

# Headlines

Summer 08

A newsletter for brain tumour patients and their families

## MEDICAL UPDATE

### ASCO 2008

**A**SCO 2008, (the general meeting of the American Society of Clinical Oncology) is the big cancer conference of the year and was held in Chicago at the beginning of June. Oncologists worldwide meet to present their research in all types of cancers. Brain tumour research took up a day and a half and we discussed some exciting new studies. Here are some links to the ASCO meeting:

[www.asco.org/](http://www.asco.org/)

[www.cancer.net/patient/ASCO+Resources/Research+and+Meetings/ASCO+Annual+Meetings](http://www.cancer.net/patient/ASCO+Resources/Research+and+Meetings/ASCO+Annual+Meetings)

Dr. James Perry from Toronto presented the Canadian "Rescue Study" results to the attendees. This trial was done with 120 patients across the country from Halifax to Vancouver and basically looked at the effectiveness of a daily low dose of temozolomide chemotherapy in patients with malignant brain tumours. The study was designed to try to combat drug resistance to the standard 5 days per month dosing of temozolomide by giving the drug in a different way. Drug resistance is a common problem in cancer therapy, as tumour cells tend to mutate in ways that make them less sensitive to treatment. For this study, patients were given a very low

dose of treatment every day. This dose was very well tolerated.

From the study results, it appears that those patients who had not been treated for prolonged periods with standard dose temozolomide had the best response to the daily dose method. Specifically, two groups of people responded well: 1) those whose tumours grew either within six months of starting the standard dose (5 days per month) of temozolomide and 2) those whose tumours grew after completing 6 months (not more) of standard dose temozolomide treatment. However, if patients had taken the drug longer than the currently recommended 6 months of standard treatment, it was rare for them to respond to the daily treatment. This fits in well with what we know about the development of drug resistance. It looks like we have a new option for patients when their tumours stop being sensitive to the 5 days dose temozolomide treatment, without moving to more harmful and toxic agents. Canadians can certainly be proud of the work that was done on this study, as it will affect brain tumour patients around the world.

Another treatment that received a lot of buzz was bevacizumab (Avastin®).

[www.bccancer.bc.ca/HPI/DrugDatabase/DrugIndexPt/bevacizumab.htm](http://www.bccancer.bc.ca/HPI/DrugDatabase/DrugIndexPt/bevacizumab.htm)

Bevacizumab is an "anti-angiogenesis

agent," a drug that prevents the formation of blood vessels around the tumour. Blood supply is very important for tumours as blood transports nutrition to the tumour and takes away waste products of metabolism. A few small studies have been published this year showing that this combination of bevacizumab with a traditional chemotherapy (irinotecan) can be very effective in controlling the most aggressive brain tumour, glioblastoma multiforme, when it fails to respond to other chemo drugs. At ASCO, further updates to those studies were presented, as well as a new study looking at 160 patients receiving either bevacizumab alone or in combination with irinotecan. All the studies had a similar message: this combination, while not a cure, certainly improves the appearance of the tumour on MRI scans and does prolong time until the tumour begins to grow again. While this news is exciting, it must be tempered by the fact that this treatment does have significant issues in terms of side effects (diarrhea, blood clots, bleeding, fatigue, high blood pressure) and cost (~\$9000/month). Nonetheless, there is no denying that this is a promising new therapy for brain tumours. Further studies using bevacizumab earlier in treatment and

*continued on page 3*

## Home Health Care

**P**ROFESSIONAL HOME HEALTH CARE TEAMS at each Community Health Centre in British Columbia include registered nurses, physiotherapists, occupational therapists, counselors and respiratory therapists. These services are designed to complement and supplement, but do not replace, the efforts of individuals to care for themselves with the assistance of family, friends and community. At various points from the time of your initial diagnosis with a brain tumour, you may benefit from their support in managing your care at home.

### What would a Home Care Nurse or Home Health Team do for me?

Home care nurses are experienced registered nurses who can monitor your general condition, advise you about managing side effects of treatment, and communicate with your cancer care team to enhance your care. A home care nurse may also help distinguish between treatment side effects and signs that suggest that the tumour may be growing. They also provide access to additional community care resources, including homemaking and respite care, or British Columbia Palliative Benefits Program.

These community based nurses are also care coordinators who can bring in additional supports as needed, and can facilitate admissions to an acute care hospital should that become necessary. They also care for people who are nearing the end of their life, and their families, at home or in a hospice.

### Who can refer me?

Any member of your cancer care team or family physician can make a referral

to your local home health centre by phoning or faxing a referral with required information. This information will include a medical history of the diagnosis and treatment, reasons for referral and requests for additional specific services, such as an occupational therapist to perform a safety assessment in your home and make recommendations about specific equipment to help you.

### When would the Home Care Nurse visit?

After the community staff receives a referral, the nurse coordinator will call you to set up an appointment. This initial assessment visit can be arranged within 24 – 48 hours if needed, and usually takes about one to one and a half hours. At the end of this appointment, a nursing care plan is developed based on the goals for care determined by you, the nurse and your cancer care team. For example, during your cancer treatment a nurse might visit every week to ensure that you're tolerating the treatment well, but after treatment visits might decrease to once every few weeks or once a month. Telephone contact with the nurse may be maintained until you both agree that this is no longer necessary.

### What is the BC Palliative Benefits Program?

The BC Palliative Care Benefits Program supports and enables individuals in the end-stage of a life-threatening illness or disease to remain at home by covering the cost of medication, medical supplies and equipment – all at no charge.

The philosophy of this program is that:

- Home and community care services will

promote the well-being, dignity and independence of patients and their families

- Palliative care services will provide the best possible quality of life for people nearing the end of their life, and will help their families as well;
- Patients and their families should have access to information in order to make their own decisions about lifestyle and care

BC residents covered under the Medical Services Plan who have been diagnosed with a life-threatening disease, or an illness with a life expectancy of up to six months are eligible. Coverage continues as long as the person is diagnosed as requiring palliative care.

### Who can refer me?

The BC Palliative Benefits referral is completed by your oncologist or family physician and faxed to Victoria where your name is then entered into Pharmanet. Once you are registered, the cost of your prescriptions is covered (there are some exceptions). This process takes approximately 24 hours. A copy of the form is also sent to the local health authority which will then cover practical support and medical supplies and equipment.

Community services include palliative care co-ordination and consultation, professional nursing services, community rehabilitation services, home support and respite for the caregiver. This care is provided wherever the client is living – in their home, in hospital, a hospice, residential care facility or an assisted living residence – during the remaining days, weeks or months of a client's life.

*continued on page 3*

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

[www.bccancer.bc.ca/HPI/CancerManagementGuidelines/NeuroOncology/PatientResources.htm](http://www.bccancer.bc.ca/HPI/CancerManagementGuidelines/NeuroOncology/PatientResources.htm)

If you would like to submit an article, ask a question, or serve on our patient and family advisory board, please contact Rosemary Cashman at [rcashman@bccancer.bc.ca](mailto:rcashman@bccancer.bc.ca) or 604 877 6072 (phone) 604 877 6215 (fax).

All content by Rosemary Cashman unless otherwise specified.

## British Columbia Online Information and Discussion Group for Caregivers of Loved Ones with Cancer

CARING FOR A LOVED ONE WITH CANCER can be challenging. Often these challenges are difficult to talk about with others. It can be helpful to meet with other caregivers and share information and support. The Patient and Family Counselling department of the British Columbia Cancer Agency invites you to be part of an online counsellor-led information and discussion group that will give you the opportunity to talk about how you are doing with others who share your experience.

**Who:** Caregivers living in BC and the Yukon. Your loved one has a cancer diagnosis and is currently in treatment or has been treated in the past by the British Columbia Cancer Agency.

**What:** An opportunity to engage in secure, private on-line chat once a week for 6-8 weeks with other caregivers and a BC Cancer Agency trained facilitator.

**Where:** In your own home or where you have access to a computer.

**When:** Tuesdays, 1:00 pm - 2:30 pm

**Start date:** July 15, 2008

For more information and to confirm your eligibility, please contact the BC Cancer Agency's Patient and Family Counselling program at:  
Toll Free: 1 800 523 2885 ext. 4000 Local: 604 930 4000

**Home Health Care**  
*continued from page 2*

### What is the Compassionate Care program?

The Compassionate Care benefits allows people eligible for employment insurance (EI) to claim benefits when they take temporary leave of absence from work to provide care or support for loved ones at significant risk of death.

For more information about this program, please contact 1 800 206 7218 or go to [www.servicecanada.gc.ca](http://www.servicecanada.gc.ca)

If you would like additional information on the home health resources in your community please check the following links:

- Coping with Cancer: [www.bccancer.bc.ca/PPI/copingwithcancer/default.htm](http://www.bccancer.bc.ca/PPI/copingwithcancer/default.htm)
- Home and community care: [www.health.gov.bc.ca/hcc](http://www.health.gov.bc.ca/hcc)
- End of life care and provincial policy statements: [www.health.gov.bc.ca/hcc/endoflife](http://www.health.gov.bc.ca/hcc/endoflife)
- Health and Seniors' Information Line  
The free, 1 800 telephone line offers seniors a single source for information about government services, including information about health programs, as well as other non-health services and initiatives.  
Toll-free in B.C.: 1 800 465 4911  
Victoria: 250 952 1742

*by Karen Levy, Advanced Practice Nurse*

**ASCO 2008**  
*continued from page 1*

combined with temozolomide are underway.

There were a number of other studies presented, but few showed superior results to our current treatments. A few new studies look interesting but there are no results available yet as the studies have just started. A tumour vaccine targeted to certain

glioblastomas was especially interesting and a trial combining the vaccine with temozolomide is underway. Hopefully by next year's ASCO we will have more results.

Where do we go from here? The neuro-oncology tumour group (the doctors and other health professionals treating brain tumours) [www.bccancer.bc.ca/HPI/CancerManagementGuidelines/NeuroOncology/default.htm](http://www.bccancer.bc.ca/HPI/CancerManagementGuidelines/NeuroOncology/default.htm) at the

## Mark your calendars

Brain Tumour Information Day

Saturday, October 4, 2008  
8:30 am to 3 pm

BC Cancer Research Agency  
675 West 10th Ave.  
(across from BCCA, Vancouver Centre)

Presentations by oncologists and other health care professionals  
Networking, support groups and more

Lunch provided

All free to patients  
and their caregivers

Registration required –  
contact 1 800 265 5106 ext. 31  
[www.infodays.ca](http://www.infodays.ca)

Funded by the Brain Tumour  
Foundation of Canada



BC Cancer Agency will be discussing the utilization of low-dose daily temozolomide and the bevacizumab/irinotecan combination and determining whether to support its use and apply for funding from the Cancer Agency's budget. We are fortunate in British Columbia, because unlike in other provinces, the cost of approved chemotherapy is covered through the provincial budget. When new drugs become available, the cancer agency reviews the results of experiments documenting their effectiveness and makes decisions about which treatments it will fund. This process may take several months to a year, but hopefully eligible patients will be able to see these drugs made available for them in the near future.

*by Dr. Brian Thiessen, Neuro-oncologist*

## Question + answer

**Q** A family member has suggested that I take some sort of mushroom to boost my immune system. What should I do?

**A** Family members play an important role in helping patients get through their cancer treatment. Suggestions about the use of complementary and alternative medicine (CAM), such as the mushrooms you've mentioned, is one way family members feel that they can be helpful to their loved one. Recent surveys report that 50-80 percent of patients use CAM along with conventional cancer treatment (chemotherapy, radiation, surgery). CAM includes a range of therapies, such as vitamins and herbal supplements, acupuncture, and meditation. Many people with cancer use CAM therapies for a variety of reasons, including, for example, managing the symptoms associated with their conventional cancer treatment, improving their feelings of well being, enhancing feelings of control over their situation, and promoting hope.

The first question to ask yourself is what do you want to do? Is using a CAM therapy such as mushrooms, in addition to your cancer treatment, something you want to explore? Does taking mushrooms fit with your beliefs, values, and goals for optimal health and healing? Also, are the financial costs of using the suggested CAM therapy reasonable for you and your family?

Secondly, if you are considering using mushrooms or other CAM therapies, it's important to talk with your oncologist and/or nurse, pharmacist or registered dietitian about it. Some CAM therapies may interfere with the cancer treatment, making it less effective, or making side effects worse. For example, shiitake mushrooms, when taken in large quantities, can increase the skin's sensitivity to light, and can make the skin-related side effects of radiation treatments more pronounced. Reishi mushrooms may increase the risk of bleeding in some people. Talking with your oncologist or another health professional may help you

to identify CAM therapies that fit with your beliefs and goals, and are most likely to be safe and beneficial in your particular case. Thirdly, it's important to become an informed consumer about CAM. Searching for information about CAM can be an overwhelming job, but can be shared with others, including family members wanting to help. Determining reliable sources of information about CAM can be difficult, especially on the internet. The BC Cancer Agency website provides links to trustworthy sources of information about CAM. These two are a good place to start: [www.bccancer.bc.ca/RES/ResearchPrograms/cameo/usefullinks](http://www.bccancer.bc.ca/RES/ResearchPrograms/cameo/usefullinks) [www.bccancer.bc.ca/PPI/RecommendedLinks/treatment/complementary.htm](http://www.bccancer.bc.ca/PPI/RecommendedLinks/treatment/complementary.htm)

Your oncologist, pharmacist or nurse may be able to help you look up the therapy you're interested in to determine what is scientifically known about it in relation to your cancer treatment. You can also contact the BC Cancer Agency librarians for help getting started looking into CAM: [www.bccancer.bc.ca/PPI/Library/default.htm](http://www.bccancer.bc.ca/PPI/Library/default.htm)

While there is more research being done to test CAM therapies, much is still unknown. It is important for you to be fully aware of the evidence that does exist about the CAM therapy so that you may make an informed choice about CAM. Given limited evidence for some therapies, you may need to make a personal decision about what level of known and unknown risks and benefits of the therapy you are willing to accept. Generally, it is recommended that people avoid taking natural health products, herbs, supplements and other biological agents until after their conventional cancer treatment is completed. This way, potential interactions can be prevented.

If you do decide to use a CAM

therapy, it is important to assess whether or not you are experiencing any benefit or side effects. Having a plan about how long you intend to try a therapy, what type of physical or psychological outcome you are interested in seeing, and what follow-up care may be necessary will help you make decisions about the continued use of the CAM therapy.

Health care providers at the BC Cancer Agency are committed to supporting patients and families to make informed decisions about CAM and cancer treatments that are right for them. To this end, a new research program, the Complementary Medicine Education and Outcomes (CAMEO) Program will explore the best ways to support patients and families, and their oncology health care professionals to make informed decisions based on evidence about CAM. Beginning in the fall 2008, CAM education programs for patients, families, and health care professionals will be available at the Vancouver Centre. Watch the CAMEO website [www.bccancer.bc.ca/RES/ResearchPrograms/cameo](http://www.bccancer.bc.ca/RES/ResearchPrograms/cameo) for announcements about enrolment opportunities in these research-based education programs. If you would like to receive periodic updates via email about the activities and opportunities for education within the CAMEO Research Program, please send your name and email address to [cameo@bccancer.bc.ca](mailto:cameo@bccancer.bc.ca).

*by Tracy Truant,  
Professional Practice Leader, Nursing  
Co-investigator, CAMEO Program*



*The CAMEO team, from left to right, Jennifer Young, Brenda Ross, Alison Brazier, Tracy Truant and Lynda Balneaves"*