. You must not suffer from any mental impairment that prevents this. You must be able to read the Will or have it read to you, and fully understand the document and its implications. You must also be acting of your own free will, and not be under pressure from anyone else. If not, the Will or any changes maybe challenged and rejected by a court.

If you do not have capacity to make a Will, a person may apply for a court order for what is known as a 'Statutory Will' to be made on your behalf. A court will only make an order for a statutory Will if satisfied that you do not have capacity to make a Will yourself. The court must also be satisfied the statutory Will reflects what your intentions would be likely, or might reasonably be expected, to be.

You can get a 'Do it yourself' Will kit, for example from the Post Office. However, you may wish to ask an expert to help you, especially if your Will is likely to be complex. They can raise potential problems with you. If you wish to find a lawyer who specialises in this area you can ring the Queensland Law Society on Phone 1300 367 757 for the name of a legal practitioner in your area. State Trustees also offer a Will-making service. In Queensland you can contact the Public Trustee to make an appointment to make a Will on Phone: 1300 360 044 or visit their website at www.pt.qld.gov.au/wills/.

When you make a Will, you can say who is to get particular pieces of your property. You can also name charities and make bequests to certain organisations. You can make bequests for any purpose that you think is worthwhile.

You may also choose to leave your estate 'in perpetuity'. This means that your estate remains as it is for good, with the person or organisation you name benefiting from the interest earned on the estate.

Appointing an executor

When making a Will, you will need to appoint an executor. This could be someone close to you whom you trust, or it could be a professional person or organisation such as the State Trustees or a lawyer. If you appoint a professional, you will need to pay fees.

An executor is responsible for distributing your assets to the beneficiaries of your Will. An executor will also often attend to funeral arrangements, pay any outstanding debts or expenses, prepare tax returns and attend to

This information is an excerpt from Cancer Council Victoria's resource Cancer: *legal rights and responsibilities – for people with cancer, their family and friends* and reprinted with their kind permission.

business interests before distributing assets to the beneficiaries. An executor can also act as a trustee to administer assets on behalf of children until they come of age. If the estate is large or complex, the executor may be under a lot of pressure. Think about this when deciding whether to nominate a person or an organisation as your executor.

Changing your Will

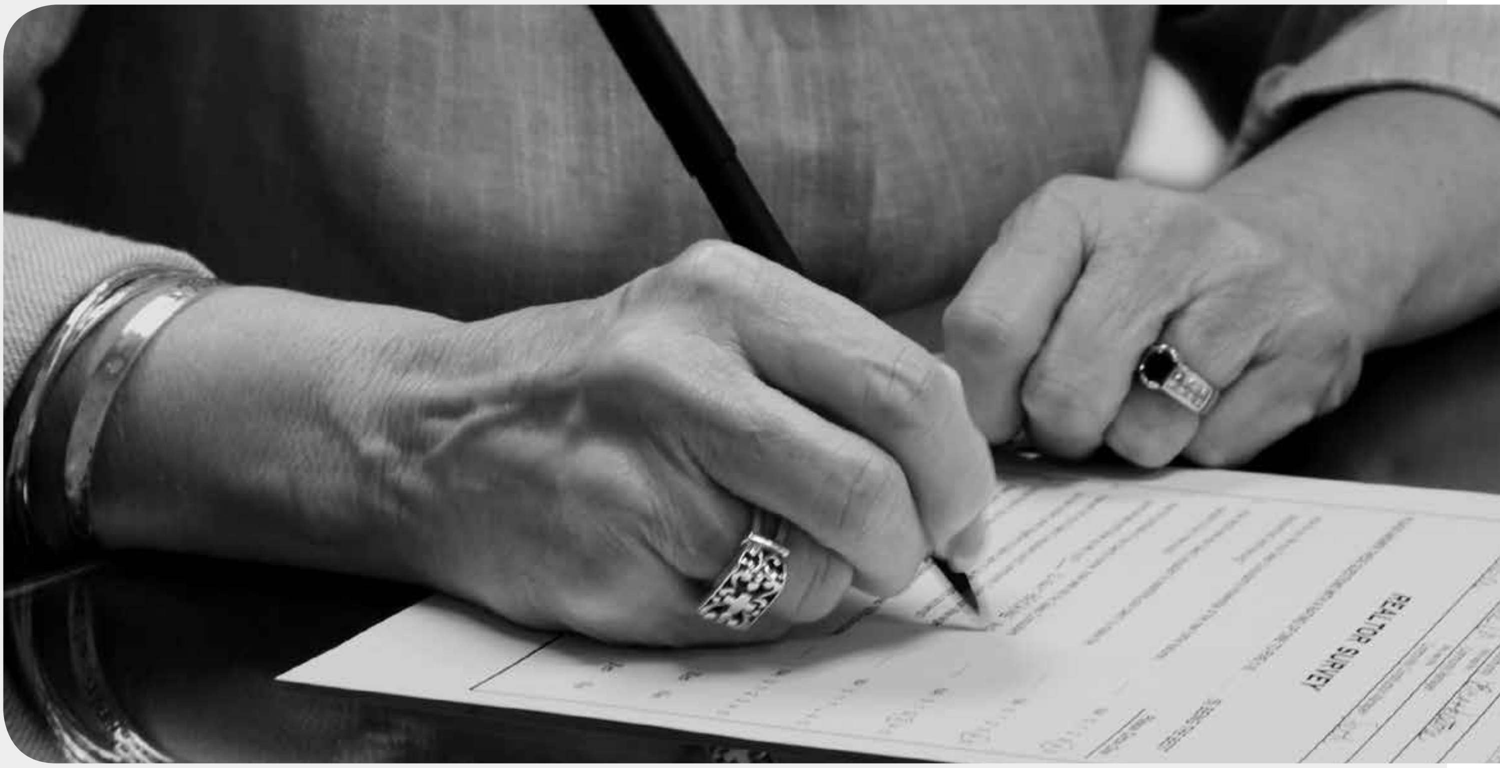
You can change your Will by:

- making a new Will (which cancels your earlier Will)
- changing your existing Will
- revoking or cancelling your Will by tearing it up
- If you revoke your Will, you will need to make a new Will to replace it.

If you make changes (including minor changes) to your Will, or you make a new Will, the changes or the new Will must be made in exactly the same way as the original Will: the changes or the new Will must be in writing, and signed by you in the presence of two witnesses. You must have the necessary mental capacity and be acting of your own free will at the time.

Reviewing and updating your Will

Regularly review and update your Will. You may want to make changes, for example, if your relationships change, a beneficiary or executor dies, or something changes about your assets. You should make a new Will if you get married, separated or divorced. Store your Will safely and make sure your family and executor know where it is.



Brain Tumour
Information Sessions 2013

Brisbane

March

Date: Tuesday, March 26
Time: 8.30am – 11.30
Topic: **Brain tumours in adolescents and young adults**
Venue: Princess Alexandra Hospital

May

Date: Tuesday, May 21
Time: 10.00am – 11.30
Topic: **Depression and anxiety after diagnosis of a brain tumour**
Venue: Cancer Council Queensland

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 – 12.00
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

March

Date: Monday, March 25
Time: 5.30 – 7.30pm
Topic: **Using art as a coping strategy**

June

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

September

Date: Monday, September 16
Time: 5.30 – 7.30pm
Topic: **TBA**

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, May 3 – A Brain Tumour Forum for health professionals
An all-day forum for health professionals working in the area of neuro-oncology will be held in May. The day will aim to; provide insight into the patient journey following diagnosis of a brain tumour; to highlight the importance of supportive care provision and care coordination; as well as providing an excellent networking opportunity.

Saturday, June 1 – Survivorship Forum for patients and carers
An all-day forum on survivorship, for those affected by all types of cancer, will be held in June. The focus of the day will be on life after a cancer diagnosis, and cover topics including; managing late effects of treatment; fear of recurrence; sexuality; and the financial implications of cancer.

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: All these events 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.

Information Sessions & Forums

Listen to podcasts

You can find our brain tumour pod-casts at Cancer Council Queensland's website www.cancerqld.org.au. The pod-casts listed here were audio-recorded at Information Sessions & Forums held in Brisbane in 2012:

Brain Tumour Information Sessions

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

Brain Tumour Forums

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

The BCAW Forum in Brisbane – May 10, 2012

Topic: **An overview of brain tumour types and surgery**
Presenter: Dr Lindy Jeffree, Neurosurgeon

Topic: **Chemotherapy and clinical trials for brain tumours**
Presenter: Dr Kate Cuff, Medical Oncologist

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

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.

Brain Tumour Support Group Self Help (telephone or face-to-face)

This independent support group calls themselves "A motley crew of people with brain tumours. We provide a quiet, friendly, comfortable social environment where we can exchange our personal stories, concerns, useful information and discuss insights for living with brain tumours and their aftermath."

The group meets from time to time for morning tea at the PCYC, 90 Klumpp Road, Mt Gravatt in Brisbane.

For more information, and to find out when the next meeting will be held, contact Bill on (07) 3372 4164.

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.

Cancer Council
Queensland

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.

☎ (07) 3376 2083
Sue Kozik, Director,
Australian Pituitary
Foundation Ltd

💻 qld@pituitary.asn.au

Beyondblue: the national depression initiative

beyondblue works to raises 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), Disability Services Queensland A free, state-wide information and resource service. DIAL can provide information about different disabilities and information about services for people with a disability.

☎ 1800 177 120

💻 dial@disability.qld.gov.au

💻 www.disability.qld.gov.au

Disabled Parking Permit, Queensland Transport

☎ (07) 3253 4071

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

Griffith University

School of Psychology
Making Sense of Brain Tumour Project
This project aims to develop and evaluate a counselling and rehabilitation program for supporting adjustment to brain tumour. 10 weekly sessions of counselling and rehabilitation are provided in your own home by a qualified psychologist. This program is currently only available to people who live within approximately 1 hours drive of Brisbane – there are plans to extend to areas outside of Brisbane with counselling provided over the telephone. Examples of support include:

- Education about the brain and effects of brain tumour.
- Individual, couple and family adjustment counselling.
- Rehabilitation strategies for managing changes in thinking abilities and behaviour.

☎ (07) 3735 3304 (Mon - Wed)
Ea Stewart
💻 ea.stewart@griffithuni.edu.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

Open Minds

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

☎ (07) 3891 3711

Support services for people affected by brain tumours continued

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
💻 relaxcentreofqld@powerup.com.au

Self Help Queensland

Information about self-help groups available throughout Queensland.

☎ (07) 3344 6919

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 though 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

TADQ

Technical Aid for the Disabled Queensland provides reliable, good quality refurbished computers at very affordable prices to people with disabilities.

☎ (07) 3216 1733

Taxi Subsidy Scheme, Queensland Transport

☎ (07) 13 23 80
💻 www.transport.qld.gov.au

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 Oligodendroglionas): 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 – Sterotactic 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 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

Cancer Voices Australia (CVA)

Cancer Voices Australia seeks to advocate on behalf of people diagnosed with cancer and provides a national, independent "voice" for people affected by all types of cancer (including brain cancer), linking with state Cancer Voices. CVA works collaboratively with the Federal Government, Cancer Australia, Cancer Councils, the Clinical Oncological Society of Australia, other clinical bodies and key stakeholders. Their objectives are:

- To effect improvements in cancer treatment, care and support by contributing to national cancer policy and program development, management and evaluation
- To promote the value and benefits of consumer participation in the development of national cancer policy and programs
- To provide a forum for member organisations to network and contribute to national activities

Cancer Voices Australia (CVA)
Website: www.cancervoicesaustralia.org.au

Cancer Voices Queensland (CVQ)Website:
www.cancervoicesqld.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

Cancer Council Queensland

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

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