Cancer Council Queensland

# Brain Tumour Support Service

Edition 2, 2016

## Palliative Care

## Index

### FEATURE NEWS & ARTICLES

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# Dear Friends

**Welcome to the second edition of the newsletter for 2016.**

**This issue focuses on palliative care – it's something we don't talk about much, however many who are diagnosed with a brain tumour know that their lives may be shortened by the tumour as well as it affecting people's lives in so many other ways – and so it's an important topic to be able to discuss.**

We have a selection of articles that relate to the area of palliative care, including a comprehensive article by Chris Sibthorpe, an Information and Support Coordinator at Cancer Council Queensland, who describes the various symptoms that can occur in relation to different areas of the brain for a palliative patient, and some practical tips and strategies to support both carers and patients with these symptoms.

We have an interesting article (with some great photos!) about the history of T*he United Brain Tumour Support Group* over the past 11 years, which spans its commencement and now its disbanding - written by one of its support group members, Sandy Alexander-Moore.

And if you weren't aware of *Cancer Council's Brain Tumour Telephone Support Group* for people living with a brain tumour, then the article by Kate Harding (Cancer Council VIC) and Sally Carveth and Kim Pearce (Cancer Council NSW) is a must read!

We finish up with some very useful information on the 24/7 PalAssist Service by Cecilia van Raders, PalAssist Coordinator at Cancer Council Queensland, together with information by Grace Keyworth, Communications manager at Palliative Care Australia, about where and how to access a very useful downloadable resource called the *Dying to Talk Discussion Starter* guide, and finally an invitation to participate in Brain Tumour Research entitled *"Staying connected after Brain Tumour: changes in social networks in relation to well-being after brain tumour"* that Lee Cubis, PhD Candidate, is involved in.

Of course, we have our regular news and information which this edition includes a summary of the recent *Footprints for Brain Cancer Walk* by Carley Wagner, and our upcoming support and information session, which for anyone who has ever been interested in the What, *Why, How, When and Who of Fundraising*, is a session not to be missed.

We've also had lots of enquiries from members about superannuation, so don't miss details on accessing this new resource we now have available on page 3, together with some new resources dealing with other common legal and workplace issues.

This edition marks a farewell to Anne, who has graciously been our *Brain Tumour Support Service Newsletter* volunteer editor for many, many years, but who has now retired from this position. Please stay tuned for our next edition which will feature an article on Anne and her history with this newsletter.

In the meantime, and as Anne would say **"Until next time stay happy, keep well and keep smiling."**

***Brain Tumour Support Service Newsletter Editing Team***

## 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**

## Brain Tumour Information Session

**Date:** Thursday, October 6, 2016
**Speaker:** Rochelle Blake

**Where:** Auditorium, Cancer Council Queensland, 553 Gregory Terrace, Fortitude Valley QLD 4006

**Topic:** Fundraising - What, Why, How, When and Who?

### Outline of Presentation

- How the fundraising arms of CCQ work
- The fundamentals of fundraising – including how to get started, and who is a fundraiser
- Explanation of how much time fundraising takes, what efforts are required, and what communication skills works best

To register, please visit:
**www.cancerqld.org.au/event/fundraising-what-why-how-when-and-who-brisbane/**

## 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.

## New Resources!

Following many recent enquiries, we are pleased to announce that we have now added the following fact sheets to our website which provide information about common legal, financial and workplace issues

- Compensation and Work-Related Cancers
- Employment and Cancer
- Getting your Affairs in Order
- Help with Bills
- New Insurance Policies
- Superannuation and Cancer
- What Happens to Debts after Death.

For more information on the Legal, Financial and Workplace Referral Services provided by Cancer Council Queensland, please visit:

**www.cancerqld.org.au/get-support/cancer-support-services/pro-bono-legal-service**

> **“This issue focuses on palliative care – it’s something we don’t talk about much.”**

# Footprints for Brain Cancer Walk

*By Carley Wagner, Fundraising Campaign Coordinator, Cancer Council Queensland*

Sunday, May 1 2016, saw over 400 Brisbane locals gather at the North’s Hockey Club in Ashgrove to participate in the 3rd annual *Footprints for Brain Cancer* walk.

Ashgrove local Dianne McGinn founded the event in 2014 following her own brain cancer diagnosis. The 4km family walk aims to bring awareness to brain cancers and to show support to local brain cancer patients and their families. Sadly in late 2015, Dianne lost her battle with cancer however with the help of her friends and family, Cancer Council Queensland is proud to continue the event and keep Dianne’s legacy alive.

The rain was not enough to deter the walkers this year with many staying at the venue after the walk to enjoy a BBQ lunch, an inflatable soccer field, cake stall and live music from a local band. This year’s event raised over $21,000 which will be granted to Professor Brandon Wainwright’s research at the University of Queensland’s Institute of Molecular Bioscience (IMB). His research takes a unique approach to treating Medulloblastoma – the most common type of brain tumours in children – by targeting cells that have abnormalities in their chromosomes.

The 2017 *Footprints for Brain Cancer* event will be held on Sunday, May 7, 2017.

For further information, or to find out about our 2015-2016 Research Project Grants, please see our website at **www.cancerqld.org.au/research/research-grants-program/research-funded-by-us/**

For more information about Footprints for Brain Cancer, visit **www.cancerqld.org.au/be-involved/fundraise/footprints-for-brain-cancer/.**

# Palliative Care and Brain Tumour Symptoms

*By Chris Sibthorpe, Information and Support Coordinator, Cancer Council Queensland*

Brain tumours as well as their treatments bring a raft of symptoms and side effects into a patient's life, and management of these is critical to a person's well-being. While patients may have experienced the impact of their cancer and its treatment during their illness, these effects can often escalate as the disease progresses to the palliative and terminal stage.

Palliative care is specialised medical treatment for those with life limiting or chronic illnesses which cannot be cured, and patients with brain tumours may receive this type of support following their diagnosis and/or during end-of-life care at home or in a hospice setting. The focus is on the provision of symptom relief whilst maximising quality of life for patients and their loved ones. This article will focus on a number of the common symptoms for people with a brain tumour in a palliative situation and discuss how these might be managed, either by the patient themselves or via health professionals delivering palliative care.

> **"The focus is on the provision of symptom relief whilst maximising quality of life for patients and their loved ones."**

Firstly, it is important to stress that the symptoms of a brain tumour for a palliative patient can be either the direct result of the disease progression, or as a side effect of treatment. This article shall focus only on the symptoms which arise as a result of the tumour, not on the side effects of treatment such as chemotherapy and other drugs, or radiation therapy.

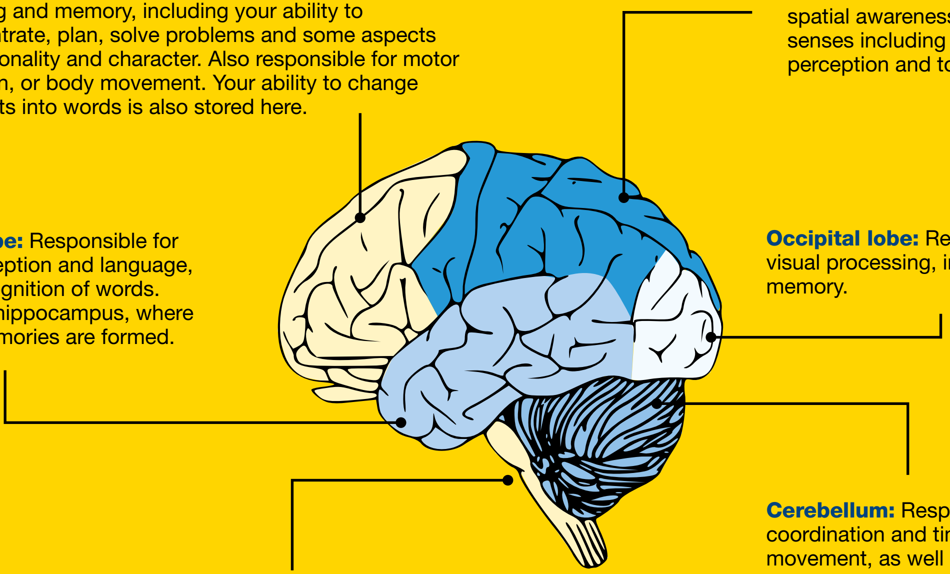
The symptoms of a brain tumour can develop slowly or rapidly depending on the type of tumour. Headaches are a common symptom but usually not the only one. Changes in personality and having a seizure (fit) are other general symptoms. A brain tumour can also increase the pressure in the skull with the main symptoms of this being headaches, sickness, vomiting and confusion.

Other symptoms depend on the position of the tumour and how it prevents that part of the brain from working properly. The following diagram (page 5) illustrates the various parts of the brain and their functions.

Depending on location, the following specific symptoms may be experienced:

- **Frontal lobe –** changes in personality or behaviour, uncoordinated walking or weakness on one side of the body.
- **Parietal lobe –** difficulty with speech and understanding, problems writing, reading and doing simple calculations, difficulty finding your way around, numbness or weakness on one side of the body.
- **Temporal lobe –** difficulties with speech or problems with memory.
- **Occipital lobe –** problems with sight or losing part of your vision.
- **Cerebellum –** lack of coordination, double vision or blurred vision, unsteadiness or problems with speech.
- **Brain stem –** dizziness, unsteady and uncoordinated walking, facial weakness, double vision or difficulty with speech and swallowing.
- **Pituitary gland –** different hormone related symptoms including irregular periods, infertility, weight gain, high blood pressure, diabetes, mood swings and enlarged hands and feet. A tumour in the pituitary gland can also cause tunnel vision because of pressure on the nerves to the eyes.

As the tumour grows it affects surrounding brain tissue and prevents that part of the brain from working normally. The tumour can sometimes cause swelling that increases the pressure inside the brain and this can cause other symptoms such as headaches, fatigue, loss of appetitie/cachexia (weight loss), nausea, vomiting, seizures, and changes in personality. People living with a brain tumour can live for many years with cumulative physical and cognitive disabilities, and subsequently deal with a decreasing quality of life before reaching the terminal stage of their condition. Often there is little discussion about end of life care for people with neurological conditions.



**Frontal lobe**: Responsible for cognition, executive thinking and memory, including your ability to concentrate, plan, solve problems and some aspects of personality and character. Also responsible for motor function, or body movement. Your ability to change thoughts into words is also stored here.

**Parietal lobe:** Responsible for spatial awareness, and integrating senses including speech, visual perception and touch.

**Temporal lobe:** Responsible for auditory perception and language, including recognition of words. Contains the hippocampus, where long-term memories are formed.

**Occipital lobe:** Responsible for visual processing, including visual memory.

**Cerebellum:** Responsible for coordination and timing of voluntary movement, as well as balance, standing and walking. Regulates fear, pleasure, attention and language.

**Brain stem:** Controls life-supporting functions including alertness, arousal, breathing, temperature, blood pressure and ability to sleep.

Additionally, there is a lack of recognition that these people may experience cognitive changes and that end-of-life care discussions need to take place earlier.

As the tumour continues to progress there are a number of symptoms which may indicate a terminal phase of the illness is underway and end of life should be considered. These may include:

- Drowsiness/increased sleep
- Significant weight loss (cachexia)/loss of appetite
- Reduced level of consciousness without reversible cause
- Dysphagia (difficulty swallowing)
- Headache
- Epilepsy
- Agitation, restlessness and delirium
- Agonal breathing (breathlessness/gasping, laboured breathing)
- Loss of control of bladder and bowel
- Cold feet, hands, legs and arms.

Palliative treatment helps to improve people's quality of life by alleviating symptoms of cancer without trying to cure the disease. It is particularly important for people with advanced cancer. However, it is not just for end-of-life care and it can be used at different stages of cancer. Treatment is not just concerned with pain relief and stopping the spread of cancer, but it also involves the management of other physical and emotional symptoms.

The management of symptoms is best achieved via a joint approach between the patient, their carers and the health professionals/Palliative Care Team. The following strategies may be beneficial in managing some of these conditions.

## Agitation, Restlessness and Delirium

Firstly, reassurance at this time is vital, because while restlessness symptoms can be distressing to see, they are normal at end of life. Before adopting any strategies to address this, check with the patient that there is not a simpler explanation for their restlessness such as:

- Are they in pain/too hot/too cold?
- Are the bed sheets bothering them?
- Do they need to go to the bathroom?
- Does the patient need to have their position in the bed changed?

Once the more obvious causes have been excluded it may be beneficial to engage in calming practices like:

- Recalling a favourite place they enjoyed or talking about a favourite experience.
- Reading something comforting (a favourite book, poetry or religious text).
- Playing music.
- Spending time with pets.
- Giving assurance that it is okay to let go.

## Fatigue/Drowsiness/Increased Sleep/Reduced Levels of Consciousness

Ascertain whether the patient has more or less energy at certain times of the day. That is, observing 'patterns' of fatigue and doing important activities when energy levels are highest.

- Prioritise activity to ensure that the most important activities are done before running out of energy. Don't sweat the small stuff.
- Take a look at activities for the day and put them in a list in order of priority. It is important that the schedule is flexible to accommodate for the unexpected.
- Consider what activity (e.g. short walk) the patient might be able to manage. Implement this as part of the daily routine.
- Encourage the patient to rest on days when they are not feeling the best.
- Encourage patients to listen to their body and let the treating team know of any symptoms they may be experiencing.

## Loss of Appetite (Cachexia)

Loss of appetite may be caused by oral symptoms and related problems such as mucositis (mouth ulcers) or oral thrush, nausea, pain, difficulty swallowing (dysphagia), difficulty breathing (dyspnoea) and constipation. These issues must be first considered and addressed by the treatment team.

Issues such as malabsorption (the inability of the body to absorb food), medication side-effects, de-conditioning/reduced level of activity, changed sense of taste and smell are more intrinsic to the disease itself. It is worthwhile considering approaches such as oral nutritional supplements / intravenous or tube-fed supplements, anti-nausea and or appetite stimulating medication.

Beyond a treatment approach, often it is worth considering family, social and cultural expectations related to food, diet, and body weight, particularly as it relates to carers. That is, we often feel that caring for our loved ones when they are sick involves feeding them, and carers can feel they are failing the patient when symptoms such as loss of appetite etc. arise. These symptoms are often a visible indication of the patient's failing health which is beyond the carer's control, and support and reassurance for carers at this time is very important.

## Headache/Other Pain

The first approach to headache and other pain is to ascertain the origin of the pain and for the Doctor to prescribe appropriate pain relief. Again, beyond a medical approach, the following may offer relief:

The experience of pain is subjective. People may perceive pain to be greater when their general resilience is lower. Patients should receive emotional support to the extent that they do not feel as isolated, alone, or vulnerable.

Some complementary therapies may reduce pain. These include relaxation techniques, mindfulness meditation, massage, and art therapy which allows people to express themselves via painting, drawing, journal writing, poetry or similar.

For more support or information on palliative care, you can call the 24/7 palliative care support and information line on **1800 772 273** or call Cancer Council **13 11 20.**

## References

Cancer Council Australia 2016, Understanding Brain Tumours, accessed 01 August 2016, **www.cancerqld.org.au/content/resources/library/understanding%20brain%20tumours.pdf.**

American Brain Tumour Association 2014, Side Effects and their Management, accessed 01 August 2016, **www.abta.org/brain-tumor-treatment/side-effects/.**

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MacMillan Cancer Support (UK) 2016, Signs and Symptoms of a Brain Tumour, accessed 01 August 2016, **www.macmillan.org.uk/information-and-support/brain-tumours/understanding-cancer/signs-and-symptoms-of-a-brain-tumour.html.**

Cancer Council Australia 2015, Overcoming Cancer Pain, accessed 01 August 2016, **www.cancerqld.org.au/content/resources/library/overcoming%20cancer%20pain.pdf.**

# Invitation to Participate in Brain Tumour Research

*By Lee Cubis, PhD Candidate (Clinical Psychology), School of Applied Psychology, Griffith University*

You are invited to participate in “Staying Connected after Brain Tumour: Changes in social networks in relation to well-being after brain tumour.”

## What is this research about?

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, inability to drive and less 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 is being undertaken by Griffith University with support from Cancer Council Queensland, and 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 invited 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.

## What is involved?

If you would like to participate, 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 researcher, Lee Cubis, will meet with you at a place of your convenience such as your home, local library or at Griffith University.

## How to take part

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

# The United Brain Tumour Support Group

## (Formerly 'The All New Gold Coast Brain Tumour Support Group')

*The start of our first 'Dianne Moore Memorial Walk' July 2009*

*By Sandy Alexander-Moore, Support Group Member*

In the very beginning Dianne Moore used to come to our Cancer Support group for my husband and wanted a similar support group for people with brain tumours and carers as she could not find any groups for people her age in their 20's or 30's to go for support. Dianne went to Queensland Cancer Fund (now Cancer Council Queensland) where she met Peter McLaughlin and they decided to start up a new support group.

So 'The All New Gold Coast Brain Tumour Support Group' was formed on November 23, 2005, with the first meeting with Frank Hughes from Cancer Council Queensland held in rooms at Pacific Fair on the Gold Coast on December 5, 2005.

From there we were able to use the Albert Waterways Hall in Mermaid Waters (Gold Coast) for free for six months through Eddy Sarroff, the local councillor for that area at the time. We met every second Tuesday of the month for two hours in the morning where we were getting approximately 20 people attending the meetings.

We bought a Teddy bear for the person talking to hold onto which provided a great comfort during our meetings, and we sat in a circle. We had speakers come and talk and listen to our stories and help where necessary. If we did not have any speakers, we all had turns about telling our story, and at the end of the meetings we had morning tea.

After the six months were up we had to find somewhere else to have our meetings, but we could not afford to pay for a hall or rooms so we gave up the meetings but not the friendships as we all kept in contact.

On July 4, 2006, a group of us from the Gold Coast went to Cancer Council Brisbane's meeting and from there we were able to go to 'Backyard Blitz' and meet stars of the show who were in Brisbane to support local residents.

We had a session with the girls from a wig shop where everyone tried on the wigs, a great opportunity to see which ones suited best. In early 2008, Peter and his father Pat, started our group up again under the name 'The United Brain Tumour Support Group', meeting at The Tugun Surf Club (Gold Coast) on the third Wednesday of

*Meeting Backyard Blitz*
*4th July 2006*

*Peter McLaughlin, Frank Hughes & Dianne Moore,*
*November 2005*

the month. We then decided to have a walk and sausage sizzle at Burleigh Heads once a year in July which we called 'The Dianne Moore Memorial Walk'. We held this event for five years from 2009 to 2013 which was very successful at first.

We also held Sausage sizzles every year at the Bunnings store in Burleigh (Gold Coast) with the help of our wonderful members. With money raised we were able to help a number of charities and pay for medical staff to go to conferences. In May 2011 we donated $5000 to Cancer Council Queensland towards the inaugural brain tumour awareness week and also donated $5000 to Dr David Walker's Neuro Foundation towards research into brain tumours.

Our group disbanded in June 2016 but during its time we met wonderful people and made great friendships.

**For more information, call Cancer Council 13 11 20 to see if there are any Brain Tumour support groups in your area, or phone Cancer Council's Brain Tumour Telephone Support Group toll-free on 1300 755 632.**

# We're all in the same boat

## Cancer Council's Telephone Support Group for People Living with a Brain Tumour

*By Kate Harding, Cancer Council Victoria, Sally Carveth and Kim Pearce, Cancer Council New South Wales*

Cancer Council NSW runs a telephone support group for people who are living with a brain tumour. It is accessible to people located all over Australia. The aim of the group is to provide emotional support to the participants, helping them to feel less isolated. It also provides an opportunity to share information and openly discuss the concerns and challenges of living with a brain tumour.

There is no cost to join and members can participate as often as they wish around medical appointments and other commitments, with many participating from the comfort of their own home. These groups are a safe and confidential meeting space for those who might not have other people to connect with in their community. Groups are facilitated by trained health professionals.

Travis, who tried a face to face group in a large metropolitan city before joining the telephone group, agrees. "Not many people came," he says, discussing the common issue of no longer being able to drive and easily get about. "I live in the outer suburbs which meant it was difficult to connect to others who have been in a similar situation. It's great, through this group, to hear and relate to other people and their situations."

Even with a wide diversity of location or personal situations, members say that talking with others who have also been diagnosed with a brain tumour gives them a lot in common and lots to talk about.

"We often can't talk to others in our life as it's a very heavy subject matter," Jade says, from her regional home town. "I have the double set of emotions of having a brain tumour and being a proud transgender woman. I felt very alone before. I do see a psychologist, but it is not the same thing."

The Brain Tumour Telephone Support Group meets for an hour-long phone conversation on the first and third Monday of every month from 1.30pm to 2.30pm (Australian Eastern Standard Time). Participants are connected into a conference call.

If you would like to know more about Cancer Council's Brain Tumour Telephone Support Group please call the team toll-free on: **1300 755 632**, enquire through the Cancer Council Information and Support Line: **13 11 20**, or email: **tsg@nswcc.org.au**

**PalAssist**
Palliative care
support & advice 24/7

# PalAssist – 24/7 Palliative Care Support and Information

*By Cecilia van Raders, PalAssist Coordinator, Cancer Council Queensland*

Palliative care is medical, nursing and supportive care received when the aim of treatment is symptom control and quality of life, rather than cure. Often we hear the term used when someone has been told they have only a few months or so to live, but some people who live with a condition that is going to limit their life span ("life limiting illness" or "terminal illness") – such as a brain tumour - will see a palliative care specialist or team to assist with symptom control over a long period of time, sometimes even years.

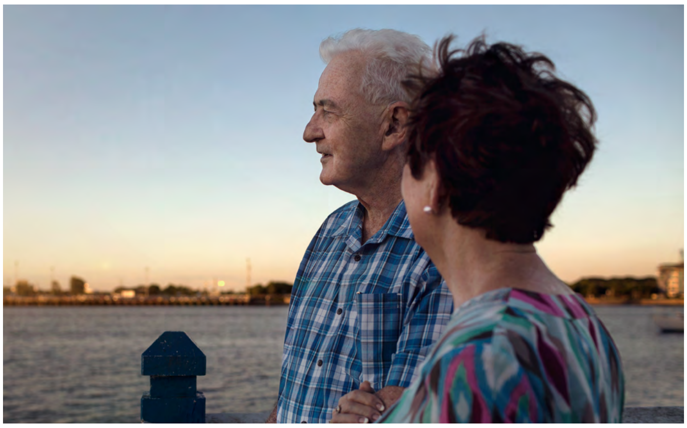
Whether a person is expected to survive 3-4 years, another few months, or even just a few more days, being told that your condition is going to lead to death can be confronting, confusing and scary. This can be so for the person with the condition, as well as for family and friends. It can be difficult to know what to ask, what to do, or even who to ask.

If you have questions or concerns about your own care, or the care of a loved one during the palliative phase of care, then PalAssist is here to help you.

PalAssist is a Queensland wide no-cost 24 hour phone and online service for anyone undergoing palliative care, caring for someone having palliative care, or simply having any questions about palliative care. The service is funded by Queensland Health and provided by Cancer Council Queensland.

The registered nurses and health professionals at PalAssist can help with:

- Accurate and up-to-date information about palliative care
- Emotional support over the phone and options for ongoing support if needed
- Guidance about practical aspects of planning for end-stage care and death
- Information about palliative care services in your local area.



If you are not sure who to ask: ask us. If we cannot answer your questions directly we can help guide you to someone who can.

If you need someone to talk to: talk to us.

We're here and we care 24/7. You can call us on **1800 772 273** or chat online by visiting **www.palassist.org.au**

> **"Many people, both patients and carers, are worried that a referral to palliative care will mean a loss of control, when in fact the opposite is true."**
> **Chris, PalAssist Advisor**

## PalAssist Resources

Carers Queensland **www.carersqld.asn.au**

Compassionate Friends Queensland, Supporting Family After a Child Dies
**www.compassionatefriendsqld.org.au**

Caresearch – Palliative Care Knowledge Network
**www.caresearch.com.au**

Palliative Care Australia **www.palliativecare.org.au**

PalAssist – Palliative care support and advice 24/7
**www.palassist.org.au**

Redkite – Provides support to children and young people with cancer and the family and support network who care for them **www.redkite.org.au**

# Dying to Talk

## A new guide to support discussions about what matters at the end of life

*By Grace Keyworth, Communications Manager at Palliative Care Australia*

Some people are comfortable talking about death and dying. Others find it upsetting and difficult. Wherever you or your loved ones might sit on that spectrum, the *Dying to Talk Discussion Starter* will help you clarify your end-of-life wishes and communicate them to others.

The Discussion Starter starts with questions that focus on what you value. It covers important issues, such as whether you would want to have your life extended for a short time, even if it meant you might be sicker during that time, and whether you would prefer to be cared for in hospital or at home. It then helps you work out who you would like to talk to about your end-of-life wishes and how much you would like to share with them. It also provides you with practical suggestions for getting discussions started.

Palliative Care Australia CEO Liz Callaghan said the more that close friends and family understand about your wishes, the better equipped they will be to make decisions on your behalf, should you be too unwell to articulate them yourself.

“In an ideal world, we would all be able to make our own decisions about what medical treatment we want at the end of life, but when people become very unwell that isn’t always possible,” Ms Callaghan said. “Sometimes friends and family have to step in and make important decisions on behalf of a loved one, which is much more stressful if they are not clear about what that person would want.

“The best time to have these discussions is when you are not in an emotion-charged environment and you are able to take your time and think clearly.” Ms Callaghan said the health system has a natural focus on trying to save lives, which can sometimes work against quality of life and a peaceful death, so it was important for people to understand they had choices.

While some people may opt for every medical treatment possible, regardless of the impact it has on their quality of life, others may want to avoid specific interventions – or decide not to accept active treatment that would not affect their prognosis.

Palliative care can be accessed by anyone with an advanced chronic illness. While palliative care has a focus on pain relief, it also treats emotional, spiritual and social symptoms experienced by people living with a life-limiting or terminal illness, and their families.

Ms Callaghan said palliative care can enhance quality of life for patients and their families for many months before death, dispelling the misconception that it is only appropriate for people in the last few days or weeks of life. Some patients benefit from receiving palliative care as well as active medical treatment, so that they are able to live their life as comfortably and fully as possible.

“There are no right or wrong answers when it comes to decisions about end-of-life care and people’s views and expectations vary widely. If you are living with a life-limiting or terminal illness, it is very important to think about what end-of-life care you would find acceptable – do not presume your loved ones will know. The Discussion Starter will help you work out what is right for you and then support your efforts to talk about it.”

To download the *Dying to Talk Discussion Starter* visit **www.dyingtotalk.org.au**

**82%** of Australians think it’s important **TO TALK TO THEIR FAMILY** about how they want to be cared for at the end of their lives

**80%** of people think it’s important to **put their preferences for end-of-life in writing**

**ONLY 21%** have actually done this

## 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.