

Dear Friends,

Welcome to the final edition of the newsletter for 2015.

This edition has a special focus on carers.

In News & Events, you'll find details of a Brisbane support group for young adults run by CanTeen, and a report from the BTAA national summit and consumer forum.

In an article on **Caring for the Carers**, Sylvia Burns discusses the importance of self-care for both patients and carers.

To improve your coping, Sylvia suggests you: be informed, find support, accept help, stay in touch and know your limits.

The Brainchild Foundation has offered some tips to assist in caring for a child with a brain tumour. It's important that parents take time out, and try as much as possible to stick to their usual routine.

Finally, we've also included a list of support services offered by Carers Queensland as well as contact details.

'Till next time stay happy, keep well and keep smiling.

Anne

**Volunteer Editor
Brain Tumour Support Service Newsletter**



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

Youthful vigour

The secret of staying young is to live honestly, eat slowly and lie about your age.

Lucille Ball

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Brain Tumour Information Sessions

The first information session for 2016 will be Thursday 3rd March. Check our website in February or call 13 11 20 for details.



About the Brain Tumour Support Service

Information, referral and support to people who have a benign or malignant brain tumour, their families and friends.

The service provides:

- information about brain tumours and treatments
- referral to support and rehabilitation services as well as Cancer Council Queensland's practical support program
- regular meetings that provide opportunities to meet other people dealing with a brain tumour and hear health professionals discuss topics of interest
- regular newsletters offering up-to-date information, stories and support.

Get in touch!

Call us on 13 11 20
Email us at askanurse@cancerqld.org.au
Visit us at cancerqld.org.au

13 11 20

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

This free and confidential service is available Monday to Friday 8am–6pm (excluding public holidays) and is provided thanks to the generous donations and support of Queenslanders

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 cancerqld.org.au or call our Donor Hotline **1300 66 39 36**

CanTeen Brain Tumour Support Group in West End

CanTeen counsellor Hiromi Ogata has started a support group for young adults with a brain tumour.

The group meets every fortnight, from 12-1.30pm at the CanTeen office in West End.

You don't need to become a member of CanTeen – any young adult (18+) affected by a brain tumour can join. Attendance is free. The group was started because young people with brain tumour have different needs to older adults or children. The aim of the group is to understand, connect, and support each other.

Where: CanTeen 33 Vulture Street, West End 4101

When: Friday 12-1:30pm, every fortnight (last meeting for 2015 is Friday 18 December, first meeting for 2016 is Friday 22 January)

Other useful information: One disabled park on premises, 2-hour on street parking nearby, wheelchair accessible, guide dogs welcome.

Contact: Hiromi Ogata (CanTeen Counsellor) hiromi.ogata@canteen.org.au or 07 3107 1524

What participants have said:

"I really appreciate that this group has started. I have felt connected to the others who are going through big challenges in life."

"Thank you for making this happen. I realised how much I needed to meet these people. I feel safe, we all are equal, and there is no judgement. Come and join us!"

"I just wanted to find one friend, one true friend without any conditions. I think that I have found one. Thank you."

Have your say!

We need your help to improve our service and make sure it is meeting your needs. What topics would you like to see covered in our information sessions? What articles would you like to see in our newsletter?

Fill out the survey at this link
<https://www.surveymonkey.com/r/BTSSsurvey2015>

To request a print copy email
btss@cancerqld.org.au



BTAA Summit and Consumer Forum – what we learned

Dominique Longshaw reports from the BTAA Summit held at Cancer Council Queensland in October 2015.

The 3rd Brain Tumour Alliance Australia (BTAA) National Summit was a cross collaboration between health professionals, several community-based brain tumour support advocacy groups, and support groups from across Australia. A total of 32 delegates included people with brain tumours, their carers, parents of children with brain tumours, as well as several advocates who have lost loved ones to brain tumour.

BTAA facilitated an update on local state activity from each of the representatives. Highlights included: the mobilisation of funds being raised for brain tumour research – both clinical and psychosocial, the philanthropic funding for a brain tumour care coordinator, and our discussion around the need to raise more awareness and funds for research in childhood brain tumours. There was a sense of collegiality between the variety of delegates.

Across lunch, a further 30 people with brain tumours, along with their family and friends joined us for our supportive care forum. Outcomes from this program included:

- People connecting with one another in a safe space, being given the opportunity to ask questions of a program of experts.

- Gaining an understanding of the latest in how emerging treatments are targeting brain tumour cells.
- Attaining an appreciation of the processes involved in setting up a clinical trial, how patients can access, online tools for communicating current trials in Australia, and the future of clinical trials for brain tumour.
- A frank discussion on some of the day to day challenges of living with a brain tumour or caring for someone with a brain tumour, including some practical strategies for coping with fatigue, pain, poor sleep, challenging behaviours, and some interesting discussion around neuroplasticity.

What the delegates said:

“Q & A very useful for practical help.”

“We are not alone!”

“Hopeful future, rehab ideas, update on current studies and who with.”

Many thanks to Susan Pitt (Chair BTAA) for leading on the summit and to Cure Brain Cancer Foundation for sponsoring our international guest speaker, Dr Martin van den Bent.



Self-care for Partners and Caregivers

Cancer Council Queensland's Sylvia Burns discusses the importance of self-care for partners and carers.

A diagnosis of cancer can be a really distressing and challenging event, not only for the individual concerned, but also for partners and close family members as well. Although brain tumours are relatively rare, the combined effects of cancer, treatment and the brain injury that follows pose not only a threat to life but to a person's sense of self.

Depending on the location, the size and spread of the tumour, people can experience diverse changes in their physical functioning, thinking abilities, emotions and behaviour. The effects of neurological damage from brain tumours and treatment can make it more difficult for individuals to fully understand and come to terms with their illness creating further barriers to talking openly about what is happening for them, their fears, and concerns with loved ones.

The long term support needs of people with brain tumours and those who care for them are complex. The combination of stress at diagnosis, the uncertainty of outcomes, and complex neurological impairments can be overwhelming. Often both the individual with brain cancer and their families are left with ongoing emotional distress and poorer quality of life.

Strategies to improve coping for partners, caregivers and family include ways of managing the stress reactions that can arise from frustration and helplessness when it is so difficult to make things better for those they love and care for. Although it is easy for us to put words to a page outlining what might help, taking the time to read and then translate these ideas into a coping kit and self-care plan is often put off and then forgotten.

Improve Coping

Be informed	Understand the circumstances you are facing Become familiar with the potential impact of the tumour and treatment Ask questions until you do understand
Find Support	Support group Peer support volunteer (CCQ) Talk with a supportive friend Access professional support from social workers or counsellors to develop your coping and caring skills
Accept help	When help is offered accept it Delegate tasks that others can readily assist with
Stay in touch	Divert calls to message bank or an answering machine Record an update message for callers – Bill is doing okay with treatment. He is mainly resting. Thank you for your concern. Nominate someone to send out a regular email update to friends/family
Know your limits	Become more aware of signs of stress Have someone organise a roster of family/friends so you can run errands or have time for yourself

Partners and family caregivers describe the feelings of guilt that make it very difficult to take time for themselves, even when they recognise they are overstretched and drained. It can seem selfish when compared to the challenges their loved one may be facing.

Even the thought of asking for support or accepting help from friends or other family members can be so uncomfortable, that this too is avoided until the pressure of trying to manage becomes too much.

With these tendencies in mind, you may find yourself dismissing the idea of developing a Self Care Plan. And

yet, if you could stop for a moment and consider how valuable you are – your presence, your energy, your time, thoughtfulness and loving care – to your loved one dealing with a brain tumour, it makes sense.

It’s actually essential to protect yourself, to ensure that you don’t burn out and meet frustration with words and actions that can never be taken back. To make sure your future memories are as good as the situation allows, there are some simple strategies that can help and be applied to a whole range of situations. Writing these down can help to remind you, when times are more difficult, of ideas that can help.

Self Care Plan maintaining your own wellbeing

Stay active	Make time to run/ride/walk/jog/ garden regularly
Eat well	Eat healthy foods and accept meals rather than resort to take-away
Relax	Do things that you enjoy and that recharge your batteries Learn meditation, yoga, tai chi or other forms of relaxation Attend mindfulness classes for yourself or together
Nurture relationships	Acknowledge and respect differences As much as possible plan and solve problems together and discuss how you can best support each other Spend relaxed time with friends and family Plan ways to include your loved one even when unwell Be patient with yourself and others

Incorporating self-care into your routine need not take up large chunks of time or money. Perhaps taking a few moments to really enjoy your first cup of tea or coffee in the morning, really savouring the aroma, the warmth of the cup in your hands and the liquid in your mouth, the sensations of swallowing and the feeling of warmth in your stomach. Being really present for small things that you do every day can take you out of your head for a moment

and ground you in your body, a simple shift that can help calm the mind.

Taking a breath (a little like counting to 10) when you feel yourself winding up or growing tense, can create a breathing space, allowing you to notice what is happening in your body, your mind and emotions, and to consider how best to respond or take care of yourself in the situation.

Be mindful especially when things are tough

S = Stop!
T = Take a breath
O = Observe/stay Open
P = Proceed with considered action

Make some time now to list a few everyday things that you enjoy doing, perhaps cooking a meal or washing the car; activities that help you feel refreshed and energised. Decide to do at least one of these things in your week. Starting small in this way helps nurturing yourself become a new and beneficial habit.

Caring for a child – Brainchild Foundation



To care for a child with a brain tumour, parents need to look after themselves – some tips from the Brainchild Foundation.

A brain tumour diagnosis is life-changing, for children and adults alike. For children, the experience is complicated by the fact that they may not understand what is happening.

Depending upon a child's age, they may have no concept of their own mortality. Very young children may perceive their illness to be no more serious than the common cold, whereas a teenager may be shocked and devastated by the news.

Whatever the age of the child, the parents usually carry the bulk of the emotional burden. Those caring for a diagnosed child often suppress their true emotions. Brain and spinal cord tumour diagnosis and treatment is a frightening topic. Parents may be selective about what is explained to their child and how. They put on a cheerful disposition in the child's presence and carefully downplay the enormity of the situation. As a result, parents can experience depression or anxiety in varying degrees long after their child has finished his or her treatment.

Parents need to talk about their feelings and concerns. Taking time out to debrief with a partner or friend can be therapeutic. The old saying, 'A problem shared is a problem halved', may not literally be true, but it can certainly help us to gather our thoughts, regroup and regain some logical order in our thinking.

Sometimes concerns need the attention of a professional. Health care teams are not only concerned with a diagnosed child's physical treatment, but also the psychosocial wellbeing of the child and their family. Discuss all of your concerns with your child's doctor, clinical nurse and social worker. Don't withhold questions for fear they may seem trivial. Expressing your concerns allows the health care team to provide the greatest amount of assistance and support that is necessary.

It may seem impossible at times, but parents caring for diagnosed children need to participate in normal routines. Any parent will agree that from the moment they heard the



news of their child's diagnosis, what was normal suddenly ceased to exist. But consciously retaining your usual routine can help alleviate the distress this change can cause.

The routine does not need to be remarkable. Walking the dog, mowing the lawn or meeting a friend for coffee are simple measures that can help you regain a feeling of control over your life. We have all heard people say, "Oh, I don't think I could cope if my child were diagnosed with a brain tumour." We do manage to find the strength and courage to cope with the situation. But we can't do it alone, and we shouldn't try.

After a child's diagnosis, the allocation of roles and responsibilities among family members varies greatly from family to family. Larger families living in close proximity to the treating hospital are better resourced to physically cope with the situation compared to a small or single parent family who lives remotely to the treating hospital. Whatever your situation, don't be afraid to ask for help!

There are several organisations that offer support, and the type of support varies among them. Just some of the services available include: financial assistance, counselling, tutoring for diagnosed children, camps and outings, holiday accommodation and provision of information. Unfortunately, some families are reluctant to seek support from these organisations.

For many, they feel too proud to ask. The reality is that many charitable organisations were started by people who have walked the same road, people who have felt the same pain and were driven to making the journey a little easier for those who follow. When families reach out and ask for support, charitable organisations are strengthened and inspired to continue the work they do.

At the end of the day, how can a carer care for another if they are needing care themselves? Carers need to think about their own physical, social and emotional needs and wellbeing. During uncertain and overwhelming times, they need to put positive strategies in place in order to help themselves, which will subsequently benefit the children in their care. In this tech-savvy world we live in today, advice and assistance is only a click or call away.

“One small query from a concerned parent may make a world of difference in the life of the child they love.”



Support for family carers – Carers Queensland

Up to 1 in 8 Queenslanders will at some point in their life identify as a carer. Carers Queensland aims for better and broader community acknowledgement of the lives of our carers, of the tiring and difficult work which they do each day – often because there is no one else who can do it. The replacement cost of the work which carers conduct, nationally, is valued at over \$40 billion per year.

The word 'carer' tends to conjure up different meanings for different people. For Carers Queensland, a carer is someone who provides unpaid care and support to a family member or close friend with a disability, mental health condition, who is frail/aged, or who has a chronic illness.

Family carers face a range of challenges by virtue of their caring role. Some of those challenges include social isolation, strained family relationships, maintaining their own physical and mental health & wellbeing, access to support & services, grief & loss, financial hardship, and of course maintaining an identity.

There are almost 500,000 carers in Queensland, many of whom have not accessed carer supports or respite in the past.

In order to assist carers, Carers Queensland provides a range of support services designed to help family carers maintain their own wellbeing. Carers Queensland aims to assist family carers to best support their loved ones by being better informed and better connected, with a view to improving their overall quality of life. All Carers Queensland programs are government funded and are delivered at no cost to carers. Programs that carers can access from most sites in the state include:

- Carer Advisory Service (1800 242 636)
- Counselling
- Support Groups
- No Interest Loan Scheme
- Better Start (for children with a disability under 6 years old)
- CALD (Culturally & Linguistically Diverse)
- Advocacy

- Training (including Certificate III & unaccredited training kits)
- Young Carers
- Community Events
- Your Life Your Choice (for families self-directing their DS funding)

If you are in a caring role and would like to connect with Carers Queensland staff, please phone either our Carer Advisory Service (1800 242 636) or one of our thirteen offices:

Camp Hill	3900 8100
Brisbane North	3624 1700
Brisbane South	3723 5001
Rockhampton	4921 4486
Toowoomba	4632 8922
Cairns	4031 0163
Mackay	4944 0544
Ipswich	3202 1852
Townsville	4725 8853
Roma	4622 1270
Gold Coast	5534 2899
Sunshine Coast:	5451 1882
Wide Bay	4124 0922



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

cancerqld.org.au