

Headlines

a newsletter for brain tumour patients and their families

winter 2018

MY STORY



By Aislinn Hunter

IN FEBRUARY 2017 my husband was diagnosed with an inoperable brain tumour. He was 53 years old and we'd been married for 24 years. The original prognosis – told to me in the hospital waiting room by the neurosurgeon who'd just completed my husband's biopsy – turned our world upside down. It was possible, the surgeon said, that my husband might only have a year to a year-and-a-half to live.

I'm not the sort of person who does well with the unknown – and brain tumours, brain tumour treatments and cancer prognoses come with a lot of uncertainty. In those first few months after his diagnosis I worked really hard to control as much of our unraveling lives as I could. I kept a big coil-bound calendar in which I managed appointments, listed contacts and lined up extra help. I kept notes on everything from his symptoms and medications to his changing weight.

I read books on brain cancer and made appointments for the two of us to see a counselor at the cancer centre, which was immensely helpful. I booked a trip for his month off radiation and chemo and then pushed him around France and Spain in a wheelchair. If I cried it was usually when I was alone and then never for too long – though I had a respectable number of public breakdowns too.

Having no control when someone you love has a brain tumour is one of the most difficult things about caregiving. You want to make the person better, to wave a magic wand over their head, but instead you're left with grocery shopping, cooking, driving to and from, filling out forms, and watching and waiting for symptoms to come or go. While I felt, for the most part, like I was acting with purpose, I also felt painfully full of uncertainty: was he getting better or worse; was he going to live or was he going to die?

What made those months okay for us was our ability to talk about almost anything. We've been married a long time but we're also best friends. My husband is also really funny and his ability to crack jokes even in the dark times has been therapeutic for both of us. (On his first day of full brain radiation the radiologist asked him if he'd like a warm blanket and my husband said, "Yes. And a cognac.") That said, I think the ability to communicate well in difficult times is more uncommon than it is common. It can take a long time to learn how to express the complexity of one's feelings in words, and sometimes, even in close marriages or close families, people have a hard time finding the right words – or stay quiet for fear of how those

words might be received. But being able to share what you're going through with someone – your loved one, a counselor, a friend, or a support group – is an important part of self-care for caregivers. There's power in the telling – in talking about whatever it is you're going through, in being understood and heard.

My husband is doing great. He's responded so well to treatment that his lemon-sized tumour is no longer visible. He continues to inspire me (and make me laugh) every day. We're full of gratitude for the care we've received, the friendships that have deepened because of this disease, and the new community we've been welcomed into. We still don't know where we'll be in a year, or two, or five, but I understand now that we've never really known – we were always just making hoped-for best guesses. I've learned a lot over this past year, chief among them: how to say "I'm not okay" when I'm not okay, how to ask for help when I need it, and how to celebrate the present, which for us means looking at each other every day and saying how happy we are to still be here, on this earth, together.



The role of a speech language pathologist in brain tumour care

By Cindy Reynolds, M.H.Sc., RSLP
Speech-Language Pathologist

A SPEECH LANGUAGE PATHOLOGIST (S-LP) is a health care professional with extensive training in anatomy, physiology, psychology, language development and linguistics. An S-LP is able to evaluate, diagnose and treat a broad range of problems related to speech production, expression through language and swallowing. Not everyone who is diagnosed with a brain tumour will develop difficulties with swallowing or communication, but if you or a loved one does, an S-LP can give you the tools to manage these problems.

For both communication and swallowing problems, the degree or severity of symptoms will depend on the size and location of the tumour.

The medical term for swallowing problems is dysphagia. **Dysphagia** can make eating meals unpleasant or lead to more serious problems such as malnutrition, dehydration and pneumonia.

Common symptoms of dysphagia are:

- Drooling or pocketing of food
- Difficulty chewing or painful swallowing
- Coughing or choking during swallowing
- Frequent throat clearing
- Sensing something stuck in throat
- Reflux of food or acid
- Prolonged eating time or inability to finish a meal



When communication breaks down, the impact can be frustrating, embarrassing or confusing for everyone involved. The most common type of problem in communication is called **aphasia**

(or **dysphasia**). There are specialized areas in the brain that are critical for communication (see diagram, areas marked 1, 2 and 3). These can be affected by a tumour or stroke.

Some of the **problems that occur when the brain's speech centres are injured** include:

- Problems coming up with words
- Difficulty understanding others
- Difficulty reading and/or writing

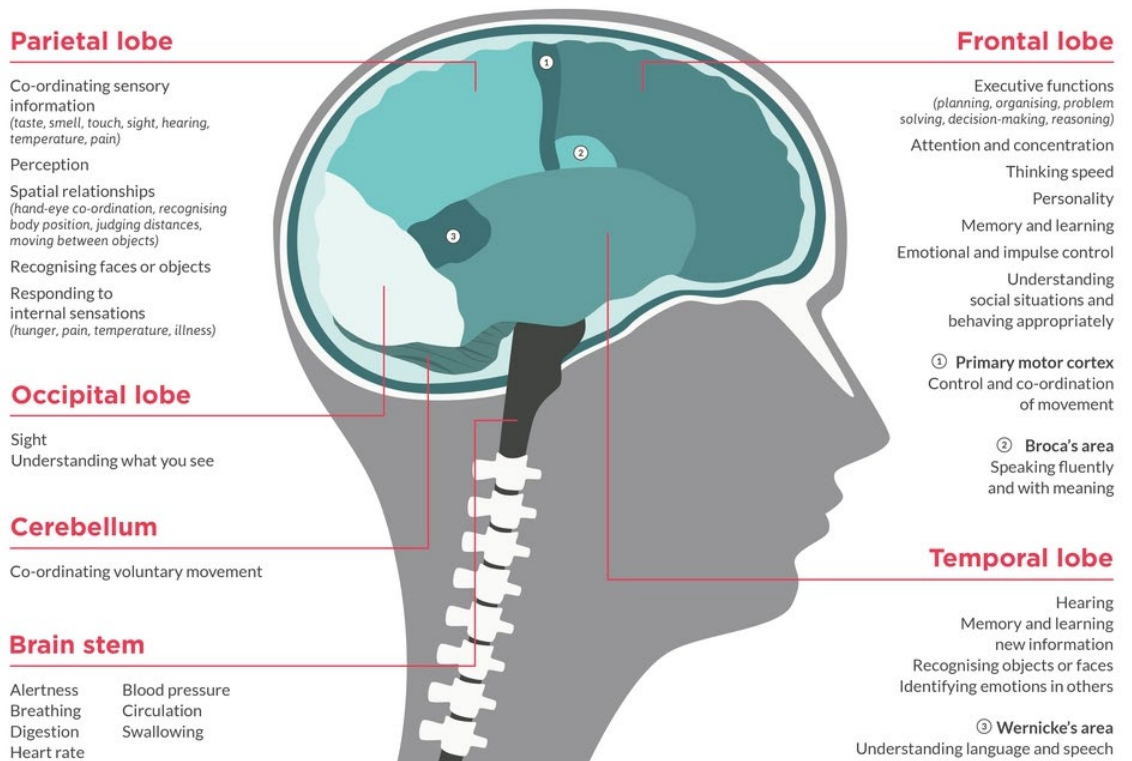
Aphasia is not due to confusion or memory problems. People who are aphasic are still the same people with the

same sense of humour, interests, likes and dislikes. They know what they want to say, but are unable to express themselves.

Remember that communication is a "two-way street" so everyone plays a role in communication. An S-LP can help patients and family members who are living with communication or swallowing difficulties by:

- Helping you understand why the problem is occurring
- Offering therapy to relearn skills necessary for proper swallowing
- Teaching you how to live better with the existing problems you have
- Finding new ways to communicate. Remember, not all communication is spoken!

If you think you or your loved one may benefit from seeing an S-LP for help with communication or swallowing, ask your oncologist for a referral.



It's all in your head

By Alan Bates, MD, PhD, BC Cancer
Provincial Practice Leader for Psychiatry

ACTUALLY, IT'S QUITE TRUE.

The new anxiety, feelings of depression, mental fatigue, unusual perceptual experiences or even the "seizures" that your doctors tell you aren't really seizures may well have their causes "in your head," but that doesn't mean they're made up, unexplainable, or a sign of weakness.

The brain is a complicated organ and there are times when brain-related problems can cause both psychiatric symptoms (for example, depression) and neurological symptoms (for example, headache). Unfortunately, there are times when patients who have both kinds of symptoms seem to fall through the cracks of the medical system. We do our best to avoid this through the close collaboration of the Psychosocial Oncology and Neuro-Oncology teams at BC Cancer. There are many examples of how the two teams complement each other.

For example, the experience of some forms of headache pain, while having a "neurological" cause related to the cells within the brain may also be affected by one's mood. We've all had the experience where we're having a bad day and stub a toe and it hurts like the dickens, where a similar event on a particularly good day might hardly trouble us at all.

Another interesting example of the overlap between Psychiatry and Neurology is *pseudoseizures*. Pseudoseizures are seizure-like events that aren't associated with seizure activity in the brain. Pseudoseizures aren't faked or unexplainable, they just require a different kind of medical help than other seizures, and that help includes psychotherapy.

Medical syndromes having both "psychiatric" and "neurological" signs and/

or symptoms can make them somewhat more complicated, but there is a positive flip-side. As is the case with many kinds of pain, psychiatric treatments and neurological treatments may act together

to be more effective than either treatment on its own. And there are actually a number of medications, such as anti-seizure medications, that are also mood stabilizers. These medications can sometimes be used to address both psychiatric and neurological symptoms at the same time.



The Psychosocial Oncology team is also available to help BC Cancer patients with difficult emotions related to having cancer. There are a number of reasons why brain cancer may be more emotionally challenging than other forms of cancer. Brain cancer and its treatment might directly affect one's mobility, speech or even one's personality. Because of this, people with brain cancer sometimes feel the cancer is attacking their very being, self, soul, or identity. Even subtle cognitive changes might cause a high-functioning professional to feel they are no longer themselves. In addition, there may be symptoms like depression, anxiety, or even hallucinations that mimic forms of psychiatric illness. Sometimes these symptoms lead to feelings of shame or embarrassment about having a form of mental illness. And to add further insult to injury, psychiatric symptoms related to brain cancer and its treatment are often more difficult to treat than the same symptoms or syndromes due solely to psychiatric disorders. This is again where the close relationship between BC Cancer Neuro-Oncology and BC Cancer Psychosocial Oncology comes into play.

There are many psychosocial services that the Neuro-Oncology team might suggest for you. They don't think you're "crazy!" They simply want you to receive the best, most comprehensive treatment possible. Examples of services that

might be offered include help accessing rehabilitation programs, financial resources to help pay for treatments, vocational counselling for work or school and supportive counselling to help with anxiety and/or depression. They might also suggest a meeting with a psychiatrist who can help with severe anxiety or depression, thoughts about suicide, hallucinations and severe mental fatigue. Our psychiatrists are experts in treating psychiatric symptoms due to any cause while minimizing (and usually avoiding) any negative impact on other symptoms or conditions and their treatment.

Our counsellors and psychiatrists are experts at helping people who feel discouraged or even hopeless as a result of a cancer diagnosis. With guidance, you can find meaning, purpose, and greater emotional stability even as you cope with the challenges related to a brain tumour. So, don't be afraid to ask your oncologist, neurologist, or nurse practitioner about seeing a counsellor or a psychiatrist. We're part of the team and we're here to help.

For more information about resources available through the Psychosocial Oncology program, contact the Patient Family Counselling department at your cancer centre or ask for help from your health care team.

Editions of *Headlines* are also available as a pdf download on our website at:

www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/headlines

If you would like to submit an article, ask a question, or serve on our patient and family editorial board, please contact Rosemary Cashman at rcashman@bccancer.bc.ca or 604 877 6072 (phone) 604 877 6180 (fax).

All content by Rosemary Cashman unless otherwise specified.

Caregiving, self-care and creativity

By Dilek Cansin

SOMETIMES I HEAR people say that it can be more challenging to be a caregiver than to be ill. I don't believe that is the case for my husband and me, but as a caregiver, at times I feel overwhelmed by the roller coaster of emotions. All those trepidations while waiting for the latest test results... then celebrations after receiving good news... not to mention the grief over our "old normal" which may never come back...

On a good day, I am in total gratitude, feeling blessed and connected, my heart overflowing with love and compassion... On a bad day, I cannot stop the tears, lacking sleep after tossing and turning, worrying about "what ifs," and wondering if there is any light at the end of this tunnel.

However, the gap between my good days and not-so-good days has been closing. Self-care is the name of the game! For me, self-care involves a hobby that has caught on fire and turned into a wonderfully rewarding passion.

The pottery studio has become my happy place, where time stops and I am in total flow. Playing with clay, I get to express



One of my favourite pieces to date

what I cannot put into words. I usually create funky forms and choose vibrant colours.

Creating pottery, I get many opportunities to practise non-attachment – a state where I am able to allow life to unfold without expectations or the need to control everything. One never knows what surprises await. While the wet clay is drying, unrepairable cracks are common. Or a crack may happen in the kiln, during the bisque firing. The glazes are also unpredictable: sometimes one "runs" unexpectedly when in contact with another. If it runs so much that it touches the shelf it is on, it destroys the piece AND the shelf, possibly leading to a hefty bill for damage to the kiln. Also outside my control is the temperature of the kiln, which can determine the shade or the tint of the glaze.

In the fall of 2015, two of my pottery pieces were selected for an art exhibit called, "Brain Cancer Got Me Thinking" at Visual Space Gallery in Vancouver. Although it was my first public participation, one of my pieces sold even before the opening gala! More importantly, publicly sharing our story of Volker's diagnosis and its impact on our life helped us become much more open about

our cancer journey. When more people in our circle know what we are dealing with, we feel more free, and more prayers and positive healing energy come our way.

Since that first show, I have participated in InspireHealth's 2016 gala, "A Night to Inspire," the 2017 "Brain Cancer Got Me Thinking" exhibit and two Aberthau Pottery Show and Sales – all very successful.

Volker also loves pottery, so much so that we sometimes turn our small living room into a studio. It is wonderful to share this passion with my beloved. It is also good for me to meditate with clay on my own.

Undoubtedly, Volker's diagnosis has taught us on many levels. One lesson is how to turn mud into art. The other is never ever to underestimate the importance of self-care!



My husband Volker and me at the opening gala of "Brain Cancer Got Me Thinking" in 2015

Look to this day
for it is life
the very life of life.
In its brief course lie all
the realities and truths of existence
the joy of growth
the splendor of action
the glory of power.

For yesterday is but a memory
and tomorrow is only a vision.
But today well lived
makes every yesterday a memory of happiness
and every tomorrow a vision of hope.

Look well, therefore, to this day.

Attributed to Kalidasa, an Indian Sanskrit playwright and poet of the 4th-5th Century AD.

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