

Dear Friends,



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

Welcome to this the first edition of the newsletter for 2014. I must wish you all a very Happy New Year and hope you had a happy, healthy Christmas. My family had a lovely time at Christmas – all the family were together and we all enjoyed it. My granddaughter Tamara and her partner Tom of nine years decided to get engaged – all of a sudden Tom was down on one knee asking her to marry him, so out came the champagne to celebrate such a very special occasion. Wow, it was really lovely! I did ask when the wedding was to be and was told maybe another nine or ten years – I said they had better hurry up or I might miss it!

Moving on, let's take a look at this edition of the newsletter, which is devoted to palliative care. You may ask what that is? To explain, there is an article about palliative care plus another from a palliative care specialist. Briefly, living with someone who has a terminal illness is very challenging both for the carer and the rest of the family. They often require specialist support and help, maybe even respite for a couple of weeks. Palliative care supports your needs, medically, and physically, providing bereavement support plus a range of other services for the client and the family so is a very vital support service.

Also, Gavin has written us a wonderful update on his progress. Thank you so very much Gavin, it is really great to hear how well you are doing. I love the way you write so humorously about such a serious health issue. You are a very special person Gavin to have survived four brain surgery operations the way you have. I love the photo you included with that bird of prey...is it a falcon? Please give my best wishes to your wife and daughter.

If anyone else can give us an update on their progress we would love to have it! Try to put fingers to pen and paper or to computer keys – that would be great.

Of course there are also all the usual updates about events and services at the end of the newsletter too.

Till next time hope the weather stays a little cooler for us, it has been so hot over December and January.

Keep smiling and happy reading.

Anne.

Thoughts for the month:

"Memory is the diary we all carry with us."

~ Oscar Wilde

"Success is the ability to go from one failure to another with no loss of enthusiasm."

~ Winston Churchill

Index

- 3 My Story – Gavin
- 5 Meet a Palliative Care Specialist
- 6 About Palliative Care
- 8 Kids Konnection – from Brainchild
- 10 What counts as a ‘successful’ outcome?
- 14 Brain Tumour Information Sessions 2014
- 15 Making Connections
- 16 Services of CCQ
- 19 Support Services for people affected by brain tumours
- 22 Useful resources
- 23 About brain tumour awareness

About the Brain Tumour Support Service

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

What the service provides:

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

For more information visit Cancer Council Queensland’s website at www.cancerqld.org.au

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 – Gavin

G'day Everyone,

Having lived with a brain tumour for many years now, life has been a bit of a rollercoaster to say the least. And recently I was having a bit of a mid-life crisis, which I'm thankful to be having given my medical history, and was thinking about what makes me special. I mean what have I actually achieved in my life? And by way of comparison I thought back to when I finished school and shared a caravan with a couple of guys from school at schoolies...as you do.

Now one of those guys, Jesse, went on to become a Producer on that "Survivor" show on TV. For the last decade he's travelled the world scouting the locations, has appeared on the show as a judge and even been nominated for an Emmy, so that's pretty special. The other guy John went on to become the drummer in this local pub band made good called Powderfinger. So that's pretty special too. And I realise that what makes me special is I've survived brain surgery four times! And I know what you're thinking – of those three kinds of special, one of them isn't jumping out at you!

But while Jess and John lived their dreams mine was more of a nightmare. I can remember the day I was first diagnosed like it was yesterday. I'd been having headaches for years so ended up being sent for a scan at the hospital. After the scan I was told it had picked up an irregularity and that I had to go see a specialist immediately. I went white with fear because I know how long specialists can take to get into see and seeing the fear on my face and in trying to comfort me they said "Try not to worry, we're quite optimistic". Now if you're being rushed off to see a specialist after having a scan you



know something is up so "Try not to worry, we're quite optimistic" translates to "Start worrying, you're going to die!"

But they wouldn't tell me what was wrong so on the way over to the specialist my mind went through all the things it could be. The possible things like it was an aneurism; the impossible things like the specialist might be short of a partner for golf on the weekend; and the obvious being I had a brain tumour. I mean what else could it be really?

So a short time later I was in the specialist's room and he pinned the scan up showing a large picture of my brain. Now what was nice was the amount of brain matter that was there. I mean I'd done some sensationally stupid things over the years to that point. For example, I once crashed a car whilst trying to work out if the spider on my windscreen was on the inside or outside. The insurance company people called me Spiderman...I kid you not. Not so smart really.

My Story – Gavin continued

Anyway so we're looking at the scan and what wasn't so nice was the big circle in the middle of my brain that clearly wasn't meant to be there. My specialist then got a very serious look on his face and said "Well what you have is a brain tumour". Brain tumour? I thought we were going for a game of golf?? Now someone was cheating! How could I have a brain tumour? My specialist then said he didn't think I would die and didn't think I would get brain damage. And I'm like, dieing? Brain damage? What happened to take two of these tablets and see me in the morning if the pain persists? He then said I needed to go straight to hospital for brain surgery, which makes you think of all the times someone uses the phrase "it's not brain surgery". And now here I was sitting in front of a guy who looked more like an accountant and he was saying "Guess what? This time it IS brain surgery!"

He then asked if I had any questions. So I thought I'd man up and ask him if he thought it was a large tumour? He paused and then said he'd seen larger. And I'm thinking "No pauses please. Just come straight on back and say it's a tiny little tadpole of tumour!" But it wasn't and the next thing you know I was in hospital. It was like I was playing monopoly. Do not pass GO. Do not collect \$200. Go straight to hospital for brain surgery.

I was in hospital for a little over three weeks in which time my surgeon performed three operations and to cut a long story short I survived...I mean these guys are brilliant at what they do and are the top of their field so you are in safe hands. I'd had two operations to insert shunts on both sides of my head to relieve the fluid and the third operation was a biopsy of the tumour which showed it to be low grade malignant.

Because of the location of the tumour, in that it's a very difficult place to remove without affecting all my walking and talking and breathing bits, they decided to monitor the tumour and only operate when there was no other option. My specialist said my life would be shortened and when I pressed him for a time frame he said it could be five years, or ten if things went well, or how long is a piece of string? It all depended on how quickly the tumour grew. But before I left he gave me the best bit of advice I've ever received and that was that "Attitude is everything".

So I went home to recover and adjusted my lifestyle, lived healthier, took stress out of my life, read up on positive thinking. All the sorts of things you might do to improve your chances. After three months I went back for a check-up and the tumour had not grown substantially. And six months after that it still appeared to have not grown much, if at all. And 12 months later it appeared to stabilise. My specialist wasn't sure why, but neither of us was complaining. And this went on for another seven years until my specialist said I should just get check-ups with my GP and come back if there were any problems.

So everything went along swimmingly (except for the fact I just about glow in the dark from all the CT scans I've had) until two years ago when my latest CT scan showed a large fluid build-up again. It was a huge shock after such a long time with good results and needless to say it was very worrying but I tracked down my surgeon who first operated on me and went and saw him in Brisbane. When he saw me he looked at my latest scan and then looked at my original scan and diagnosis from 18 years ago and then looked at me and

said "You've done very well to be here". And I said "I know, traffic was a nightmare on the Bruce Highway!" But seriously, he was genuinely surprised to see me and said I was doing very well given the type and grade of tumour on the original diagnosis. As for the fluid build-up the good news was it turned out I had a blocked shunt. The bad news was I was off to hospital for brain surgery number four. And you can join the dots about how well that went by the fact I'm writing this story.

At my recent check-up late last year the scan showed the shunts were working well and the tumour had not grown. It has my specialist perplexed. "Good perplexed" he said. He's unsure given the grade of tumour how it has not grown, although there is historical evidence of this happening in a small percentage of cases. So he sent me on my way again and I don't have to go back to see him for another three years. So to quote Jimmy Hendrix, "Excuse me while I kiss the sky!"

It's now over 20 years since I was first diagnosed and although I still have the tumour it has stopped growing. And I guess for any of you early on in your cancer journey I can truly say there is always hope. When I was diagnosed at the age of 21 and given my original prognosis I was hoping to make it to my 30th birthday – I'm now 42. And I'm by no means anything special, there are many survivors out there who have had it a lot worse than I have and have come out the end of a cancer journey with an amazing story of survival. So if you are recently diagnosed, you need to find a way to be one of those survivors.

Best regards,
Gavin Grant

Meet a Palliative Care Specialist



Dr Carol Douglas, Clinical Director, Palliative Care Service, Royal Brisbane and Women's Hospital talks to the Brain Tumour Support Service about palliative care services.

Q: Dr Douglas, what led you to specialise in the area of palliative care?

A: For a number of years in the mid-1990's I supported my husband as he led major construction projects in Asia. On our third secondment starting in 1996, we were living in Kota Kinabalu, Sabah for the construction of a major water storage dam for the city. I was asked to provide support to the Palliative Care Unit at the local government hospital, the Queen Elizabeth. This was in essence the first unit for all of Malaysia and established by the inspirational Chief Government Surgeon of the time, Ranjit Mathew Oomen. With the vast majority of village people presenting with cancers too advanced for curative management there was a need to do more. He had undertaken post graduate studies in Palliative Care through the University of Wales, with Professor Ilora Finlay, and then went about training nurses in the unit.

A couple of years later, I found myself providing firstly a four wheel drive vehicle to access more remote villages to support the nurses, and then later direct clinical care in the unit.

During a two year period, I also undertook the post graduate degree from Cardiff, Wales and Professor Finlay and Dr Ranjit became my mentors. Returning to Australia, I completed my training and started working as a Staff Specialist at the Prince Charles Hospital.

Q: What is most important to you about working in palliative care?

A: During the time spent caring for a patient and family, there is a sense that this is a very privileged role that is intimate in relationship and results in greater satisfaction for patients and families struggling to cope with end of life. The type of care provided allows the clinical team to focus on the person and his or her values that help determine choices at this time. This is in contrast to disease focused care. This is very satisfying. It is wonderful to be part of a larger team, with each member contributing uniquely to care. There can be a sense of urgency, especially if the patient is imminently dying, that means getting the care 'right' and ensuring it is tailored to the unique needs of a patient and family.

Q: What benefits can palliative care offer patients and their families?

A: Excellent palliative care demands very close attention to detail in the assessment and management of any symptom including pain and depression. Understanding the social circumstances of a patient may identify early that there are specific carer risks that can be anticipated and plans put in place to avoid crises. Ensuring that there is continuity of care and palliative needs are met regardless of location and complexity requires the development of a good and trusting relationship with the patient and family. This is more likely to be achieved through an early referral. Advance care planning and a knowledge of what a patient and family want for end of life

care can be openly discussed and time in hospital minimised, if this is appropriate, so as to spend "precious" time in the community.

Q: What's the biggest myth you'd like to dispel about palliative care?

A: There is a myth that palliative care is about giving enough morphine until someone dies. Palliative care never intends to shorten life. Palliative care is not a form of passive euthanasia. Palliative care supports a good death but is focused on maximising the time for living.

I want people to understand that palliative care can support patients from the time they learn that their disease is incurable. The needs of patients are varied and complex, from addressing psychological distress, to controlling symptoms, to finding more support for a carer. Some patients will only need to see their palliative care doctor when there is a problem their GP or specialist cannot manage.

Q: How can a patient get a referral to the palliative care team?

A: A referral to your local hospital palliative care service can be requested by your GP or by your treating doctor in the hospital. Any patient can request a palliative care review.

Contact details for the Palliative Care Service at the Royal Brisbane and Women's Hospital

Royal Brisbane and Women's Hospital Palliative Care Service
Monday to Friday, 8.00am to 5.00pm
Phone 07 3646 6138
After hours 07 3646 8111
Fax 07 3646 6137

About Palliative Care

This edition of the Brain Tumour Support Service newsletter has been prepared to help you, your family and carers understand more about palliative care. The aim of palliative care is to enhance your quality of life and support you to maintain your independence as long as possible.

The way palliative care services are delivered varies across Australia. For specific information, contact your treating medical team, the palliative care team at your nearest health service, your GP or our Helpline on 13 11 20.

Q: What is palliative care?

A: Palliative care allows people with advanced cancer to maintain their quality of life in a way that is meaningful to them. It also provides support to families and carers. The role of palliative care is to:

- Help you achieve the best quality of life that you can for as long as possible.
- Make sure your physical, practical, emotional and spiritual needs are catered for.
- Help you feel in control of your situation and make decisions about your treatment and ongoing care.
- Make the time you have as valuable as can be for you and your family – not prolong or shorten life.

Q: Does it mean end-of-life care?

A: Palliative care is about living for as long as possible in the most satisfying way you can, within the limits of your illness. It's not simply about dying. While some

people may only use palliative care services for a few weeks or months, the number of people receiving care for several years is increasing. Because improved treatments can help stop the spread of cancer and relieve side effects, cancer may be considered a chronic (long-lasting) disease. You can have palliative care while you are having active treatment. One reason that some people don't access palliative care services early – or at all – is because they have the fear or misconception that by doing so, it will mean they have given up hope or are going to die soon. The reality is that some people do die from cancer. As people draw closer to death, the end-of-life care aspect of palliative care becomes important.

Q: How can palliative care help?

A: The palliative care team is there to help make life easier for you, your family and carers. Besides the specific medical and support services that palliative care offers, there are many general benefits:

- If you're home, the team helps to keep you out of hospital by regularly checking on you, either by phone or house visits.
- Your care is coordinated by someone, usually a community or palliative care nurse, who communicates with the team on your behalf.

- Communication with the palliative care team may help reduce feelings of isolation or not being able to cope, and it may help your family look after you.
- Learning how to make adjustments around the house can reduce stress for both you and your family.
- The team can help you plan for the future, such as the type of care you may need and where you will receive the care.
- Many palliative care services offer a free 24-hour hotline to offer support and information after hours and on weekends.

Another aspect of palliative care is giving you and your family emotional support. Your team can talk to you about any needs or desires that you may have, and can help you achieve your goals.

Q: When can I access palliative care?

A: It's advisable to access palliative care as early as possible, even if it's just to make contact with the palliative care team. You can find out what the different team members do and which services might be relevant now or in the future. Being able to deal with problems earlier rather than later will help reduce stress on you and your family.

Q: Who will organise my care?

A: The way you receive palliative care depends on your situation:

- Your primary health care provider, such as a GP or a community nurse, may coordinate your palliative care.
- If your needs are complex and beyond the scope of your primary health care providers, you may be referred to a specialist palliative care team. Your GP and community nurse will continue to be involved.

Q: Where do I receive palliative care?

A: You can have palliative care in different settings depending on your situation, where you live and the support available to you (e.g. if you have family or friends who can help). Care can be provided at home or in an aged care or residential care facility, palliative care units, hospitals or hostels. Patients can move between these settings if their needs change.

Q: Will I still have medical treatment?

A: Medical treatment for palliative patients is an important part of care. It aims to manage the physical and emotional symptoms of cancer without trying to cure the disease. Some examples of palliative medical treatment are:

- Radiotherapy to reduce pain if cancer has spread to the bones.
- Chemotherapy to stop the cancer growing into other organs.
- Medication to relieve constipation, nausea or pain.
- Medication for depression, anxiety or insomnia.

Q: Will I lose my independence?

A: The palliative care team gives you choices to help you remain independent for as long as possible. An example is getting a ramp installed at home so you don't have to use the steps. The team respects your wishes if you don't want to take up their suggestions.

Q: Do I have to pay for palliative care?

A: The Federal, State and Territory Governments fund core palliative care services so that they are free in the public health system, whether you receive care at home or in a public setting. However, sometimes you may

need to contribute to the costs of care. Some examples are:

- Hiring specialised equipment for use at home.
- Paying for your own nursing staff if you elect to stay at home and require 24-hour assistance.
- Paying for complementary therapies, such as massage therapy.
- Paying an excess if you have health insurance that covers palliative care and you got to a private hospital.
- Accessing respite services that may charge a small fee.
- Paying a dietician's fee that isn't covered by a Medicare rebate.

Finding hope

Sometimes people don't access palliative care services because they hope that a cure will be found for their cancer. You may also find that your primary health care provider, such as your GP, is reluctant to talk about palliative care because they don't want you to think that they have given up hope. However, you can still benefit from palliative care without giving up hope. People can have palliative care for several months or years and continue to enjoy many aspects of their life. You may take pleasure in various activities, such as doing small projects, talking to friends, or exploring new hobbies. You may find that a creative activity, such as writing or art, allows you to record your feelings and helps you to make sense of your changed situation. As your disease progresses, you may hope to live as comfortably as you can for as long as possible.

This is an edited extract from "Understanding Palliative Care", Cancer Council NSW. For further information or support, contact our Helpline on 13 11 20.

Kids Konnection BrainChild

When a child is diagnosed with a brain or spinal cord tumour, family and friends experience a vast array of emotions as a result of the news. Often chaos reigns as people are desperate to make sense of the situation, and all are concerned with the prognosis of that child's condition. In many cases, a diagnosis is followed by a period of treatment with a view to recovery, friends and family remaining cautiously optimistic, able to maintain a positive and upbeat demeanour which is of tremendous support to that child and their immediate family.

There are cases, however, when a diagnosed child's care is deemed to be palliative. The child may have received previous treatment for their condition, or the child may be newly diagnosed. Whichever may be the case, the news that a much loved child's care is palliative impacts greatly on the way in which family, friends and associates react.

The Child

Children don't seem to appreciate their own mortality the way adults do – and why should they? Children have hopes, dreams and plans for their future. That need not change in the face of palliative care. Children are very perceptive and take their cues from those around them. If family and friends are visibly distressed by the situation, it is reasonable to expect that the diagnosed child will have cause to be fearful also. As difficult as it is to display positive emotion when we are hurting so badly within, it is necessary in maintaining the child's positive attitude.

There are times when the question arises as to whether a child should be informed about their prognosis. This is a very personal decision to make. Careful consideration must be given as to the child's age and maturity. Are they likely to understand? If it is not a topic that they initiate, is there any

reason to discuss it? Is there any emotional benefit to the child by being informed? The same applies to siblings of the diagnosed child. Siblings may be older or younger, and depending on their age, may need varying levels of explanation given as to the prognosis of their brother or sister. It is very important for families not to negotiate these topics alone. Consultation with the child's health care team is imperative to ensure the emotional wellbeing of everyone concerned is maintained.

Parents

For any parent, the thought of their child falling ill is unsettling. The more serious the diagnosis, the more overwhelming it can be. For a parent to be told that their child's care will be palliative is simply incomprehensible for most.

It is normal for parents to experience grief long before the passing of their child. That grief will last a lifetime and manifest itself in a many ways – every individual's experience of grief is unique. For this reason, it is beneficial for parents to seek support not only from family and friends, but also from the health care team and associated support groups. Whilst family and friends can offer a tremendous amount of practical and emotional support, there are times when further assistance is needed.

It is hard enough for a parent to break the news of their child's tumour diagnosis to others. Sometimes just holding back the tears to find the words to talk with people is a difficult task. Trying to share the news of their child's treatment being palliative can be near impossible.

It is worth considering asking a close family member or friend to inform other people of significant developments related to the child's care. They may be able to share news and updates with members of the family's extended community groups – school, sports clubs, church etc. on behalf of the parents. It can be exhausting to continually retell your child's story countless times over to concerned people, so enlisting the help of a spokesperson to pass on that information eases some of the emotional strain.

Friends

Friends are obviously a wonderful source of support and compassion for a family facing the impending loss of their child. It is vital for friends and associates to maintain contact. Some people do not know what to say and so avoid the family for fear of saying the wrong thing and upsetting them. What needs to be understood is that it is a stressful and uncertain time for the child's family and expressing grief is a normal part of



that experience. Parents will want to talk about their grief and it will upset them at times.

On the other hand, some friends may be so desperate to assist that they become overbearing. They feel compelled to provide support in excess of the family's needs. Whilst kind gestures such as cooking, gardening, childminding of siblings etc., are often welcomed, such assistance should only be provided after consultation with the family.

The Family

It is natural to want to spend as much quality time with a family member whose care is palliative, creating memories that will be cherished for years to come by those who are left behind. This desire is probably even greater when that family member is a child.

Considering a child's relatively short life, it is important for families to make what remaining time they have worthwhile. Some parents are able to take extended leave from work to spend time with their child. Some families arrange to take the dream holiday they had been putting off. Whatever a family decides to do in the remaining time they have together, the important thing is to not count the days, but make the days count.

Different people have different coping mechanisms, and whilst it is of utmost importance to spend time together, all family members need their own time as well. Whether that time away from the family is spent at work, at social events or alone, it allows individual family members an opportunity to express their feelings, focus on unrelated topics and generally gather their thoughts to help maintain their emotional wellbeing.

Whether you are a parent, family or friend of a diagnosed child whose care is palliative, it is important to remember that you play an important role in the final chapter of that child's life. As upsetting and overwhelming as the situation may be, death is a normal part in the cycle of life. Our lives may be long or a short, and whilst we may influence our lifespan to some degree by the lifestyle choices we make, at some point for all of us, it will come to an end.

No one would argue the sense of injustice felt when a child passes away. It raises more questions than it answers, but one thing is for certain – your thoughts, actions and words will impact greatly in making their final chapter as satisfying as possible.

For further support or information to help you during your child's journey, contact:

BrainChild: info@brainchild.org.au

Paediatric Palliative Care Service,
Royal Children's Hospital:
Phone 1800 249 684 or email
PPCS@health.qld.gov.au

Bereavement Support Program,
Royal Children's Hospital:
Phone 1800 080 316 or email
bereavement.ppcs@health.qld.gov.au

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.

What counts as a ‘successful’ outcome? By Simon Crompton

Every patient wants to be cured. But a culture that defines success as ‘cure’ condemns many patients and doctors to failure. Should the cancer community be looking to broaden the concept of success to better reflect how well care plans deliver the best possible outcome tailored to each patient’s personal priorities? What does treatment ‘success’ mean in cancer? Does it only mean curing the cancer? Or controlling it? Extending life? Or providing a good quality of life, even for a short time?



How we define success and failure is important because it has a profound impact on the goals that patients and their doctors set themselves and the experience of the cancer journey. Developing a shared understanding of what success means is also essential for informed public debate about the value of different interventions in different settings and how to get the best outcomes from the resources we have.

Roger Wilson, who has lived with sarcoma for 13 years, has pondered deeply on these issues. He says there

is an urgent need for the cancer world to address the cultural influences that affect treatment decisions in advanced cancer: “We need to look at the patient demand for a ‘right to live’, the medical attitude that ‘success equals cure’ and the funder’s view that a dying patient is just a financial burden,” says Roger, who is a founder and President of Sarcoma UK.

Somewhere, amid these influences, what’s right for the individual can get lost. Perspectives from patients and family on these issues provide a

rich vein of insight for professionals and policy makers. In all their variety, they offer a central message: for a treatment to be ‘successful’ patients and their families must be properly engaged.

Negotiating expectations

Kathy Oliver says that when her son Colin was diagnosed with a brain tumour in 2004 at the age of 24, her only measure of success was cure. “I didn’t know any better then,” says Kathy, who is co-director of the International Brain Tumour Alliance.

When the diagnosis was given to us, we were sitting in a tiny room in a London hospital, but we may as well have been sitting on a planet in outer space. We had no map, no compass, no anchor to steady us. In our naïvety, we believed at that stage that treatment success could only be measured in terms of cure: we anticipated that neurosurgery would remove nearly all the visible tumour, followed by radiation that would eliminate every last cruel cancer cell, and then chemotherapy to guarantee a long and healthy life. Unfortunately, it didn’t work out like that.”

“As my son’s journey progressed, and his tumour’s level of malignancy did too, each successive treatment carried with it a different measure

of success and expectation. With each treatment stage, the successes became more modest, but at the same time the availability of each treatment represented renewed hope.”

Annemie Spaak (not her real name) from Belgium, diagnosed with multiple myeloma in 2002 at the age of 37, tells a similar story of revising expectations. Since it is a disease “that doesn’t go away”, she says, patients often have a lasting relationship with their doctor, with treatment options being constantly discussed and renegotiated.

“My idea of success has definitely changed over time,” she says. “After my diagnosis, we discussed whether I should have more aggressive treatment which would extend life, or softer treatment that would give me better quality of life. At that stage, I was ready to go for the aggressive treatment – to go as close to a cure as was possible, because I had just given birth, had two young children, and I wanted to be with my family for as long as possible. But then I realised quite quickly that a cure was not going to happen, and once you accept this, you reset your definition of success. Now success means reaching certain milestones, to get the children through adolescence, and now to bring them to graduation.

“For someone over the age of 70, the objectives might be very different,” says Annemie. “And people late on the journey sometimes say they’re fed up with treatment and just want not to suffer and to be with their families.”

Expectations, and thus definitions of success, are also heavily shaped by cultural and social influences, says Luzia Travado, head of the psycho-oncology unit at the Champalimaud Cancer Centre in Lisbon, Portugal. Patients with advanced cancer who come from lower socio-economic groups tend to be more passive recipients of care, she says. Their

expectations of treatment ‘success’ may be far less ambitious than better educated patients with higher incomes, who tend to want more control, and push more not only for a right to live but a right to a good quality of life.

What doctors do will be partly defined by this. Those working with higher socio-economic groups are more likely to propose active treatment towards the end of life.

“There are some patients who want to control, and some who are happy that the doctor controls,” she says. “But if you want properly responsive health systems, you have to keep asking people questions, whichever group they fall in, so that they can be involved if they want to. That doesn’t always happen.”

Buying time

The question of when active treatment should cease will always be difficult to negotiate, but with health services operating under ever tighter cost constraints, many patients now feel they are being denied a worthwhile shot at achieving a valuable added few weeks or months not because their expectations are unrealistic, but because they are considered unaffordable.

Bettina Ryll, whose husband Peter died of melanoma in February last year after treatment in Sweden and the UK, is one among many representatives of cancer patients who worry that, despite high-level debate about ‘best’ treatment towards end of life, what actually happens is often dictated by economic considerations.

She has watched with interest as academics and policy makers have grappled with the cost of new cancer drugs, and she stands alongside the many patient groups who criticised the 2011 report of the Lancet Commission on cancer costs. This claimed that giving expensive care to patients during the last weeks of life is ‘futile’

“Expectations, and thus definitions of success, are also heavily shaped by cultural and social influences, says Luzia Travado, head of the psycho-oncology unit at the Champalimaud Cancer Centre in Lisbon, Portugal.”

and argued that too many of the new cancer treatments only extend life by a few weeks.

“Terminally ill people are members of society too,” says Bettina, who jointly founded the Melanoma Independent Community Advisory Board – an international network and resource for people affected by melanoma – in 2011. “They have paid into their health system, have made their contribution to their health care, and as a society we have a duty to honour that. I think it’s shocking to see how, suddenly, people who are no longer in the ‘healthy club’ are considered not worthy of receiving any more from the health system.”

Bettina, who trained as a doctor herself, questions how far doctors really understand what a few extra weeks can mean to families, and she rejects the way active treatment tends to be counterposed to palliative care, arguing that treatments that extend life can also improve the quality of life.

“Peter’s melanoma was extremely aggressive,” she says. “It was diagnosed in February and by April the tumour had encased his whole arm so that he couldn’t move it and it was very painful. We didn’t expect him to see the summer.

“Then he went on a trial for a new drug and the tumour regressed – so much so, that he could even start

rowing again. He died in February last year, so being on that drug bought us nearly a year. I remember thinking, before he went on the trial, 'What's the point of another month or so?' But it gave us a chance to adjust, to say goodbye, to give our two daughters a chance to prepare, to get things in order. I think that year was the most valuable year of my life."

"As healthy individuals, I think we underestimate the value of time for the person with cancer and their family. A month can be the equivalent of a year if you have limited life expectancy."

"Of course, the experience of each family will be very different. Treatment plans will be influenced by the nature of the disease, its stage, and according to the character, socio-economic background, circumstances and wishes of the patient."

Something to hope for

Kathy Oliver stresses that encouraging realistic expectations must be tempered with giving patients and their families something to hope for. If there is nothing to hope for there can be no hope of success.

"I wish that in the early days of my son's diagnosis we had not faced such nihilism from some of the medical professionals we met," she says.

"We often think of successful treatments that are either swallowed, injected, zapped or surgically performed. But to be given hope

is just as important a treatment, and brings benefits not just for the patient, but for the family too. I cannot stress enough how important it is to maintain hope for patients facing devastating diagnoses.

"I know that in my son's case, when there were no more surgeries, no more chemotherapies, no more radiation to be done, he still insisted that there was a plan for him. He kept receiving experimental therapy until the day he died, and in the last days kept reminding us not to forget to give him his treatment. Was the treatment futile in terms of medical benefit? Yes, it probably was. But what was important to my son, and also to us, was that there was a plan even towards the end."

Of course, the experience of each family will be very different. Treatment plans will be influenced by the nature of the disease, its stage, and according to the character, socio-economic background, circumstances and wishes of the patient. With all those variables, doctors have a task on their hands when it comes to managing expectations while keeping hope alive.

Towards personalised measures of success

Roger Wilson says that a way forward is to provide doctors with "prognostic/risk assessment tools" that will give them the means to look at living with cancer in a rounded manner, not just in terms of medical treatments. This kind of personalised approach could yield a new integrated idea of treatment success for each patient.

"Such tools could be based on biological, behavioural, social and psychological markers: 'this patient will do better if treated this way, another patient will need treating another way, and a third yet another way' – even when clinically they are at the same stage with the same

disease. Each treatment may involve lifestyle elements, would draw in expertise from non-cancer healthcare specialists, and would include practical support tuned to the needs of patients' families."

There have been tentative steps towards this kind of patient-centred research, he says, and it would sit very neatly with personalised cancer therapy approaches. "If we could reach the two objectives together, that would be a genuinely new definition of success."

For Annemie Spaak a good relationship with their doctor remains the key for patients to perceive their treatment as successful. "It's about partnership. I didn't feel on the same wavelength with my first doctor and felt very unhappy, but when I changed I could accept my situation much better."

However, a study published recently in the New England Journal of Medicine warns against jumping to the conclusion that a 'good relationship' necessarily improves the chances of patients achieving an outcome they perceive as 'successful'. Quite the reverse in fact.

The surprise findings show that misunderstandings about treatments and their objectives are more common, not less, when doctors and patients have a good relationship. The study, published in October last year, examined the expectations of 1193 patients receiving chemotherapy for metastatic lung or colorectal cancer. This can prolong life by weeks or months, or relieve symptoms, but does not cure. However, 69% of patients with lung cancer and 81% of those with colorectal cancer did not understand that chemotherapy was unlikely to cure their cancer. Surprisingly, perhaps, the risk of reporting inaccurate beliefs about the chemotherapy was higher among patients who rated their communication with their physician very favourably.

The implication is that the cost of a good relationship between doctors and their patients is an inability to face up to difficult facts – or at least a tacit agreement to collude in unrealistic expectations. The consequences of this may only come home to roost when patients and doctors are both faced with a sense of failure late in the cancer journey.

A planned and transparent transition

Bettina Ryll believes that altering the emphasis at medical school would go a long way. “At medical school you still have a rose-tinted view of how medicine saves lives, and maybe more could be done to demonstrate how palliative care is an important part of medicine too, and about the palliative ability of advanced treatments.”

Luzia Travado agrees that both patients and doctors find it difficult to acknowledge when cure is no longer possible. But it is up to the doctor to regulate expectations, right from the point of diagnosis. “It’s difficult,” she says. “Patients cling to any hope, and doctors want to avoid their patients getting too emotional. I’ve seen some patients who want to continue with their chemotherapy whatever the circumstances, because their coping mechanism is to not even consider the possibility of death.

“So it all depends on establishing a proper partnership and negotiating where you are heading at different stages. That’s why it’s so important that doctors are given the communication skills, and understand, for example, the SPIKES six-step protocol for delivering bad news.

“Patients need to be helped to understand that the doctor can do something for them at all stages, even if they can’t cure. Here, we have abolished the phrase ‘There’s nothing more I can do for you.’ If there isn’t open communication from the start,



patients and their families can easily feel frightened and isolated when the language doctors use changes, and doctors stop talking about ‘active’ treatment.”

Roger Wilson agrees with that prescription. But given the cultural influences that make it so difficult for doctors and their patients to look forward and discuss dying, he believes we have to look further than training time-strapped doctors. Healthcare systems need to plan for greater involvement from palliative care experts with psychological training from early on in the cancer journey.

“The truth is that we do not do communication well, but is unfair to look at it solely as a clinical problem best resolved by training cancer doctors better than we currently do,” he says. “Our healthcare systems have a general lack of will to support cancer patients with professionals who have had psychological training first and have then learned about cancer.

“A treatment approach which starts as curative but which recognises the ‘point of no return’ in a positive way would go a long way to challenging the current cultural influences on doctors and patients. The transition to palliative

treatment should be planned and transparent. Expert palliative support should be seen as constructive and introduced to the patient long before there is the recognition that curative treatments are no longer feasible. Those who die will not die as ‘failures’, while those who are ‘cured’ will have had a better experience.”

Such planning could redefine everyone’s ideas of treatment success, he says. And it might mean that people with cancer and their families are helped to make decisions that are better suited to them as life reaches its end.

“It might mean that a few more patients die a few days earlier than they might otherwise have done, but the whole family experience and remembrance of dying would be more positive,” says Roger Wilson. “That would also be a benefit to society.”

This article was first published in Cancer World magazine, Issue 54, May-June 2013, and is reproduced with permission. www.cancerworld.org

Brain Tumour Information Sessions 2014

Brisbane

May

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

July

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

September

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

November

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

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

Don't forget!

You can find many of our brain tumour podcasts at Cancer Council Queensland's website www.cancerqld.org.au



Would you like to share your story with us?

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

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

Brain Tumour Support Service
Email: janinerhodes@cancerqld.org.au
Phone: 07 3634 5307

Making Connections

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

Cancer Connect (telephone)

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

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

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

Brain Tumour Patients Telephone Support Group (telephone)

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

Any adult who has been diagnosed with either a benign or malignant brain tumour can join.

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

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

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 0422 784 885, visit their website at www.braintumourhelp.com.au or find them on Facebook.

Services of Cancer Council Queensland

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

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

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

Brain Tumour Support Service

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

Cancer Counselling Service

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

Cancer Council Helpline 13 11 20

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

Look Good... Feel Better Program

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

Practical Support Program of Cancer Council Queensland

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

Cancer Connect

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



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

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

Regional office contacts:

Bundaberg

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

Cairns

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

Gold Coast

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

Mackay

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

Rockhampton

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

Sunshine Coast

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

Toowoomba

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

Townsville

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



c·vivor
active cancer support

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

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

HAS CANCER CHANGED YOUR LIFE?

Help change the lives of others.

Share your story.

"The more that we know about the impact of cancer, the more that can be done to support those affected - your children, your partner, your parents, and of course, you."

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Too often, cancer survivors learn to 'just live with' the emotional, physical and practical effects of the disease because they can't find the right resources or support.

That's why Cancer Council Queensland launched the Survivor study. The more people participate, the better we can build programs offering tangible support to change the lives of Queenslanders diagnosed with cancer.

survivorstudy.org.au

13 11 20

Call if you require assistance



**SURVIVOR
STUDY**

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

Support services for people affected by brain tumours continued

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

Open Minds

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

☎ (07) 3896 4222

💻 www.openminds.org.au

Palliative Care Information Service

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

☎ 1800 772 273

💻 www.pcis.org.au

Queensland Acoustic Neuroma Association

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

☎ (07) 3397 3291

💻 www.qana.asn.au

Relaxation Centre of Queensland

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

☎ (07) 3856 3733

💻 relaxationcentreqlld.com.au

Self Help Queensland

Information about self-help groups available throughout Queensland.

☎ (07) 3344 6919

💻 info@selfhelpqlld.org.au

💻 selfhelpqlld.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/

Useful resources

Resources available through our Cancer Council Helpline. Call on 123 11 20 or helpline@cancerqld.org.au

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

Useful websites

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

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

Cancer Directory (Cancer Council Australia)
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)

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 2014 – Annual Brain Tumour Awareness Events

March 26
Purple Day for Epilepsy

April 27 - May 3
Brain Cancer Action Week

October 26 - November 1
International Brain Tumour Awareness Week

November 7
BrainChild Awareness Day



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

www.cancerqld.org.au