

Headlines

Fall 12

A newsletter for brain tumour patients and their families

OUR STORY

The experiences of a father and daughter

By Neil McAskill and Jennifer McAskill

Neil's story

MY WIFE NANCY (AKA Pooh Bear) and I were childhood sweethearts. She was sixteen when we started dating. We married when she was twenty and I was twenty-two. We have two daughters and are a very close family. We are also spiritually Christians.

We were at our summer place on Nelson Island, a place we all love dearly. Nancy was experiencing unexplained nausea and vomiting. Within three days of our visit to Powell River Emergency, a brain lesion was diagnosed. Within five days of the diagnosis the tumour had been removed and recovery was rapid. On our 37th anniversary, we learned that the tumour was a glioblastoma (GBM). An immediate search of the internet gave us the grim prospects.

Our well planned future radically changed direction. After the shock of our new reality sank in, my beloved wife, our two daughters and I made the conscious decision to do the best we could to live each day to the fullest with no regrets.

Nancy made it through radiation and chemotherapy quite well and her positive attitude was an inspiration to all who came in contact with her. I on the other hand was fearful of losing my partner. After over a year of disease stability I was beginning to become complacent and thought we had beaten it. Not so.

Two great pieces of advice came from a close friend whose husband died a few years ago: "Don't borrow tomorrow's trouble" and "live each day one day at a time as well as you can." This is often difficult, but it is what we strive for. My love for Nancy and my strong desire to care for her has become the fulfillment of our commitment to each other, sustained over 40 years since the days when we were young lovers.

Now that caregiving is truly in high gear, what tools do I / we use to cope with this dreadful illness?

- Continue to live life to the fullest extent possible.

- Our daughters and close friends rally around me to fill in the blanks that fall by the wayside (and there are many).
- Our Pooh Bear is my primary focus (career takes a back seat).
- Be observant and keep track of all of the small changes that occur and discuss with the trusted professionals at the BCCA. They are truly helpful and caring.
- Stay focused on being the best caregiver possible.
- Keep spiritually focused.
- Keep loving your partner without any expectations.

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From left to right: Neil, Jennifer, Nancy and Rebecca McAskill

Staying healthy while undergoing treatment for a brain tumour

By Holly Anderson, BSc.
UBC Nursing Student



WITH FLU SEASON just around the corner, it is especially important to protect yourself from illness and infection. Unfortunately cancer and some cancer treatments may make you more susceptible to infections. Here are some ways that you can keep you and your loved ones safe from the flu, the common cold and other infections:

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Flu vaccine

In most cases, oncology health care professionals recommend that patients and their family members receive the seasonal flu vaccine. Talk to your health care team for more information about this.

If you are taking chemotherapy, you are particularly at risk for developing infections. Most chemotherapies target rapidly dividing cells such as tumour cells. However, some normal body cells also divide rapidly. Chief among these are blood cells. Thus, blood cells may also be killed by chemotherapy used in the

treatment of brain tumours. White blood cells are important for fighting infection, and if their numbers are reduced, you should monitor for signs of infection.

Know the signs of infection

For patients receiving chemotherapy, often the only sign of infection is the presence of a fever. Ensure that you have a working thermometer in your home so that if you feel unwell you can take your temperature. Signs of a fever include chills, fatigue, shaking, flushing or a temperature greater than 38°C. However, fever may also be accompanied by a general feeling of sickness including nausea, vomiting, diarrhea, headache, sore throat or new cough. If you have a fever with or without these accompanying symptoms contact your health care team or go to the hospital emergency room. Tell the staff that you are receiving chemotherapy for a brain tumour, and provide the date of your last chemotherapy dose.

Hygiene

Wash your hands thoroughly with a mild antibacterial soap several times a day. A useful rule of thumb for effective hand washing is to wash for as long as it takes you to sing Happy Birthday twice. It is especially important to maintain proper hand hygiene when you go to any health facility, whether it is your doctor's office, the clinic or the hospital. Other times to wash your hands include before you eat, after you go to the bathroom, before and after cooking or preparing food, after you cough, sneeze or blow your nose, after touching or picking up after a pet, and after changing a diaper.

Ask those who live with you to also wash their hands and make sure your environment is clean. If someone sneezes or coughs they should do so into a tissue, dispose of the tissue and then wash their hands.

Most infections result from bacteria and viruses which the patient carries on his or her body, but it is important to avoid close contact with those who are coughing, sneezing or ill.

Diet

There is no particular diet known to help treat brain cancer or prevent its recurrence, but good nutrition is essential for everyone's health and will help you better tolerate your treatment. The Canada Food guide offers excellent advice about nutrition and is easy to follow: www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php. If your blood counts should fall when you're on chemotherapy, they will likely recover without assistance, but a nutritious diet will also help. Foods rich in protein, iron, folate and vitamin B12 are especially important for healthy blood cells. Here are examples of such foods:

Protein: meat, poultry, fish, beans, eggs, soy products

Iron: Organ meat (kidneys, liver), eggs, dried fruit, blackstrap molasses, soy products

Folate: Beans, leafy vegetables, peas

B12: Organ meats, eggs, milk and milk products

Rest and Activity

Being physically active will help you to maintain strength and energy, and will aid sleep and provide a healthy distraction from stressful concerns. You may also need to incorporate more time for rest in your day when on treatment.

For more information about staying healthy while on treatment, see these past issues of Headlines at www.bccancer.bc.ca/PPI/copingwithcancer/pamphlets/brain.htm

Exercise: Winter 07

Nutrition: Spring 07, Fall 08, Summer 09, Winter 09, Spring 11, Winter 12

Sleep Hygiene: Winter 07

Terrence Bryan Kennerley

December 3, 1959 – September 20, 2010



TERRY WAS BORN to Al and Joan Kennerley in North Bay, Ontario and graduated from high school in Moose Jaw, Saskatchewan. He was a bright student who showed an early love for athletics and the accordion. He joined the Canadian Air Force in 1980 and earned his paratroopers wings before entering the world of finance. He received an MBA from Dalhousie University and started his own consulting company in Vancouver, which he managed until his death.

In June 2006, at the age of 46, he was diagnosed with a malignant brain tumour. The shock of this development was profound. He was a young and vigorous man with a successful business and a thriving family, including a partner and four children. Terry remained positive throughout his treatment with

chemotherapy and radiotherapy and was always an active supporter of other patients. He drove those who could not drive to the support group sessions, established a second support group outside the cancer agency, met with newly diagnosed patients who needed some words of encouragement from a "veteran," and even spoke to oncologists about delivering a message of hope to patients with brain tumours.

His death left a very large hole in the lives of those patients and cancer agency staff who had come to admire him so deeply, who were cheered by his unflinching good spirits and sense of humour, and who benefitted so much from his compassion and courage.

It is in gratitude and fond memory of Terry that this award is established, to honour those patients or family caregivers who make a significant contribution to the brain tumour community.

If you would like to nominate someone for the Terry Kennerley Award, please contact cpelleti@bccancer.bc.ca or rcashman@bccancer.bc.ca. Include:

- 1) your name and contact information
- 2) the name of the person you are nominating
- 3) a short paragraph describing the reason(s) for your nomination.

Follow Headlines newsletters for more information about this award.

Expert Advice

Down the Hatch

Are your chemotherapy pills hard to swallow because of a bitter taste? Try coating them in marmalade, honey or jam. This disguises the taste and makes them slide down a little easier. A word of caution: when you finish your chemo treatment, you may never again want to taste the food you used to coat your pills, so choose carefully! For example, if you really like honey you might not be prepared to give it up for life, but you might be more willing to sacrifice marmalade.

— From Paul

The Coffee Nap

Do you feel tired because of treatment but worry that prolonged naps in the daytime will affect your nighttime sleep? Try chugging (not sipping!) a cup of strong coffee and then taking a nap immediately afterwards. This should allow you to get the rest you need before the caffeine hits your bloodstream. You'll wake up 30 minutes later feeling alert and ready to go.

— From James

Living with Dying

A young physician with an incurable cancer offers insights about staying positive and finding a new normal while living with a terminal illness.

<http://gu.com/p/3afpk/em>

<http://theothersidestory.co.uk>

— From Ray

Many readers of *Headlines* have expertise in living with a brain tumour.

If you would like to share your helpful hints, inspiration, insights and expert advice about what has helped you, please contact Rosemary Cashman at rcashman@bccancer.bc.ca 604 877 6072

This newsletter is published through the generous support of the BCCA Neuro-oncology Fund. For more information about how you can support enhanced patient care, patient information and brain tumour research, please contact Sharon Kennedy at the BC Cancer Foundation, 604 877 6160 or 1 888 906 2873 or skennedy@bccancer.bc.ca

Vancouver Hospice Bereavement Walking Program

This walk offers a chance to walk and talk at a relaxed pace with others who are grieving; to share ideas and support, and to benefit from fresh air and exercise.

Trained hospice volunteers will join you.

The group gathers and walks for about an hour at a casual pace, wrapping up with a stop for coffee and more conversation.

There is **no charge** to participate.

We stroll together, rain or shine, for eight mornings. Please dress comfortably for the weather.

WHEN: Saturdays or Wednesdays starting September 29th or October 3rd, 2012

Gathering Time: 9:45 am.

Walk starts at 10 am sharp

WHERE: The Museum of Vancouver (Planetarium) 1100 Chestnut Street (in front of the crab sculpture) (If driving, bring change for parking meters.)

Bus schedules: 604 953 3333

www.translink.ca

PRE-REGISTER please by contacting:

Sue Wong 604 731 7805 — adwong@telus.net

OR Maggy Kaplan 604 736 0877 — maggyk@telus.net

www.vancouverhospice.org/programs-and-services

Our story

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Jennifer's Story

I FREQUENTLY HEAR, "I don't know how you and your family do it. I certainly couldn't." The truth is, I don't think anyone knows how to do it — until they do it. Support from family and friends has contributed greatly to our success in coping. Confiding in a few close friends has provided an opportunity to escape from the ever present, "How's your Mum doing?" We have found love and understanding at every turn. People in general — acquaintances, close friends, or even the cable company customer service agent — have so often been touched by cancer, and this has resulted in many moments of grace and compassion.

As always, there are good days and bad days, but we try to remember that today is all anyone has, and we are grateful for it. As time stretches on, I find myself becoming more emotional at seemingly unrelated things. Allowing myself those feelings and expressing them with someone I trust helps me to get through each day and assist my Dad. Given that I don't live with my parents, it may be easier on me since I don't see the day to day realities. We know that any changes in my Mum's behaviour can be blamed on the disease. To us she is still the Mum we love, and who loves us.

The experience of my Mum's illness has changed the way I make decisions about how to spend my time. I don't ever want to look back and feel like I missed

a chance to share a thought, prayer or moment with my Mum.

Grief comes and goes. "Why us," "why her," are always questions. A good friend once asked, "Why does the why matter?" This changed my thinking. As if we could control things if we understood the why. The truth is — why doesn't matter. It's what you make of what happens to you that matters. Illness may be challenging, but it still allows experience, and may even present an opportunity to learn something you would otherwise never have known.

My faith has also helped me. Things of this world are fleeting and the more we cling to them, the harder it is to accept their inevitable loss. To cherish what we have now is key.

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

www.bccancer.bc.ca/PPI/copingwithcancer/specificresources/Neurooncology.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 6180 (fax).

All content by Rosemary Cashman unless otherwise specified.