

Headines



a newsletter for brain tumour patients and their families

spring 2019





By Yaron Butterfield

N FEBRUARY, I attended one of the Callanish quarterly retreats. I was told that it would be a healing space for those who have been touched by cancer, but I wasn't really sure what to expect. Little did I know it would be such a wonderful experience with such a positive impact on my healing.

From the moment a car rolled up to my door step I sensed that this would be an adventure like no other. I was surprised to see that the front passenger seat was held for me while three women I'd very quickly connect with in powerful ways were seated in the back seat. I recognized one of the women, since she and I had met earlier in the month at the brain tumour support group. We were greeted by friendly staff as soon as we arrived at Brew Creek Centre, a beautiful, serene place in Whistler, BC. The nervousness I'd felt about spending six days with a bunch of strangers, including other cancer survivors, melted away when I met the group, which also included counsellors, an art therapist, musicians, a massage therapist, a yoga and gigong teacher and some wonderful volunteers and fabulous cooks.

By the end of the first day I realized that I would be tapping into new areas

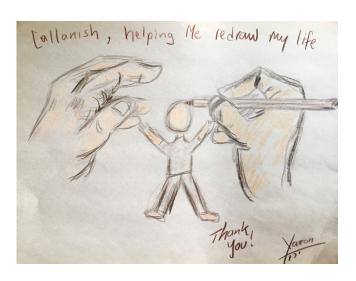
of my consciousness. As a 15+ year survivor of a glioblastoma, I have often thought "the cancer is gone...I am healed." Through the various engaging activities we undertook, I realized my healing was not complete. Deep emotions that I didn't know existed came to the surface.

I learned a lot from the others, much like our monthly support

meetings, but at another level. Though we were all together for a short period of time, by the end I felt I had known everyone for much longer. I felt comfortable being open to others. I talked about some things I have never told anyone else—some thoughts just came out and surprised me, but that felt good. I often have trouble tapping into my emotions but through various ways, I felt supported to explore and share my feelings with others.

As it turned out, two other participants had been diagnosed with brain cancer and one of these was in the middle of treatment for glioblastoma. She told me how happy she was to meet a long-term survivor. That is something that means a lot to me, to give others hope.

We were advised to turn off cell phones. We meditated. We practised qigong every morning. I sang (and was even told I have a nice voice, though I disagree) and played the ukulele. There were group sessions and individual sessions with staff, We all savoured the incredibly tasty and healthy food. Each night the staff and group participants settled in front of the fireplace and chatted comfortably. It felt



like we were one big family, giving each other support and sharing wisdom.

When I got home, I made a decision to commit to being more compassionate towards myself. I am often hard on myself, and the retreat helped me to see this and taught me how to let go and quiet my mind, as if I had come back from 6 days of meditation. The effects of this amazing experience still linger and I am hopeful that I will continue to feel this way for a long time.

For more information about Callanish, see back issues of Headlines, Winter 2011 and Winter 2016, or visit the Callanish website at: www.callanish.org

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For more information about how you can support enhanced patient care, patient information and brain tumour research, please contact Fatima Hassam, Associate Vice President, BC Cancer Foundation.

Dir: 604 877 6226 Cell: 604 218 0508 fatima hassam@bccancer.bc.ca

QUESTION & ANSWER

By Dr. Nafisha Lalani, Radiation Oncologist, BC Cancer – Vancouver

How does radiotherapy kill brain tumours? Is there anything I should do – or not do – to help it work as well as possible and to

work as well as possible and to keep myself healthy during the treatment?

Radiotherapy is a safe, effective and non-invasive form of cancer treatment. Radiotherapy can be used as the primary treatment for many types of brain tumours or it can be used in combination with surgery and chemotherapy.

The most common type of radiotherapy used for brain cancers is called "external beam radiation." This uses high dose x-ray beams targeted towards the cancer cells. External beam radiotherapy at BC Cancer is delivered using large machines called linear accelerators.

When the radiation is delivered to the cancer, it creates small breaks in the DNA of cancer cells. DNA is a long molecule inside the control centre of a cell and it contains the instruction manual for the functions of that particular cell. When

the DNA in a cancer cell is damaged, it is no longer able to grow and divide; thus, the cancer cell eventually dies. The surrounding normal body cells may also be affected by radiotherapy. However, normal cells are better able to heal after the radiation damage in comparison to cancer cells.

In order for the radiotherapy to work as well as possible,

you should consider the following steps:

 It is important to speak with your radiation oncologist regarding any medications, vitamins, or natural health products that you currently use. In some cases, these substances can interact with your treatments and can even decrease the

- ability of the radiation to work properly. Speaking with your physician at the onset of treatment can ensure that these potential interactions are addressed.
- Smoking cessation may help the radiation treatment to work better.

 Studies have shown that tobacco smoke can decrease the ability of radiotherapy to kill cancer cells. Quitting smoking will help you to better fight your current cancer while also decreasing the chance of developing another cancer in the future.
- It is important to attend all of your scheduled treatments. Missed radiation doses may impact the effectiveness of the treatment. Plan other activities in such a way that unnecessary treatment gaps are prevented or minimized.

It is important to take care of yourself throughout your radiation treatment. You can consider the following lifestyle changes in order to stay healthy, but speak to your radiation oncologist for specific recommendations:

- The most common side effect of radiotherapy is tiredness and it usually gets worse throughout the radiotherapy course. Ensure that you are getting enough rest throughout your radiation treatment. It may be necessary for you to modify your schedule to allow for a short nap, or to engage in activities which you find restful, such as listening to music or meditation. Mild to moderate physical activity, such as taking a walk, may also help you to get a better night's sleep and feel rested the following day.
- Drink plenty of fluids. Radiotherapy can cause dehydration which can contribute to feelings of tiredness, dizziness and headache. Therefore, it is important to stay well hydrated throughout your radiotherapy.
- Maintain a healthy diet. This will help you to keep up your strength and energy during the treatment and ensure that you receive sufficient nutrients to repair the effects of radiotherapy on your body.
- Lastly, it is important to let the health care team know about any side effects that you experience. Side effects can often be managed with supportive medications. In rare cases, radiotherapy treatments may need to be changed.





Dr. Brian Thiessen, head of the BC Cancer brain tumour site group, receives a cheque for almost \$2,500 from Jeanette Bonar, widow of Andrew Bonar, who was affectionately known as "Boney." In his memory, Jeanette holds an annual fundraiser, the "Boney Music Invitational Bagpiping Competition," with all proceeds going to brain tumour research.

For more information about Andrew Bonar, the legendary and beloved bagpiper, see: www.pipesdrums.com/article/andrew-bonar-1966-2017

On spiritual health

By Alison Cumming, MATS Spiritual Health Practitioner

PIRITUALITY IS A NATURAL ASPECT of being human. People often contemplate or seek out their own sense of meaning and purpose in life. Spirituality can be quite broad, being expressed in many ways—through beliefs and values, cultural traditions, religion, as well as practices and rituals. It is often experienced through our relationships—with self, family

and friends, community, sacred rituals and even nature. There are many benefits that come from understanding and meeting one's spiritual needs, such as increased inner peace, resiliency and ability to cope with pain and suffering, and decreased feelings of anxiety, depression, anger and loneliness.

Sometimes when people face a crisis, they experience spiritual distress. Their beliefs about life may come into conflict with their lived reality. For example, someone may feel like God has abandoned them in their suffering, as their prayers for healing have not been answered. Or they may feel betrayed and angry because life was not supposed to turn out the way it has. Others may feel deep disappointment, hopelessness and confusion because their positive thinking has not showed the results they expected. People may feel isolated and struggle to take part in their regular spiritual practices or rituals. Spiritual distress can occur when patients are waiting for a diagnosis, or if there is a substantial setback or prolonged pain and suffering, or when a patient's beliefs are in conflict with the treatment recommendations, or when the family needs to make a decision on behalf of another family member.

My role as a Spiritual Health Practitioner is to help patients explore their spirituality and their meaning and purpose in life, as well as help those who are experiencing spiritual distress. Sometimes I meet with patients who wish to ask specific spiritual questions, and I help them find appropriate resources.

Other times I lead patients in meditation or help them see how their spirituality can be an inner resource in the midst of their current clinical situation. Spiritual Health

Practitioners are trained by the Canadian Association of Spiritual Care to serve people of all faiths, and we offer care based on the person's individual beliefs and values, cultural background, traditions and practices. At BC Cancer, the Spiritual Health Practitioner is a part of the Patient and Family Counselling Team.

For the person desiring to explore their spirituality, here are a few starter questions: Do you have any practices or rituals that

bring you a sense of peace, comfort or joy? Do you have any sacred spaces where you feel rested and rejuvenated? Are you a part of a community that has shared beliefs, values or traditions? Do you have any cultural traditions that re-inforce your identity and that help you feel rooted in something beyond yourself? When you experience sadness, fear, pain or suffering, what has brought a sense of inner strength and comfort to you? Do you have any values, traditions or beliefs that have influenced your medical decisions?

If you are interested in meeting with a Spiritual Health Practitioner, regardless of where you live in B.C., contact Patient and Family Counselling at 604 877 6000 X 672194.

Brain Tumour Foundation Walk Join the movement to end brain tumours!

Victoria

Sunday, May 26, 2019

Registration: Opens at 8:30 am

Opening Ceremonies: 9:50 am

Survivor Photo: 9:45 am

Walk Begins: 10:00 am

University of Victoria –

Parking Lot 10 3800 Finnerty Rd

Vancouver

Sunday, June 9, 2019

Registration: Opens at 8:30 am

Opening ceremonies: 9:30 am

Survivor Photo: 9:45 am

Walk begins: 10:00 am

NEW LOCATION!

Central Park - Swangard Stadium,

3883 Imperial St, Burnaby





For more information, see the Brain Tumour Foundation of Canada website: https://secure2.convio.net/btfc/site/SPageNavigator/BTW_EventCentral_Landing.html

What happens behind the counter of the BC Cancer Pharmacy?

By Nancy Coady, BSc (Pharm), Tanya Leduc, BSc (Pharm), Sanna Pellatt, BSc (Pharm), Lisa Wanbon, BSc (Pharm), BC Cancer – Victoria

Step One: Prescription assessment



Your pharmacist needs to check that the correct therapy has been prescribed and that there is a valid reason for any changes to your usual therapy.

The interval needs to be checked to ensure you receive your therapy at the appropriate time.

Blood counts need to be checked to ensure it is safe for you to take your medications.

The dose needs to be checked to ensure that it is correct for your current weight, height, and blood work results.

Your pharmacist needs to check that your prescribed therapy does not interact with any other prescription medications, overthe-counter products, or natural health products that you may be taking.

Any irregularities with the prescription need to be clarified with the prescriber before dispensing.

Editions of *Headlines* are also available as a pdf download on our website at: www.bccancer.bc.ca/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).

If you are taking part in a clinical trial, there are extra requirements that need to be assessed.

New prescriptions usually take more time to assess than refills of existing prescriptions.

Delays in checking your prescription may occur if there is a long time before your chart arrives at the Pharmacy (while the prescription, tests, follow-up appointments, and dictations are being completed by your doctor), or if the pharmacist must wait for blood work results.

To make sure your take-home prescription is ready when you arrive, you should call the Pharmacy ahead of time to request your refill.

Step Two: Computer Entry



Your prescription needs to be entered into the pharmacy computer system and a correct label for the medication needs to be printed.

Medications that you are given to take at home must also be entered into your personal PharmaNet profile which contains a record of all of your prescriptions.

Step Three: Prescription Preparation

Medications given by injection require preparation in a special biological safety cabinet to ensure medication sterility and worker safety.

Some of these medications are only stable for a few hours or are very expensive, therefore, to minimize drug wastage due to unforeseen circumstances they are prepared only after you arrive.

Medications taken by mouth (tablets, capsules) may require less preparation time, however, they require just as much assessment time.



At this point a final check is performed to ensure that all aspects of your prescription have been assessed and are correct.

Step Four: Counselling

For oral medications, your pharmacist will provide written and verbal counselling about possible side effects, how to manage them, signs to watch for, etc. A nurse will review your injectable medications with you during your first chemotherapy appointment.



Your pharmacist is a valuable source of information about medications and other health issues. He or she will take the time to address any questions or concerns that you may have about your current medications and products you are considering taking.

For more information about your BC Cancer Pharmacy, speak to your BC Cancer pharmacist.