

Headlines

Fall 15

A newsletter for brain tumour patients and their families

RESOURCES

A Program to Improve Memory, Attention and Emotional Well-Being in Survivors of High Grade Brain Tumour

By Douglas Ozier (PhD.),
Research Clinician

LIVING WITH A BRAIN TUMOUR brings many challenges. Survivors may develop problems with attention and memory, and many report emotional difficulties, such as anxiety and depression. There are few formal programs aimed at helping brain tumour survivors to cope with changes in thinking and emotional well-being.

Brain tumours may cause symptoms such as seizures and impairment in vision and mobility, and treatments may produce side effects such as nausea and fatigue. In addition, because some patients live far from treatment centres, it can be challenging to develop practical psychological interventions for this population.

In order to address these challenges, the BC Cancer Agency is currently enrolling participants for a feasibility study of a new program that our research team has developed. A feasibility study is a small, first stage study that is conducted to discover if a new intervention seems both practical and effective enough to warrant being tested in a larger study, called a randomized clinical trial.

In this intervention, one of our research counsellors will meet with a brain tumour survivor for a one hour session, once a week, for ten weeks. The counsellor will help the participant to learn a range of

practical coping techniques that have been designed to improve memory functioning, problem solving skills, and stress management. The program will also involve watching a series of videos that our team has developed; the participant will watch these videos in between the weekly counselling sessions. The videos feature expert professionals discussing relevant topics and brain tumour survivors discussing how they have successfully adjusted to a "new normal."



Each participant will be invited (but not required) to include a family member in the program. The family member's role

would be to act as an observer during the sessions and then to support the survivor in practicing the relevant skills.

In order to lessen barriers to access, participants will participate in their counselling sessions from home, via securely encrypted, easy-to-use video phones that our team will courier to them.

We will soon be offering this intervention to BC Cancer Agency patients living anywhere in British Columbia. In addition, we are also conducting this research in cooperation with another team of researchers based at the Northeast Cancer Centre in Sudbury, Ontario. The Sudbury based team will be offering the same intervention to brain tumour survivors living across Northern Ontario.

You may qualify to participate in this research study if you:

- Are a BC Cancer Agency patient
- Are at least 19 years of age
- Have been diagnosed with a high grade brain tumour (WHO grade 3 or 4)
- Speak English well enough to benefit from participation
- Have a high speed Internet connection at home (minimum 2.5 Mbps upload speed)

If you are interested in participating, or would like more information, please contact Dr. Douglas Ozier: 604-877-6000 ext 672185
dozier@bccancer.bc.ca

Interested in other treatments in addition to your oncologist's recommendations?

Here are some questions to guide your decision making

- 1) Why am I interested in this treatment ("Treatment X")?
 - To manage my brain tumour symptoms (such as seizures) or treatment side effects (such as nausea)

- To cure my brain tumour
 - To improve my general health (for example, by "boosting my immune system")
- 2) What sort of evidence is there for Treatment X's usefulness?
 - Clinical trials with brain tumour patients have shown it is helpful
 - Clinical trials with cancer patients

- have shown it to be helpful
- Tests on laboratory animals have shown it to have some activity
- Tests done on cells in the laboratory have shown it have some activity
- My friends/family members says it has been helpful for them or someone they know

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David Kelly Award



YARON BUTTERFIELD OF VANCOUVER was awarded the Brain Tumour Foundation of Canada's 2015 David Kelly Award for Community Service in a ceremony on September 24. This award honours an individual who exemplifies the spirit of community service to the brain tumour community and is named in honour of brain tumour advocate and fundraising leader David Kelly of Fredricton, New Brunswick, who passed away of a brain tumour in 2014. <http://www.braintumour.ca/5216/chairs-award>

Yaron is truly deserving of this award as a tireless champion of brain tumour

patients since his own diagnosis with a glioblastoma in 2004. He is a longstanding member of the brain tumour support group and is the co-chair of the Patient and Family Advisory Council (PFAC), an important committee composed of patients, family members and health care professionals that provides guidance to the BC Cancer Agency brain tumour care program. In addition, Yaron has undergone special training to serve as a "peer navigator," meeting with new patients to provide support and information. He has repeatedly served as a coordinator of the annual Brain Tumour Foundation

of Canada Spring Sprint, a fund-raising initiative to support our national brain tumour organization. He also raises funds for the BC Cancer Agency through the Ride to Conquer Cancer. On top of all that, Yaron is a researcher at the BC Genome Science Centre where his work is aimed at discovering a cure for brain tumours. He is also a loving father to his beautiful daughter, Hana.

We are thrilled and proud to honour Yaron for his many accomplishments and his unstinting dedication to the brain tumour community.

Terry Kennerley 2015 Award



THE TERRY KENNERLEY AWARD was founded in 2013 by a group of Terry's friends, affectionately known as the Hamburger Hockey League. After his diagnosis with a malignant brain tumour in 2006, Terry quickly became a central figure in the brain tumour community. He was unfailingly positive, offering support, encouragement and a wicked sense of humour to his fellow patients, and speaking to health care professionals about the importance of delivering a message of hope to those affected by brain tumours. His death in 2011 left a large hole in our community. This award, which is presented every two years, was established to honour Terry's generous spirit and to acknowledge others who, like Terry, find a sense of meaning and purpose in the face of a brain tumour diagnosis.

Paul Chapman, the 2013 recipient of the Terry Kennerley Award, presented the 2015 award to Margaret Ng on October 9, 2015.

Margaret has been actively involved in the brain tumour community for the last two years. Shortly after her diagnosis in 2013, Margaret began to volunteer her time and efforts to the Brain Tumour Foundation of Canada's BrainWave program for children with brain tumours. Among her BrainWave initiatives, Margaret organized day long events at the Vancouver Aquarium and the Sea to Sky Gondola in Squamish, focusing special attention to the children's dietary and mobility concerns. She is a regular participant in brain tumour support groups where she has shared her story and her expertise regarding nutrition and meditation. Margaret radiates a positive attitude and this has served as a source of inspiration and encouragement to other patients. She has also raised thousands of dollars for brain cancer research and participated in the Ride to Conquer Cancer, an annual two day bicycle ride aimed at raising funds for cancer research.

It is our pleasure to celebrate Margaret's achievements and to thank her



for her outstanding commitment to the brain tumour community.

To read more about Margaret Ng, see http://www.bccancer.bc.ca/patient-and-public-info-site/Documents/Headlines_2014_Spring.pdf

To read more about the Terry Kennerley Award, see <http://www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/brain-central-nervous-system/terry-kennerley-award>



Editions of *Headlines* are also available as a pdf download on at: www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/brain-central-nervous-system/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).

All content by Rosemary Cashman unless otherwise specified.

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For more information about how you can support enhanced patient care, patient information and brain tumour research, please contact Erik Dierks, Vice President, Development at the BC Cancer Foundation TOLL FREE at 1 888 906 2873 or by email at erik.dierks@bccancer.bc.ca

Brain Tumour Awareness Month Art Show



OCTOBER IS Brain Tumour Awareness Month and this year our Patient and Family Advisory Council chose to celebrate the talents and creativity of the brain tumour community through an art show. The name of the show - Brain Cancer Got Me Thinking – is taken from a work of art created by a patient from his radiotherapy mask.

We asked anyone affected by a brain tumour diagnosis – patient, family member, friend, health care professional, adult, child – to submit a work of art, any medium, along with an artist's statement about how he or she was affected by a brain tumour. The response was amazing. Twenty-two artists submitted works of art

in a range of media. A jury selected 30 for a public exhibition which was held at the Visual Space Gallery from October 7-13 on Dunbar Street in Vancouver. The stories, in combination with the art, provide a remarkable glimpse of the resilience of the spirited individuals who make up the brain

tumour community.

The Art Show was made possible through the generous support of the Brain Tumour Foundation of Canada and the Visual Space Gallery.

For a video of the art show, please see <https://youtu.be/ObemEWZ4Jxc>



Other treatments

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- The store where Treatment X is sold says it is helpful
 - Articles on the internet claim it is helpful
- 3) How will I know if Treatment X helps me achieve my goal in using it?
- How long do I intend to use it?
 - What criteria will I use to determine that it works/does not work?
- 4) What is known about Treatment X's potential side effects or medication interactions?

- Could Treatment X reduce or negate the effectiveness of my other treatments, including cancer treatments?
 - Could Treatment X cause toxic effects when used in combination with my other treatments, including cancer treatments?
- 5) Have I shared my interest in Treatment X with my health care team? What do they know about its effects?
- Could there be any other harm to me in using Treatment X?

For more information about complementary and alternative therapies,

speaking to your health care team, see your BC Cancer Agency librarians or see also: <http://cameoprogram.org/about-cam>

For the BCCA recommendations on Natural Health Products and cancer therapies see: <http://www.bccancer.bc.ca/health-info/coping-with-cancer/complementary-alternative-therapies> and <http://www.bccancer.bc.ca/our-services/services/library/recommended-websites/cancer-treatment-websites>

For information about clinic trials, see <https://clinicaltrials.gov> and <http://www.bccancer.bc.ca/our-research/participate/clinical-trials>