

## Dear Friends,

Welcome to the first edition of the new digital Brain Tumour Support Service newsletter. We have some excellent reading for you this month! Here are a few highlights:



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

**A team of researchers from the UK, US and Finland have created a modified version of Temozolomide,** which is often used to treat glioblastoma. Tests have shown that it is better at killing cancer cells, which is very encouraging news. Although it is still early days, the researchers are hoping it may be able to treat other forms of cancer too.

**You will also read about Ken's battle with a brain tumour.** Ken gives us a good account of his symptoms and tests, as well as an insight into his thoughts and feelings and details on how he and his wife learnt how to cope. This is a wonderful story, and I hope you enjoy it as much as I did. I wish Ken and his wife all the best of luck in the future. Ken - please let us know how you are doing.

**At the end of 2014, Dianne McGinn represented the Brain Tumour Support Service of Brisbane** at the National Brain Tumour Patient Advocate Summit in Melbourne. In her article, Dianne reports that the group unanimously agreed that all brain tumour patients should have access to a Neuro-oncology nurse from the time of their diagnosis, treatment and beyond, and that this would be a great help and support to one and all.

**Danette Langbecker has provided us with a list of support services** available to brain tumour patients. Interestingly, 40 patients were asked to list their most important unmet needs, five of which are listed at the end of the article. I am sure you will find this information most helpful.

There is of course the usual information pages and meeting details and reports.

Till next time, keep smiling, happy reading, and keep well.

**Anne**

### Thought for the day:

*Some people come into our lives and quickly go. Some people become friends and stay a while leaving beautiful footprints on our hearts and we are never quite the same because we have made a good friend.*

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## About the Brain Tumour Support Service

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

### What the service provides:

- Information about benign and malignant brain tumours and treatment.
- Information about support agencies, rehabilitation services and CCQ's Practical Support Program.
- Regular meetings 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](http://www.cancerqld.org.au)  
Email: [helpline@cancerqld.org.au](mailto:helpline@cancerqld.org.au) or call 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.*

# BTAA Report by Dianne McGinn

During the recent International Brain Tumour Awareness Week, I had the pleasure of representing Brisbane's Brain Tumour Support Group as one of their facilitators at the 2014 National Brain Tumour Patient Advocate Summit in Melbourne. This meeting was hosted by Brain Tumour Alliance Australia (BTAA), the only national Brain Tumour patient and caregiver organisation in Australia, and chaired by a representative of Cure for Life Foundation.

The background to the summit is building collaborations, and they had their inaugural summit in 2013.

An objective was to discuss the working draft of the National Action Plan for Brain Tumours. It would serve as a guiding post to the 1600 patients diagnosed with primary brain tumours each year in Australia and their families and caregivers.

The draft continues to be a work in progress, and while funding is low from the government, BTAA will be making a submission to the Treasurer for the 2015 budget. It is widely known that funding for research into this field is extremely low and it was discussed that if funding for one other aspect of brain cancer care was available, the group unanimously believed all brain tumour patients should have access to a neuro oncology nurse practitioner (such as those available at the Wesley Hospital) during their diagnosis, treatment and beyond.

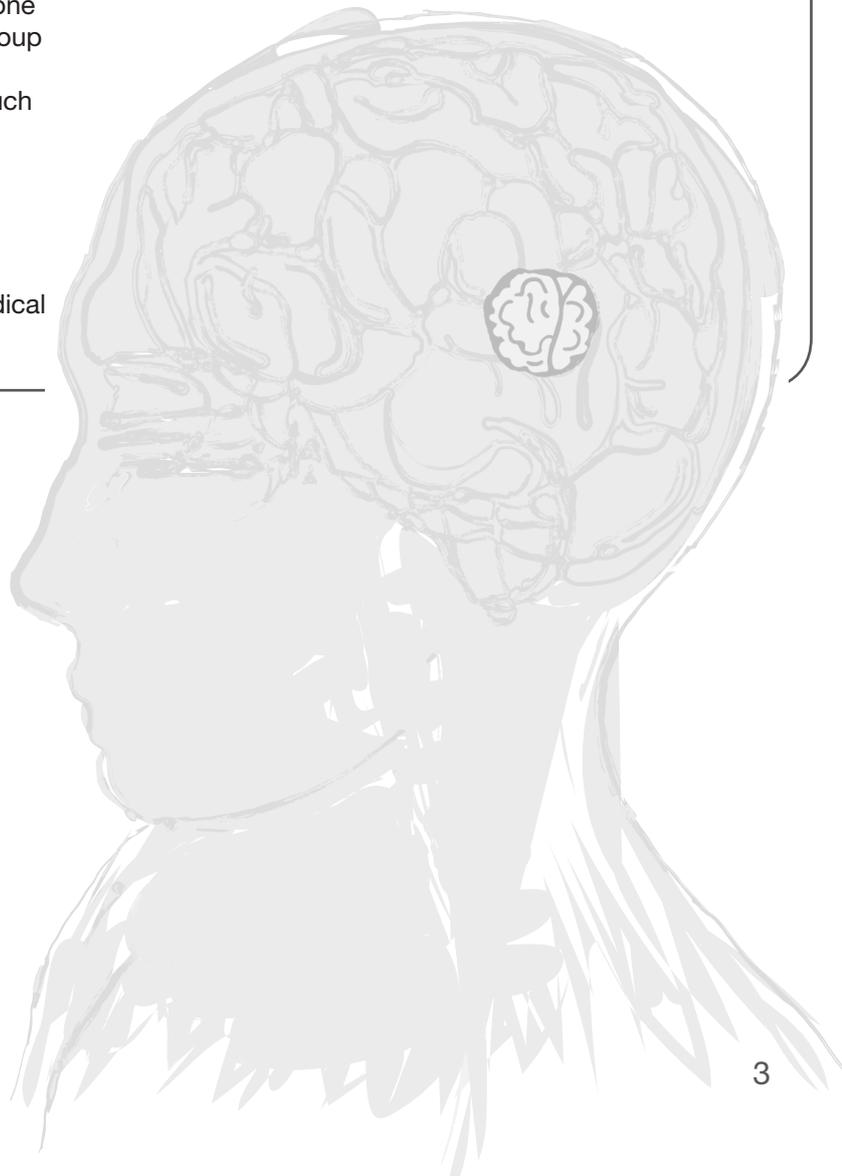
Some of the other topics that were covered included dealing with change, loss and progressive disease in groups. The summit was attended by support group facilitators, allied health professionals, clinical and medical research professionals.

Representatives from many Brain Tumour Support Groups from around Australia, research organisations and fundraisers spoke about challenges that they faced to provide the support and care that is desperately needed.

From a patient's perspective, I came away with a greater understanding of the different foundations around Australia and their link in the chain and as a facilitator armed with the knowledge that our support group BTSG are moving in the right direction. We will welcome the 2015 National Brain Tumour Patient Advocate Summit to Brisbane next year.

BTSG meets on the 1st Thursday of each month at 10am – 12 noon at the Cancer Council Queensland building, 553 Gregory Tce, Fortitude Valley.

Call 13 11 20 or email [Braintsg@gmail.com](mailto:Braintsg@gmail.com) for more details.



# Ken – from 100kmh to walking pace in 8 days

**It's late October 2014 and life is bubbling. I am a nearly 58-year-old winemaker/ cellar hand living in the South Burnett. My wife and I are enjoying a quality and very active life:**

- Winemaking (a career/tree change thingy) is a very physical profession – a big day was 26,000 steps, an average about 15,000 steps. So I was physically fit and trim.
- Looked like I had a fantastic job at a premium winery in Margaret River, WA. Packing and moving was probably next on the agenda.
- Playing competition squash each week.
- Completing some major renovations on the house.

Booked and ticketed to go to Phokara in Nepal on October 27. Some trekking, local food and a weekend of motorbike riding with my daughter and her partner in the mountains

## The beginning

It's Saturday and I am working at the Cellar Door. At close time, I rang my wife to come and collect me as I wasn't feeling the best. She didn't get the message so I drove home. I wasn't feeling well so I slept most of Sunday. My wife took me to the local hospital emergency on Sunday night. My speech was "something". She said she thought I may have had a stroke. Nothing stood out as requiring emergency treatment.

Monday morning off to the local GP, who fortunately I had been to just recently for a sinus infection. After discussion with my wife, it all happened:

- Ambulance to regional base hospital in Kingaroy and a barrage of tests (CAT Scan, CG, blood tests).
- Into ER and waiting for next available Royal Flying Doctor flight into Brisbane.

- After midnight finally into the Mater Private in Brisbane.
- Tuesday morning, another barrage of tests (MRI, x-rays, blood tests). This is when I found out that Chewbacca (the affectionate name I have given my Grade IV GMB brain cancer) had entered our lives. Why the name? I figure that Chewbacca is going to be with me for the rest of my life and needs a proper name. While all this was happening, my wife had returned to our house, packed some clothes, drove four hours to Brisbane, put our dog in a kennel and was by my side in the morning.
- Briefing with the neurosurgeon and surgery Tuesday night to remove the tumour. Surgery was as successful as you could wish for; no collateral damage and a significant removal.
- Checked out of hospital six days later.

So now we are into the first cycle of therapy (self-administered chemotherapy and radiation) which ends on December 24. Then we get to go home; nothing like sleeping in your own bed and your kitchen. The ongoing chemotherapy cycle (five days per month) continues after a month break.

## What worked for me

A brain cancer diagnosis and treatment is different for everyone, and it often has special and additional issues to deal with if you live in a regional area. I would like to share my thoughts on the things that made our lives easier and worked for us. There are many wonderful organisations and people out there who are there to support and help, in most cases you simply need to ask.

- To my mind, the single most important thing that provided quality in our lives was a positive and go forward attitude. Yep – no question, brain cancer

is a very serious life threatening illness. However, in our case, we treated it as just another problem to be resolved. How – be informed as best you can and understand what you are dealing with, use the support offered by organisations, the many dedicated professionals who work in the cancer field, and friends, and keep an open mind. The future (of Chewbacca) is what it is and if you are flexible and open minded about what you may be able to do, you will be surprised at what there is to look forward to. Having brain cancer doesn't mean you can't provide value to other people, and contribute to society.

- Being informed with reliable information means working with your doctors and nursing staff; ask questions if you don't understand. The most reliable and useful information comes from your doctors and nurses, organisations like Cancer Council, and fellow cancer sufferers.
- Being the partner and family of a brain cancer sufferer is not easy. It is just as difficult for them as it is for us. They have to deal with our mood swings, side effects, sometimes self-centred attitudes, be a taxi driver and all the time knowing that the person they love has a terminal illness. We can wear them out if we are not careful. I have learnt to apologise, think "us" not me, include my wife in all decisions and meetings, and allow her to find her "self" time.
- Learn to cope, manage and deal with your steroid medication. As a brain cancer patient, you will most likely be given a steroid after surgery and during your radiation therapy to prevent brain swelling. I was prescribed dexamethasone, which in my case the side effects were weight gain, broken sleep patterns (average 5-6 hour per day) and feeling wired like a disco ball during the rest of the day. This has an effect on the people you live with and come into contact with daily – it is easy to wear them out. Work with your doctors and nurses to find the right levels, and remember to consider other people; it's not just about us – we need our support base.
- Coming to the city from a regional area for surgery and therapy puts a whole different perspective on life – "normality" becomes what you make it. The additional financial considerations, living out of a suitcase, little time with friends and home support groups, not being to work in off-therapy times – all the "fish out of water" things can distract from recovery and getting well. We were lucky enough to have some close friends in the city that helped ease the burden. Being only four hours' drive meant we were able to go home most weekends for some normality.

## Thank you

The beginning of my cancer journey would not be complete without recognising the many wonderful people and dear close friends who have ensured that we are well and truly pushing forward.

To:

- My wife and life partner for being there all the time, caring for and managing me when it was tough at the start and putting up with the 'changed' me.



## KEN – FROM 100KMH TO WALKING PACE IN 8 DAYS (Continued)

- The many friends who have supported and helped us, and usually without being asked.
- The health professionals whose paths I crossed on the journey; from ambulance officers, RFDS people, to hospital and support staff. The professionalism, the patient care and concern, and people awareness was, without exception, excellent.
- A special thanks to the neurological team at Mater Private (surgery, recovery and the neurological ward). I reckon world class.
- Also a special thanks to the oncology treatment team at the Princess Alexandra; a very classy, well run and managed organisation full of real people.

**Where to  
from here**

**How do you eat an  
elephant?**

***Teaspoon at a time.***

**It's all good – Ken and Christine.**

# Use of supportive services

By Dr Danette Langbecker, Queensland University of Technology (QUT)

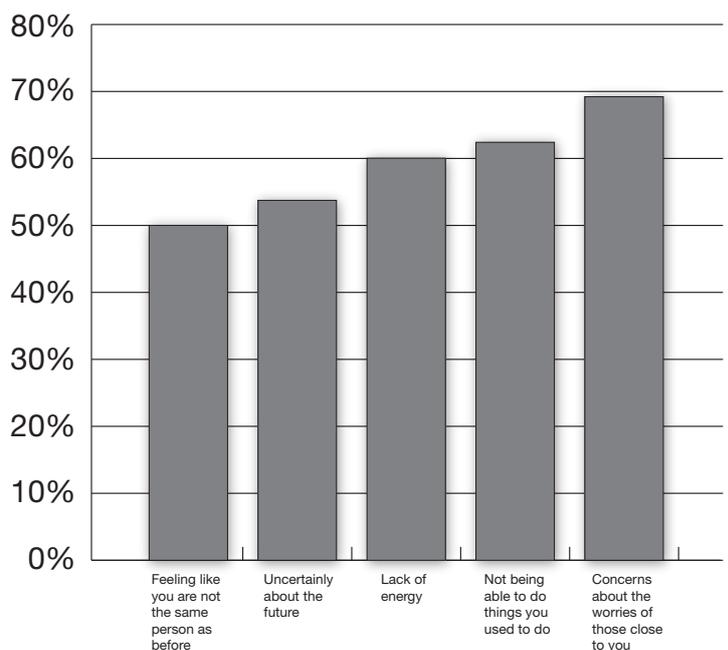
As this newsletter describes, there are a lot of different services and sources of help and support that you can access when diagnosed with a brain tumour. The services people want to use may depend on what issues they are having, but also whether they know what help is available and how to access it, and any barriers (such as distance and cost) that may get in the way. If we can understand what services people use, together with the issues they face, it will help us to develop services (and better publicise services) to help people with brain tumours and their families manage their cancer journeys. This was the idea behind the Brain Tumour Support Study, a small research study conducted by QUT in 2013

## What we found

We invited adults recently diagnosed with primary brain tumours in Queensland to participate. Forty patients participated, 11 with the assistance of family members or carers. Just over half of participants were male, and almost two thirds had a malignant tumour.

We asked participants a series of questions to identify their most important 'unmet needs' during each interview – these are concerns that people have that have not been

(adequately) dealt with. The five most important unmet needs identified from the initial interviews are shown below.



We asked participants about persons or services which had helped since their diagnosis. For each service, we asked if people were aware that the service existed, if they had ever been referred to this service by a health professional (whether or not as part of a formal referral process), and whether they had used the service. Overall, all or almost all participants were aware of at least one type of information source or service (e.g. information booklets), health professional (e.g. physiotherapist), support service (e.g. support group) or source of practical assistance (e.g. social worker). Referrals were highest for health professionals, and lowest for support services. Use of services was greatest for health professionals, and lowest for sources of practical assistance.

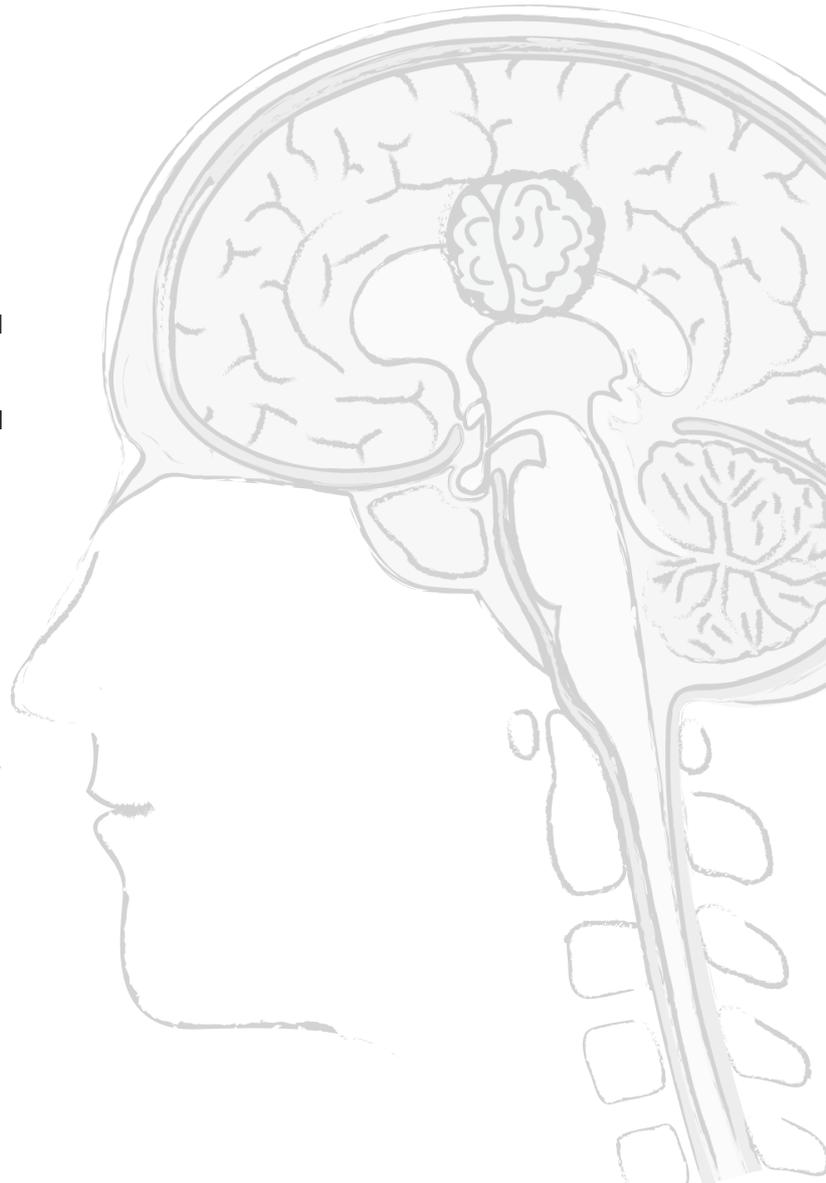
Looking at individual services, over half of participants used a physiotherapist (56 per cent), and just under half used information booklets about the diagnosis (47 per cent) and information available on the Internet (47 per cent). In contrast, no participants reported using the services of Brain Tumour Alliance Australia, an exercise physiologist, or psychiatrist.

We also discussed with participants the reasons why people did or did not use services, especially when it was apparent that they may have helped them. One important reason that came up was that many participants weren't made aware of many services which are available, and which may be beneficial.

## Where to from here?

This study was useful in highlighting the services that are not well known by people diagnosed with brain tumours, and which should be further promoted. We will be discussing these findings with health professionals and services to encourage them to make patients aware of the services available. It also showed that more than half of patients experienced difficulties with issues such as lack of energy and uncertainty about the future, which new interventions should address.

We are currently planning our next studies, which will explore the issues experienced by caregivers, and how we can assist caregivers to support and care for patients. We are also planning to investigate the concerns of people who are long term survivors of high grade glioma (anaplastic astrocytoma or glioblastoma multiforme), with the aim of understanding the support or services needed to meet their needs.



**“I never know where these things are until all of a sudden someone will say, ‘oh didn’t you know you could’ve got that for free?’ and I think oh really?!”**



Further information and support can be provided at any Cancer Council Queensland office throughout Queensland or by calling 13 11 20.

[www.cancerqld.org.au](http://www.cancerqld.org.au)