

Headlines

Summer 14

A newsletter for brain tumour patients and their families

RESOURCES

Peer support program for newly diagnosed brain tumour patients

By Matt Heemsker, volunteer navigator and brain tumour survivor

YARON BUTTERFIELD AND I SERVE as peer navigators in a special program for brain tumour patients at the BC Cancer Agency in Vancouver. This program was initially trialed as a research study to find out if newly diagnosed patients with brain tumours would find it helpful to speak with a fellow

patient who has been through treatment already. The overall results were very positive. All the patients reported feeling that speaking with a fellow patient was helpful and many patients reported that they felt more hopeful after they had spoken with a brain tumour survivor. The program is now a regular volunteer program at the BC Cancer Agency, Vancouver Centre and is overseen by Patient and Family Counselling Services.



Yaron Butterfield, a brain tumour researcher and 10 year survivor of a glioblastoma is in Tsfat, Israel, refurbishing a mural he created 17 years ago to honour the memory of a young man who passed away of cancer in 1994.

The program consists of a one hour meeting of a “veteran” patient and a newly diagnosed patient who will soon be starting treatment (either chemotherapy or radiation treatment or both). Yaron and I received training regarding observation of patient confidentiality and ethical concerns. Much of the session is largely unstructured so that the new patients are

able to explore the topics of most concern or interest to them.

I usually set up the session similar to a brain tumour Support Group meeting. I introduce myself and give a brief statement about my medical history and then relate a few basic personal details. Then the fellow patient introduces him/herself and the

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Matt Heemsker with his son, Aidan.

American Society of Clinical Oncology (ASCO) meeting highlights

By Dr. Brian Thiessen, Neuro-oncologist

ASCO, THE LARGEST ONCOLOGY CONFERENCE in the world, has come and gone. Despite Neuro-oncology being a small player in the Oncology universe, it seems every year there are practice-changing studies presented in Chicago. This year the big news was the RTOG 9802 clinical trial: <http://am.asco.org/adjvant-chemotherapy-after-radiation-improved-overall-survival-low-grade-glioma>. This multi-institutional study, started over 15 years ago, looked at patients with low grade gliomas. Patients with low grade, but high risk tumours were randomly assigned to receive either radiation therapy alone or radiation combined with chemotherapy. After 5 years, it appeared there was no difference in survival between the two treatment groups. With further follow-up, however, they noticed

the group that received chemotherapy was doing better. By 10 years, there was a 20% improvement in survival for those that received chemotherapy with their radiation.

This large difference in survival means that instead of treating low grade tumours with either radiation or chemotherapy alone, we should be using both treatments together, especially for those with higher risk tumours. Despite this knowledge, there are still questions raised by the study. Should we also be treating lower risk tumours this way? Should we use the old chemotherapy regimen from 15 years ago or use more modern chemotherapy drugs? Will genetic testing reveal a group of patients that benefit more from this therapy? Or maybe a group that doesn't benefit at all? Are the long term survivors suffering any harmful side effects from the more aggressive treatment?

At the BCCA, we are struggling with

these questions and trying to alter our treatment plans accordingly and, hopefully, in the best interests of our patients. Our goals, as always, have been to prolong life if at all possible and to make sure that we preserve quality of life in the process. With those goals in mind, we have decided as a group to recommend radiation and chemotherapy for patients with high risk, low grade tumours.

Regarding new advances for other brain tumours, there was not much presented showing any benefit over our current strategies. But importantly, there were several new agents in early trials, indicating the pipeline of new possibilities hasn't run dry and scientists are continually using new technology and information to devise new treatment strategies. We look forward to following these agents along and hope some of them can turn out to be beneficial in the future.

Peer support program *continued from page 1*

content of our discussion revolves around the patient's concerns or interests. Usually, the meeting flows from the introduction. The patient may have immediate questions or concerns and may want feedback about my personal experience. We also have a list of frequently asked questions that are of interest to many new patients. I usually mention the side effects I experienced with my treatment and how I managed them, as well other treatments I have tried. This seems to engage the fellow patient and allows him or her to bring up additional concerns or questions they may have. Finally, in the last 5-10 minutes of the session, Yaron and I go over a resource book that was prepared by Patient Family Counselling and is given to the patient to take away.

Through our training we're alert to potential situations and topics that may be especially challenging and are given some ethical guidelines to follow to support patients. For example, I always make sure to let the new patient know that his or her experience will not be exactly like mine because everyone's journey is different. I do not advocate any standard, alternative or complementary treatment. I relate my experience but let the patient know that if they have any medical questions they should speak with the health care team.

Sometimes meeting with a new patient can be an emotional experience for me, especially if certain topics are mentioned. For the most part, those emotional "triggers" for me are related to seizures and my concern about leaving my son and wife behind. We are trained to be alert to these triggers and seek assistance if we need it. If

a patient notices I am becoming emotional, for example if I become misty-eyed when talking about my wife and son, I focus the meeting back on the patient by saying something like "this meeting is about you."

I get a lot out of being a volunteer in this program. It helps me to help someone else with a diagnosis of brain cancer by relating my journey or listening to another person's story. In the space of that hour, I can talk about something that is scary, both for me and the other patient, in a vulnerable but authentic way and not resort to my mask of being brave for my family, friends and the doctors. I truly hope that the program will lead to better outcomes for other brain cancer patients.

For information about other BCCA support programs see: www.bccancer.bc.ca/PPI/copingwithcancer/emotional/supportprograms/default.htm

The Canadian Cancer Society

By Sheila Craigie,
Canadian Cancer Society

BC'S WORLD-CLASS CANCER CARE comes from the BC Cancer Agency and from a network of hospitals, specialists and associated staff. But do you know that the charity sector also plays an important role?

The Canadian Cancer Society has a range of free programs for people with any cancer including malignant brain tumours. In addition, people with non-malignant brain tumours can access this support, as can their friends and family members. The services fall into three main categories:

Peer Support The Society's phone-based program called CancerConnection connects clients with trained volunteers who have had a similar cancer experience. For example a patient with a brain tumour will be connected with a volunteer according to whatever is most important to the patient. A patient may wish to speak to someone who has had radiation and surgery for a brain tumour, or they may ask for a volunteer who is dealing with epilepsy in the wake of their disease, or perhaps they want to talk to someone the same age... Whatever the request, staff will comb a national pool of trained volunteers who have had a comparable experience. Services are also available for friends and family members. People close to a person with a brain tumour can ask to be

connected with a volunteer who has been a caregiver for someone in this situation. Contact is over the phone, with volunteers' long distance charges (if any) paid by the Canadian Cancer Society. The service is free and confidential, and volunteers are supported by professionally qualified staff.

"We had a long chat, it was brilliant! It was good to hear about the side effects and how she copes with them."

"It just helps to hear of someone's success. Since our conversation, I often think back to what he said & it helps me hold on."

Additional peer support services are available online at cancerconnection.ca

Practical Support The Canadian Cancer Society services can include help with transportation, and financial assistance. There are times when simply getting to treatment can be difficult. Patients who have no other way of getting to treatment appointments, are encouraged to contact the Society's Volunteer Drivers service. Our financial support program provides limited subsidy for cancer-related transportation and accommodation. Those eligible are current cancer patients who are in financial need, and who are not covered for transportation or accommodation assistance through another program. In addition the Canadian Cancer

Society partners with the BC Cancer Agency to administer the Financial Support Drug Program which provides symptom-control prescription medication recommended in current treatment protocols at a subsidized rate for people in financial need who are undergoing cancer treatment. Of course most chemo drugs are provided at no cost to patients, but this program covers drugs like prescription anti-nausea medications taken at home.

Information A diagnosis can leave patients feeling that they don't know enough about their disease. Physicians and other healthcare professionals are the primary source of information, but it is often the case that questions arise between appointments. The internet is a valuable resource,

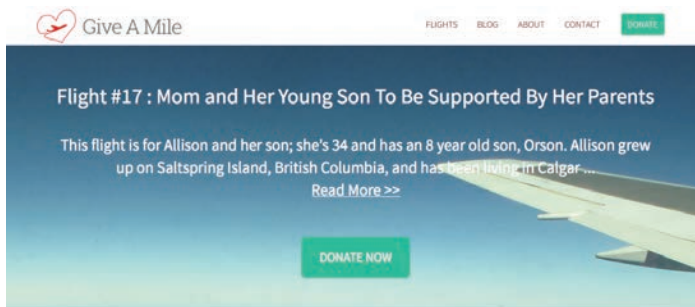
but unfortunately information is not always accurate. The Canadian Cancer Society's Cancer Information Service is a source of reliable information that can be accessed over the phone. Covered are

- basic information about treatments,
- explanation of terms,
- information about support groups and other community resources,
- techniques to help in decision-making, and
- suggestions of reputable websites

All Canadian Cancer Society services are available via 1-888-939-3333 or online at www.cancer.ca

Information about cancer and support is also available on the BC Cancer Agency website at bccancer.bc.ca

Give a Mile



Our goal is to provide 1 billion miles of travel loyalty Points to those in need of visiting a terminally ill or critically sick loved one.

By Kevin Crowe

GIVE A MILE IS A NOT FOR PROFIT Canadian organization which aims to enable people to visit terminally ill friends or family through the use of donated travel points. Give a Mile's big goal is to provide 1 billion miles of customer loyalty program points to those wishing to visit critically or terminally ill loved ones.

There are three key elements to the Give a Mile program:

1) Donated miles go to a specific individual in need whom the donor chooses to help, not to an organization.

- 2) Operating funds for Give a Mile are raised separately.
- 3) The transaction is simple for those donating and receiving points.

The idea for Give a Mile came from my experience of helping to support my amazing friend Ryan Westerman, who lost his battle with brain cancer in Calgary in 2010. Ryan was a husband, the father of a four year old son, a brother, a son and an amazing friend to so many people. Although he fought heroically against his disease, his doctors ultimately told him there were no further treatments and he and his family turned their efforts to making his final days

as positive as they could. Thus began an experience that is impossible to put into words, as we all came to see that every moment is valuable and every day is a gift. Being with Ryan and his family in those final days was an incredibly heartbreaking and heart touching experience. Ryan told us how much we helped him – and we all know how much it helped us to be with him.

Many people cannot afford to travel to see critically or terminally ill loved ones.

That got us thinking...

Ten trillion airline travel miles went unredeemed in 2011. These points could be used to bring family and friends closer to a loved one at a critical time. That presence could brighten

someone's final days and provide comfort to all of the people within the circle of care, as it did for Ryan and his family and friends.

Give a Mile makes use of unwanted or un-needed travel points and allows donors to make a difference in the lives of those suffering from a terminal illness. To request a flight or donate travel miles, send an email to us at info@giveamile.net If you are requesting a flight, please provide your story: who you want to see, why and where. Our team will review the request and do our best to get that flight.

For more information: giveamile.org



Editions of *Headlines* are also available as a pdf download at: www.bccancer.bc.ca/PPI/copingwithcancer/specifiresources/Neurooncology.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).

All content by Rosemary Cashman unless otherwise specified.

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