

Headlines

Spring 08

A newsletter for brain tumour patients and their families

MY STORY

Hurry Up and Wait

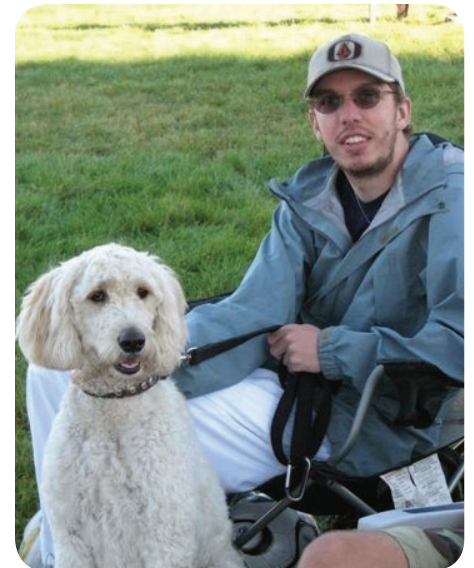
By Jared Brick

Eyes try to open after surgery
 a strange goop in them prevents this.
 I try to yell I'm awake,
 but the ventilator down my throat stops me.
 I reach up to pull it out
 but my hands are tied,
 to stop me from doing just this.
 Eventually, a nurse notices.
 My hands untied
 The ventilator removed
 The substance wiped out of my eyes
 I lie on the bed
 waiting for the doctor to tell me
 I can go home
 until treatment has to continue.

Chemotherapy, the second step in
 treatment.
 Nurse pokes me with needles
 until she strikes a vein.
 Sitting and waiting
 while poison courses through my veins.
 They call it chemotherapy
 and tell me it is making me better.
 I watch my hair fall out.
 I roll over in bed and throw up.
 I am too tired to sit.
 Better, I think,
 Yeah right.

Radiation, the last step in treatment.
 A clear plastic mask
 to strap me to the table,
 straight out of a medieval torture room.
 A bed,
 cold and hard.
 An apron,
 lead, so stray radiation does no damage.
 I am fastened to the table with my mask.
 "Lie still, this will only take a minute" they
 tell me.
 Technicians leave the room,
 and I hear nothing as the machine works.
 A technician enters the room.
 "You are finished" they tell me.
 Treatment is over.
 Refined by the trip through hell,
 new appreciations for life arise.
 A strength within discovered,
 to carry me through future struggles.
 The waiting over,
 No more restraints,
 No more poison,
 No more radiation.
 Appreciative to those before me,
 Who didn't make it.
 Their passing was not in vain.
 They made it so that I could survive.
 Thankful.

Jared Brick is a student at Douglas College who will complete his associate science degree after this semester. He hopes to transfer to UBC in September to begin a biochemistry degree. Jared was diagnosed in 2000 with a germinoma tumour of the pineal gland and underwent two brain surgeries, chemotherapy and radiation therapy. This poem first appeared in Pearls, a student anthology published by Douglas College



Jared Brick and friend

Life after treatment: Monitoring your condition

AFTER YOU FINISH YOUR TREATMENT, you will continue to have regular assessments, including a CT or MRI to ensure that the tumour is not becoming active and a general physical examination to monitor for symptoms and treatment side effects. When tumours become active after treatment, they usually do so in their original location. As a result, signs of recurrence are often similar to the original signs and symptoms of the tumour. Although primary brain tumours sometimes regrow in a new area of the brain, they rarely spread outside the brain.

In 30-70% of people, a seizure is the first sign of a brain tumour. If you have had a seizure in the past, you may be on medication to prevent seizures and this will reduce your risk of having a generalized seizure (that is, one causing loss of consciousness) in the future. However, even with seizure medications some people continue to have milder forms of seizures, termed partial or focal seizures. Your lifetime risk of all types of seizures, including generalized seizures, will always be higher than for someone without a brain tumour. This is because there is abnormal tissue (for example, a scar or area of tumour cells) in the brain which causes disruption of electrical communication between brain cells. Seizure activity should be reported, but it does not necessarily mean that a tumour is growing.

“Focal signs” of brain tumour activity are related to the location of the tumour within the brain.

Selected focal signs and symptoms of brain tumours

Location of tumour	Potential focal signs and symptoms
Frontal lobe	Changes in behaviour and personality; difficulty with problem solving, judgment and insight; problems with speech and word-finding; arm or leg weakness on one side of the body
Parietal lobe	Changes in sensation on one side of the body; inability to recognize numbers or letters; difficulty with dressing
Temporal lobe	Seizures; memory problems; visual problems; speech and language problems
Occipital lobe	Visual problems, especially loss of peripheral vision on one side
Cerebellum	Problems with balance, coordination and eye movements

Growing tumours create increased pressure within the brain, either because of inflammation and swelling around the tumour, or through the solid mass itself. A protective rigid skull encompasses brain tissue, blood and the cerebrospinal fluid which bathes the brain and spinal cord. This material fills the skull so completely that there is little room for anything else. Nonetheless, a tumour may grow very slowly in the brain for a time without causing symptoms, while a rapidly growing one may quickly cause signs of pressure. At your follow-up visits, your doctor or nurse may use a light to inspect the back of your eye for signs of pressure on the optic nerve.

Fatigue may continue for months after treatment, especially if radiation was given. Long-term side effects of treatment include changes in memory and thinking abilities. These side effects may impact your ability to return to work or school. Sometimes medications can help to alleviate problems related to mental

slowness. Radiation to the brain can also cause changes in hormone levels, leading to decreased energy levels, weight gain, changes in hair and skin, and alteration in sexual function. Depression may also occur, and unfortunately often goes unrecognized or untreated in cancer patients.

Talk to your health care team, including your family doctor, for advice about diagnosing and treating these conditions and about the onset of any signs suggesting that the tumour has become active again.

Signs of increased pressure in the brain

- Headache, especially occurring in the morning or awakening a person at night
- Nausea and vomiting
- Double vision or transient darkening of vision
- New onset of confusion
- Weakness on one side of the body

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

www.bccancer.bc.ca/HPI/CancerManagementGuidelines/NeuroOncology/PatientResources.htm

If you would like to submit an article, ask a question, or serve on our patient and family advisory board, please contact Rosemary Cashman at rcashman@bccancer.bc.ca or 604 877 6072 (phone) 604 877 6215 (fax).

All content by Rosemary Cashman unless otherwise specified.

Resource Guide

By Diana Hall, Librarian, Vancouver Centre.
To borrow books and videos, please call the BCCA Library at 604.675.8001 or toll free 1.888.675.8001, local 8001 or request items via the Catalogue at www.bccancer.bc.ca/Library.

About brain tumours

Brain tumors: leaving the garden of Eden: a survival guide to diagnosis, learning the basics, getting organized and finding your medical team / Zeltzer, Paul M – Encino, CA: Shilysca Press, 2004. Call Number: WL358 Z53 2004

Brain tumour patient resource handbook: adult version, 5th ed. / Brain Tumour Foundation of Canada – London, ON: BTFC, 2005. Call Number: WL358 B814b 2005
Internet: www.braintumour.ca/braintumour.nsf/eng/NewHandbook_getInfo

Primer of brain tumors: a patient's reference manual, 8th ed. / American Brain Tumor Association – Des Plaines, IL: ABTA, 2004. Call Number: WL358 P953 2004. Internet: www.abta.org/index.cfm?contentid=170

Resource directory: a guide for patients, families and health professionals / National Brain Tumor Foundation – San Francisco, CA: NBTF, 2007. Call Number: WL22 N277r 2007. Internet: www.braintumor.org/NBTFPublications/

Personal stories

Chasing daylight: how my forthcoming death transformed my life: a final account / O'Kelly, Eugene; Postman, Andrew – New York, NY: McGraw-Hill, 2008. Call Number: BF789 D4 041 2008

From top to bottom...and back! / Hicks, Peter – Victoria, BC: Peter Hicks Productions, 2005. Call Number: WL358 H631 2005

I had brain surgery, what's your excuse? : An illustrated memoir / Becker, Suzy – New York, NY: Workman Publishing, 2005. Call Number: WL358 B396 2005

Living with cancer

100 questions and answers about cancer and fertility / Oktay, Kutluk H; Beck, Lindsay Nohr; Reinecke, Joyce Dillon – Boston, MA: Jones and Bartlett Publishers, 2008. Call Number: QZ200 041 2008

100 questions and answers about cancer symptoms and cancer treatment side effects / Kelvin, Joanne Frankel; Tyson, Leslie B – Sudbury, MA: Jones and Bartlett Publishers, 2005. Call Number: QZ201 K29 2005

American Cancer Society's guide to complementary and alternative cancer methods, 2nd ed. / American Cancer Society – Atlanta, GA: American Cancer Society, 2007. Call Number: QZ266 A5138

Cancer is a word, not a sentence: a practical guide to help you through the first few weeks / Buckman, Robert – Toronto, ON: Key Porter Books, 2006. Call Number: QZ201 B925c 2006

Chasing rainbows: young adults living with cancer / Taylor, Pat – Vancouver, BC: Chasing Rainbows Productions, 2006. DVD. Call Number: QZ200 C487 2006.

Crazy sexy cancer tips / Carr, Kris; Crow, Sheryl – Guilford, CT: Skirt! 2007. Call Number: QZ201 C311 2007

Eating well with Canada's food guide / Canada. Health Canada – Ottawa, ON: Ministry of Supply and Services Canada, 2007. Internet: www.hc-sc.gc.ca/fn-an/food-guide-aliment/fg_rainbow-arc_en_ciel_ga_e.html

Exercising your right to decide: an introduction to advance health care planning / Vancouver Island Health Authority – Victoria, BC: Vancouver Island Health Authority (B.C.) 2006. DVD. Call Number: W85.5 E96 2006

Financial information for cancer patients / BC Cancer Agency. Patient and Family Counselling Services – Vancouver, BC: BCCA. PFCS, 2007. Internet: www.bccancer.bc.ca/PPI/copingwithcancer/practical/default.htm

From cancer patient to cancer survivor: lost in transition / Hewitt, Maria; Greenfield, Sheldon; Stovall, Ellen; National Cancer Policy Board (U.S.). Committee on Cancer Survivorship: Improving Care and Quality of Life – Washington, DC: National Academies Press, 2005. Call Number: QZ266 F931 2005. Internet: www.nap.edu/catalog.php?record_id=11468#toc

Living with hope / University of Saskatchewan. Division of Media and Technology – Saskatoon: University of Saskatchewan, 2004. DVD. Call Number: QZ266 L785 2004

Mayo Clinic book of alternative medicine / Mayo Clinic – New York, NY: Time Inc. 2007. Call Number: WB100 M474 2007

My voice: advance care plan / Fraser Health Authority – Surrey, BC: FHA, 2006. Call Number: W84 F841 2006. Internet: www.fraserhealth.ca/HealthInfo/AdvanceCarePlanning/Default.htm & www.fraserhealth.ca/HealthInfo/AdvanceCarePlanning/Workbook.htm

Relaxation tapes and CD's [titles & descriptions] / BC Cancer Agency. Patient and Family Counselling Services – Vancouver, BC: BCCA. PFCS, 2007. Call Number: QZ266 B364 2007. Internet: www.bccancer.bc.ca/ppi/copingwithcancer/emotional/resources.htm

Resource guide for Chinese cancer patients (Lower Mainland) / Kwong, Sandy; BC Cancer Agency. Patient and Family Counselling Services – Vancouver, BC: BCCA, 2007. Call Number: QZ201 K98 2007. Internet: www.bccancer.bc.ca/PPI/copingwithcancer/practical/default.htm

Visions for cancer recovery: a guided visualization and health meditation / Hallman, Mary – Crown Sign Productions, 2004. DVD. Call Number: QZ266 H191 2004

What you really need to know about cancer: a comprehensive guide for patients and their families, 2nd ed. / Buckman, Robert – Toronto, ON: Key Porter Books, 2006. Call Number: QZ201 B925 2006

Caregivers and Families

100 questions and answers about caring for family or friends with cancer, 1st ed. / Rose, Susannah; Hara, Richard – Sudbury, MA: Jones and Bartlett Publishers, 2005. Call Number: QZ201 R797 2005

Everyone's guide to cancer supportive care: a comprehensive handbook for patients and their families, rev. and updated / Rosenbaum, Ernest H; Rosenbaum, Isadora – Kansas City, MO: Andrews McMeel Publishing, 2005. Call Number: QZ201 R813 2005

Reaching out to your children when cancer comes to your family: a guide for parents / Slakov, June – Vancouver, BC: BC Cancer Agency. Multi-Media Services, 2007. Call Number: QZ201 S631r 2007

When someone you love has advanced cancer: support for caregivers / U.S. National Cancer Institute – Bethesda, MD: NCI, 2005. Call Number: QZ201 U58w 2005. Internet: www.cancer.gov/cancertopics/When-Someone-You-Love-Has-Advanced-Cancer/allpages

Q My husband was diagnosed with a brain tumour in the fall of 2006. He went through treatment and was well for about 3 months, but had to go back on chemo again last year. He is not working now, and I'm working full-time. My boss is very sympathetic, but I wonder if he would be if I didn't show up for work since there isn't anyone to replace me. We also have 2 kids in high school. Our daughter has taken her dad's diagnosis very hard and seems to take everything out on me. I feel like I'm in a pressure cooker all the time, worrying about money, the kids, my husband. People tell me to take time for myself, but that doesn't help – I just feel guilty for not doing anything right. I sometimes feel like I'll snap, even though I know I can't.



*John Wolford (1971-2007)
and Dhalie Patara Wolford*

Question + answer

A I remember when my husband John was first diagnosed with his brain tumour, it was Valentine's day 2005, our anniversary. I was only 30. We knew instantly that things had changed. It was a shock, but we knew that we had to accept this diagnosis. It wasn't just John's diagnosis, it was mine too. That didn't mean that we were going to be experiencing the same thing, but it did mean that we were going through this together. It was crucial to our happiness to understand and accept that yes, John is very likely going to die from this tumour in some short number of years. We knew too that anything can happen – I could die first from something else, John could also die from something else, he could experience a miracle cure, he could have a long remission. But the odds were life expectancy shortened to a few years.

I had to make some choices. The actual details of the choices weren't that important (choices about working, how much to work, making time for myself), but my commitment to those choices was my sanity. That's what I needed to do to be okay with the situation. To my family and

friends it looked a lot like I put my life on hold. I did in a lot of ways, but not in every way. I still made time for myself, and John really enjoyed having time for himself too. I worked, but less, and gave up one of my businesses.

I'm not saying, put your life on hold and you won't feel angry or frustrated. And I'm not saying make time for yourself and you won't feel angry or frustrated. Getting angry or frustrated still happened, for both John and I. Most of us feel angry or frustrated with or without cancer. For the most part we were a regular married couple with all the ups and downs. We just knew that we had a lot less time than other couples to work out our issues.

There are a lot of really practical things that John and I did that helped us immeasurably, like marriage counseling and grief/loss counseling, support groups, meditation, travel, and just spending a lot of time together on things that were fun for us, no matter how mundane. But I think the thing that really made this diagnosis bearable was our feeling of gratitude that we had so much time to say goodbye, to be together, to grow together, and to walk on a spiritual journey together. So many people don't get to do all that.

by Dhalie Patara Wolford

Vancouver 2008 Spring Sprint!

Be one of the thousands of people walking, running and sprinting in support of those affected by a brain tumour this Spring. Vancouver's event will be held on Saturday, May 3rd, 2008 and is aiming to raise \$43,500. Help the Brain Tumour Foundation of Canada fund research and provide support. Imagine a cure! www.springsprint.ca

Saturday, May 3rd, 2008

Location: Deer Lake Park, Shadbolt Centre

Distance: 5 km route

Check in: 10 am

Start: 11 am Rain or Shine!

Please contact the coordinator if you would to help with this event:

Yaron Butterfield ybutterf@bcgsc.ca 604 707 5900 x 5446

Directions from Vancouver (from East Hastings) » Take Trans Canada Highway 1 east – go 6.0 km
» Take ramp RIGHT onto Sprott St – go 0.5 km » Turn LEFT on Norland Ave – go 1.1 km
» Turn LEFT on Deer Lake Ave – go 0.3 km » Arrive at 6430 Deer Lake Ave, Burnaby

