



# Headlines

Spring 06

*A newsletter for brain tumour patients and their families*

## MEDICAL UPDATE

### Advances in treatment of brain tumours

**I**N JUNE 2004, at a meeting of the American Society of Clinical Oncology in New Orleans, the most important cancer research findings of the year were presented in a (standing room only) plenary session. Included in these findings were the results of an international clinical trial for patients with a brain tumour called glioblastoma multiforme. This tumour is highly malignant and has proven to be difficult to control, even with surgery, radiation therapy and chemotherapy. The trial, the result of collaboration between European and Canadian researchers, studied the results of treatment with a combination of radiation and a pill form of chemotherapy called temozolomide.

This study was initiated for a number of reasons. First, temozolomide is so well tolerated that it makes sense to combine it with other treatments to see if tumour cells can be killed more effectively without making people sick. Second, lab experiments indicate that combining temozolomide with radiation seems to improve the effectiveness of radiation. Finally, there is some evidence that a small, daily dose of temozolomide tackles one of the biggest problems in cancer treatment – the ability of cancer cells to become resistant to therapy.

In the clinical trial, patients with glioblastoma were “randomly assigned” to one of two treatment groups. This means that, in the interest of fairness and impartiality, a computer chose which treatment each person would receive.

One group of patients received the standard treatment of the time, radiation therapy. The other group received the experimental treatment, daily low-dose temozolomide throughout the six weeks of radiation therapy, followed by six cycles of the same chemotherapy at a higher dose, for five consecutive days of each 28 day cycle.

Patients who received the “concurrent” or combined treatment lived longer and did not suffer significantly greater side effects than the patients who received radiation treatment alone. Furthermore, the group of patients who received the combined treatment enjoyed a longer

period of time without regrowth of their tumours. As a result of this study, patients with glioblastoma and some other malignant brain tumours now receive the combination of radiation and temozolomide, followed by six months of temozolomide alone as standard therapy for their disease.

Scientists and clinicians are now focussing efforts on the biological factors that favour the growth and development of brain tumours, on a better understanding of the ways brain tumour cells become resistant to treatment, and on finding new combinations of drugs that more effectively control these diseases.

## Welcome to Headlines

Welcome to the first issue of Headlines, a newsletter for people who have been diagnosed with a brain tumour. Published quarterly, this newsletter will help to make you aware of:

- the latest news in research about brain tumours
- resources available to you and your family to help you cope
- tips for staying healthy
- updates on natural products and complementary therapies
- websites and books for information about brain tumours
- the stories of other brain tumour patients and their families
- questions and answers about brain tumour disease, treatment and help for patients and families

If you would like to submit an article, ask a question, serve on our patient and family advisory board, or receive an electronic copy of this newsletter, please contact Rosemary Cashman at [rcashman@bccancer.bc.ca](mailto:rcashman@bccancer.bc.ca) or 604.877.6072 (phone) 604.877.6215 (fax).

## Living with seizures

**S**EIZURES are a common side effect of brain tumours, and in fact are the first sign of disease in about one third of people who are diagnosed with a brain tumour. Seizures may also occur in people who do not have brain tumours.

### What should I do if I witness a seizure?

Try to remain calm. Remember that although seizures may be very distressing for the person experiencing them and for those who witness them, most seizures are not harmful in themselves. You should:

- Stay with the person who is seizing so that you can try to prevent injury and provide reassurance.
- Do not try to restrict the person's movements.
- If he/she falls to the floor, cushion the head and turn him/her to the side to allow any secretions to flow out of the mouth (rather than be drawn into the lungs).
- Do not put anything in the person's mouth – especially your hand or fingers!
- Try to record the amount of time the seizure lasts so that you can report this to the health care team.
- Speak gently to the person when the seizure stops. He/she may be disoriented or unable to speak for a time after the seizure. Sleepiness is common after seizures. More rarely, a person may be temporarily paralysed.
- If the seizure lasts for more than 5 minutes, if it stops and starts again, or if there are injuries sustained during the seizure or other concerns go to the nearest emergency room. In all other cases, simply notify your doctor or nurse by telephone at your earliest convenience. They may advise you to have blood drawn to ensure that your seizure medication is circulating in therapeutic amounts in your bloodstream.

**What is a seizure?** The cells of the brain communicate through electrical impulses. When this communication between cells is interrupted because of the presence of abnormal tissue, including tumour cells, blood or scar tissue, a seizure may occur. If the abnormal electrical impulse is confined to a small, focussed area of the brain, a focal seizure results. These may include a feeling of "pins and needles" or numbness; involuntary movements; strange smells or tastes; or some change in consciousness. If a focal seizure spreads over a larger portion of the brain, a generalized seizure may occur. Generalized seizures typically result in loss of consciousness, loss of bowel and bladder control, and uncontrollable jerks and spasms. Sometimes people experience a warning, termed an aura, that a seizure is about to occur. This might be a strange taste, smell, or other unusual sensation, including a feeling of déjà vu.

**Can seizures be prevented?** The best way to prevent seizures is to take seizure medications (also called antiepileptics). Some of these include:

- Dilantin (phenytoin)
- Tegretol (carbamazepine)
- Lamictal (lamotrigine)
- Epival (valproic acid)
- Keppra (levetiracetam)
- Frisium (clobazam)

All of these medications can cause drowsiness and dizziness. Your doctor will help you determine the best drug and best dose to control your seizures with the least side effects possible. It is sometimes difficult to prevent seizures completely, but by taking seizure medications, the risk of generalized seizures is significantly reduced.

Special cautions related to seizure medicines include:

- The appearance of a rash after beginning a new seizure medicine is a serious event that should be reported immediately.
- Seizure medicines should never

be discontinued abruptly. Sudden withdrawal from these medicines can cause seizures.

**What other factors may promote seizures?** Certain predisposing factors act as triggers to make a person particularly at risk for seizures, even if they are taking their medicines correctly. These triggers include:

- fatigue
- poor sleep
- emotional stress
- alcohol
- flashing lights
- menstruation
- fever

Remember that seizure medicines interact with a number of other medications, including antibiotics, birth control pills and antacids and that this may alter the effects of the medications. It's a good idea to let your health care team know about the medicines you are taking so that they can advise you about the potential for drug interactions.

**Can I live a normal life if I am prone to seizures?** With some sensible modifications in lifestyle, most people carry on with their normal lives, even if they sometimes have seizures. Protect yourself from situations that are potentially dangerous if a seizure does occur by:

- Wearing a helmet when cycling, roller blading, skiing, etc.
- Swimming with a buddy and letting family members know if you're taking a bath or shower.
- Following the Ministry of Transportation's guidelines for driving if you have had a seizure.
- Exercising common sense and good judgment when climbing ladders, using power tools, etc.



## Green tea

**G**REEN TEA, also known as Japanese tea or Epigallo Catechin Gallate, is widely used for a number of health concerns. These include headaches, diarrhea, heart disease, and a variety of cancers. Some people use it to improve mental alertness and thinking abilities.

**Safety:** Green tea is likely to be safe in moderate amounts (no more than three cups daily). Because it contains caffeine, it can produce the side effects of coffee such as irregularities of the heartbeat and sleep disruption. It should not be consumed in high doses by pregnant or breastfeeding women.

**Drug interactions:** There are no proven drug interactions associated with the use of this tea, although there are data suggesting that it may make some diabetes medicines and some blood thinners (such as coumadin) less effective. At the same time, green tea appears to have its own effect on platelets, the blood cells responsible for clotting the blood. As such, it may increase the risk of bleeding with other drugs that affect platelets, such as aspirin, ibuprofen, Plavix, and Fragmin.

**Effectiveness:** Research has shown that green tea may “wake you up” like coffee does, and can lower cholesterol and triglyceride levels. Drinking green or oolong tea for one year or more may reduce the risk of high blood pressure; other studies done in elderly people with low blood pressure suggest a role for green tea in raising the blood pressure. Unfortunately, few well-designed, large studies have been conducted to determine the effectiveness of green tea in preventing or treating cancers. In breast cancer, 3 to 5 cups of green tea daily may prevent breast cancer and reduce the risk of recurrence of disease in some women. Similarly, green tea may help to prevent gastric, prostate, pancreatic, esophageal and bladder cancers, although a specific therapeutic dose has not been identified. Early evidence suggests that remission of some leukemias and lymphomas may be effected through drinking green tea. The specific effects of green tea in brain tumour patients have not been studied.

More research must be undertaken in order to understand the precise role



of green tea in preventing and treating different types of cancer, and to document other side effects this therapy may have. Preliminary studies indicate a number of potential effects. These include:

- the protection of normal DNA from the mutations common in the development of many cancers;
- the prevention of the growth of blood vessels (anti-angiogenesis) supplying new tumours with nutrients;
- the promotion of programmed cell death (apoptosis) or “suicide” of tumour cells;
- the improved effectiveness of some cancer drugs such as Adriamycin.

For now, it appears likely that you can safely drink 3 cups of green tea daily as an alternative to coffee and other teas – although recent studies suggest that caffeine itself may have a role in cancer therapy!

---

## Brain tumour information websites

Having trouble figuring out which electronic resources you can trust? These websites have been reviewed and offer reliable information.

1. [www.btfc.org](http://www.btfc.org) The Brain Tumour Foundation of Canada: Canadian website for the national foundation (located in London, Ontario) which provides support and education for patients and families and funds research.
2. [www.tbts.org](http://www.tbts.org) The Brain Tumor Society: information and support for patients and families
3. [www.brainumor.org](http://www.brainumor.org) The National Brain Tumor Foundation: support, information, survivor network, links to other sites
4. [www.abta.org](http://www.abta.org) The American Brain Tumor Association: award-winning website for patients and families
5. [www.clinicaltrials.gov](http://www.clinicaltrials.gov) Clinical trials in North America: sponsored by the National Institutes of Health and frequently updated
6. [www.cancer.gov/cancertopics/types/brain](http://www.cancer.gov/cancertopics/types/brain) The National Cancer Institute’s website
7. [www.bccancer.bc.ca](http://www.bccancer.bc.ca) BC Cancer Agency homepage includes library, cancer information, other links
8. [www.naturaldatabase.com](http://www.naturaldatabase.com) Natural medicines comprehensive database provides information about complementary and alternative herbal therapies
9. [www.discern.org.uk](http://www.discern.org.uk) Designed to provide health care consumers with a useful tool for assessing health information on the internet
10. [www.quackwatch.org](http://www.quackwatch.org) Panel of medical advisors provides assistance in distinguishing between proven and unproven therapies
11. [medlineplus.gov](http://medlineplus.gov) Online medical encyclopedia, dictionary, drug information, links to other health sites

# Supporting children when a parent has a brain tumour



## The Thursday Club and The Saturday Club



**W**HEN A BRAIN TUMOUR joins your family, it is a most unwelcome guest... but like so many other problems that come up in family life, you don't have any choice but to deal with it. At the Cancer Agency there are many programs to help you and your family deal with a diagnosis of cancer. For the children of cancer patients (ages 5 to 12), these programs engage kids through fun activities to get them talking and sharing feelings about a situation that can be confusing and scary.

The Thursday Club in the Fraser Valley Centre meets after school, three weeks in a row, every four months. The Saturday Club in the Vancouver Centre meets for a single half-day session every two months. Families are welcome to return for more than one session. The program includes a children's support group run by a nurse and an art therapist. The children learn about cancer and its treatments through playing, talking, listening and art therapy. While the children meet, parents meet separately with a counselor and have a chance to discuss family concerns. There are also parent information nights at both centres to help

you learn strategies for meeting the challenges of life with cancer.

There is no cost to your family. The program has been offered by the Cancer Agency and well-received for over 12 years. Your children may be nervous at first, but we guarantee they will be eager to come again and again. The kids love the art and fun they have while learning with "other kids that are just like us!" It is so nice to know that you are not alone.

Ask your doctor or nurse about the program, or register simply by calling the numbers below. Registration is mandatory so that we can accommodate all interested in attending. The next group is planned to start in March at the Fraser Valley Centre, and on April 8th at the Vancouver Centre, so don't delay and let your kids "get into the Club"!

*Catherine Jarvis, RN  
Nurse Facilitator,  
The Thursday Club and The Saturday Club  
Patient Family Counselling  
VCC 604.877.6000 FVCC 604.930.4000*

## Question + answer



**Q** I took temozolomide chemotherapy throughout my radiation and again for 6 months after my radiation stopped. I did really well on it, never felt sick, and my tumour didn't grow. Three months after completing my last cycle of temozolomide, I had a scan which showed my tumour was growing. I wanted to go back on temozolomide, but my doctor started me on a different chemotherapy. I felt sick when I took it and I understand it can be hard on the blood cells. I'm worried that it won't be as effective as the temozolomide at controlling my tumour. Why did my doctor change my treatment when it was working so well for me?

**A** There are several options for treating a malignant brain tumour at recurrence. Using the same chemotherapy that was tried previously can be an option provided the tumour clearly showed a response and that response was for a good length of time.

A recurrence soon after use of a chemotherapy agent often indicates resistance to that particular agent and may warrant trial of an alternate medication in hopes of countering that resistance. Unfortunately, there are no clear answers to indicate when to abandon a prior chemotherapy agent in favor of an alternative. This is where experience of the treating physician comes into play. In this instance, a 3 month interval from end of treatment to recurrence would be borderline for indicating a reasonable response to temozolomide. As such, it may be better to try an alternate agent that the tumour cells haven't been exposed to and reserve temozolomide for the time being, recognizing it still is a consideration if the newer agent is unsuccessful.

*Dr. Brian Thiessen, Neuro-oncologist,  
BCCA, Vancouver Centre*

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](mailto:skennedy@bccancer.bc.ca)