

Headlines

Fall 13

A newsletter for brain tumour patients and their families

TERRY KENNERLEY AWARD



Paul Chapman, the inaugural Terry Kennerley Award recipient

TERRY KENNERLEY'S brain tumour diagnosis in 2006 was a tremendous shock to a young man in his prime with a family, a successful business, a circle of supportive friends and a passion for hockey. Terry's love of life was clearly evident. His illness inspired him to reach out to others who were also struggling to find meaning, hope and continued love of life after a brain tumour diagnosis. Terry was a star member of the brain tumour support group and even established a second group outside of the BC Cancer Agency. He reached out to newly diagnosed patients and families to offer encouragement, offered rides to those patients who could not drive, spoke to oncologists about providing honest information to patients without destroying hope and even spoke movingly to the makers of temozolomide chemotherapy about his experience as a patient. His death left a hole in the brain tumour community of patients, families, friends and staff who benefitted so much from

Terry's generous spirit. The Terry Kennerley Award was established to recognize others who make significant contributions to patient support, research, care and public awareness about brain tumours.

Paul Chapman has continued Terry's tradition of service to others and embodies the qualities honoured by the award. Paul was diagnosed with a glioblastoma in

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Paul Chapman, front row, second from right, with award presented by Terry Kennerley's "Hamburger Hockey League" team.

A new treatment for anxiety and depression in brain tumour survivors

Dr. Douglas Ozier

DEPRESSION AND ANXIETY are common challenges for people diagnosed with brain tumours. The rate of depression in patients with brain tumours is about 6 times greater than in the general population. Similarly, anxiety is more common in the brain tumour population than in the general population. There are likely many reasons for this, including tumour effects, possible treatment side effects, and of course, the understandable stress that comes with facing such a profound health challenge. Unfortunately, there has been little work done to develop psychological interventions to address this distressing problem.

Research suggests that variability in the heart's rhythm promotes a more effective autonomic nervous system (ANS). The ANS is believed to play an important role in depression. Studies have shown that it is possible to "exercise" the ANS by inducing varying rates of the heart beat. In turn, this increased ANS efficiency is believed to facilitate an improved response to stress. In support of these ideas, numerous researchers have shown that those who learn the techniques of Heart Rate Variability Biofeedback (HRVB) and practice the relevant breathing exercises once a day for 8 weeks can significantly improve a variety of symptoms including those related to depression, anxiety, pain, and insomnia.

HRVB has been tested in a variety of patient populations, but never with brain tumour patients. Given its evident promise and straightforward nature, Drs. Douglas Ozier from the BC Cancer Agency and Wolfgang Linden from the UBC Department of Psychology are currently conducting a study that will test the ability of HRVB to lessen symptoms of anxiety and depression in brain tumour survivors.

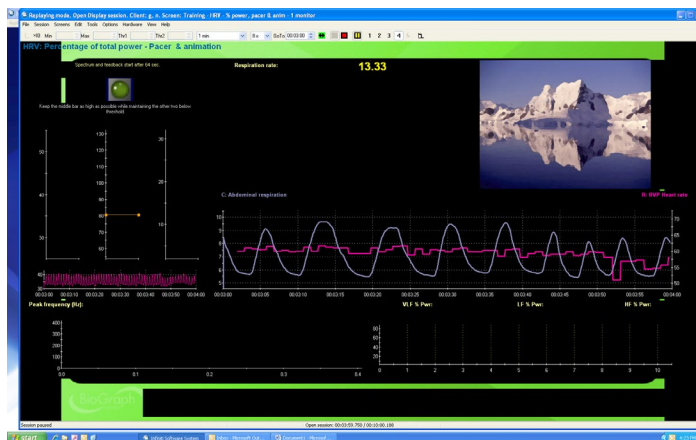


Figure 1: Patient is breathing at 13.33 breaths per minute. Her breath and heart rate are not synchronized and her heart beat is only varying from 57-60 beats per minute.



Dr. Ozier teaching the Heart Rate Variability Biofeedback technique

During this intervention, individuals are given real time, computerized feedback about the way that their breathing is affecting variation in the speed of their heart beat. Using this feedback, they can quickly learn to comfortably breathe in an effortless, diaphragmatic way while also breathing at a very slow pace (from around the usual 15 breaths per minute all the way down to around 5 breaths per minute). In the images below, the blue lines represent the breathing pattern and the red lines represent the heart rate.

You may qualify to participate in this research study if you:

- Are at least 19 years of age
- Are living with a primary brain tumour (grades 2, 3 or 4)
- Have not undergone any major treatment (chemotherapy, radiation, surgery) in the **last three months**
- Are currently experiencing symptoms of anxiety (such as having a racing heart, feeling nervous, or having repetitive and scary

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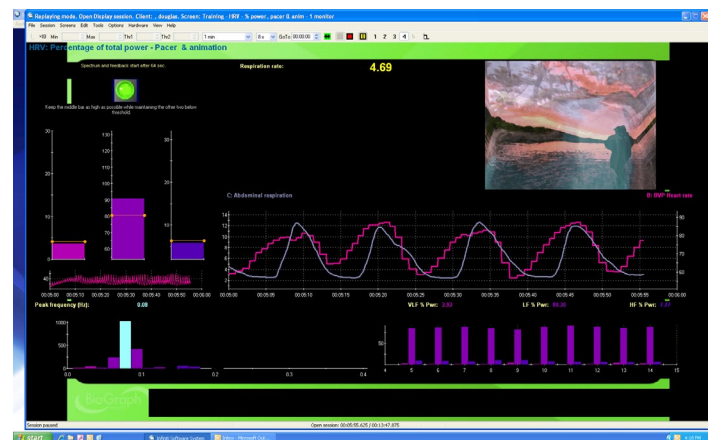


Figure 2: Patient is breathing at only 4.69 breaths per minute and in a relaxed, smooth manner. His breath and heart rate are now synchronized and his heart beat is varying all the way from 60-85 beats a minute.

Dexamethasone

DEXAMETHASONE (Decadron®) is a steroid medication that has powerful anti-inflammatory and immunosuppressant activities. Steroids are lipids (fats) that possess a certain chemical structure. They occur naturally in plants and animals or may be made in a laboratory. Examples of steroids include cholesterol, hormones and some drugs. Dexamethasone is similar to a natural hormone called cortisol which is produced by the adrenals, two small glands which sit on top of the kidneys. Dexamethasone is commonly used in cancer treatment. For example, it may be used to prevent nausea associated with chemotherapy, to stimulate appetite and energy, or even as a treatment for some forms of cancer.

Brain tumours are often associated with swelling and inflammation in the brain, leading to headache, nausea, weakness, and other problems depending on the precise location of the tumour. Dexamethasone is extremely effective in treating brain swelling that may occur during radiotherapy or when tumour cells are actively dividing. Relief from headache may occur within a few hours, but the full effect of dexamethasone can take 24-72 hours. Unfortunately, this miraculous effect has a downside in the form of a host of potential side effects from dexamethasone.

To prevent side effects, dexamethasone is used for as short a time, in as low a dose as possible. Adrenal gland production of cortisol ceases when you take dexamethasone. For this reason, a person must be tapered off the drug

slowly. This allows the adrenal glands to begin production of the natural hormone again. Coming off the drug too rapidly may result in signs of steroid withdrawal such as headache, fatigue, and muscle or joint pains. Be sure to let your oncologist or nurse know if you're running out of dexamethasone so that they can guide you with a tapering schedule or provide a refill of the prescription if you are to continue taking the drug. Also, be sure to report all symptoms and side effects so that these can be treated.

The many complications of dexamethasone treatment have prompted an interest in alternative approaches to treating brain swelling. So far, an equivalent response from another drug has been hard to find. The drug bevacizumab (Avastin®) is used to treat brain tumours and works by pruning off leaky blood vessels supplying tumour growth. As a result, tumour cells are deprived of nourishment and swelling is also arrested.

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Treatment for anxiety and depression continued from page 2

thoughts) or symptoms of depression (such as feeling blue, or having lost interest in things that you usually care about or enjoy)

If you participate you will:

- Come to the BC Cancer Agency Vancouver Centre (600 West 10th Avenue) once a week for a period of 8 weeks

Dexamethasone side effects:

- Weight gain
- Muscle weakness, especially in the legs
- Mood disturbances
- Sleeplessness and agitation
- Poor wound healing
- Skin thinning and breakdown
- Weakened bones
- Diabetes
- Stomach ulcers
- Infections

Unfortunately bevacizumab infusions are extremely expensive and also may be associated with potentially lethal side effects, so it's hard to justify the use of bevacizumab for brain swelling alone.

For more information about dexamethasone see:

www.bccancer.bc.ca/HPI/DrugDatabase/DrugIndexPt/default.htm#D

- Have one to one meetings with Dr. Ozier
- Be taught to breathe in a special way
- Be asked to practice this breathing technique for 20 minutes a day

If you think you might qualify and are interested in participating, please call Dr. Ozier at 604.877.6000 ext 672185 or email dozier@bccancer.bc.ca

For more information about this study see: <http://clinicaltrials.gov/show/NCT01772498>

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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.

Q I completed chemo with my radiation treatment a few months ago and unfortunately now my tumour has already grown. My oncologist recommended that I start a new chemo treatment. My wife and I are devastated. We trust the medical people and feel we're getting good care, but how does a person deal with a blow like this? We have kids and I want to be strong for them, but secretly wonder: what is the point of carrying on with more treatment?

A I am sorry to hear about the recurrence of your tumour. One thing you should be aware of is that even when the cancer returns, successful reduction in tumour size can potentially be achieved with further chemotherapy. I am an example and I hope my experience provides you with some inspiration moving forward.

Approximately a year after completing chemotherapy and radiation, like you, my cancer came back and after two months on a clinical trial drug, it doubled in size. So this alternative drug did not work. While we have yet to find a cure, there is progress every year with new drugs and new techniques. In my case, I was placed

back on the same chemotherapy that I first took. Over the course of 8 months, the tumour decreased significantly in size. That was 7 years ago. I am a survivor of grade 4 astrocytoma (glioblastoma multiforme) for almost 10 years now since the initial diagnosis.

Question + answer



The point is, further treatment can be successful. Different chemotherapies attack the tumour cells in different ways. In addition, the genetic makeup of tumour cells is unique for each individual. Cancer is essentially caused by changes in a person's DNA, and what works for one person may not work for another person. A drug given to one individual might suppress cancer growth or eliminate it and not work at all or have negative side effects for a second individual.

Researchers are actively studying these effects. Cancer patients are already receiving different forms of treatment at the BCCA based on the genetic makeup revealed by DNA sequencing. While this has yet to happen in the context of brain cancer, this could certainly be the case one day soon. In fact, in the past few years, researchers at the BCCA have made discoveries about specific genetic changes associated with some forms of brain

cancer. This knowledge could eventually lead to treatments that target these unique features of an individual's tumour. I take some comfort in knowing that if the cancer returns again, we might have new treatments that did not exist when I was first diagnosed.

It is certainly psychologically difficult to deal with the recurrence of the cancer. I remember well the moment I was told that the tumour was growing again and that the support of family and friends was very helpful at that time. Reaching out to the brain tumour community, for example through support groups, can also be comforting. In my case, learning everything I could about available treatments helped me. I remained hopeful and employed whatever methods I could to help me feel like I was in control. Even now, I look at my daughter and tell myself that I am obligated to do anything and everything I can to heal and remain healthy for her sake. I aim to enjoy my life and every minute I have with my daughter. I wish you all the best moving forward.

*Yaron Butterfield
Brain cancer survivor and researcher at the BC Cancer Agency's Genome Sciences Centre*

For more information about coping with cancer see: www.bccancer.bc.ca/PPI/copingwithcancer/

Paul Chapman *continued from page 1*

2007, devastating news for a husband and father of two young girls. In short order, Paul became determined to fight his disease and then to help other patients do the same. He was a founding member of the Brainiacs, a group of brain tumour survivors and their supporters who participate annually in the Ride to Conquer Cancer, a 200 km bike ride to Seattle which raises money for cancer research. He also serves on the Patient Family Advisory Council which provides guidance to the staff of the BC Cancer Agency regarding care of brain tumour patients. Paul regularly attends the brain

tumour support group and also meets with patients on his own to listen and offer support.

The following comments received from those who nominated Paul exemplify his generous spirit:

"As a brain tumour survivor Paul seems passionate about personally helping others suffering with brain tumours and he also seems willing to take on new tasks that might make the journey through diagnosis, treatment and recovery less onerous."

"Paul gave me his card (when we met at a support group meeting) and offered to meet, which we did later that summer. Knowing it was possible to beat

back a terrible prognosis fueled my own determination."

"Paul's optimism, positive attitude and zest for life provide a sense of hope and reassurance to those who struggle daily with the brutal realities of their illness. Paul hopes that his willingness to listen to others and help them through their struggle will mean one survivor who is a little less lonely and all the more hopeful."

It is our privilege to celebrate Paul's contributions and honour him for his dedication to others. For more information about Paul's Ride to Conquer Cancer see: www.conquercancer.ca/site/TR?px=1835601&fr_id=1514&pg=personal