

BTAA newsletter

Special Edition - International Brain Tumour Awareness Week
27 October - 2nd November 2013



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Letter from the Chair

International Brain Tumour Awareness Week

Welcome to the Spring/Summer edition of BTAA's newsletter. Planning is well underway for **International Brain Tumour Awareness Week from 27 October to 2 November 2013**.

In brief, within this issue we reproduce a post from blogger **'Slummy Mummy'** that puts the spotlight on carers. **Mark Dalliston** provides an insight into the patient's view, and why caregivers can indeed be taken for granted. Sydney author and photographer **Cam Lavac** discusses his experience of being diagnosed with a brain tumour and feelings on end of life choices, to which **Denis Strangman** provides his response. These are controversial, important issues. Denis also outlines upcoming international conferences and urges Australian health professionals to attend.

I recently represented BTAA at the consumer consultation forum run by Cancer Australia to help develop their new five year strategic plan. Cancer Council CEO, **Prof Helen Zorbas**, pointed out that one in two men, and one in three women in Australia can expect to develop cancer. This concord's with my family's experiences. Describing survival rates over the past twenty years, she noted most had improved but that pancreatic, brain, and unknown primary were notable exceptions.

The breast cancer advocates in Australia have been working for over fifteen years as a cohesive, national whole, and held their first National Conference in 1998. As leaders for all patient/caregiver advocates, they provided BTAA with the inspiration to host a national summit in October, with the aim of reaching a consensus on a national action plan. The starting point for the priorities would be those identified by consumers and clinicians in 2012. They include:

1. Continue advocating for brain (neuro-oncology) care coordinators so that every newly diagnosed patient/family would have access to a 'navigator'.
- BTAA WILL continue to advocate for this as our number one priority.
- Very few hospitals in either the private or public system have access to a general, let alone specific brain tumour, care coordinator.
- The role is to support patients, carers and health professionals and make sure patients have support and are not lost in the system. To learn more about it, see care coordinator Alanah Bailey's You Tube video from last year: www.youtube.com/watch?v=c80AKvFDQns

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2. Strengthen patient support group alliances Australia-wide.
3. Translate vetted information into common non-English speaking languages.
4. Advocate for brain tumour clinical centres of excellence
5. Advocate for maintaining ongoing funding for existing research.
6. Obtaining additional funding for new research.
7. Improved grant reporting transparency, to track brain tumour specific grants.
8. Advocate that tissue banking be prioritised, and identify funding models.
9. Advocate for routine subsidisation of genetic markers to assist treatment options and clinical research.
10. Reduce the costs associated with treatment and rehabilitation.
11. Obtain home assistance care for young patients currently in aged care.
12. Increase access to PET imaging, trials and other new tracers.

In a silly 1980s movie called "Field of Dreams", Kevin Costner's character is informed that: "If you build it, they will come". What follows in that movie is entirely implausible but the statement, amended to he/she, is true of most things in life.

The US Congress recently took this step by passing a bipartisan bill, the Recalcitrant Cancer Research Act of 2012. It places the strategic focus of the National Cancer Institute squarely onto so-called 'recalcitrant cancers'. This is defined as cancers with 5-year relative survival of less than 50%.

Brain cancer/tumours fall into this category. There's a good argument that Australian Commonwealth, State and Territory governments should pass similar legislation. Contact your (re)elected Federal, State and Territory representatives and inform them that you like the look of the USA Recalcitrant Cancers Act of 2012, and would like to see a similar initiative adopted. If you have the energy and resources, take the plunge into hosting a fundraising activity, be it a walk, charity dinner, or otherwise. You could host a walk during 2013 International Brain Tumour Awareness Week, and join the global awareness effort while fundraising for existing or proposed brain tumour support/research efforts of your choice.

Long-term glioblastoma survivor Sarah Mamalai is the brain tumour community's own patient champion building long-term successes, with her Brainstorm for a Cure initiative next year on her 40th birthday. A recent highlight for cancer patients, caregivers, and referring health professionals seeking treatment services in NSW is the Cancer Institute NSW's 'Can Refer' website (www.canrefer.org.au). It is searchable by cancer type. BTAA held its Annual General Meeting on 22 September. My report to the meeting and a list of the committee is available on the BTAA website under "News". The volunteers that co-founded BTAA five years ago is still largely the same, but with valuable additions of other energetic survivors and caregivers, without which we could not provide anywhere near our current range of services. Just like treatment developments, developing effective organisations is a step by step process that takes time, but is always worth the effort and patience. I am confident BTAA is making a real difference to the lives of Australians. For those supporting BTAA in turn, on behalf of the committee I heartily thank you.

Matt Pitt. BBiotech(Hons), MPH.

Chair, BTAA

btaa.org.au

Slummy Mummy

What about the Carer?

"As you know my husband was diagnosed with a malignant brain tumour in June 2011. There is no denying it has been a long and difficult journey so far, particularly in the early stages. BUT thankfully we are now in the watch and wait stage.

The chemo has worked beautifully and has halted the tumour growth at this stage. My husband now has three-monthly MRI's and will have no active treatment until the tumour starts to show new growth.

How long we get before the tumour continues its growth is unknown - some patients have a few months, some a year or two, others maybe 5 years or more.

Life is slowly gaining back a routine for us. It will never return to what we knew as 'normal' but we are slowly developing a new 'normal'.

So now it is time for me to get selfish and ask what about the carer?

The Brain Tumour Support Service, Cancer Council Queensland have asked me to give a speech as part of a forum for health professionals. I will be talking about the impact a diagnosis of brain tumour has on the whole family from a carer perspective.

*"Life is slowly gaining back a routine for us.
It will never return to what we knew as 'normal'
but we are slowly developing a new 'normal'."*

Although in some ways rewarding, the one point I would ask people to understand is that a carers journey can be very isolating. I know from personal experience that the carer is often unintentionally forgotten.

For example when people ring me at home, or run into me in the street I get asked three questions:

1. How is your husband going? Is he feeling better?
2. How is your son going? Any problems with him being two months preemie?
3. How is your daughter? It must have been hard for her being so young?

It is maybe one person in ten who follows up by asking me how I am. I do not want to sound like I am complaining as I fully understand their concern is for the patient and any children in the family. BUT carers can often become the forgotten link in the chain.

Carers (whoever they are looking after - spouse, child, and parent) can often lose their own identity. Carers often have their life altered as much as the patient.

We often have to give up full time work or in some cases altogether. We may lose contact with friends as we cannot spend as much time with them as previously. We may also have to give up any hobbies or interests due to a lack of finances and time.

Carers can face as much of an uncertain future as the patient.

- It is the carer who lays awake in the middle of the night worrying about how to pay the mortgage.

- It is the carer who sees what the patient is really like in their worst moments.
- It is the carer who shelters the patient from negative comments by people who don't understand that with (brain) cancer there can come permanent personality changes.
- It is the carer who has a constant worry at the back of their mind, about how they will cope when the patient gets worse towards the end of their illness.

I appreciate that I am very fortunate to have this time with my husband. I could have lost him instantly in a car crash or something equally awful as many people sadly go through.



www.slummynotyummy.com

Knowing how lucky I am though, does not stop me worrying about the future. It does not stop me from being scared about how I and my children will cope when the going gets really tough.

There is a wonderful blog written by Denis Wright. He has a Grade IV GBM brain tumour and is slowly moving towards the end stage of his illness. He has written a wonderful post about the impact of his illness on his primary carer - his wife. In the post (link below), he shows how much he appreciates what his wife has been through as his carer. It is a beautiful piece of writing that totally resonates with me.

<http://deniswright.blogspot.com.au/2013/03/lets-get-practical-3.html>

Thank you for reading today's post. I would love to hear your thoughts on it and the role of carers in general.

See you tomorrow."

International conferences

By Denis Strangman, Chair, IBTA. BTAA committee member

I am writing this article before leaving Australia to attend the European Cancer Congress in Amsterdam during 27 September – 1 October where the International Brain Tumour Alliance (www.theibta.org) has a display which I will help staff.

There will be about 15,000 Doctors and others attending the gathering but I do not expect to run into any other Australians. Australian brain tumour researchers and clinicians on the whole do not appear to have close personal connections with

the centres in the USA, Europe and Japan, where the major brain tumour-related research is taking place.

Sometimes, experts are brought to Australia to make a flying visit, such as Dr Mitch Berger (USA) who will be attending the COGNO meeting in Sydney in October but Australians seem to be imprisoned on our continent by the "tyranny of distance" and probably a lack of funds.

When I attended the Asian Society of Neuro Oncology/ISNO conference of 500 people in Mumbai, India, in March there were just three Australians present – myself and Professors Mark Rosenthal (Vic) and Stewart Kellie (NSW), yet a majority of those present were our geographical neighbours.

Rather than see generous Australian donors just hand over the funds they have raised to be spent how Australian brain tumour researchers determine, I would prefer to see a proportion of donated funds earmarked for:

- (a) attendance by researchers and health professionals at important international brain tumour-relevant scientific meetings; and
- (b) research that explores the quality of life burden on brain tumour patients and their carers.

In regard to forthcoming conferences there are two that would be very relevant. In November the Annual Scientific Meeting of the US-based Society for Neuro-Oncology (SNO) will be held in San Francisco. Despite its US origins it is the de facto major international gathering for anyone who is serious about brain tumour research. There are several Australian clinicians who attend the SNO meeting regularly but only a very few allied health professionals have ever participated and they could particularly benefit from participating in the growing number of quality of life sessions. The attendance at SNO has been growing each year and the organisers are now looking at 2,000 people being present in November.

The second meeting is the biennial International Symposium On Paediatric Neuro-Oncology (ISPNO) which is being held in Singapore during 28th June – 2nd July 2014 under the Chairmanship of Professor Stewart Kellie (NSW). I attended the previous ISPNO conference in Toronto in order to staff the IBTA display and although I did not actually meet any Australians there I know that a handful of researchers were present because of the listed presentations. However, I am rather sure that there were no Australian paediatric social workers or nurses present, despite a number from other countries.

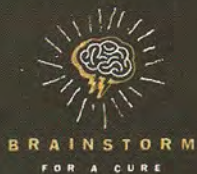
As with the SNO meeting, the ISPNO meeting is the place where anyone interested in paediatric brain tumour research and clinical practice gathers.

It would be great to see a much higher representation of Australian researchers and health professionals in Singapore in 2014. Do you know of a particularly skilled Australian paediatric oncology nurse specialist or social worker who might benefit

from attendance? If so, make some enquiries now about possibly supporting their travel.

PS. Just for the record – BTAA does not support my IBTA work financially in any way.

Sarah's Brainstorm for a Cure 8 February 2014



February 8, 2014 will be a very, very big day for Sarah Mamalai. Sarah was hoping to celebrate Sarah's 40th and Dainere Anthony's 16th birthday, both on 8

February 2014. Sarah and Dainere were 'soul sistas', having met at an ACT brain tumour support network meeting in 2008. Sadly Dainere won't be at the party, but she will be remembered at the "splendiferous party".

In May 2007 Sarah was 33 years old when she was diagnosed with a Grade 4 GBM. Her sons Joe and Will were 4 and 18 months. In May 2007, Sarah trekked Kokoda in May 2008 for Cure for Life. In 2010 she helped BTAA and beyond blue launch a fact sheet on depression and anxiety for brain tumour patients at Parliament House. In April 2012 she ran the Swisse Colour Run and backed it up in May 2012 with the Canberra Times Fun Run with her friends - the Mamalai Mamas – raising funds for Cure for Life. Now she plans to celebrate her 40th birthday in super style.

Please visit www.brainstormforcure.com.au for more details! BTAA is part of a committee that will help her pull off her big Brainstorm "Cocktails for a Cure and Hope". Sarah has a target of \$100K to support the Cure for Life Foundation, Ronald McDonald House, and BTAA.

BTAA is seeking donations of goods and services for an auction to be held in conjunction with Sarah's 40th. Please email secretary@btaa.org.au



International Brain Tumour Awareness Week

(27th October – 2nd November)



International Brain Tumour Awareness Week
27th Oct - 2nd Nov 2013

Brain Tumour Alliance Australia (BTAA) is the only national support advocacy organisation for brain tumour patient, family and caregiver in Australia.

Wear a hat for one day during International Brain Tumour Awareness Week to raise funds to help support those affected by brain tumours.

To find out more please visit: fundraising@btaa.org.au or visit our Facebook Group 'Brain Tumour Alliance Australia'



Mark International Brain Tumour Awareness Week by taking part in "Wear a Hat for BTAA". Receive your fund raising kit by calling BTAA's Freecall (free from landlines) **1800 857 221** or email fundraising@btaa.org.au. MaryAnne Rosier will be delighted to send you a kit to get you started!

Please send your photos to fundraising@btaa.org.au or post them on the BTAA Facebook page so we can share your events!

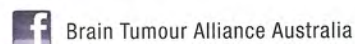
Contact us

Freecall (free from landlines) **1800 857 221** or email enquiries@btaa.org.au to speak to someone who has travelled the BT journey, receive free and impartial advice and support or have ideas on how to support BTAA



Spread the word via our social media websites

Please like, add, share, comment and spread the word via our twitter, facebook and linkedin accounts! This not only helps our voice to be heard but also gives you a chance to reach out, interact and communicate with BTAA and the wider brain tumour community!





Brain Tumours and Relationships

By Mark Dalliston, BTAA committee member.

Introduction

A diagnosis of a brain tumour is likely to prove stressful for everyone involved. Roles are likely to change too and with change comes stress.

Some people will show a commitment to the patient, while others will drift away from the patient's life.

The key person is the person's partner. They suddenly shift from being equal to the patient, to having to cope with a multitude of changes. Some of these changes include: medical decisions, which may be life and death, quality of life choices; and the rush of trying to come up to speed on all the information about brain tumours. All of which make the diagnosis the start of a stressful chain of events.

When I was diagnosed my wife was seven and a half months pregnant and we had only been married one year. If we could make it through this, then we would be ok.

Telling People About My Diagnosis

I had never thought that this was going to be difficult. From the very first call it was obvious this was not going to be the case. Being told I had cancer was bad enough; being told brain cancer intuitively they knew was the worst. It was an eye opener to see that news of the diagnosis was as much of a shock to friends and relatives as it was to me. Some reacted with alarm, one said they would have to hang up, while another reacted as if she had not heard me and continued to chat about an upcoming holiday. We learned to tell people in stages. If we told them I had brain cancer, then we could feel the shock the person was undergoing. A better approach was to tell them the sequence of events that led to the diagnosis. If the friend or relative was in a medical profession, this made the whole thing easier.

It was the start of a change in the relationships between us and others. Some friendships grew stronger, while others drifted away. Overall the number of friends dropped but of those who stayed their support grew stronger, once they got over the shock. We have heard of others whose partner left them. We have also found that our relatives have coped in different ways.

Stress Of Being A Carer

With the diagnosis of a brain tumour a partner is usually turned

into a carer at some point in the journey. It takes an already strong relationship to survive this transition. I now appreciate what my wife went through. With my treatment and a baby in tow it was certainly stressful.

As well as suddenly being lumped with responsibility for running the family, they may have share the burden of the extra financial strain. Although I managed to go back to work after four months and my employer was really good, not all are so fortunate. The loss of work can lead to uncertainty. Loss of income may affect ones self-esteem or lead to depression. Financial strain is a situation that only adds extra stress.

Changes in patient's personality may be apparent post treatment. I became disabled after my surgery. This was difficult for someone who was used to training (read over-training) their whole life. Surgery, radiotherapy and chemotherapy may have many different effects on a patient. My most recent progression affected my speech and not being to hear what was being said when more than one person was talking.

When you are unsure whether the person you love is going be around for long, this increases the stress felt. One reaction is to stare into space like when caught in headlights. Uncertainty can lead to poor or no choices being made. Calmness goes a long way in a situation like this. Sometimes the reality is that the carers, and patient, have little choice in their coping mechanisms. I came from a difficult upbringing, which I now believe was an asset in this situation.

Friends

Dealing with relationships and cancer highlights the importance of communication. If you stop talking, it's going to start eating at you. We were surprised how keen close friends were to help. All we had to do was ask.

Cancer can make an okay relationship worse. It can also make a close relationship stronger. While we were amazed about the friends who withdrew from our lives, we pleasantly surprised how many were strengthened. A trouble shared definitely eased the load in a stressful situation.

Friends may provide the partner turned carer support. It is too

easy for everyone to focus on the patient. If this happens, then I believe that it is more like that no one will be providing the direction needed. This may be rectified if the carer is coping well and is active in making decisions. Friends can make helpful suggestions and provide practical help, especially if there are children involved. They shouldn't assume that everything is okay - everybody will struggle in these circumstances. We have called on the help of friends numerous times.

Doctors

Unfortunately, too many doctors look at the statistics and write you off. To be fair to them, it is not an easy diagnosis to give. This is where experience comes in on their part. I believe that they can provide an accurate prognosis, while still outlining a plan and providing hope. Hope is an essential quality of life. Joy, peace and love can still create a high quality of life. A negatively stated diagnosis can make things worse. I was told to get my affairs in order and that I would probably live between six and twelve months. No wonder depression is so common among us. Alternatively, a friendly approach may make you have hope and think about things that may help your situation. It is very important to ask questions. My wife took notes, for which I'm eternally grateful to her. It cannot be overstated how important second opinions are; you never know when they might be needed.

The worst experience we had was when one doctor talked about his relative with cancer for half the appointment, then proceeded to walk out of his office before we had time for questions. If the doctor/ patient relationship fails, don't try to go it alone - change doctors.

Patient

I never noticed that I had become quite selfish after treatment; one never does. While it is understandable that I became more selfish, it didn't help matters especially with a baby around. I found I was able to help with one thing. Our daughter would scream every evening for two hours. My wife could not stand this, while I finally found myself useful by babysitting.

Whether the patient is positive or negative makes a difference. I have always been an optimist, which served well in these circumstances. Being positive was a blessing as it attracted liked minded people. Strangers would come up to me and remark how well they thought I was doing. You may not be able to control your personality or the effects of cancer on your brain, but certain things may help: physical activity, fresh air, plenty of sleep, eating well, limiting TV and alcohol.

Other changes may social situations difficult. During my latest progression, I had speech changes. Until the swelling was reduced through medication I could barely talk; in fact for a week I could not talk at all. So I began talking less and that situation worsened until my latest course of treatment.

Conclusion

It was enlightening to view firsthand the affect the diagnosis of a brain tumour had on others. Of course, there were shocks for us in how people reacted. We found that giving the sequence and timing of events helpful.

Carers need to ask for help if they are to keep their heads above water. There is plenty of stress in taking on extra roles and responsibilities. Being able to take time out and having others help are two of coping mechanisms. Friends can be a good resource - you just need to ask for help.

Minding children especially during medical appointments or treatment is a great benefit. They can also be a source of driving.



Susan Dalliston (left) with Brain Tumour Patient Renee Hindson.

Doctors attitude, I believe, may be an important source of the placebo effect. Certainly depression does help any chronic condition. To this overcome you should ask your doctors plenty of questions, take notes and seek second opinions.

In all, I can't claim to have enjoyed my cancer journey, but it has gotten easier. Where it will me next I don't mind (notice I didn't say care) as long as there is joy, peace and love.

**Wear a silver
ribbon for Brain
Tumour
Awareness
Week!**

Brain Tumour Awareness



A fun new way to support our Cause!

BTAA has now joined the fund raising channel Everyday Hero so you and your friends and family can swim, run, ride or walk for BTAA...or simply make a donation!

<http://www.everydayhero.com.au/charity/view?charity=2051>



Susans support team for the Canberra Times Fun Run

BTAA trialled this new channel with a team in the Canberra Times Fun Run on 8 September 2013. Team BTAA captained by committee member/Mark Dalliston's wife Susan raised \$1,900!



BTAA support team

A special mention to Jesse & Rowans Beard Challenge for BTAA!

Jesse writes:

My step dad was diagnosed with a GBM stage IV brain tumour in July 2010 and given less than twelve months to live. This is the worst type of brain tumour one can get with the worst survival rates of any type of brain cancer. After two traditional surgeries and gamma knife treatment in the first two years from diagnosis he has not had any treatment since February 2012. Before he got sick my

stepdad was a successful well paid businessman and although he can no longer read or write he remains in high spirits and is always positive about the future. My step dad always has been and remains an absolute inspiration to myself, my mum, my brother and sister and everyone we know. The BTAA are non profit charity run by volunteers who give up their time to help families in need with not only financial support but most importantly emotional.



Jesse Caridi and Rowan Webb

The BTAA supported my family by providing information and putting my mum in contact with other families in similar circumstances and it made a real difference to my families journey. Rowan & I would now like to offer some support to the BTAA so that they can continue their work supporting Australian families unlucky enough to have someone they love diagnosed with a brain tumour. We will be growing our beards till December to try and raise some money for a good cause. :)

Thanks heaps

Jesse Caridi & Rowan Webb

<https://give.everydayhero.com/au/jesse-4>

Thank you to all our supporters – Please remember to get in touch and share your story and events with us!

A special thank you to our Vice Chair **Kelly Webster** for suggesting this initiative and to her father (Alex Webster) for funding the set up costs of Everyday Hero in memory of her mother (Penny Webster).

Author Cam Lavac shares his Brain story and his plans...

As well as being a bestselling novelist, Cam Lavac is also a fine art photographer with a number of sold-out gallery exhibitions.

He is hoping for at least one more exhibition. You can check out his author website on www.camlavac.com.au or his fine art site on www.beautifulpictures.com.au.

"Prior to August 2012 I had been enjoying life as a reasonably successful novelist with a couple of international bestsellers under my belt. I had been putting the finishing editing touches to my latest book, "The Cult" when disaster struck. I had admitted myself into the Mater Private Hospital for elective spinal surgery, to fix a pinched nerve. There were problems with physio when unfortunate event necessitated a second spine operation.

Following on from this operation, I began to experience very strange symptoms, such as severe headaches and hallucinations. It was only due to my wife's very verbose insistence, as well as bringing in our own doctor, that it was agreed that something was seriously amiss. After much cajoling from my wife and our family doctor it was finally agreed that I should have a CT scan. This revealed a brain tumour the size of a golf ball.

I had been putting the finishing editing touches to my latest book, "The Cult" when disaster struck.

As it happened, a very fine neurosurgeon was in attendance at the Mater, along with his entire surgical team. It was decided he would operate without delay. In theatre I asked the anaesthetist to hold off for a few minutes in order to allow me the opportunity to deliver a pep talk to the team, which, much to their bemusement I did.

Following what I was told was a successful operation, the doctor attended me in recovery and gave my wife and me, what he referred to as, "the bad news." He explained I had a grade 4 glioblastoma multiforme (GBM), explaining further that this was the most aggressive type of malignant brain cancer and that it was incurable with a median survival rate of 12 to 14 months. I remember very clearly what went through my head at this news.

"!*, this is serious," I thought.*

After four operations (I was also diagnosed with prostate cancer at the time – just for good measure) and after three weeks in hospital, I was finally allowed to go home to my beloved wife and best friend, Jill, as well as my

gorgeous friend, Pepe (the faithful dog), who I'd missed terribly. What followed was the usual stint of daily radiation and chemo therapy.

This is when Jill and I learned who our real friends were. One part of our friends set up a meal roster, delivering food on a daily basis, so that was one chore Jill did not have to worry herself over. Another set, my golf mates set up a transport roster to take turns to drive me to the hospital every day for therapy, as I was not allowed to drive. Not being allowed to drive for three months was the worst part, as I felt as though I were under house arrest.



Cam Lavac with his prized brown trout

As soon as I was allowed to, I returned to driving and Jill and I took a break in New Zealand where we trekked into the foot of Mt Cook, something I had always wanted to do. As well as that I tried my hand at fly fishing, landing a whopper 16lb brown trout, another thing I had always wanted to do. After kissing his snout and thanking him for the experience, I released him, but not before a trophy photograph.

We've travelled a bit since then, Bali and Europe, from where we returned recently, and the day after we arrived back in Sydney, I went and bought myself a brand new, magnificent, Harley Davidson motorcycle, something else I had always wanted to do, and which my wife said, I should do, so I did.

Ten years ago I quit smoking, but had enjoyed it so much, I determined to take it up again when I turned 80 (when it wouldn't matter anymore). So now, I decided to fast track things and took up smoking a couple of cigars a day. I particularly enjoy a cigar on the back deck of an evening, watching the stars and meditatively contemplating the mysteries of life and death. It's not only highly enjoyable but, I believe, therapeutic.

The next time Jill and I visited my oncologist, Jill could not help herself, announcing, "Cam will hate me for asking this doctor, but what do you think of him smoking?" The

oncologist wasn't sure whether Jill was referring to marijuana or tobacco. Once that was cleared up she said, "Well Jill, far be it for me as a doctor to condone smoking, but under the circumstances – what does it matter?"

"Yes!" I exclaimed, punching my fist into the air! For a while, I had lost all interest in completing my latest, and in all probability, last book. Who could blame me, I was too busy living to spend my days behind a computer.



However, with Jill's encouragement, "You owe it to your fans, and to yourself to finish – it represents a year of your life." I finally finished, "The Cult," delivered it to my happy publisher and had it published and officially launched at the Novotel Hotel in Manly recently. There is still one more book I've been working on (The New Australians), but will it see the light of being published? I really don't know, but **WATCH THIS SPACE.**

Many people marvel at my stoicism (their word not mine), at the prospect of a premature death. But the way I see it is, that I have a couple of choices. I could curl up in the foetal position and lament at my bad fortune, and how badly done by I've been, or alternatively, I could get on with the business of living every remaining minute to the fullest possible. I choose the latter. I choose not to feel sorry for myself, but I do feel sorry for my poor wife, as I watch the stress get to her daily as she tries to come to terms with losing her life partner. I keep telling her, "it's not how many years we live that matters, it's how we live

those years." Jill has been an incredible support through all this, and I don't know how I would have coped if it were not for her incredible support, love and friendship, and just being there for me.

At the time of writing this article, I had my latest MRI scan and was told by my oncologist, "you are in trouble." The tumour has returned and I have an appointment with a neuro-surgeon in a couple of days to ascertain if it is operable. One must continue to live in hope.

I recently attended a great brain cancer conference organized by that wonderful NSW Cancer Council. It was there that I asked a question that had been niggling me, and which to date had not been answered to my satisfaction, and one that perhaps many fellow sufferers may have felt too timid to ask. "I know that this thing will eventually get me, but what I'd like to know, is how will it actually kill me, and what can I expect leading up to my demise?" The answer was that finally I will lapse into a coma and slip away without any suffering. That was kind of a relief, but it is not something I wish to subject my loved ones to, and that is why I am an advocate of voluntary euthanasia.

I believe we all have the right to die with dignity. I do hope I will have some warning as to when the end is near so that I can organise a living wake to celebrate the great life I've had with my friends and to have the opportunity to say my farewells. If this does transpire, I intend to make a spectacular entrance by skydiving into the party.

A fitting entrance to reflect on my adventure-filled life."

Denis Strangman comments on Cam's support for Euthanasia;

Cam has written a very interesting article about his journey with a brain tumour but I do take issue with his support for voluntary euthanasia and/or, presumably, assisted suicide.

One of the most comforting pieces of information I received when my late wife Marg was diagnosed with a GBM was from another husband who said he had checked with his GP and was told that "generally, brain tumour patients just fade away".

That is similar to what Cam discovered in asking his question at a Cancer Forum.

"Fading away" is precisely what happened with my own wife when she died as a result of her brain tumour after a 11 month journey. On her deathbed her major organs simply shut down one by one and, as far as I could determine, she was not in any pain because that was well controlled by the very experienced nurses who looked after her. As a matter

of fact I can assure Cam that my wife's death experience was not distressing to me in a physical sense. We both knew what was coming. I would have been very disappointed if my wife had decided to "spare" my sensibilities by obtaining one of Dr Nitschke's plastic bags and nitrogen container and taking her own life.

To use a hackneyed phrase "death is a part of life" and it is the one certainty we will all experience. Unlike previous generations some people want to write death "out of the script" but it is not possible.

I fear that introducing euthanasia and assisted suicide into our health system will muddy the field for proper funding and the availability of palliative care to look after people with a life-limiting illness. I meet so many people these days who say to me "The palliative care people were wonderful, I didn't know they existed and the work they did."

Denis Strangman

(Foundation Secretary, Brain Tumour Alliance Australia; Foundation Chair, the International Brain Tumour Alliance; Consumer representative, ACT Palliative Care Plan Strategy Committee).



www.theibta.org.au

Greater collaboration.

Greater knowledge.

Greater hope.

Thanks from BTAA

The gold coin entry to the **Music@Midday** concerts in May raised over \$1,900 for BTAA. The Royal Military College Band played and the Rugby Choir sang. Great fun. Thanks to **MaryAnne Rosier** for organising this.

Also a special thanks to **Ellen Gooding** and the patrons of the Oppy shop in Darkan, WA. Out of the blue BTAA received a donation of \$650 from the June sales.

Our appreciation to **Peter Scott** and the ORS Group for support of the Wear a Hat for a Day for BTAA in 2012 and another donation in 2013. Also to **Tony Lomas**, Citipower Powercor Australia, and many others (in memory of **Sharyn Elizabeth Leroy**). Thanks to AQWEST (in memory of Iris Johns).

Thanks also to **Warwick Burr** and **Chris Cullinan** and the family and friends who made donations in memory of Nellie Reid.

Thanks to **Andrew Simpson**, **Diane Gray** and **Debbie Pollard** who make regular donations to BTAA.

Thanks also to both **Steve Conole** and **Daniel Sanguinetti Media** who have helped BTAA get their community TV announcement ad run in many places across Australia, leading to lots of new callers to BTAA's Free call.

Also to the ACT BT network's **Colin McCulloch** from **Bartercard** for his help with the Wear a Hat for a Day for BTAA posters and flyers and with **Brainstorm for a Cure**.

Thanks to **Jon Shirley** from **Pixeltopaper** for his complimentary graphic design work for the ACT support group flyers and posters and Hat day collection boxes and flyers.

Also to the **Canberra Southern Cross Club** for a community grant and support in holding our meetings at the club each month.

Thanks to **Leigh (Laddie)** and **Lesley Hindley** for donating all proceeds from Laddie's book launch on 20th September 'The Joys and Dangers of an Aviation Pilot' to BTAA

Finally thanks to **Gavin Turnbull** from **Brainchild Project Management** for ongoing help with design and printing of the BTAA newsletter, awareness ribbons and other bits and bobs we need.



BTAA SUPPORT GROUPS

Location	Organisation	Contact
National	Brain Tumour Alliance Australia	1800 857 221 info@btaa.org.au
	Cancer Council	13 11 20 www.cancerconnections.com.au
NSW	Sydney hospitals – various	www.btaa.org.au/support_groups.html
	Hunter Brain Tumour Network – Kaye	Kduffy42@gmail.com
Victoria	BrainLink Services Ltd – Carolyn	www.brainlink.org.au admin@brainlink.org.au
	Grey Matters (benign and low grade) – Janet	thegreymatters01@gmail.com 0422 639 993
	Brain Tumour Ahoy – Low Grade	www.braintumourahoyhoy.org
Queensland	Brain Tumour Support Service – Sarah	Ask via Cancer Council National Helpline on 13 11 20
	Gold Coast – Peter	petershark72@hotmail.com 0422784885
South Australia	Adult Brain Cancer Support Association	andy.stokes@sa.gov.au or search Facebook
Western Australia	Brain Tumour WA	news@braintumourwa.com : braintumourwa.com/go/
Australian Capital Territory	ACT Brain Tumour Support – MaryAnne and Susan	vicechair@btaa.org.au
International	Worldwide listing of Patient groups	www.theibta.org/websitelinks.html

Diary Dates for 2013

To add any events to the diary for our next quarterly newsletter & for us to promote them on our social media sites please email: secretary@btaa.org.au

18th October 2013

Blackwood Gala Ball – Melbourne

<http://blackwood8.com.au/gala-ball-friday-18th-october-2013/>

25th–26th October 2013

6th Annual COGNO Scientific meeting – Sydney

<http://www.cogno.org.au/content.aspx?page=cognoasm-home>

25th–26th October 2013

6th Annual COGNO Scientific meeting – Sydney

<http://www.cogno.org.au/content.aspx?page=cognoasm-home>

27th October 2013

BTAA brain tumour support group meeting

Convenors of health consumer led brain tumour support meetings
and by invitation. secretary@btaa.org.au

27th October – 2nd November 2013

International Brain Tumour Awareness Week

<http://www.theibta.org/>

3rd November 2013

Walk 4 Life – Sydney, Melbourne, Adelaide

<http://www.cureforlife.org.au/walk4life/>

3rd November 2013

Ben Donohue Run & Walk for fun – Canberra

<http://www.hawkerc.act.edu.au/runandwalkforfun>

17th November 2013

City to Sea – Melbourne

<http://www.thecity2sea.com.au/>

24th November 2013

Beach walk for Brain Cancer – Sydney, 10am

www.Beachwalkforbraincancer.com

8th February 2014

Sarah's 40th Brainstorm Cocktails

<http://www.brainstormforacure.com.au/>

List of all fundraising events Australia wide available via Everyday hero available: <http://www.everydayhero.com.au/events/calendar>

Disclaimer: The material provided in this Newsletter and on our website is general in nature. It is made available on the understanding that BTAA is not engaged in rendering professional or medical advice. Before relying on the material users should carefully evaluate its currency, completeness and relevance for their purposes, and should always obtain appropriate medical advice relevant to their particular circumstances.

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