

Headlines

Winter 11

A newsletter for brain tumour patients and their families

MEDICAL UPDATE

Dichloroacetic Acid (DCA) for brain tumours

DICHLOROACETIC ACID OR DICHLOROACETATE (DCA) is a drug that has been used for decades to treat children who are born with mitochondrial diseases. Mitochondria are organelles found in human cells and they play an important role in the production of energy required for many cellular functions. DCA has a number of effects on cellular metabolism and stimulates mitochondrial function in children who are born with defective mitochondria.

The effects of DCA on cellular processes and metabolism have raised hopes of a targeted therapy against cancer cells, since cancer cells are typically rapidly dividing and characterized by abnormal cellular processes and energy requirements. DCA's ability to alter cellular fuel, such as sugar, might provide a way to starve tumour cells and kill them. There is now extensive research on the effects of DCA occurring at cancer research centres all over the world. This research is still in preliminary stages, and much of it is funded through public donations. This is because DCA is not a new drug, and no pharmaceutical company has expressed interest in doing costly research projects on a drug that is

readily available, inexpensive, and thus unlikely to result in a financial profit.

In 2010, researchers at the University of Alberta, led by Dr. Evangelos Michelakis, published their findings on the use of DCA in brain tumours (see link): www.ncbi.nlm.nih.gov/pubmed/20463368

Over a two year time period, the researchers took tumour tissue from patients with glioblastoma multiforme (an aggressive grade IV brain tumour) and exposed this tissue to DCA in the laboratory. They found that the DCA had a number of significant effects on the tumour cells, including the prevention of tumour cell growth and division, as well as tumour cell death. However, treatments given to tumour cells in a laboratory, outside a human body, do not always produce the same results as treatments given to a living person.

Dr. Michelakis and his team also gave DCA pills to five patients with glioblastoma. The drug easily crosses the blood-brain barrier when given in a pill form and there is no evidence that it is more effective when given intravenously. Three of the patients in Dr Michelakis's study had already received radiation as well as a number of chemotherapies;

the other two were newly diagnosed and went on to receive the standard combined treatment of radiotherapy and chemotherapy. Overall survival in these patients was comparable to that of patients treated with the standard therapies that would be given in a cancer centre. The small number of patients treated, and the fact that these patients also received other therapies means that no conclusion can be made about the effectiveness of DCA for the treatment of brain tumours. However, the initial research findings support the need for larger studies to determine what role, if any, DCA has in brain tumour therapy.

An additional important finding of the University of Alberta study relates to the dose of the medication. Patients who received doses of DCA higher than 6.25 mg per kilogram of body weight twice daily ran the risk of nerve damage, including numbness of the feet leading to problems with balance and inability to walk. Since Dr. Michelakis's study was published, a number of clinicians and researchers have reported severe brain and nerve damage in patients treated with high doses of DCA. This has emphasized

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Care for the Caregiver

BRAIN TUMOURS HAVE FAR REACHING EFFECTS, not just for the individual who is diagnosed with a tumour, but also for the individual's family and loved ones. Supportive family and friends can be an incomparable asset to patients who are trying to deal with the psychological effects of such a serious diagnosis, while undergoing new treatments and monitoring for side effects and other problems. The role of caregivers is critical to the health of patients, and although caregiving can be rewarding, it can also be challenging. If you are caring for a loved one with a brain tumour, you know that this job came without warning or special training, and may force you to juggle many other responsibilities and commitments. This can lead to burnout, isolation and depression. It can even compromise your own physical health.

Caring for yourself is absolutely essential if you are going to be able to care for someone with a serious illness in a proficient, loving and sustained manner. Because family caregivers play such an important role in health care, extensive research is underway to identify the best ways to help caregivers cope, and there are a number of websites and programs that aim to provide caregivers with information and support.

Here are some essential tips for caregivers:

1. **Don't try to do it all yourself.**

Friends, other family members, community health care workers and paid attendants can all provide respite care so that you are not providing care alone and in isolation. Sharing the workload is good for you and allows others the opportunity to contribute to the circle of care. Grocery shopping, childcare, taking notes during clinic visits, picking up prescriptions, bringing patients to appointments — the list of responsibilities is long. Consider which jobs can be delegated to

another trusted friend or family member.

2. **Be flexible.** Do the best you can, but try not to sweat the small stuff. Even if you're used to doing things one way, be open to new ways of getting things done and relying on others who might do things somewhat differently.

3. **Acknowledge your feelings.**

Caregiving can sometimes be hard and lonely work. It's natural to feel frustrated and angry at times, but it's also important to recognize the positive aspects of caring for someone you love. Time away with friends or by yourself can restore your spirits and help you feel better able to cope. Support groups or individual counseling (both available at your cancer centre), yoga, a walk on the beach — these and other relaxing and supportive activities can help. Online support is also available through the BC Cancer Agency 1.800.663.3333 ext 4965 www.bccancer.bc.ca/PPI/copingwithcancer/emotional/supportprograms/online.htm and the Brain Tumour Foundation of Canada 1.800.265.5106 www.braintumour.ca/braintumour.nsf/eng/VirtualSupportGroup

4. **Take care of your health:** Rest and relaxation, exercise, good nutrition and some restorative recreation help us all to be emotionally and physically healthy. Thirty minutes of daily moderate exercise has been shown to prevent depression, aid sleep, promote energy and lead to better physical health. Following the Canada Food Guide www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php ensures optimal nutrition.



5. **Arm yourself with information:** Find out what you need to know about brain tumours and treatments, as well as the practical advice that can help you and your family live better when a loved one is unable to work or fulfill his or her normal responsibilities. Speak to your health care team, including your oncologist, your family doctor, your nurse or counsellor or see the BCCA librarians (see Q&A, this issue).

Family caregivers play a critical role in the care of an individual with a brain tumour. Caregiving responsibilities draw on many different strengths and abilities, and can be shared so that no one feels overwhelmed or inadequate, and so that the best care can be provided to the person you love. For more information about caregiver support, see: www.bccancer.bc.ca/PPI/RecommendedLinks/coping/caregivers.htm

Walking Program

The Vancouver Hospice Society invites you to a **Bereavement Walking Program** for those who have suffered the loss of a loved one

This program offers a chance to walk and talk at a relaxed pace with others who are grieving; to share ideas and support, and benefit from some fresh air and exercise.

Joining in on the walk are trained hospice volunteers.

The group gathers and walks for about an hour at a casual pace, wrapping up with a stop for coffee and continued conversation.

There is no charge to participate.

We stroll together, rain or shine, for 8 mornings either Wednesdays or Saturdays starting January 26th or 29th, 2011 (Dress warmly)

Where: Meet at the Museum of Vancouver (Planetarium) 1100 Chestnut Street in front of the crab sculpture (If driving, bring change for parking meters.)

When: Gathering Time: 9:45 am
Walk begins at 10 am sharp

Contact: PRE-REGISTER please by contacting either Sharon Harowitz 604 731 8643 sharowitz@shaw.ca or Sue Wong 604.731.7805 adwong@telus.net



Callanish Society

www.callanish.org

2277 West 10th Avenue, Vancouver BC V6K 2J1

Callanish Society is a non-profit organization dedicated to improving the emotional and spiritual health of those living with cancer. Weeklong retreats and ongoing support programs offered by health care professionals and volunteers aim to develop resilience and healing in the face of illness and loss through authentic dialogue and sharing of experiences and feelings.

Facilitators include professionals from Nursing, Palliative Medicine, Counselling, Art Therapy, Music Therapy, Massage Therapy and Nutrition, as well as cancer survivors. In addition to retreats and follow up support, Callanish offers a monthly support group for young adults between the ages of 18 and 39 who are living with a diagnosis of any type of cancer.

Week-long retreats are held every 2 to 3 months at the Brew Creek Centre near Whistler. For more information, contact info@callanish.org or 604 732 0633.

Question + answer



Q I would like to learn more about brain cancer, but I don't have a computer or know where to begin. My mother was diagnosed in the fall and is getting her treatment now. Do you have any suggestions?

A Cancer patients sometimes have both too much and too little information. They get lots of pamphlets and pieces of paper at the beginning of their journey, and brain tumour patients also get a free copy of a book called *Brain Tumour Patient Resource Handbook*, by the Brain Tumour Foundation of Canada. But somehow questions can come up that aren't answered in the handouts or the book, or the answers are hard to find. Sometimes patients feel that the question is too small to waste the doctor's or nurse's time, or they just want to find it on their own. Or maybe it's a family member who wants information, but doesn't want to bother the patient. When a question comes up, people wonder where they can get accurate information. The BC Cancer Agency Library is a great place to start. The Library can't provide medical advice, but the librarians can find you good information, answer questions and provide books, videos, pamphlets and other audiovisual materials. The BCCA Library assists the patients, families, friends and healthcare workers of B.C. and the Yukon.

You can call us on the telephone toll-free and we'll help you get the answer to your question. The BC Cancer Agency Library has a librarian in each BCCA treatment centre in the province, so you may have a librarian close to you. www.bccancer.bc.ca/PPI/Library/Contacts.htm. You can also call the central library in Vancouver at 604 675 8001, or 1 888 675 8001, local 8001

to talk to a librarian. If we can't find the answer for you, we can find out who can answer the question. We can recommend books and other resources that will help you find the information, or suggest resources that may help you cope with your situation.

If you want free access to a computer, we have computers that you can use in our library in Vancouver. Free computer access is also available in your city or town's public library. If you can't come in to our library, call your local public library to find out more.

Our Library is listed on the home page of the BC Cancer Agency website at www.bccancer.bc.ca. The people of B.C. and the Yukon can use our online catalogue to look up items online or make requests online or in person. We also lend items by mail and Canada Post's library book rate ensures that books sent out by mail can be returned free of charge.

The BCCA Library also has a substantial role in providing Patient/Public information on the Agency's website. We are in charge of the Types of Cancer – basic patient-level information that we produce with the assistance of the oncologists. www.bccancer.bc.ca/PPI/TypesofCancer.

We also head up the website section known as Recommended Websites – our librarians evaluate websites around the world for reliable, current information www.bccancer.bc.ca/PPI/RecommendedLinks. In this section of the website, you can find information on brain tumours, plus other topics of interest, like how to deal with side effects such as fatigue and hair loss, or how to talk to children and teens about cancer.

Your cancer library is a great resource for patients and families.

By Beth Morrison, BCCA Librarian

Dichlorocetic Acid (DCA) *continued from page 1*

the potentially harmful effects of this drug when taken without close medical supervision, and the need for ongoing evaluation of this unproven therapy,

For more information about DCA or other treatments, talk to your oncologist or health care team. You may also wish to contact the Complementary Medicine and Education Outcomes (CAMEO) Program. This research program is sponsored through the BC Cancer Agency and the University

of British Columbia and provides education and support for cancer patients in making decisions about the use of complementary and alternative therapies.

www.bccancer.bc.ca/RES/ResearchPrograms/cameo/default.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 advisory board, please contact Rosemary Cashman at rcashman@bccancer.bc.ca or 604 877 6072 (phone) 604 877 6215 (fax).

All content by Rosemary Cashman unless otherwise specified.