

BC Cancer Agency www.bccancer.bc.ca

Headlines

Winter 15 *A newsletter for brain tumour patients and their families*

Brain Tumour Information Day

By Yaron Butterfield

THE 2014 BRAIN TUMOUR Information Day on October 25th was a great success. The day kicked off with an inspirational video created by several brain tumour survivors. Afterwards, information was provided in the form of presentations by health care specialists in brain tumour biology and treatment.



Dr. Brian Thiessen started the day's sessions with a review of "brain tumour basics," followed by updates on radiotherapy by Dr. Andrea Lo and on neurosurgery by Dr. Julia Sharma. There was an informative panel discussion involving five individuals whose lives have been affected by a brain tumour diagnosis. Question and answer periods followed each presentation and also took place during the panel discussion.

Refreshments, including a nice lunch, were provided. Attendees could participate in either a patient or caregiver support group session in the afternoon. Following this, Sarah Sample, a counsellor and relaxation therapist, and Cathie Dunlop, an art therapist, held concurrent sessions.

Rosemary Cashman, a neuro-oncology nurse practitioner, then gave a talk regarding decision making about the use of complementary and alternative therapies for brain tumours. Finally, Dr. Stephen Yip, neuropathologist and Genome Centre scientist, updated the conference participants on recent developments in



the field of genomics. He explained how Canada's Michael Smith Genome Sciences Centre in Vancouver is looking at cancer at the genetic level to detect DNA changes in individuals that might be causing uncontrolled cell division. This allows for the development of personalized treatment.

The day was well attended by newly diagnosed patients, those undergoing treatment, veteran survivors and family caregivers. Results from evaluations submitted by participants indicated a high level of satisfaction with the day as a whole. Hearing from researchers and medical specialists and meeting other patients and families were noted as the most valuable aspects of the day.

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Arts-Based Support Group for Brain Tumour Patients

By Amy Rappaport, RSW, MSW
and Cathie Dunlop, Ph.D., DVATI

THE PATIENT AND FAMILY ADVISORY COUNCIL (PFAC), comprised of brain tumour patients and their loved ones, meets quarterly to discuss issues pertaining to the care of brain tumour patients. PFAC provides guidance and feedback to the BC Cancer Agency about the brain tumour care program and advocates for improved care for brain tumour patients and their families.

In the spirit of improving care, the members of PFAC suggested we begin offering art therapy to the brain tumour community. Members felt strongly that art therapy provides an important means for individuals to express themselves, cope with a challenging diagnosis and receive support. In the words of one participant - art allows people to express what might be difficult to do with words.

As a result of PFAC's efforts, the Arts-based Support Group for brain tumour patients was born. The group, facilitated by Amy Rappaport (counsellor) and Cathie Dunlop (art therapist), took place over six weekly two hour sessions in September and October, 2014. After an initial check-in circle, the session was devoted to art-making, and then ended with a closing circle. Participants engaged in a number of activities including drawing portraits (without looking), sketching landscapes with a white oil pastel and revealing them with watercolour, creating mixed media layered paintings and fashioning nylon and wire sculptures. The group also worked in pairs on a collaborative art project. This involved transforming the mesh moulds used in radiotherapy delivery into sculptures. The finished sculptures

were titled by the artists and included "The Warrior", "the Braindeer Trickster", "More or Less Me" and "Brain Cancer Got Me Thinking." The group's body of artwork was displayed during the Brain Tumour Information Day in October.

We followed up with the group members to see what participating in the Arts-Based Support Group meant for them. Here are some of their comments:

"A great mix of sharing / dialogue and creative work."

"A great way to share, explore feelings."

"Kindled my fires. Blazed a true self."

"It is like a calming mediation with a level of comfort and informal discussion with other patients and long term survivors."

"Through the collage / painting, I have a permanent piece that symbolizes some of my thoughts about the cancer. I also learned some things about myself through this process that were unexpected and might not have arisen in any other way."

"Was nice to learn the universal language of arts and crafts in a way that I can share with my children. The way Cathie and Amy supported and communicated and silenced everyone's inner critic is a helpful tool for everyday life."



"I felt more relaxed and less anxious after every art therapy class. I have taken the art skills learned in class and applied them to my own projects at home. The collage that I created in class is beside my bed and it calms and centers me anytime I need it."

"The art therapy group gave me an opportunity to engage in new activities to stimulate my body, mind and spirit. I also enjoyed the company and the opportunity to do something fun. The art therapy taught me how to let go and be present. It has also taught me to try new things, enjoy all of life's experiences, and to not overthink things and judge myself so critically. I really appreciated the opportunity to connect with others that have had brain cancer and to learn from each other."

We will be offering another Arts-Based Support Group for Brain Tumour Patients in 2015. Stay tuned for more details, coming soon!

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

Starting treatment?

Here are some suggestions to help get you through it

WITH THE DIAGNOSIS OF A BRAIN TUMOUR, life for you and your family takes a dramatic turn.

You will meet many new people, learn a new vocabulary, acquire information that you may never have imagined and find your days filling up with appointments and scheduling. Each person handles these challenges in his or her own way, but here are some suggestions to make the road as easy as possible.

At your first BC Cancer Agency appointment

Bring family members or friends to hear the information provided, to keep a written record and to ask questions.

If you are given written patient information, put aside some time to read through it or ask someone else to do this for you.

Ask whom you should contact with questions about your health and record this person's name and phone number. You should also record and keep handy your

BC Cancer Agency ID number, as well as the names of your oncologists and other important care team members.

During treatment

You will be seen in clinic at regular intervals, but you can also notify the care team should you experience new or worsening symptoms or other concerns between visits.

At the end of treatment

Confirm your next appointment time or find out when you can expect the next appointment after treatment ends. You might also ask whom you should contact if you're not able to make a scheduled appointment.

Make an appointment with your family doctor so that he or she is aware of how you're doing. If you do not have a family doctor, let us know so that we can try to help you find one. If you are receiving home care services, contact your coordinator so that the team is updated

about your care.

If you are on medication, make sure that you have enough to last until your next appointment. If you are on dexamethasone, ask if your dose should remain stable until the next appointment or if you can begin to taper it.

If you are interested in returning to work or school, ask your care team about whether this is advisable, what you can expect and if there are other specific recommendations about this.

Review the information regarding Advanced Care Planning that was provided to you at your first visit (in the blue patient binder) and ensure that your Advanced Care Plan is up to date. **Note:** An Advanced Care Plan is recommended for everyone, not just BC Cancer Agency patients.

Should you need medical care outside the BCCA before your next appointment, keep handy the names of your oncologists, your diagnosis and treatment to date, and your BCCA ID number in case these are required.

Online Books and other Library resources

The BCCA Library has recently acquired some online books for patients and families in BC and the Yukon. We don't lend these out the same way that we lend out other material. They are accessible to one person at a time and the user must login with an id/pw. Once you open a book, you can read it for as long as you want but if you stop actively using the book, it will log you out after 10 minutes of inactivity.

To obtain a username and password for these online books call the BCCA Library, 604-675-8003 or 1.888.675.8001 x 8003 (toll-free).

Patients' guide to brain cancer / Glass-Macenska, Deanna; Olivi, Alessandro – Sudbury, MA: Jones and Bartlett Publishers, 2012. www.r2library.com/Resource/Title/0763774251

100 questions and answers about brain tumours 2nd ed. / Stark-Vance, Virginia; Dubai, Mary Louise – Sudbury, MA: Jones and Bartlett Publishers, 2011. www.r2library.com/Resource/Title/0763760544

100 questions and answers about cancer symptoms and cancer treatment side effects 2nd ed. / Kelvin, Joanne Frankel; Tyson, Leslie B – Sudbury, MA: Jones and Bartlett Publishers, 2011. www.r2library.com/Resource/Title/0763777609

100 questions and answers about caring for family or friends with cancer 2nd ed. / Rose, Susannah; Hara, Richard T – Sudbury, MA: Jones and Bartlett Publishers, 2011. www.r2library.com/Resource/Title/0763762571

BCCA libraries offer numerous resources to help support people through their cancer journey. Check out the pathfinders for recommended books, AV material and website on special interest topics such as Coping with cancer, Life after cancer, Young Adults with cancer, Sexuality and Partner Support, and many more topics: www.bccancer.bc.ca/PPI/Library/default.htm

Question + answer



Dr. Brian Thiessen,
Neuro-oncologist

Q Do all brain tumours eventually become malignant?

A The simple answer to this question is “No, not all brain tumours eventually become malignant.” There are over 30 different types of brain tumours as classified by the World Health Organization. Some are malignant from the start, such as glioblastoma, medulloblastoma, primary central nervous system lymphoma and germ cell tumours. Other tumours almost always remain benign, including schwannomas, pleomorphic xanthoastrocytoma, pilocytic astrocytoma, and subependymoma.

But there is a large group of tumours that start out as low grade or benign tumours but become malignant over time. Some meningiomas will do this, but not many; some ependymomas may also become malignant. The largest group of tumours that almost always progress from low grade to malignant tumours are the infiltrating gliomas. This group consists primarily of oligodendrogliomas, astrocytomas and

oligoastrocytomas. Over time, genetic mutations occur in enough cells of these indolent, slow growing tumours to turn them into rapidly progressive diseases.

The timing of this change can be quite variable and depends on a host of factors. Age at diagnosis, type of glioma, molecular genetics, treatment, tumour size and other factors all play a significant role in determining when a glioma will change from low grade to malignant. Favourable factors consist of young age at diagnosis, oligodendroglioma sub-type, 1p/19q chromosome deletion, IDH 1 mutation, near complete surgical resection and small size. For patients with these favourable factors, it can take decades to advance from a low grade tumour to a malignant tumour.

In summary, there are tumours that almost always progress from low grade to malignant and these consist predominantly of the gliomas. As such, we never refer to these tumours as truly benign. They are pre-malignant tumours that require active surveillance throughout an individual's life.

For more information about brain tumour types, see the following links:

Headlines Summer 2009

www.bccancer.bc.ca/NR/rdonlyres/C88B0C23-F6F9-454B-BF33-0A6AEBADC250/57161/Headlines_2009_Summer.pdf

Headlines Summer 2010

www.bccancer.bc.ca/NR/rdonlyres/C88B0C23-F6F9-454B-BF33-0A6AEBADC250/57157/Headlines_2010_Summer.pdf



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To watch a video of the day see these links:

Morning session: Brain Tumour Biology, Update on Radiotherapy, Update on Neurosurgery and the patient/caregiver panel presentation

<http://webmedia.bccancer.bc.ca/clients/player/play.html?video=/bccca/BrainCareBC/2014/InfoDay2014oct25am.mp4>
or <http://tinyurl.com/oz2p62p>

Afternoon session: Decision making about CAM; Update on Research

<http://webmedia.bccancer.bc.ca/clients/player/play.html?video=/bccca/BrainCareBC/2014/InfoDay2014oct25pm.mp4>
or <http://tinyurl.com/n8cexxd>

To see the seven minute inspirational video that started the day:

http://ybweb.bcgsc.ca/BT_Info_Day2.mp4

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

www.bccancer.bc.ca/PPI/TypesofCancer/BrainCentralNervousSystem/Headlines.htm

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).

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