

Headlines

Winter 13

A newsletter for brain tumour patients and their families

MEDICAL UPDATE

A vaccine for glioblastoma – the ACT IV study

An International, Randomized, Double-Blind, Controlled Study of Rindopepimut/GM-CSF with Adjuvant Temozolomide in Patients with Newly Diagnosed, Surgically Resected, EGFRvIII-positive Glioblastoma

A VACCINE APPROACH to the treatment of glioblastoma aims to engage the body's natural defense system to fight cancer cells. Brain tumour cells are supported by a host of cellular processes that promote malignant changes and cell growth. The epidermal growth factor receptor (EGFR) gene is associated with cell growth, metastasis, invasiveness and cancer cell survival. It is often dysfunctional in human cancers, including over one third of glioblastoma tumours. The vIII subtype type of the EGFR gene is especially common in glioblastoma and is associated with poor outcomes for patients.

The rindopepimut vaccine has been studied extensively in clinical trials with

glioblastoma patients and has been shown to be well tolerated and to have a positive effect on patient survival. The vaccine selectively targets glioblastoma cells and spares normal cells, thus limiting toxic side effects. By prompting an immune response, the vaccine helps the body fight against the cancer. This study is now open and will enroll approximately 440 newly diagnosed glioblastoma patients at cancer centres around the world. In order for patients to be eligible for the study, their tumours must be characterized by the EGFRvIII mutation, as confirmed by pathology review.

Patients who agree to participate in the study will be randomized to receive either the rindopepimut vaccination or a placebo vaccination, a harmless substance that is injected under the skin just like the real vaccine. The placebo vaccination causes a local reaction consisting of slight swelling and redness, just as the real vaccination does. This reaction is common to most vaccinations, and is due to the stimulation of the immune system. As a result of the placebo, there will be no tell-tale sign to distinguish one treatment from another.

This ensures that the “double-blind” is maintained throughout the study, so that no one knows which treatment a study patient is receiving and all patients receive the very same care.

The vaccination process begins after completion of the standard six weeks of combined chemoradiation. An initial priming dose is given before the chemotherapy alone portion of treatment begins, and then once a month thereafter. The use of steroid medication (dexamethasone or Decadron®) must be limited, as its anti-inflammatory effect has the potential to affect the immune response induced by the vaccine.

This clinical trial is an exciting development as vaccine therapy for brain tumours has the potential to revolutionize the management of this disease. For more information about vaccine therapy or clinical trials for brain tumours speak to your health care team or see *Headlines* Spring 2007, Spring 2010, Summer 2010, Spring 2011 or Spring 2012. www.bccancer.bc.ca/PPI/copingwithcancer/pamphlets/brain.htm

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

www.bccancer.bc.ca/PPI/copingwithcancer/specificresources/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.

Adapting to a “New Normal”

By Dr. Douglas Ozier,
PhD, Research Clinician

EVERYONE’S ABILITY TO DO THINGS changes from day to day. If you sleep well you will probably be able to accomplish more the next day than if you don’t sleep well. Living with a brain tumour causes special challenges and may lead to even more variability and changes in abilities. This can be difficult and confusing, especially for those who have a tendency to demand a lot from themselves.

Below, I identify four keys to learning how to decide what to expect of yourself as you adjust to changing abilities and your “new normal.”

- **Tune into your body to help you set your expectations:** Before your diagnosis you were likely able to set expectations for yourself in a pretty routine way. “Whenever I go to the gym I should be able to ride the bike for 30 minutes.” Now however your capabilities on any given day depend on a wide range of factors including how well you slept, the presence of seizures, difficulties with mobility and treatment-related side effects. So it becomes very important to really tune in and “listen to your body” on an ongoing basis. How is your concentration? Your energy? Your mood? Only with this “status report” in place will you be able to set expectations for yourself that are in line with your current physical and mental resources.
- **Use the “lower bar/upper bar rule” for setting goals.** Once you have tuned into yourself and have a sense of how you are doing on a given day, you are ready to begin setting

goals using the “**lower bar/upper bar rule.**” This rule dictates that on “bad days” (low energy, concentration, patience, etc.) your goal should be to get above a minimum target (the “lower bar”) rather than doing nothing at all. So for example, on a bad day, your goal might be to walk around the block for 5 minutes rather than staying on the couch all day. On the other hand, on a “good day” your goal should be to stop before going above the upper bar, to avoid overdoing it and “crashing” the next day (thereby increasing the chances that tomorrow will also be a good day). So for example, on a good day, your goal might be to stop after walking for 30 minutes rather than pushing yourself to that day’s absolute limit of 45 minutes or an hour.

- **Develop self-compassion.** On bad days (even if you have done your best and gone above the bottom line) it is very easy to judge yourself as “weak” or “not trying hard enough.” Don’t beat

yourself up with thoughts such as “I only walked around the block today! Last week I walked all through my local park . . . and before I was diagnosed I was a rock climber. I’m such a loser!” Instead, on a bad day it is more helpful to see your efforts in a positive light. For example, try thinking “Today my energy was really low and yet I *still* got myself to walk around the block. That is actually as big a success as walking around the park was last week when I felt good.”

- **Be mindful of possible depression.** Depression is quite common in brain tumour survivors as well as their family members. It is important to be mindful of the risk of depression for many reasons. However, in the context of this article, depression is particularly relevant because it interferes with a person’s ability to “listen to their body” in a useful way. When we’re depressed, our thinking and our bodily sensations become distorted. As a result, our bodies and minds will *always* tell us to do less and less when we’re depressed. In this case, listening to your body during goal setting is actually counter-productive, because it leads to inactivity and social isolation. So when learning to set goals in a flexible way it is important to separate out any influence of depression. If you think you may be experiencing depression you can talk to your doctor, contact Patient and Family Counselling, and/or go to

www.bccancer.bc.ca/PPI/copingwithcancer/emotional/dealingemotions/depression.htm



Group Counselling for Cancer Caregivers: CancerChatCanada's Online Support Groups

By Joanne Stephen, PhD, Clinician Scientist and Aazadeh Madani, MA, Research Coordinator for CancerChatCanada

"I am now aware of what caregiving is, I'm aware of what a patient goes through and what caregivers go through."

CancerChatCanada is a BC Cancer Agency-led program that hosts private, professionally-led, live chat support groups for family members of cancer patients, regardless of where they live in Canada. The groups are facilitated by psychosocial oncology professionals at collaborating cancer centres from BC to Nova Scotia. The team is united around a vision of ensuring all Canadians can access free high quality support and education – and link with others who face similar challenges.

"I had some wonderful 'aha' moments. The most important thing is that I'm not alone in the intensity and complexity of my thoughts about cancer and caregiving. That was important."

CancerChatCanada Caregiver groups:

- Have 6-8 members and meet weekly for 10 weeks
- Are free and easy to navigate
- Are hosted on a password protected website – only members of your group have a password to log in and join the discussion
- Include an online discussion board to continue the conversation outside group times
- Are 90 minutes per session
- Have group discussions that are focused around common experiences or concerns and questions
- Allow space for members to speak openly and to support each other

The online groups are structured to provide emotional support and a place to safely discuss personal topics. Over 500 Canadians have participated in the online groups and our research shows that members appreciate the convenience and privacy of online groups and also experience feelings of



kinship, strength and relief knowing that they are not alone. Caregivers who have participated in our groups have also reported such benefits as enhanced wellbeing, better mood, increased coping and improved interpersonal relationships.

"You feel guilty but you have got to set time aside for yourself and that's something I've started to do. I've started reading more than I have been; others in the group go hiking, and fishing. It was good to learn how other people cope."

If you are a caregiver for a cancer patient and are in need of emotional support or think you could benefit from meeting with other people who are also caring for a loved one, you can register on our website, www.cancerchatcanada.ca, or call 1-800-663-3333 ext 4955.

Call for nominations!

The Terry Kennerley Award is intended to honour a British Columbian who has made outstanding contributions to the brain tumour community. Such contributions might include raising public awareness about brain tumours, contributing to research efforts, or helping to develop the program of care provided in the cancer agency or in the community. You may have other examples of contributions. If you know someone who has made a difference in the lives of people affected by brain tumours contact cpelleti@bccancer.bc.ca or rcashman@bccancer.bc.ca

For more information about the Terry Kennerley Award see: www.bccancer.bc.ca/PPI/TypesofCancer/BrainCentralNervousSystem/terrykennerley.htm

Q My husband has been battling a grade 4 brain tumour for over a year and now the oncologist says there are no other treatments for him and he may only have a few months to live. We knew this was coming and have accepted it. Do you have any advice for me about what lies ahead? I am trying to work, but worried about my husband and not sure if I should tell my boss about this since we need my income. Home care nursing has been notified and will come out next week, but I don't know what they will do for us and I'm trying to be prepared for what lies ahead.

A I'm very sorry for the difficult news you've received about your husband. I can only imagine what you and your family are going through now. I can offer a few pieces of practical advice based on feedback from other patients and caregivers like you and your husband.

Home Care services can help people with serious health conditions to remain in their homes as independently and safely as possible. This support is not meant to replace the support that family and friends provide, but rather, to add to it. Community support workers provide assistance with activities of daily living such as bathing, dressing and meal preparation and can offer a break from caregiving for family members. Home Care Nurses are registered nurses who conduct assessments, manage symptoms and provide support in line with the needs of patients and their caregivers. This may include referrals to other health care professionals such as physiotherapists and occupational therapists. Home Care teams work in partnership with the cancer

agency and the family doctor to provide the best quality of care. They also work with a Home Hospice Team made up of physicians, clinical nurse specialists, social workers, and spiritual care advisors to optimize care at the end of life. Should you and the Home Care team decide that your husband's care needs are too great or complicated to manage at home, hospice care may be suggested. A hospice offers a home-like environment with 24 hour specialized nursing care to ensure comfort and safety.

Another thing to consider at this time is **Advance Care Planning**. This process is really about making sure that your husband's wishes are followed should he be unable to express these wishes. If you have not already done this, I encourage you to sit down with your husband and talk about important beliefs, values and wishes that he has regarding his health care, including the type of care he wants and the interventions he would refuse. The Home Care professionals can help you with this discussion if you like. This process may involve the creation of three documents: (1) an Advance Care Plan, (2) Advance Directive, and/or (3) Representation Agreement. An *Advance Care Plan* is a written summary of a person's wishes and serves as a guide for a substitute decision-maker (or representative) in the event that that person becomes incapable of making decisions. An *Advance Directive* gives or refuses consent to health care directly to the health care provider if there is no appointed representative. A *Representation Agreement* is a legal document that allows a patient to designate an individual to act as their decision maker for both health and financial issues should they not be able to clearly communicate their wishes.

Question + answer



For more information about Advance Care Planning, visit:

www.fraserhealth.ca/your_care/advance-care-planning/
www2.gov.bc.ca/gov/topic.page?id=E7A581A9BC0A467E916CFC5AD2D3B1E8
www.bccancer.bc.ca/PPI/RecommendedLinks/coping/wills.htm

Compassionate Leave through EI (Employment Insurance) allows family caregivers to take time off work to care for their loved ones for up to six weeks and still receive a portion of their income. To qualify for EI, you must have worked 600 insurable hours in the past 52 weeks. To find out more information or to apply go to: www.servicecanada.gc.ca/eng/sc/ei/benefits/compassionate.shtml, or visit a Service Canada station near you, or call 1-800-206-7218. You can also speak to your social worker for more information.

Last but not least, **emotional support** is available to you and your family as you move through this difficult time. It is natural to experience a range of emotions, including sadness, fear, anger and helplessness. You should not have to go through this experience alone. There is support and counselling available to you through Patient & Family Counselling, Home Care and your local hospice society. The Brain Tumour Support Group allows you to connect with other patients and family members affected by Brain Cancer. CancerChatCanada is an online resource that offers professionally-led online support groups for people affected by cancer. For more information visit www.cancerchatcanada.ca or see the Resources article in this issue of Headlines. Another great online resource can be found at www.virtualhospice.ca This website offers discussion forums, articles, links to other information sources, and an 'ask a professional' tool that allows you to ask medical, emotional, and practical advice from a team of professionals.

I wish you much support and gentle transitions ahead. For more information or for other concerns, contact your cancer agency social worker or health care team.

*Amy Rappaport, MSW, RSW
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