

BC Cancer Agency Headlines

Fall 06 *A newsletter for brain tumour patients and their families*

MEDICAL UPDATE

Finding the best treatment for low grade brain tumours

Chemotherapy vs. radiotherapy

IN THE NEXT FEW MONTHS, a new clinical trial will open at the BC Cancer Agency and other sites around the world for patients with low grade brain tumours, also known as gliomas. These tumours arise from glial (from the Latin word for glue) cells, which support and nourish the neurons in the brain. This international study will determine whether radiation therapy or chemotherapy is more effective in controlling tumour growth, and will examine some of the other factors that affect the behaviour of low grade gliomas. Researchers will also be interested in the effects of these treatments on patients' overall quality of life and well-being.

Low grade gliomas include astrocytomas, oligodendrogliomas and "mixed" tumours (those that have features of both astrocytomas and oligodendrogliomas). Low grade gliomas occur most frequently in young adults, especially in males younger than 35. Currently, treatment for these tumours is controversial. Some patients with low grade gliomas receive radiotherapy, especially if they have symptoms because of their tumours. Although radiation may delay progression of disease in these cases, studies show that it does not make patients live longer. For some patients who do survive for many years, radiation may cause long-term side effects, such as the development of problems with thinking and memory. Chemotherapy, on the other

hand, has only been used very selectively in these cases. Its role in the treatment of low grade glioma is not well understood, although we do know that some tumours may be very responsive to it.

Many gliomas have some oligodendroglial features. These types of tumours may be more responsive to both radiation and chemotherapy. Recent advances in our understanding about tumour biology have demonstrated that oligodendroglial-type tumours that are missing some chromosomal material, specifically from chromosome 1 and 19, are likely to be especially sensitive to radiation and chemotherapy and that either of these treatments may control the tumour for a long time. So it may be that by giving chemotherapy first, we can prevent tumour growth without risking the development of the longterm radiation

side effects on thinking and memory. As a result, radiotherapy could be delayed as long as possible.

This study will register patients with low grade gliomas, even when they do not yet require treatment. When their tumours require treatment, a computer will assign patients to one of two treatments in a fair and non-biased manner. This is called "randomization." Patients will receive either 1) radiotherapy every day for 5 weeks or 2) chemotherapy every day for 21 days, with a week long break before starting again, for a total of 12 months (unless the tumour grows on treatment, in which case another therapy would be started). Testing will be done on all study patients to determine whether their tumours are characterized by the favourable chromosomal deletions on

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How You Can Help

The BC Cancer Foundation welcomes donations which support brain tumour research at the BC Cancer Agency. To discuss how you can make a difference – by contributing to the Hershey & Yvette Porte Endowment Fund for Neuro-oncology, by establishing a similarly named fund, or by contributing directly to brain tumour research and patient comfort initiatives – please contact Sharon Kennedy at 604.877.6160.

Tax receipts are issued for gifts of any amount. Donations should be directed to BC Cancer Foundation at 200 - 601 West Broadway, Vancouver, BC V5Z 4C2

Together we can
make a difference!



BC Cancer Agency
CARE & RESEARCH

An agency of the Provincial Health Services Authority

BC Cancer Foundation
Supporting research & care at BC Cancer Agency

Making decisions about the use of complementary or herbal therapies

PATIENTS AND FAMILIES play a more active role than ever in decisions about their health care. Greater access to information through the media and the internet has helped us all to become more familiar with health promotion, disease prevention and treatments for cancer and other conditions. But the wealth of information can also be overwhelming and may leave you feeling more confused than enlightened. If you're considering using complementary or herbal therapies, a clear and systematic approach to decision-making will help you determine your best choices.

Health care professionals have learned through training and experience to evaluate different sources of information when planning treatments and addressing the health concerns of their patients. The best decisions take into account a number of factors, including evidence that a treatment or approach "works," that it doesn't have significant risks to health or safety, that its use is consistent with the goals of the patient, and that he or she is able to participate in its implementation.



Brain Tumour Awareness in Toronto!

The Toronto Blue Jays vs Boston Red Socks game provided the Canadian Alliance of Brain Tumour Organizations (CABTO) with an opportunity to educate the crowd about brain tumours. Booths were set up distributing information and Public Service announcements were made at the Rogers Centre on Sunday, September 24, 2006.

As far as cancer treatments are concerned, oncologists rely heavily on "best" evidence when deciding which treatment to prescribe for their patients. Evidence is "graded" according to how convinced the findings of a treatment study make them feel that the results can be attributed to the treatment under investigation – and nothing else. The "gold standard" for conclusive findings is the randomized clinical trial (RCT). A RCT separates study participants into groups that are as similar as possible in every respect (age, disease status, and general well-being), except for the fact that each group receives a different treatment. If there is a difference in outcome, we can be reasonably confident that this is due to the treatment, since other factors were "controlled," meaning they were kept to a minimum. As well, RCTs usually involve large groups of patients. This decreases the likelihood that the results were "a fluke," and increases the likelihood that the treatment will work the same way in other patients. RCTs are used to compare the difference in outcomes between the usual or standard treatment and an experimental treatment for a given condition.

Health care professionals do not restrict themselves to findings from RCTs when making decisions about caring for patients. RCTs are time-consuming and expensive to conduct, so they may not always be available. Reports from other health care professionals may be considered next. These reports may be from smaller groups of patients in which all of the relevant factors may not have been controlled. Testimonials from patients constitute the lowest level of evidence, since in a single patient, it's impossible to know if an improvement was due to the treatment or some other factor. However, testimonials may indicate that further studies are warranted to clearly document the benefits and risks of any given therapy.

Since they want to be as sure as possible that the care they give is likely to do more good than harm, health care professionals rarely, if ever, make important treatment decisions on the basis of this lowest level of evidence.

If you are interested in using a particular therapy, try to find out as much as possible about it. Especially, ask yourself these questions:

- What do I hope to accomplish through taking this therapy?
- Is there any evidence that this therapy will help me to achieve my goal(s)?
- Does it appear to be safe (that is, does not have serious side effects and does not interfere with my other treatments)?
- How much does it cost? If it is very expensive and there is no evidence that it will be effective, do I still want to take it?

If you decide to use a complementary or herbal therapy, please share your decision with your health care professionals. They will need to be on the lookout for side effects and drug interactions. Finally, make a plan:

- How will I know if the therapy is working?
- What side effects should I watch for and who should I report them to?
- How long will I use the therapy before re-evaluating my decision?

These resources may be helpful for you:

<http://www.naturaldatabase.com>

The Natural Medicines Database is an excellent starting place for your research of natural products.

<http://www.bccancer.bc.ca/PPI/UnconventionalTherapies/default.htm>

The BC Cancer Agency website offers information about a number of specific therapies, as well as general advice about the use of these approaches.

SUPPORT GROUPS FOR PATIENTS AND FAMILIES

ARE YOU INTERESTED in talking to others who are undergoing treatment for a brain tumour, or returning to work and home life after treatment? Or have you or a loved one been recently diagnosed with a brain tumour and find yourself in need of some extra support? Support groups are a place where you may be able to find help for yourself and help others at the same time. Health care professionals act as facilitators for these sessions, and there is never any pressure to talk if you would rather just listen.

Consider attending a session in one (or more) of these groups. No registration required, but a contact number is provided for each group should you require more information.

Quotes from the group:

"I'm learning so much in my support group."

"Everybody's reality of living with brain cancer is such a different story."

"You have to reinvent your life when this happens."

Fraser Valley, Surrey

BCCA, 13750 - 96th Avenue
Room 3011

3rd Thursday of each month
10:30am to 12noon

Facilitators: Maureen Parkinson
and Rosemary Cashman
604-930-4000

Vancouver

BCCA, 600 West 10th
John Jambor Room

1st and 3rd Wed. of each month
11:00am to 12:30pm

Facilitators: Maureen Parkinson
and Rosemary Cashman
604-877-6000 x 2194

Kelowna

Okanagan Room

3rd Monday of each month
11:30am to 1pm

Facilitators: JoDee Hecko
and Lorriane Toph
250-712-3963

Victoria

BCCA, 2410 Lee Avenue
Quiet Room, 2nd floor

2nd Thursday of each month
11:00am to 12:30pm

Catherine Traer-Martinez
250-519-5528

"We must be willing to let go of the life we have planned, so as to have the life that is waiting for us."

– EM Forster, British novelist, 1879-1970

Brain Tumour Information Day

Saturday, October 28, 2006, 9am to 4pm

BC Cancer Research Centre

675 W. 10th Ave (across the street from the BCCA)

Program

- Biology and treatment of brain tumours
– Drs Juliette Hukin and Brian Thiessen
- Neuropsychology (effects of brain tumours and treatment on brain function, thinking, memory) for children and adults
- Care for the caregiver
- Complementary therapies (herbal and natural products)
- Brain tumour survivors: a panel discussion
- Patient and family stories
- Relaxation therapy and yoga
- Brain Tumour Foundation of Canada booth
- Hats Tribute – a display of hats honouring individuals with brain tumours across Canada
- Informal networking

for more information contact: Rosemary Cashman 604 877 6072
or Maureen Parkinson 604 877 6000 x2194 at the BCCA
or Suzanne Steenburgh 604 875 2345 x6017 at Children's Hospital

Supported through an educational grant from Schering Canada



Information, support,
refreshments, catered lunch

Free of charge for
patients and families

REGISTER BY CALLING:

Diana Hass 604 877 6000 x2194

Deadline Friday, October 20



BC Cancer Agency
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An agency of the Provincial Health Services Authority



Q I was diagnosed with a grade 4 tumour in July. I am going through treatment now and it is going pretty well. My big problem is that I can't work. My balance is affected by my tumour and I don't have much strength on my right side, so I can't walk very well. Is this going to get better? My doctor says he doesn't know. I have 3 young kids and my wife stays at home with them. I used to work as a construction manager and my boss has been great. He says just take care of my health and come back when I'm better, but I don't know how long they can say that because work is really busy lately and they need someone to do my job. I'm really worried about money. Any suggestions about what I should be doing?

A Patients going through treatment for a brain tumour often take time off from work and consequently have concerns about money. I suggest that you investigate which benefits apply to you through your place of employment. Start by determining whether you are eligible for sick leave, short term disability and/or long term disability. These benefits vary and are not offered through all employers. Also inquire if your employer has an extended health care plan to pay for medications and other costs not covered by the Medical Services Plan. I recommend that you review the information booklet "Financial Aid Booklet" from the BC Cancer Agency website: (<http://www.bccancer.bc.ca/PPI/CancerTreatment/SupportCopingwithCancerIntroduction/PracticalResources/default.htm>) or pick up a copy at the Patient and Family

Counseling office in the BC Cancer Agency. This pamphlet outlines many of the financial resources that are available (and often dependent on income level), including government assistance, adaptive equipment and assistance with medical costs, transportation, travel, and housing. If you need some help sorting out these resources, speak to the social worker/counselor at your local cancer agency.

Sometimes people with cancer worry that if they take time off work, their employer might not keep their job for them in the future. Fortunately, legislation in Canada provides support in some situations for employees with disabilities (including a brain tumour) as they undergo treatment and when they return to work. For more information about your employment rights contact the B.C. Human Rights Coalition: www.bchrcoalition.org 1-877-689-8474

Finally, it is not always clear early in treatment whether some of the changes in your abilities related to the tumour, eg. balance, strength, thinking, speech, and energy, will recover. If your doctor is unable to predict how you will be after your treatment, it becomes a bit of a waiting game until the effects of treatment are clear. This is understandably hard for patients and families, and makes coping and planning difficult, especially with respect to work. On the other hand, coping with a brain tumour is a profound

experience that sometimes leads people to see their lives in new ways. As a result, some people come to re-evaluate whether they want to return to their

former work after treatment. This is particularly true if you notice changes in your abilities. If, after recovering from treatment, you are not sure that you are capable of returning to your old job, it may be beneficial to undergo a rehabilitation assessment. A rehabilitation program can help assess your strengths and weakness and assist in planning your return to work by teaching you strategies to adapt to any changes in your abilities. If you'd like more information about vocational

rehabilitation, please contact me and we can discuss your particular situation.

*Maureen Parkinson, Rehabilitation Counselor, Vancouver and Fraser Valley Centres
604-877-6000 local 2189 or
1-800-663-3333 local 2189*

Question + answer



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Finding the best treatment for low grade brain tumours *continued from page 1*

chromosome 1 and 19. Patients' quality of life will be assessed at regular intervals, and their memory and thinking abilities will also be routinely evaluated.

This clinical trial will answer important questions about when and how to provide treatment for patients with low grade gliomas, with a view to controlling disease and maintaining the best quality of life possible. In addition, tumour samples will be banked for future use. This will result in exciting opportunities for future research. Specific molecular features of tumour cells might predict different responses to treatment, allowing future therapies to be tailored to individual patients

Editions of *Headlines* are also available as a pdf download at:
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 or 604.877.6072 (phone) 604.877.6215 (fax).

This newsletter is published through the generous support of Bernie & Lee Simpson, the Hershey & Yvette Porte Neuro-oncology Endowment Fund and Schering Canada. For more information on 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