

Notes for a presentation by Denis Strangman (Secretary BTAA, Chair IBTA) to a Public Forum for Brain Tumour Patients and Family, Ewing Lecture Theatre, Royal Melbourne Hospital, Saturday 7 November 2009.

On the one hand it is good that not too many brain tumours are diagnosed – there are only 1400 malignant primary brain tumours diagnosed in Australia each year.

But while their incidence might be low – about Number 17 on the list of all cancers - they jump to Number 4 when you take into consideration the chaos and havoc they cause in terms of years of potential living that are lost.

Because of their low incidence you don't quite run into other brain tumour patients down your street, at the club, the Church, the workplace, or wherever. And because Australia is such a big country geographically and its population is dispersed, at any one time you are likely to have isolated brain tumour patients all around Australia, but they might never know of each other's existence.

Enormous strain from diagnosis

Not only can a diagnosis of a brain tumour prompt fear and confusion, it can place an enormous strain on the patient, their loved ones and family. Make no doubt about it I believe that all of you people deserve a medal for the caring and the work you do.

Some people bring down the shutters and place themselves entirely in the hands of the surgeon or oncologist. An increasing number go in search of information – to verify what they have been told, or to obtain extra information about the options available.

I know all this because that is what happened when my late wife was diagnosed with a GBM in 2000. The reason I am a patient advocate today is because I found it difficult to access useful information at the time.



Margaret Strangman

First off I asked my wife's neurosurgeon if there was a brain tumour support group in our city and he replied "Sure, I'll get the nurse to give you their contact number".

What happened then was a comedy of errors where a puzzled coordinator for the *acquired brain injury* group in Canberra tried to answer my questions over the telephone about radiation therapy for brain tumour patients, which was the next stage of my wife's treatment. He knew nothing about radiation therapy.

Needless to say, there was no brain tumour support group in existence.

Nor was printed information readily available, so I hit the Internet, as many do, and came across the "*Primer of Brain Tumors*", a very useful book which is published by the American Brain Tumor Association and downloaded it.



There was also a paucity of books written by people, patients or caregivers, who had travelled this journey before me. There was one book available on-line and I started reading it to my wife but the more we read the more dispiriting the story became and we soon abandoned it.

Of course, we knew what the likely prognosis was and the nature of the grading system for malignant brain tumours but there was still that desire to contact someone, anyone, who had a clue about what was up ahead.

I did happen across an international email discussion group based in the USA and joined it, which was quite useful. Later, a number of the Australians on it established an Australian-based email discussion group which is still going today.

Canberra Hospital

After my wife passed away in 2001 I determined to do something about the lack of the ready availability of useful support information. Doctors who I pestered at the Canberra Hospital steered me in the direction of an in-house committee to establish a general Cancer Resources Centre for patients and families which we achieved in February 2003 and which is still active today in the oncology wards.



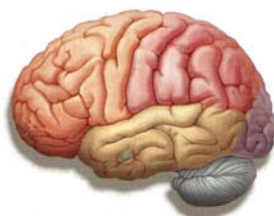
Opening of Canberra Hospital Cancer Resources Centre

Meanwhile, I started importing brain tumor Primers and other printed materials from the USA and established an organisation called “Brain Tumour Publications and Resources”. I printed a brochure and distributed it to every oncologist and neurosurgeon in Australia whose address I could locate. It worked on an “honour basis”. If you thought the publication you received was useful then you were welcome to donate to fund the purchase of further publications.

BRAIN TUMOUR

Publications
&
Resources

Dedicated to bringing the latest published
information to brain tumour patients
and their carers.



Brain Tumour Australia 2003

Through contacts made during this activity, I and others established the national patient advocacy group “Brain Tumour Australia” at a meeting at North Shore Hospital in Sydney in 2003 and I was elected Chair. We held several more national conferences – one at Liverpool Hospital in Sydney in 2004 and one in 2005 at RMH.

At the meeting at RMH in 2005 I and several others retired from the national committee. I then set about establishing an international brain tumour group, which occurred at the World Federation of Neuro Oncology meeting held at Edinburgh in 2005 and I have been Chair of that group – the International Brain Tumour Alliance (IBTA) - since then, sharing the leadership with my co-Director Kathy Oliver of the UK, who has a 30 year old son with a brain tumour.



IBTA foundation meeting, Edinburgh, 2005

Meanwhile, for reasons that are not completely clear, the leadership of Brain Tumour Australia decided in 2008 to wind up the organisation. Several of us, who had been involved with its foundation, then set about “reinventing the wheel”, using our own personal funds, to establish a replacement body which is known as “Brain Tumour Alliance Australia” and which is incorporated in the ACT. It has a website and a Freecall number – 1800 857 221. It is chaired by a brain tumour survivor Matt Pitt, and I am the secretary. We receive a steady stream of enquiries from people to whom we send a package of printed material if they require it.

**BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.**

Brain Tumour Alliance Australia (BTAA Inc) is the national organisation for people diagnosed with central nervous system tumours, and their family and carers.

BTAA Inc offers:

- links to brain tumour support groups
- information to assist making treatment decisions
- peer support
- hope

from the patient, family and caregiver perspective.

www.btaa.org.au

**Freecall
1800 857 221**

ABN 97 733 801 179 Incorporated in the ACT AD4837

Many of the phone enquiries are from people who are simply pleased to establish contact with someone who understands the strange world that they have been thrown in to. When you pronounce “glioblastoma” correctly they sometimes say “Yes, that’s the one, how do you know about it?”.

More traumatic than other cancers

I have a personal belief that the journey for a brain tumour patient and their family can be more traumatic than that experienced by people who have other cancers. For example, they can be

subjected to many forms of distress. BTAA is collaborating with the depression organisation “Beyond Blue” to research and produce a brochure on brain tumours and depression and are working with researchers at Edinburgh in the UK on this project.

The brain tumour journey can be so compressed and uncertain, full of ups and downs, which is why it is described as a “roller coaster journey”. The prognosis is also more deadly than most other cancers, on a par with pancreatic cancer, however, as I mentioned earlier, the numbers are not huge, so it is one of the “less common” cancers. It can be as intractable as lung cancer and that is why the annual scientific meeting of the Clinical Oncological Society of Australia (COSA) will concentrate on brain and lung cancers in two weeks time, both being intractable and having been neglected to some extent.

More support needed for patients and caregivers

Not only is there a need for more research into the causes and treatments of brain tumours there should be more support for the patients and their caregivers.

There are only a handful of specifically-designated brain tumour coordinators in Australia, to work with patients, and they could easily meet inside the proverbial telephone box. On the other hand there are so many breast cancer nurses that they can hold a three day conference with visiting overseas experts giving lectures.

I am not saying that we should have an equal number but I do suggest that when hospitals are considering the appointment of nurse care coordinators in the cancer area that they bear in mind the special needs of brain tumour patients and accommodate those needs in some way, for example, by providing after hours access to Wards when disturbing but non-life threatening events occur. Similarly, they could appoint one coordinator who might share several cancers in their area of responsibility.

Compared with eight years ago there are now many more resources available to the interested brain tumour patient and caregiver and I would like to refer to some of them.

Virtual trials website

The virtual trials website (www.virtualtrials.com) remains the best resource for the newly diagnosed patient and their caregiver in the English-speaking world. It is run by Al Musella who had the unfortunate experience of having several relatives develop brain tumours. It contains access to news reports, clinical trial results and patients’ stories.



Al Musella

Email discussion groups

The main internet discussion groups are still operating and for the very interested there is a new group called the Brain-research Yahoo group: <http://health.groups.yahoo.com/group/brain-research/>

During 17-19 September the members of this group organised a Brain Tumor Advanced Treatments conference at a place called Ashland in Oregon which I attended and spoke at. Ashland is a nice town which specialises in Shakespearian plays. (See: <http://braintumorconference.com/>) Its scenery reminded me of Olinda in Victoria, which I once holidayed at 40 years ago!

The conference attracted some top-rate presenters. Here is a photo of Dr Susan Chang, head of the Society of the US Neuro Oncologists.



Dr Susan Chang

One of the presenters told me that they don't even get asked questions of such depth at the scientific conferences they lecture at.

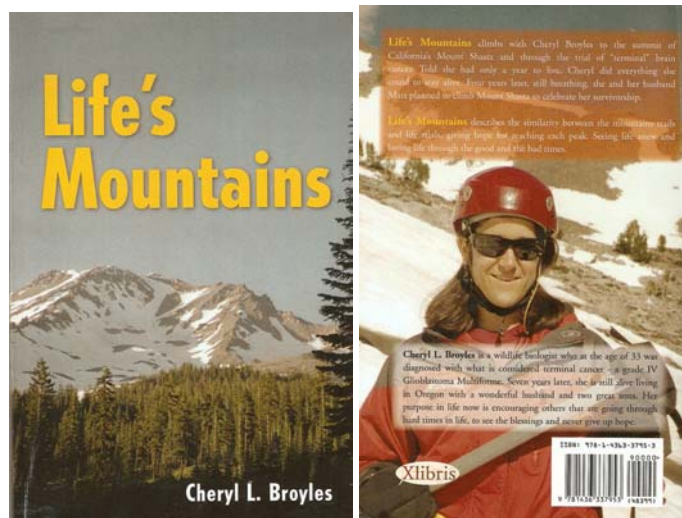
Publications



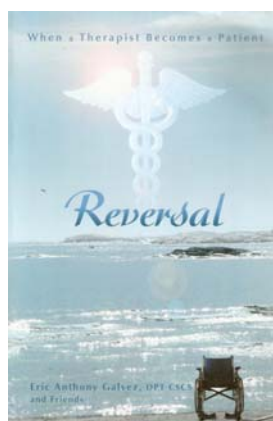
Dr Ben Williams, Mr John Williams.

This is a photo of **Dr Ben Williams** – left – a psychology professor at the University of California who is a long term survivor of a GBM and has written a book “Surviving Terminal Cancer”. The other person is **John Williams**, no relation, whose father died fairly recently from a GBM. John was one of the co-organisers of the Conference. He is 42 and was a software programmer in Silicon Valley who now devotes his life to seeking our promising new therapies and helping others with their research.

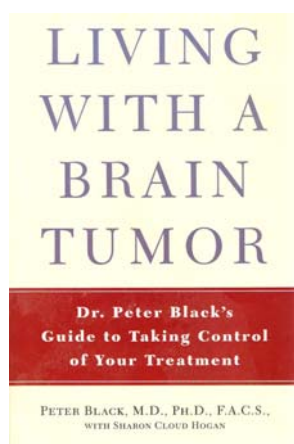
This is **Cheryl L Broyles**, another long-term GBM survivor, who has written a book about her personal challenge of climbing a mountain in the USA. (Life’s Mountains: www.Xlibris.com) She is a full time homemaker with two young boys.



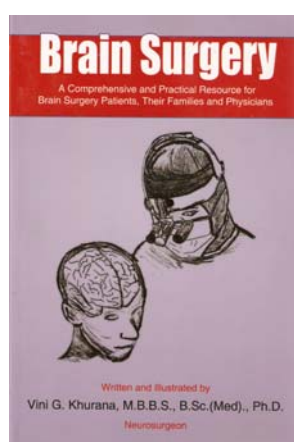
Another patient who has written a book about his experience is **Eric Galvez**. Eric wasn't at Ashland but he sent me a copy of his book, which is called “Reversal”: www.iuniverse.com. He is a physical therapist and has founded the group called “Tumors Suck!”



Other people have written books helpful to the patient. Neurosurgeon **Dr Peter Black** from Harvard has written “Living with a Brain Tumor”.



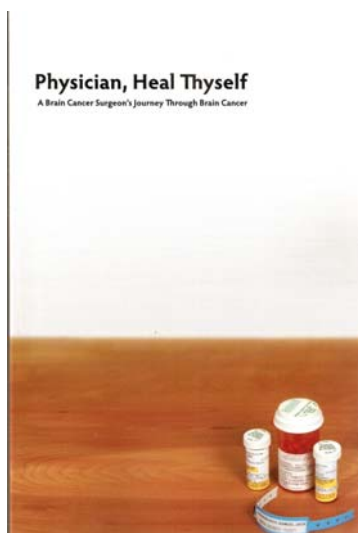
Neurosurgeon **Dr Vini Khurana** from Canberra has written a book “Brain Surgery”, which he gives to his patients. Sydney neurosurgeon **Dr Charlie Teo** has also had books written about his work and, of course, has appeared in many television documentaries on Australian television.



Another neurosurgeon **Dr Paul Zeltzer** from UCLA, has written two books for patients and caregivers: “Brain Tumors, Finding the Ark” and “Brain Tumors, Leaving the Garden of Eden”.

See: <http://www.survivingbraincancer.com/> He told me in Oregon that he is also now involved with a start-up company designed to assist patients in seeking appropriate treatment programs.

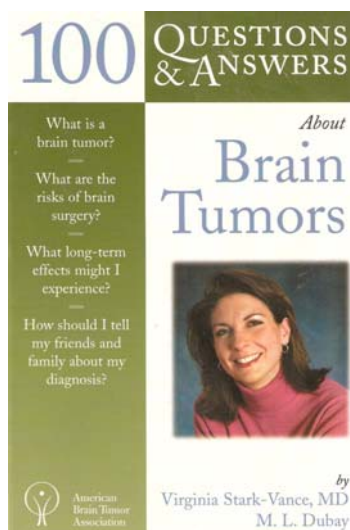
Another neurosurgeon, again from the USA, **Dr Samuel J Hassenbusch** from MD Anderson, was diagnosed with a brain tumour in 2005 after twenty years of caring for brain tumour patients. He wrote a book about his experiences called “Physician, Heal Thyself”. Unfortunately, he died after 33 months.



When diagnosed he said publicly that he wanted to become a “six foot lab rat” to try and identify promising new therapies for brain tumour patients. His situation was reminiscent of **Professor Chris O’Brien** who, after a career as a head and neck surgeon in Sydney, was diagnosed with a GBM and also wrote a book, but it was more about his entire life than his time as a brain tumour patient.

There have been other strange coincidences like that. **Mr Hubert Stuerzel** from Sydney was the national marketing manager in the early 2000’s for temodal, distributed by the Schering Plough company. He was instrumental in obtaining grants for us for the importation of some of the printed materials mentioned earlier and also in arranging for me to meet officials at the New Jersey headquarters of his company when we were seeking funding to establish the IBTA. Ironically, he also developed a GBM and passed away. There is a scholarship for oncology students named in his honour.

Another useful book is “100 Questions and Answers About Brain Tumors”, written jointly by Texan Oncologist **Dr Virginia Stark-Vance** and one of her patients **Mary Louise Dubay**. When I was Chair of Brain Tumour Australia I arranged for the importation of several hundred copies of this book from the USA and we distributed them for free around Australia. That free supply has now dried up.



However, the two authors have updated the book and my colleague Mrs Kathy Oliver and I were invited to contribute a preface to the book. Dr Stark-Vance was hoping to obtain sponsorship from a large US pharma company to subsidise its printing. If the project is finalised then I will try to ensure that we can access copies for Australian patients and their families. Meanwhile, the ABTA “Primer”, which has been the BTAA’s stand-by resource, will be updated in January 2010 by the ABTA and we will also seek copies of it for distribution in Australia.

Avastin

Mention of Dr Stark-Vance reminds me of the new therapy called Avastin, or bevcizamub. She is actually credited with first discovering its efficacy when she tried it on one of her brain tumour patients.

Several of you have probably heard about Avastin. It is not available on the Pharmaceutical Benefits Scheme in Australia but some glioblastoma patients are using it, either paying for it themselves, or accessing it on a compassionate basis. There are two big clinical trials, one run by the manufacturer (Roche) and the other by the EORTC, which are due to commence in Australia.

The IBTA has adopted a wait and see attitude about Avastin. We are patient advocates and so we believe we have a duty to make representations when it is appropriate. We have met with representatives of the Swiss-based company in Canberra, London and Berlin, during the past eighteen months and we have agreed that the price for the drug is too high and that the compassionate access schemes in various countries are inconsistent between countries and in comparison with its use for other cancers. We have also asked that the company consider access plans for brain tumour patients in the low and middle income countries.

It has been very gratifying to have some of the world’s leading neuro-oncologists come up to us at conferences and say that they support our viewpoint on this drug.

IBTA projects

Today marks the conclusion of the 3rd International Brain Tumour Awareness Week and the 3rd Walk Around the World for Brain Tumours (see: www.theibta.org). In 2009 there were 182 organisations supporting these two projects, compared with 158 last year. This past week particularly has seen dozens of awareness-raising events held around the world. Not only have there been the activities at Royal Melbourne Hospital but there were walks in Sydney and Brisbane, displays in other centres, and picnics for patients and families in Adelaide and Perth.



Brain tumour display in foyer of Canberra Hospital

We are also reasonably confident that the accumulated distance covered by the walkers in the awareness and fund-raising walks held as part of the Walk Around the World will reach our target of 200,000 kms – five times around the world at the Equator. We are indebted to Tara Gent, who is present today, for keeping a record of these walks, the distances covered, the people involved, and the funds raised – I might add, not for the IBTA, but for research and support in the area where the walk is held.



Brain tumour awareness raising walk in Paris

Minister's message

The Federal Minister for Health, Nicola Roxon, sent us a message of congratulations for the Week but, regrettably, there was not much she could say about Federal Government support for brain tumour research or patients, instancing only the COGNO project which Professor Mark Rosenthal and Dr Kate Dummond are involved with, and a \$500,000 grant in 2007 for a three year research project which is about to expire.

Much more could be done by State and Federal Governments. The Cancer Institute NSW has been pro-active but I have not seen a similar contribution by other State governments.

The big priority is that funding is needed for specialised brain tumour care co-ordinators who will act as genuine contacts for the patients and families and will not be diverted to other tasks which, although important, are not of immediate assistance to the patient.

Nor should we neglect our overseas obligations. Our nearest neighbour is **Papua New Guinea**. There is only one surgeon in PNG and their 40-year old radiation therapy machine for cancer therapy has been out of action for five years. I am aware that **Professor Jeffrey Rosenfeld** from Melbourne has been trying to assist this country for several years. There are needs in other neighbouring countries as well.

I wish you well in all your roles – be it as a patient who is trying to cope with this disease, a family member or caregiver, nurse, health professional, or specialist. Let us hope that those breakthroughs we so earnestly seek are just around the corner.