Brain Tumour Support Service

Edition 1, 2017

I'm okay are you okay?

Index

Dear Friends

Welcome to the first edition of 2017.

This issue focuses on the theme, 'I'm okay are you okay? Patients and Partners – Looking after one another.' The impact of a brain tumour is enormous and obviously extends to loved ones. How then do partners discuss this impact without both being so concerned about protecting the other's feelings that no one can share the extent of their suffering?

In this issue we report on an important research project currently underway, 'Staying connected after brain tumour'.

There is also some space devoted to brain teasers and a crossword to stimulate your thinking or to work on together over a cup of tea (or beverage of choice).

In keeping with the theme of patients and spouses we have included a story (from a spouse's perspective) with some honest, practical advice from someone who has been at the coalface.

The American Brain Tumour Association website makes a significant contribution with two of their sections modified for the Australian setting; 'How to care for a brain tumour patient' and 'Caring for the care giver'.

Brain Tumour Support Service Newsletter Editing Team

For more information contact btss@cancerqld.org.au

Resource

Partners guide to coping with cancer.

We have a wide variety of resources available online at cancerqld.org.au which include easy-to-read information about specific types of cancer, treatments, and emotional and practical issues for people with cancer, their families and friends.

Donate now

Your donations help fund our research and support services for Queenslanders affected by brain cancer and benign brain tumours, including provision of the Brain Tumour Support Service. Donate online at www.**cancerqld.org.au** or call our Donor Hotline **1300 66 39 36**

13 11 20

Call 13 11 20 for cancer and brain tumour support information, emotional and practical support. Our Information and Support Coordinators can also refer you to Cancer Council Queensland support programs and other community services.

This free and confidential service is available Monday to Friday 9am–5pm (excluding public holidays) and is provided thanks to the generous donations and support of Queenslanders.

Brisbane Brain Tumour Support Group

First Thursday of the month

Next session July 6th

Watch this space!

We will be evaluating the Brain Tumour Support Service shortly, and we want to hear from you. At Cancer Council Queensland our goal is to provide you with a service that is informative and supportive, but to do that, we need your feedback. Stay tuned for information on how you can have your say.

The view from a spouse: Supporting a loved one with cancer.

By Marni Weiss

Editor's note: This story was originally published August 24, 2004 in The Dallas Morning News. It is republished here to accompany Jeffrey Weiss' personal narrative about his 2016 cancer diagnosis.

Marni Weiss, Jeffrey Weiss' wife, offers these principles for loved ones of cancer patients from her experiences during the past six months:

1. Don't waste psychological and emotional energy faking cheerfulness.
2. Be honest with yourself and everyone else - especially the cancer patient.
3. Maintain your own diet and exercise routines as much as possible. Keeping your life in order helps limit your anger and emotional upheaval, and it sets a good example for the patient.
4. Cut yourself a break where you can. Watch a little extra TV, read a book, watch a movie.
5. Stop waiting for the 'right time' to do something. Change jobs, get a new haircut, take a class. Yeah, yeah, even positive change adds to your stress load. But you've just been reminded how bad things can happen, without warning, to good people. It's time for you to take some risks. You'll also be creating something you can focus on besides the cancer and giving yourself some control over another part of your life.
6. Be true to yourself. Don't suddenly act differently. The cancer patient already has too much that's unpredictable in his life. Don't add to it.
7. Make good on old promises. This is a chance to really stick to your end of all agreements and arrangements you've made.
8. Insist that your 'patient' carry out as many of their normal personal chores as possible.
9. Pay close attention to their mental, physical, and emotional fluctuations. They may need a kick in the butt or a special romantic activity.

http://www.dallasnews.com/business/health-care/2004/08/24/view-spouse-supporting-loved-one-cancer

Brain Teasers

Your name puzzle

The latest puzzle doing the rounds on social media was posted by Try Life with the caption: “Experts say that if you can find your name in this puzzle then you’re in the top 8 per cent and one of the smartest people in the world.”

But, as with many puzzles taking over social media, all is not what it seems. The challenge may seem a simple one, but the difficulty of this word search soon becomes apparent. While many people search for their own name, the puzzle is actually asking them to spot the words ‘your name’.

J	K	L	P	S	T	K	P	Y	C	J	L	L
Q	R	Z	T	M	B	X	W	U	X	Z	O	W
D	Z	J	T	M	Y	O	U	R	N	A	M	E
Y	L	M	B	R	M	Z	H	D	D	Q	H	M
G	J	Z	M	F	U	F	K	R	Z	T	J	K
X	U	J	C	V	G	H	I	V	X	H	I	H
J	D	J	B	G	C	Y	K	S	I	M	G	E

Dog search

Can you find the word dog?

D	G	O	O	D	D	O	D	G	O	O	D	D	O
O	D	O	O	G	G	G	D	O	D	G	O	G	G
O	G	O	G	D	O	O	D	G	O	O	D	D	D
D	G	D	O	O	O	G	G	O	O	G	D	G	O
O	G	D	G	O	G	D	G	O	G	G	O	G	D
D	D	D	G	D	D	O	D	O	O	G	D	O	O
O	D	G	O	G	G	D	O	O	G	G	O	O	D

DOG

How to care for a brain tumour patient

The role of the caregiver

As the caregiver of someone with a brain tumour, you will have multiple roles. You may find yourself becoming a medical researcher, a financial manager, a patient advocate, and a communicator. Caregiving can become a fulltime job, even if you already have a fulltime job. As the patient's needs change over the course of the disease and treatment, so will the tasks you undertake.

The American Brain Tumour Association has drawn on the experiences of thousands of people who have cared for patients with brain tumours to create a map to help you navigate the many roles you may take on as a caregiver to a brain tumour patient.

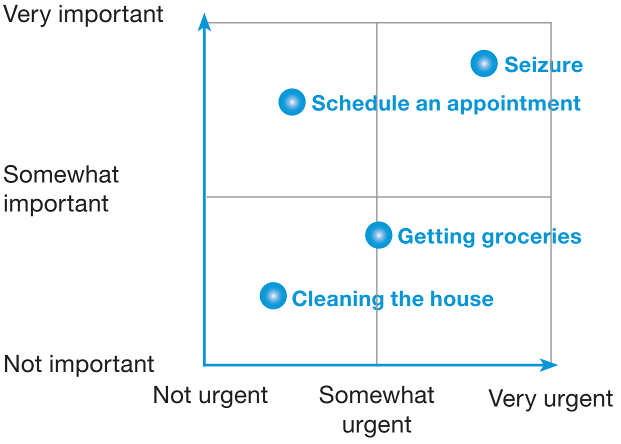
Prioritise and solve problems

> *"I focused on getting through each day, breaking steps into manageable pieces."*

Your role as a caregiver can be complex and filled with uncertainties. As situations change daily, or even hourly, as a caregiver you can help identify and solve problems. Handling a seizure is obviously more critical than setting up a doctor's appointment.

In the book Orientation to Caregiving, written by experts at the University of California, San Francisco, the authors suggest that caregivers categorise problems and tasks based on both their urgency and their importance.

Prioritising and solving problems



A severe fall in the home is both urgent and important, so of course you would need to handle it immediately. Researching treatment options is important, but not urgent, so can be scheduled later. Other tasks can be delegated to others, and, as you prioritise all you need to do, you will discover that some items are simply not priorities now and can be ignored.

Other caregivers have prioritised tasks by following the below advice:

- Take it one day at a time.
- Break tasks into manageable pieces.
- If it's hard to ask for help, start by picking just three things someone else can do.
- Don't be too hard on yourself or try to be perfect. It's difficult to adjust to the 'new normal.'
- There's no one right way of doing things.

Learning to be a patient advocate

The medical care for a brain tumour is complex, and you will likely come into contact with a large, multidisciplinary medical team.

While there are many aspects of coordinating the care for a brain tumour patient, most caregivers understand that they need to be the patient's advocate throughout the process. You can be an advocate by:

- Understanding the medical team and their roles, including hospital staff, clinic staff, specialists, and other health care professionals. Detailed information on each can be found in *Orientation to Caregiving*, Chapter 4: Tasks of Caregiving in the Hospital and Clinic.
- Involving the patient as much as possible. This can become an increasingly important responsibility, particularly if the patient has difficulty communicating. You can be the patient's voice, making sure the patient has a thorough understanding of the choices he or she must make and ensuring his or her questions are answered.

This can also be a challenging task, particularly if you are unsure of the patient's cognitive state. One caregiver was extremely distraught when his wife refused to go to treatment at a hospital that he had chosen, not knowing whether her refusal was a result of a cognitive impairment. He made the difficult decision to go to the hospital she chose as to not disempower her.

Learning about treatment options.

In this capacity, you are the researcher. Becoming the patient's chief communicator.

> *"We are very private and it's hard for me to ask for help…"*

Although it can be difficult for some, in your role as a caregiver you can help communicate about hard-to-discuss topics with others, whether that means with the medical care team or friends and family. More information is available on each of these topics:

- Advocating for the patient in medical settings.
- Informing family and friends of the patient' medical condition.
- Asking for help.

Performing day-to-day management

As caregiver, you will have a role in ensuring daily activities can help facilitate a good quality of life for the patient. This may include routine tasks around the house such as food preparation or arranging travel to a clinic. Other jobs could include creating a safe home environment for the brain tumour patient, or changing surgical dressings. You could also become responsible for helping the patient with personal hygiene tasks, such as bathing, oral hygiene, and skin and hair care.

Attempting to live as normal a life as possible for yourself and for the patient can be demanding. One way to do this is to simply provide companionship to one another, as well as to avoid isolation by planning and joining in on recreational activities with family and friends whenever possible. You may also begin to consider home care or palliative care options.

Time management tools

The ABTA has a variety of checklists and calendars **(http://www.abta.org/brain-tumor-treatment/caregivers/caregiver-worksheets.html)** to help you organise both every day and caregiving activities.

With all you need to handle, being able to manage your time efficiently becomes critical. Scheduling both routine tasks (laundry, grocery shopping) as well as tasks related to brain tumour treatment (appointment scheduling, performing physical therapy exercises at home) can take up much of your time. Added to your calendar may be times when you receive help from family or healthcare workers, as well as rest and recreational activities for both you and the patient.

Keeping up-to-date records

Because the patient may not be able to keep track of his or her own symptoms and treatments, it most often falls to the caregiver to become the record keeper of all that the disease involves. In his book *Brain Tumours: Leaving the Garden of Eden*, author Dr. Paul Zeltzer recommends keeping a binder with the following sections:

- Pathology reports, MRI and CT scans, which contain critical information about the tumour and diagnosis you can bring to other medical professionals.
- Lab reports and blood tests.
- Medication log.
- Treatment log, which includes the procedures and services the patient has received, plus dates, side effects, problems, and physician information.
- Resources and information.
- Calendar.
- Health history.

Managing medications

People with a brain tumour often need multiple medications, not just for management of disease, but for management of many of the side effects of treatments. Medications may be prescriptions and also include herbal supplements and vitamins.

It can be problematic to sort through when, where, and how to take all the medications, but mistakes made either by taking the wrong medication or the wrong dosage can lead to serious health consequences. Tips to help manage medications include:

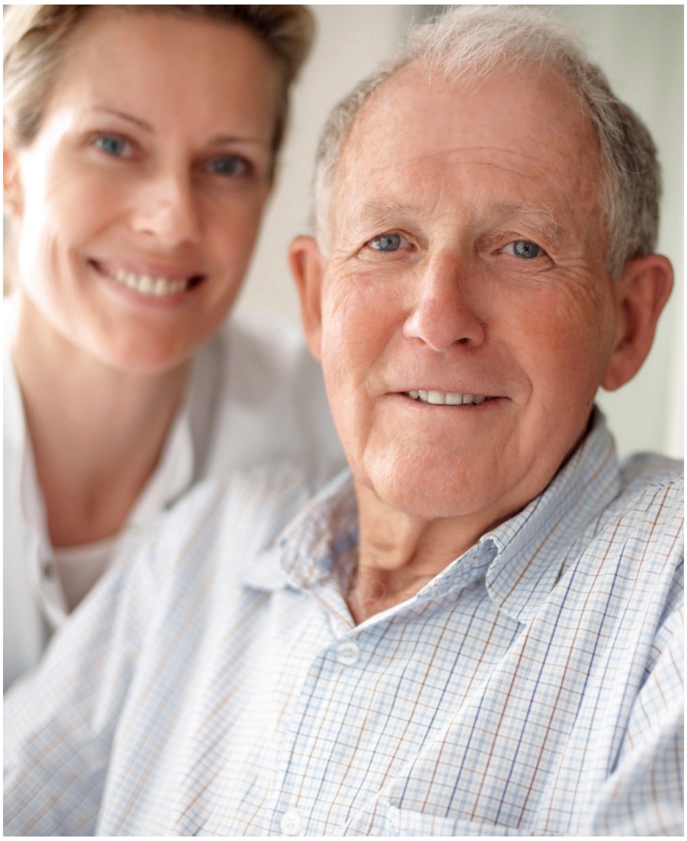
- Inform the doctor of any and all other medications the patient is taking, including supplements.
- When the physician writes the prescription, make sure to ask what the name of the medicine is, what it is for, and what side effects there might be.
- When receiving the prescription at the pharmacy or by mail, double check that you have received the correct medication and dosage.

Click here to download a blank medication log. **(http://www.abta.org/resources/care-and-treatment-section-resources/caregiver-medication-daily.pdf)**

Maintain a medication log that tracks all prescription and non-prescription items, including over-the-counter medications and herbal supplements, vitamins, or other holistic treatments. Include what the medication is for, the dosage, the time to take it, side effects, and the name of the doctor who prescribed it.

Your changing role

Your role as a caregiver will change throughout the course of the patient's illness. For example, after diagnosis, you may be focused on educating yourself about brain tumours **(http://www.abta.org/brain-tumor-information/)** and types of brain tumour treatments **(http://www.abta.org/brain-tumor-treatment/treatments/)**. At another point, you may be helping the patient manage side effects from treatment **(http://www.abta.org/brain-tumor-treatment/caregivers/brain-tumor-side-effects-symptoms.html)**. In addition, you may be caring for the patient as he or she goes through cognitive changes **(http://www.abta.org/brain-tumor-treatment/caregivers/brain-tumor-psychological-symptoms.html)**.



This may seem overwhelming. But, according to Ashley Varner, an oncology social worker who has worked with hundreds of caregivers of brain tumour patients, most people eventually fall into a rhythm of care, which can be a time to focus on the patient's quality of life.

"Once families settle on a medical facility and plan of treatment, it's often a time for caregivers to catch their breath," she says. "After feeling fairly helpless where the patient is concerned, they are finally in a place to be proactive, whether it's researching alternative therapies, focusing on diet and nutrition, finding a support group, or investigating home care options."

"Although Dad couldn't speak, he had been a workaholic, so it was the first time he was at home for an extended time period. He was alive for five more years, and although it was difficult, our whole family treasured that time with him".

Caring for the caregiver

Caring for the caregiver

Self-care for the caregiver of a brain tumour patient is critical for both your own health and the health of the patient. Although few studies have been able to capture the unique experience of being a primary caregiver for someone with a brain tumour, we do know that caregivers report high levels of stress and poor physical and emotional health, as well as career sacrifices, monetary losses, and workplace discrimination.

Research also suggests that caring for someone with a brain tumour can have added burdens compared to other diseases. Following the shock of the initial diagnosis, ongoing care often requires strong coping skills to deal with both the physical and cognitive changes of the patient.

What are the best ways to balance taking care of yourself and the person you are caring for? The ABTA website **(http://www.abta.org/)** is full of information on brain tumours as well as caregiving **(http://www.abta.org/brain-tumor-treatment/caregivers/)** , so you can educate yourself as much as possible.

The importance of knowing you're not alone

> *"Being part of a support group helped me realise I wasn't the only one caring for someone with a brain tumour. It also helped me understand the severity of the illness."*

Peer-to-peer resources are particularly important. These groups allow you to talk in person or online with others who have gone or who are going through the same experience as you. Caregiving for someone with a brain tumour can be an isolating endeavour; connecting with others can make you feel less alone.

- To find out the location and contact details of Brain Tumour Support Groups across Queensland, call Cancer Council **13 11 20**.
- For online support, join the Online Cancer Community **https://onlinecommunity.cancercouncil.com.au/.**
- To join the Brain Tumour Telephone Support Group visit **https://www.cancercouncil.com.au/1375/uncategorized/telephone-support-groups/?pp=42833** or call **1300 755 632**.
- Carers QLD **www.carersqld.asn.au** also offers a range of support services.

The resilience of caregivers

Mary Lovely, an ABTA nurse and researcher, who also co-facilitates a support group for patients and their loved ones, is often struck by the resilience exhibited by caregivers.

"The bottom line is that everyone finds a way to cope," Lovely says. "They find a way to get through the days because they have to, and they're caring for someone they love, and that's what they do."

Coping strategies can run the gamut from increasing faith and spirituality, to humour, to finding other means of self-care. To begin to care for yourself, however, it's important to understand the emotions you may experience.

Common caregiver emotions

Learning about, acknowledging and talking about the emotions you are experiencing during this time can be a great help. Consider the emotions expressed by other caregivers:

Anger and guilt

"Sometimes I don't know how I did it. Cleaning him, going to all the appointments, massaging him, exercising him... and then doing it all again. I'd get angry at him for getting sick, and then feel guilty for getting angry."

You may feel angry at the patient for getting ill. Many caregivers feel this, as well as resentment for the changes in their lives. On top of that, you may feel guilty for feeling angry at all.

Anger can also be directed towards the caregiver. A husband who cared for his wife described his experience with her family:

"After she died they became resentful, blaming me for the way I took care of her. They still don't speak to me, two years later."

This cocktail of relationships and emotions can be draining. Talking about your feelings with a mental health professional or counsellor can be worthwhile. Cancer Council Queensland have a free counselling service, available by referral by calling **13 11 20**.

Grief and feelings of loss

Often, caring for someone with a brain tumour brings about grief and feelings of loss. Because learning of a brain tumour often happens very quickly, caregivers may suddenly find themselves in a situation they had no preparation for. Caregivers may grieve the loss of the life they once had with the patient, the roles they identified with (spouse, parent, co-worker), and the loss of income, either from their own inability to work because of caregiving duties, or because of the patient's loss of work.

"It was like caring for a stranger with only glimpses of the person she used to be."

Behavioural and cognitive changes are also a cause of grief. To many, it can seem like they are losing someone they love before they are actually gone. The sweet person who loved funny movies may no longer enjoy those same types of activities. A previously caring person may not react to your smiles or tears. The patient may even become violent at times. It may be difficult to accept that the person you have loved for years is now different, perhaps forever. They may not realise they have changed, which makes the situation even more heartbreaking.

In addition to mourning the current state of their situation, caregivers of brain tumour patients often experience grief about the future: Will my loved one survive? If they do survive, what will life be like? Some caregivers and their families begin to see the future only as a source of suffering, without anything to look forward to. This feeling that the future is lost can lead caregivers to neglect their physical and emotional well-being.

A mix of emotions

Many caregivers and patients feel a mix of emotions, sometimes all at once. You may feel both denial and anger, joy and sadness, strength and anxiety. One caregiver felt resentment that she could not plan a vacation, but also felt relief that her life was simpler and less busy than it had been in a long time. Many caregivers feel great empathy for others who are going through the same experience, another reason why peer-to-peer support is so beneficial.

Additional coping strategies

As you find yourself experiencing a wide range of emotions, be compassionate with yourself as you take on the role of a caregiver for a brain tumour patient. You will need all the support and care you can get. There are many ways to care for yourself, including the following suggestions:

For your body

- **Make a doctor's appointment for a check-up.** You may want to share with your doctor your role as a caregiver and discuss anxiety, depression, or other symptoms you may be experiencing.
- **Eat healthy.** Both you and the patient will need a nutritious, balanced diet to get through this journey.
- **Enjoy physical activity.** Carve out some time every day for exercise to help with stress management. This can range from stretching, gardening, or a walk around the block to more formal types of exercise in a gym or with a class.
- **Because you may need to move the patient, or assist the patient in physical activities, it's important to learn how not to hurt yourself.** If you hurt yourself, you will be unable to care for the patient. Learn more about how to protect your physical health in the section on safety at home **http://www.abta.org/brain-tumor-treatment/caregivers/caregiver-brain-tumor-home-safety-accessibility.html**

For your mind

- In addition to keeping a log of the patient's medications and treatment, log your own emotions and physical symptoms. Note what activities and actions help you cope.
- Keep a written, ongoing list of tasks and make an effort to accomplish one a day. Include trivial items. Checking those off may seem insignificant, but accomplishing little victories' may give you a greater sense of control of your environment.
- Re-evaluate your priorities. Caregiving can be an opportunity to de-clutter your life. Look at your obligations, routines and even relationships, and make sure that they support or nourish your life as it is now.
- Work can be a salvation for many caregivers. While it can be difficult to work all day, and then come home to take care of your loved one, work can also be an opportunity to shift your focus and experience feelings of competency and accomplishment.

For your spirit

- Find activities that lower your stress levels. A recent study found that not only did mindfulness training reduce stress in caretakers, their reduced stress levels in turn lowered the anxiety of advanced-stage cancer patients. Whether you practice mindfulness, visualisation, meditation, yoga, or you simply make time to do things you enjoy, such as reading a book, watching a movie, or pursuing a hobby, you will improve your health as well as the patient's. Cancer Council Queensland have a relaxation CD and guide available by calling **13 11 20** or downloading directly from the website **https://cancerqld.org.au/cancer-information/find-resources/podcasts-audio-files/**
- Paying attention to your spiritual life can also help lessen the effects of depression. For many, practicing religion and being part of a religious-based community provides a sense of inner peace and contentment. Houses of worship also have outreach programs, and can assist families who need help.
- **Find support.** You will also need day-to-day emotional and physical help. It can be difficult to reach out. Read more about getting help from friends, family and care services at **http://www.abta.org/brain-tumor-treatment/caregivers/brain-tumor-nursing-home-care-friends-volunteers.html** this includes information about how to communicate your needs as well as outside resources for financial and home care help.

When caregiving gets too hard: signs of caregiver burnout

Many caregivers feel intense emotions in their role. However, if you find yourself wanting to hurt yourself or the patient, or you stop feeling empathy for the patient, these could be signs of caregiver burnout.

"I'm awake all night. I can't stop thinking about this."

"My life is so different now. It's never going to get better."

"I get so angry every time I have to help her complete a simple task."

"I don't care what happens anymore."

Although most caregivers experience strong emotions and fatigue, caregiver burnout is a pervasive state that occurs when caregivers are unable to get the help and care they need.

Warning signs of caregiver burnout are similar to depression and include:

- Attitude changes: from caring about the patient's condition to anger, hostility or apathy.
- Thoughts of wanting to hurt yourself or the patient.
- Extreme guilt or shame caused by spending time on yourself.
- Withdrawal from friends and family.
- Loss of interest in activities you previously enjoyed.
- Feeling hopeless.
- Physical changes: changes in appetite, weight, sleep patterns, more susceptible to colds/flu.
- Feeling unable to control emotions.

Caregiver burnout occurs for many reasons. Some caregivers are forced into their role and feel resentment. Others feel pressure from family to provide care in a specific way. Still others may feel that they aren't doing enough to help the patient get better, even if there is little that the caregiver can control. Whatever the cause, it's important to seek help.

When you need help now

If you are experiencing thoughts of hopelessness, or thoughts of hurting yourself, the patient, or others, there is support available. Contact:

- Lifeline on 13 11 14
  www.lifeline.org.au
- Beyond Blue on 1300 224 636
  www.beyondblue.org.au
- Suicide Call Back Service 1300 659 467
  www.suicidecallbackservice.org.au/

If you feel that you are at immediate risk of harming yourself or another person call 000.

Caregiving is a critical and difficult job. Taking care of yourself can truly improve the quality of life for the patient. Remind yourself you are doing the best you can, and that asking for help is both necessary and brave.

References

American Brain Tumour Association Website

http://www.abta.org/brain-tumor-treatment/caregivers/how-to-care-for-brain-tumor-patient.html

http://www.abta.org/brain-tumor-treatment/caregivers/caregiver-health-care-brain-tumor.html

CALL FOR PARTICIPATION

Staying Connected After Brain Tumour

Investigators: Student Researcher: Lee Cubis
Chief Investigator: A/Prof Tamara Ownsworth. Associate Investigators: Prof Suzanne Chambers (Griffith University), Prof. Joanne Aitken (Cancer Council Queensland)

People with brain tumour can often feel alone in their experience.

Changes in physical abilities, communication, behaviour and mood may lead to loss of employment, driving cessation and reduced ability to attend social and leisure activities. The loss of valued social activity and relationships can mean that people's social network is depleted when they most need support.

This project aims to gain a greater understanding of changes to social networks after a diagnosis of brain tumour from the perspective of those living with brain tumour. The findings of this research will inform interventions aimed at supporting social participation after brain tumour.

If you have been diagnosed with primary brain tumour and are aged 18-85 years of age you are eligible to participate. Your participation will improve our understanding of how people stay connected to important social networks, and the effect that this has on their health and wellbeing.

Outline of Participation Requirements

You will be asked to complete an interview lasting approximately 45 minutes over the telephone. This will include questions about your demographic and health information, a brief assessment of memory, language and attention, and questions regarding your emotional well-being and participation in social activities before and after your brain tumour.

If you live in South-East Queensland and would prefer to complete the interview face-to-face, the Student Researcher will meet with you at a place of your convenience (e.g. at your home, a local library or at Griffith University).

How to take part

If you would like to take part in this study or require more information, please contact Lee Cubis on **0438 208 783** or by email **lee.cubis@griffithuni.edu.au**

Ethics Approval Number: PSY/37/15/HREC

About the Brain Tumour Support Service

Cancer Council Queensland's Brain Tumour Support Service provides free information, support and referral to people diagnosed with a benign or malignant brain tumour, their families and friends.

The service provides:

- Information about brain tumours, treatment, support agencies and rehabilitation services.
- Referral to Cancer Council Queensland's practical support program and counselling service.
- Regular information sessions in our Brisbane office, providing opportunities to meet with other people who have been impacted by a brain tumour and hear guest speakers discuss topics of interest.
- Regular newsletters offering up-to-date information, stories and support.
- For further details on the Brain Tumour Support Service, visit: **www.cancerqld.org.au/get-support/cancer-emotional-support/brain-tumour-support.**

Cancer Council
Queensland

Further information and support is available at cancerqld.org.au or by calling Cancer Council 13 11 20.