BC Cancer Agency www.bccancer.bc.ca

Headlines

Winter 07 A newsletter for brain tumour patients and their families

My Story

By Tony Cropo

Cancer is not prejudiced.
Cancer is not discriminatory.
Cancer has affected almost everyone
I know in some way, including me.

MY NAME IS TONY CROPO and in 1991 I was diagnosed with a brain tumour. An oligodendroglioma to be exact. I was lying on the beach in Puerto Vallarta with my wife when I had my first seizure. My wife, Pat, and I had never experienced anything like this before. I was taken to the hospital and flown back to Vancouver the following day. At this point we did not know what was wrong with me; it was not until after I had been given a MRI that I learned the news. My neurosurgeon told me that I only had three years to live. After being dealt this blow I was in shock.

My therapy began soon after and consisted of 30 treatments of radiation. Surgery was not an option because the location and type of tumour made it inoperable. When I completed the radiation treatments the tumour had shrunk considerably and stayed that way for almost ten years. I started to feel like I was back to my old self. I started to work out again and even ran five marathons. My life felt like it was back on track.

In 2001, I was starting to feel funny but I ignored my symptoms and did not tell anyone. One day, at the gym, during my regular workout on the treadmill I had another seizure and collapsed. I felt like this horrible nightmare was starting over again. This time, instead of radiation, I received chemotherapy. The chemotherapy seemed to do its trick and I started to feel better again.

In November 2005, while vacationing by myself in Palm Springs I had another seizure. After this seizure I was suffering from aphasia, which makes it hard for me to speak and communicate with people. I ended up spending four nights in the hospital in Palm Springs before I was flown back to Vancouver on a private jet. This time my oncologist treated me with a different type of chemotherapy. This chemotherapy did not work and I suffered through a series of seizures overnight in March, 2006. I ended up at Vancouver General Hospital for two months followed by three months at GF Strong Rehabilitation Hospital. My recovery from that series of seizures has been quite slow; I still am struggling with my speech and the strength and dexterity in my right hand. I am currently being treated with the same chemotherapy that I had in 2001 and it seems to be working. I am back at home and very self- sufficient. I am getting better everyday.

We have better treatments now then when I was first diagnosed or when my brother had a brain tumour (dead at 29 years old) and we know more. If you suspect that something is wrong, don't wait, get help from your doctor right away.

Everybody is different.
I'm lucky to be alive.
I'm stubborn.
I'm myself.

Never give up.

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Dealing with fatigue while on treatment for a brain tumour

FATIGUE IS THE MOST commonly reported problem affecting people with cancer, although the experience of fatigue may vary from person to person. Cancer-related fatigue is more severe than the kind of fatigue that can affect anyone from time to time, and often is not relieved by rest. It's hard to point to a single cause of fatigue when cancer is involved, and it may be challenging to treat or alleviate fatigue. However, effective management of fatigue may help you to tolerate your brain tumour treatments better, and may reduce distress and improve your overall quality of life. So here are some ideas that may help you to prevent, treat or reduce fatigue:

- Regular exercise is the only intervention that has been definitely proven to be of benefit to cancer patients suffering from fatigue. This may seem odd, as exercise may be the last thing you think you need when you feel tired! Strenuous exercise is not necessary. Walking, cycling, swimming, and home exercise programs tailored to individual abilities are excellent ways to obtain the benefits of exercise. Check with your doctor or nurse for advice about activities that are best for you so that you don't overdo it.
- Balance periods of activity with adequate rest, and plan your day to coincide with your energy reserves. For example, plan to go for a walk in the early morning or after you've had a rest in the afternoon so that your strength is at its peak. Factor in a brief rest period after an activity that is tiring.
- Practice "good sleep hygiene." In other words, try to do the things that promote good sleep at night. For example:
  - Avoid long naps in the afternoon
  - Avoid large meals just before bedtime
  - Limit caffeine, alcohol and stimulating activities such as exercise before bed
  - Engage in relaxing activites before bed, such as listening to calming music or taking a warm bath
  - Use your bed only for sleep and sexual activities, not for reading or other activities, like watching television
  - Go to bed at the same time every night
  - Take seizure medicines at bedtime when possible, as they may make you sleepy - Avoid taking dexamethasone (Decadron) at bedtime, as it may cause agitation

  * Note that sleep-wake cycles are disrupted by brain surgery. It may take a few weeks to restore normal sleep patterns after your operation. Also, some seizures may result in sleepiness lasting for days.
- Eat nourishing foods that will help your body to be as strong and healthy as possible. This will help you to fight the tumour and tolerate your treatments better.
- Delegate responsibilities to family and friends. Make sensible choices about what you can reasonably accomplish in a day. Use a notebook or calendar to keep track of appointments, names, responsibilities, and other information so that you don't have to rely on your memory.
- Treat pain and depression. Talk to your doctor about ways to manage these problems, including the use of medications. You might also ask whether medicines that help memory, thinking and alertness could be helpful for you.
- In some cases, brain tumour treatments may cause anemia or hormonal changes which lead to fatigue. Ask your doctor if assessments are indicated for these potential problems, as they may be treatable.

For more information about fatigue and its management, see the BC Cancer Agency website: http://www.bccancer.bc.ca/PPI/PSMPC/Fatigue/default.htm

The experience of fatigue may include

- weakness
- decreased energy
- need for more rest
- poor concentration and memory
- difficulty completing daily tasks
- difficulty multi-tasking
- changes in sleep habits
- a general feeling of being unwell

Factors that may cause fatigue

- anxiety
- depression
- changes in nutrition
- pain or pain medications
- poor sleep
- cancer treatments' effects on the body
- the body's efforts to fight the cancer

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.

Update on Research

THE BRAIN TUMOUR FOUNDATION OF CANADA recently awarded almost $14, 000 to BC Cancer Agency researchers to study the experiences of people whose brain tumours have led to changes in their usual abilities. This effort unites staff from the BC Cancer Agency and G.F. Strong Rehabilitation Hospital. The research team, headed by rehabilitation counselor Maureen Parkinson, includes representatives from various disciplines, including psychology, radiation oncology, rehabilitation medicine, occupational therapy, social work and nursing. The goal of the study is to better understand how brain tumours affect the day to day lives of patients and their families. Researchers will be interested to learn about patients' abilities to perform everyday activities such as dressing, carrying out household and family responsibilities, and working. They will also want to learn what sorts of strategies patients and families use to deal with disabilities, and how successful these strategies are. Ultimately, they hope that this research study will identify gaps in support, improve access to appropriate resources, and help patients and families optimize their functioning.

If you have recently been diagnosed with a brain tumour and will soon be starting chemotherapy and radiation, you may be eligible to participate in this study. If you would like to learn more about the study, ask your doctor or nurse for more information, or contact Maureen Parkinson at 604 877 6000 x2194.

Researchers Rosemary Cashman, Maureen Parkinson, Michael McKenzie

Progress for Brain Tumour Research and Care!

In December, twelve year old Brandon Dempsey and his mother Jennifer Dempsey, of Halifax, met with Prime Minister Stephen Harper and Minister of Parliament Mr. Bill Casey to discuss the plight of brain tumour patients in Canada. Brandon was diagnosed with a brain tumour in 1998. His mother, recently elected vice-chair of the Canadian Alliance of Brain Tumour Organizations (CABTO), has been involved in that organization's efforts to change the way that information about brain tumours is collected. Moved by Brandon's situation and by discussions with members of CABTO, Mr. Casey and his assistant Lorne Berndt have championed this cause through Private Member's Motion M-235, presented in the House of Commons by Mr. Casey on December 12, 2006. M-235 calls for a standardized national system of data collection for benign and malignant brain tumours. This effort will provide a solid foundation for scientific research on these diseases and improve access to resources for those living with brain tumours.

Question + answer

by Natalie teBrinke

Q It's bad enough that my wife has a brain tumour and has had to stop working. Even though we don't have to pay for her chemo, the pills for nausea cost a lot and we pay for the ferries and gas and parking at the hospital. We're glad to get the care she needs, but could use a break on the costs. Any ideas?

A After my diagnosis with a brain tumour, my accountant told me about different medical expenses I could claim against my income tax return each year. As a result, I developed a filing system that I continue to use. I have been audited twice for the medical expenses that I claimed over the years. I'm not an accountant, but I've been through the wringer twice and survived, and I'm happy to pass on what I know to others.

The government accepted all the expenses claimed except the herbs and supplements, which I submitted in 2005. They wrote, "Vitamins, herbs including over-the-counter medications, and similar substances are not deductible as a medical expense unless they are prescribed by a medical practitioner and dispensed and recorded by a pharmacist."

You may claim medical expenses for yourself, spouse and any dependents. **Make sure that you keep all the receipts!** The expenses have to be more than 3% of net income or $1,844 to use in your tax return. For example, for our family I claim the following which are the most common types of medical expenses. This is not a complete list of everything that may be deductible by other families.

- Orthodontics
- Physiotherapy
- Chiropractic
- Massages
- Eye doctor and glasses/contacts
- Dentist
- BC Biomedical test
- All prescriptions

In addition, if medical treatment is not available locally and you must travel more than 40 km each way, you could claim:

- Mileage: 0.455 cents per km, return trip
- Meals: $15.00 per person, per meal (if you need an attendant when traveling, claim for two people)
- Parking fees: (save the slips)
- Lodging: (if you have to stay overnight for an appointment the next day)
- Taxi, bus, etc.: (keep receipts) if you don't drive your own vehicle

I know this might sound like a lot of work, but it isn't at all. What I do in the beginning of each year is mark 4 different pieces of paper:

1) "Trips to Vancouver"
2) "Other Medical Expenses"
3) "Vitamins and Supplements"
4) "Prescriptions"

I keep them in one file folder. Each time I have to travel to Vancouver for an appointment, I mark the date, which doctor I saw and for what, the parking fees, and the mileage, all on one line. At the end of the year I add up the total mileage and multiply by .455/km. I calculate the total parking fees, add up the trips and claim 1 meal/person for one appt, and 2 meals/person if it's a full day. I keep all my receipts for other medical expenses in my wallet and every week or so when I clean it out, I record the expenses on the correct papers and I clip the receipt onto the back of it, since you have to have **all** copies for audits, and this way it isn't hard to keep track of them for the year.

You have to be reasonable and true in your claims; if you exaggerate, they will notice and not be very accepting of the whole claim. These amounts mentioned are usually reviewed each year by Canada Revenue Agency and new rates set.

Also, I read that there is a refundable tax credit available (up to $750 for 2005 and possibly $1000 for 2006) for working individuals with low income and high medical expenses called, "Refundable Medical Expenses Supplement." In addition, new laws in BC state "that the terminally ill in BC can now declare friends as family, entitling the friends to compassionate leave under provincial law. Under the law, an employee seeking time off to care for a loved one is eligible for eight weeks of unpaid leave."

I hope this helps. Ask your accountant for assistance if you need to, or you can contact your social worker at the Cancer Agency.

The Patient & Family Counseling Department also recommends that ALL patients apply to Fair Pharmacare, a government program that provides additional financial assistance to residents of British Columbia: **www.healthservices.gov.bc.ca/pharme/**

In addition, please see this link for financial support **www.bccancer.bc.ca/NR/rdonlyres/5C67EB9E-692A-47F0-B095-4C932A5D4B96/19972/FinancialInfoCancerPatientsDec2006.pdf** or contact your social worker or the Patient & Family Counseling Department in the BC Cancer Agency.

How You Can Help

The BC Cancer Foundation welcomes donations which support brain tumour research at the BC Cancer Agency. To discuss how you can make a difference – by contributing to the Hershey & Yvette Porte Endowment Fund for Neuro-oncology, by establishing a similarly named fund, or by contributing directly to brain tumour research and patient comfort initiatives – please contact Sharon Kennedy at 604.877.6160.

Tax receipts are issued for gifts of any amount. Donations should be directed to BC Cancer Foundation at 200 - 601 West Broadway, Vancouver, BC V5Z 4C2

Together we can make a difference!

BC Cancer Agency
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