

Headlines

Fall 14

A newsletter for brain tumour patients and their families

RESOURCES

Relaxation Therapy and Mindfulness-Based Stress Reduction

By Sarah Sample MSW, RSW and
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PEOPLE LIVING WITH CANCER often experience intense emotional upheaval, as well as pain, uncertainty and loss of sleep.

Relaxation techniques have been documented to help people deal with stress and distress. The goal of relaxation is the "Relaxation Response," which produces a state of mental and physical tranquility. The term Relaxation Response was coined by Dr. Herbert Benson in the late 1970's. Benson noted the physiological effects of relaxation from his experiments with transcendental meditation. These effects include reduced oxygen consumption; decreased heart rate, breathing rate and blood pressure; decreased levels of lactic acid and cortisol; and decreased arousal of the sympathetic nervous system which is activated in stressful situations. The subjective experience of relaxation is a sense of calm and well-being.

There are numerous kinds of relaxation techniques including breath work, guided imagery and visualization, muscle release, and the "body scan" (through which participants bring awareness to each part of the body). The **Relaxation Program at BC Cancer Agency** offers drop in sessions for guidance in each of these techniques. Ask your health care team when the group meets, or call the Patient and Family

Counselling (PFC) Office at your cancer centre, or see the link at the end of this article:

Below are some guidelines for practicing relaxation:

1. Find a quiet place and remove all distractions, including your phone
2. Find a comfortable position that you can maintain (sitting or lying down)
3. Select your technique
4. Let go of unwanted thoughts and expectations about outcomes of the technique or concerns about "getting it right."
5. Breathe.

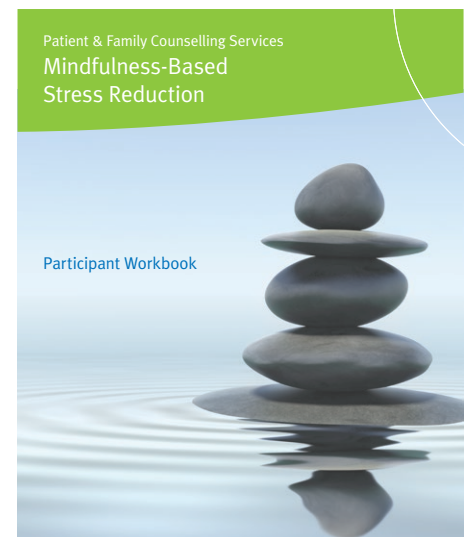
Mindfulness-Based Stress Reduction (MBSR) is different than relaxation, however it offers some of the same benefits. MBSR is a systematic approach to "being in the present moment." MBSR is a unique synthesis of Eastern and Western techniques for cultivating wisdom, awareness and insight. Its object is not to fix or cure but to connect with what is most vital in our lives.

MBSR was pioneered by Jon Kabat-Zinn at the University of Massachusetts Medical Centre in 1979. MBSR teaches numerous forms of meditation and the qualities of mindfulness.

Research demonstrates that mindfulness practice can help to calm the body and mind, increase awareness of our emotions, and decrease levels of stress, anxiety and pain. Research has also shown that mindfulness practice can decrease

levels of stress hormones and can slow the heart rate and decrease blood pressure.

The MBSR 8 week program is offered at BC Cancer Agency 3 times per year through the PFC department, usually starting in February, April and October. Currently this program is available at the Vancouver and Centre for the Southern Interior cancer centres. Please call PFC to pre-register for MBSR courses.



Patient & Family Counselling Services
Mindfulness-Based
Stress Reduction

Participant Workbook

www.bccancer.bc.ca/PPI/copingwithcancer/emotional/supportprograms/default.htm

For further information about relaxation and mindfulness programs offered at the BC Cancer Agency see: www.bccancer.bc.ca/PPI/copingwithcancer

For more resources, see the Library Pathfinder on Meditation and Mindfulness at www.bccancer.bc.ca/PPI/Library

Treatment of low grade brain tumours

RESearch in the treatment of brain tumours, also known as gliomas, continues to be very active, and it's always satisfying when experimental studies point to a better way to manage these diseases. Gliomas are classified by their behaviour, from the least aggressive, grade 1, to the most aggressive, grade 4 (also known as glioblastoma). Grade 2 gliomas are sometimes called low grade tumours, and may be considered "pre-malignant."

The results of a large international study (the RTOG 98-02 clinical trial) comparing the use of radiotherapy alone versus radiotherapy plus chemotherapy for low grade gliomas were recently updated. When the results were presented 5 years after the study closed, there didn't appear to be any difference in the effectiveness of the two treatments. However, the 10 year results showed a clear advantage for the combined radiotherapy and chemotherapy treatment group, with a 20% improvement in survival for patients who received this treatment compared to those who received radiotherapy alone.

Over the last decades, the particular genetic features of some low grade gliomas have been found to be important in predicting the way they will behave and these features have been used to determine treatment. Those patients whose tumours were characterized by loss of chromosomal material on chromosome 1 and 19 typically received temozolomide chemotherapy as their first treatment; those who did not have this chromosomal loss were treated with radiotherapy first. This is because the loss of chromosomal material on 1p and 19q has been found to be associated with greater tumour sensitivity to treatment. Thus, it was felt to be safe to treat 1p and 19q chromosome deleted tumours with chemotherapy alone and hold radiotherapy in reserve, thereby delaying any potential harmful effects from radiotherapy, especially those effects on memory and thinking. At this point we

don't know whether inclusion of patients with 1p/19q loss in the RTOG 98-02 trial is the reason for the better survival results, or whether all low grade glioma patients benefit equally from the combined treatment.

The 10 year results of the RTOG 98-02 trial have persuaded oncologists that there is a clear advantage to combination therapy with radiotherapy and chemotherapy for low grade gliomas. As a result, the BC Cancer Agency has instituted a change in the management of these diseases, and patients with low grade gliomas will be considered for radiotherapy followed by adjuvant chemotherapy using PCV chemotherapy, which is the same chemotherapy used in the clinical trial. Chemotherapy will start when the radiotherapy is completed.

PCV chemotherapy is a combination of three drugs: procarbazine, lomustine (also called CCNU[®]) and vincristine. Procarbazine and lomustine are pill forms of chemotherapy which act as alkylating agents, meaning that they interfere with the tumour cells' DNA and prevent their replication, arresting the growth of the tumour. Vincristine is made from the periwinkle plant and is given as an infusion in the vein. It kills the tumour cell through effects on the microtubules in the cells; these structures are important for cell division and replication.

Each cycle of PCV chemotherapy lasts 6 weeks, and 4 to 6 cycles of treatment will be planned.

Lomustine is taken on day 1 of the cycle. This medication can cause fatigue and nausea; medication will be given to prevent nausea. Lomustine also typically affects the blood cells, so lab work will be

monitored closely. Sometimes lomustine cycles need to be delayed or doses need to be reduced to allow the blood cells to regenerate so that patients don't develop bleeding problems, infections or anemia resulting from the reduction in the blood cell counts.

Procarbazine will be taken on days 2 to 15 of each chemotherapy cycle. Procarbazine cannot be taken with certain other medications so you should make sure your health care team has a complete list of your medications and that this is regularly updated. There are also some food restrictions, including alcohol.

Vincristine is given as an injection or short infusion on day 1 and 22. The most common side effects of this medication are numbness and tingling of the hands and feet and constipation. Vincristine burns if it leaks from the vein into the tissues; the chemo unit nurses will monitor closely for this. After the day 22 vincristine, you will have completed the chemotherapy for that cycle and the next cycle will begin 6 weeks after the day you took the lomustine.

A study is underway to determine if temozolomide chemotherapy is as effective as the older PCV chemotherapy used in the RTOG 98-02 trial. While it is uncertain if the new combined treatment will have more late toxicities, a 20% improvement in 10 year survival is too compelling to overlook. It is hoped that further studies will help identify patients at undue risk of toxicity or who achieve greater benefit from combined therapy. Knowing this will help us further personalize therapy in this disease.

For more information about the treatment of low grade gliomas, contact your health care team.

This newsletter is published through the generous support of the BCCA Neuro-oncology Fund. For more information about 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

Brain Tumour Information Day

For patients, families & their supporters



Saturday, October 25, 2014

BC Cancer Agency Research Centre
675 West 10th Avenue, Vancouver
(across the street from the BC Cancer Agency)

Program:

- 8:15–9 am: Breakfast & Registration
- 9 am–3:45 pm: Brain Tumour Basics
 - Update on Radiotherapy for Brain Tumours
 - Update on Neurosurgery for Brain Tumours
 - Panel discussion with patients & family caregivers
 - Art Therapy
 - Relaxation Therapy
 - Patient & caregiver support group sessions
 - Decision making about the use of complementary & alternative therapies
 - Research Update

Register by October 17: Attendance is FREE but you must register with:
Colleen Pelletier Phone: 604.877.6000 x 672418 Fax: 604.877.6182 cpelleti@bccancer.bc.ca

October is Brain Tumour Awareness Month

The Hats Tribute: A collection of hats that's anything but ordinary

FOR MORE THAN 10 YEARS, brain tumour patients and their loved ones have contributed to an inspiring display of strength and hope at the Brain Tumour Foundation of Canada. The Hats Tribute showcases the diversity of patients affected by brain tumours, from babies to senior citizens. Each hat represents someone who has been diagnosed with a brain tumour. Hats are submitted by patients currently in treatment, by those who have completed their treatment and by families who have lost loved ones. The Hats Tribute can be viewed online at www.BrainTumour.ca/HatsTribute or viewed as video slideshows, also available on the website.

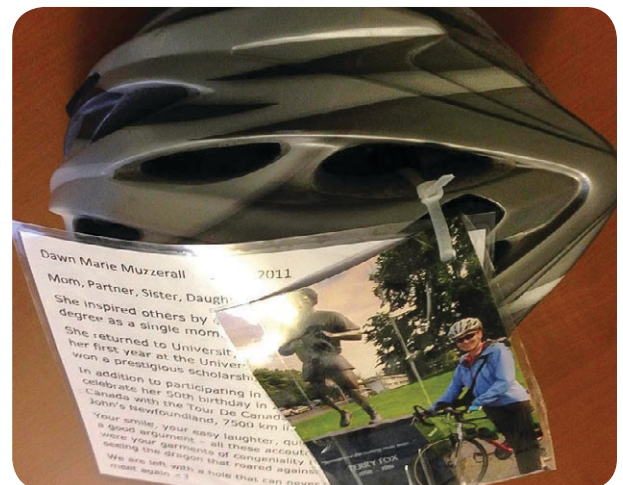
To date, 157 submissions from all across Canada have been collected to

honour or remember a special someone with a brain tumour diagnosis.

If you would like to raise awareness in British Columbia about brain tumours, contact your elected officials www.leg.bc.ca/mla/3-1-1.htm. Let them know that brain tumour patients need better access to care, enhanced resources for families, improved brain tumour treatments and increased funding for research that will lead to a cure for brain tumours.

For more information about efforts underway and how you can help to advocate for brain tumour

patients and families, contact the Brain Tumour Foundation of Canada
www.braintumour.ca/29/advocacy



Communication with your Health Care Team

By Amy Rappaport, RSW, MSW

BEING DIAGNOSED with a brain tumour can be scary and overwhelming. Furthermore, becoming a patient in the health care system is like entering a new world – unfamiliar territory, a foreign language, a culture of policies and procedures that can be bewildering. Needless to say, there's a lot to learn.

At the BC Cancer Agency, brain tumour patients are cared for by a multi-disciplinary team made up of nurses, radiation therapists, oncologists, social workers and pharmacists. Each of these providers plays an important role in your care. The relationship between a patient and his or her care team is seen as a partnership. Patients play a critical role in their care by asking questions and expressing concerns to direct and inform the care they receive.

Good communication is essential to good health care. Sometimes people find it hard to speak with their health care providers about their illness. For example:

- They may not want to seem overly worried or demanding
- They may be afraid to hear details or learn about what may happen next
- They may find it difficult to understand health care information or to think of what questions to ask
- The health care system is busy and can create a sense of feeling rushed
- Memory problems or heightened emotions may make it hard to remember or report concerns.

Below are some tips to help you communicate effectively with your health care team:

1. **Plan your time.** Before your appointment, take a few minutes to list everything you want to ask or tell your health care provider. Decide which items are most important, rank them in order of importance, strategize about how, when and to whom these concerns/questions should be directed. You may even consider sharing the whole list at the beginning of your appointment and prioritizing the list in collaboration with your health care provider.
2. **Bring information you may need.** Consider bringing in your medications and supplements and/or writing a complete list of them. Be ready to discuss your symptoms. It may be helpful to keep notes about your symptoms: frequency, severity, things that make symptoms worse or better.
3. **Use interpretation services** if needed. Ask your health care team to arrange this for you.
4. **Bring a friend or family member with you.** Another set of ears in the room can help to interpret and record information. As well, those who know you and care about you can provide helpful collateral information to your health care team.
5. **Keep a notebook.** Use this to record questions and answers, side effects, symptom tracking, lists of medications and supplements, and "to do" lists.
6. **Ensure you understand** what

the doctor is saying. Ask clarifying questions, consider summarizing information back to the doctor to confirm you understand correctly.

7. **Ask for information in writing** if that would be helpful. Written information can help you remember important things. For example, you may want to request a printed copy of the treatment plan or test results for your records.
8. **Remember: not all questions have answers.** Sometimes it's helpful to talk through concerns with your health care team, even if there isn't a clear answer to your question.
9. **Give feedback.** If your health care provider's responses were helpful, say so. This serves as a reminder to your team of what is helpful to you, so they know how to better serve your needs.
10. **Consider sharing some important details about you.** To care for you well, it's helpful to know what is important to you. What activities do you want to be able to do? What kinds of stresses or major events are going on in your life? What are your hopes for the future? When you think of what lies ahead, what worries you most?

This list is not exhaustive and you may have other ideas. Or you may feel that communication is already quite good; "if it ain't broke, don't fix it!"

If anxiety, stress, and/or worry are getting in the way of good communication with your health care team, there is support. Please contact your health care team or the Patient and Family Counselling (PFC) department at your cancer centre for further information about support services. www.bccancer.bc.ca/PPI/copingwithcancer

For more information on communicating with your health care team, the Canadian Cancer Society has some good resources. See the link below. www.cancer.ca/en/cancer-information/cancer-journey/your-healthcare-team/?region=bc

Editions of *Headlines* are also available as a pdf download at:
www.bccancer.bc.ca/PPI/TypesofCancer/BrainCentralNervousSystem/Headlines.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.