

Headlines

Spring 13

A newsletter for brain tumour patients and their families

MY STORY

Walk Me Home

By Becky Livingston

ONE THING WE KNOW ABOUT LIFE is that we don't know anything at all. Life has a way of calling on us to step up when we least expect, or want it. Twice now, I have cared for a dying loved one: my fiancé, Bob, in 2006, and then my 23 year-old daughter, Rachel, in 2010. Both had brain tumours.

"When something is dying it is the greatest teacher," said Zen monk, Shunryu Suzuki.

Indeed, I never knew there'd be so many phone calls to make, appointments to keep, or people to update. I never realized the emotional demands of this journey and the need to bend with changing moods, all the while having to



Becky and Bob, Christmas 2004.

imagine the unimaginable.

But I also never knew that grief, paradoxically, is filled with joy. I never knew it would be a time of such deep, unconditional love, or that in accompanying someone to the end I would be blown open with such gratitude for having shared the journey. It was a transformative experience.

The Importance of Self-Care in Caregiving

The way we help our loved ones on their brain tumour journey requires that we, too, help ourselves in some small way. Caregiving is depleting. We need to recharge our batteries. Here's what worked for me:

'Be with' as much as 'Do for'

When the demands of appointments, prescriptions, communications and running a household are all consuming, it's easy to get caught up in the doing. More than anything, your loved one wants you to just be with them. So be with them, however and whenever they need you. Let them take the lead. Listen without judgment. Be OK with silence, and snuggle a lot.

Receive, Receive, Receive

On numerous occasions when I wanted to 'do-it-all,' Bob urged me to accept help



Becky and Rachel, on Rachel's 21st birthday, 2007

from others. "They need to help, Beck. They don't know what else to do. Besides, to be constantly strong is a weakness." When I was able to accept help from others, I became the recipient of more generosity than I would ever have imagined.

Find Ways to Replenish Yourself

Know what sustains you. Denying your own needs can manifest into more fatigue, even anger. When Bob was sick, I stopped my weekly yoga classes and quit walking in the woods, activities that had previously helped me find calm and solace in a busy life.

Instead I began to write. Journaling became a lifesaver. I kept track of daily events and documented his deteriorating health, all the time pouring out my sadness, anger and frustrations. I also took up gardening. (We had just moved into our new home, which had a large backyard.) I dug and planted and sweated away in the dirt for months. Gardening gave me hope, the promise of new life in a future without Bob.

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Care for the Caregiver

By Amy Rappaport,
Registered Social Worker

BRAIN TUMOURS CAN have profound effects on people's lives – not just on those diagnosed but also on the family and loved ones supporting them. Being a caregiver can be a rewarding experience, but it also can place lots of demands and challenges on your life. Below are some suggestions and a list of community resources that you may find helpful as you continue doing the important work of caring for a loved one with a brain tumour.

- Get a break from caregiving each day. Schedule 'mini retreats' into your day – even if just for 10 minutes. During these scheduled times, focus on you. Do something that has nothing to do with caregiving (cat nap, go for a walk, take a bath).
- Ask for help. You cannot do this alone. Get help from friends and family with daily chores, and tasks around the house. Write a list of things you need help with and delegate!
- Focus on the basics – adequate sleep, exercise, and a healthy diet. Check in with yourself each day and make sure you are meeting your basic needs.
- Validate your own health and wellness. You wouldn't miss an appointment with a specialist – try adopting this attitude toward your own health and wellness. Taking care of yourself is not an act of selfishness – it will help you to take better care of your loved one. For example, meet with your own family doctor to discuss your health and wellness.

- Know your limitations. What are some of your signs of burnout or depression (fatigue, short temper, irritability)? Notice these signs and get help by: communicating with your friends and family, attending a support group, connecting with other caregivers and/or reaching out for professional help. There is great strength in knowing you're not alone.
- Be flexible. Be open to new ways of getting things done. Others may not do things your way but can be helpful in their own ways. Try and let go of some of the expectations of 'how' things need to get done.
- Educate yourself. Access all the information you can about the illness and the possibility of its progression. Visit the library (BC Cancer Agency library), speak to the doctor and attend disease-specific events.
- Trust your instincts. Much of the time they will move you in the right direction.
- Supportive friends and family play an integral role in the care of those diagnosed with a brain tumour. You don't need to do it alone.

Some other community resources that you may find helpful:

- **Brain Tumour Support Group.** See the article about support groups in this issue for more information about

session times in Kelowna, Vancouver and Victoria.

- **Cancer Chat Canada** offers a 10-week online support group for people caring for a loved one with cancer. Visit www.cancerchatcanada.ca or call 1.800.663.3333 x4965.
- **Home Care Community Services** offer nursing visits, Personal Support Workers for help with bathing and dressing, and safety assessments in the home by Occupational Therapists. Ask your health care team for more information about these services.
- **VCH Caregiver Support Program** offers information and support to caregivers. Support groups for caregivers meet monthly at three locations around Vancouver. Contact the program at 604.709.6437 for more information.
- **Vancouver Hospice Society** offers a variety of supports including a home hospice visiting program that allows a caregiver to take a break for a short period. Visit www.vancouverhospice.org or call 604.737.7305. There is other useful caregiver information at the Virtual Hospice website: www.virtualhospice.ca
- For more caregiving support resources, visit the websites listed at www.bccancer.bc.ca/PPI/RecommendedLinks/coping/caregivers.htm

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

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.

Attending a support group: a caregiver's perspective

By Holly Anderson

I PARTICIPATED IN A CAREGIVER support group which took place as part of the Brain Tumour Information Day last October. Before that, the only people I ever talked to about my dad's brain tumour were members of my immediate family and a few special friends. Of those people, only my brother could truly understand how it felt to have a father with a brain tumour. However, I worried about burdening my family by talking about my feelings because I knew they all were dealing with so much emotional stress and I did not want to make things worse for them.

This is where the idea of a support group appealed to me. I appreciated the connection with people who have actually experienced the highs and lows of supporting a loved one with a brain tumour and who understand how these experiences impact and ultimately change your life. Additionally, since support group participants are not family members, you can share your worries or ask those burning questions that you couldn't bring yourself to ask of a loved one.

The members of my support group session helped each other in a way that no doctor, nurse or counselor could. A person whose sister had been a survivor for over ten years could provide hope to someone whose husband had just been diagnosed. A mother whose husband had been diagnosed could ask others how they dealt with speaking to children about the diagnosis.

There were two things about the support group I liked best. 1) I realized that my family and I are not alone. Other people are living with the same triumphs and tribulations and I derived great comfort from that. Once you have a safe place to talk to others going through this experience you can see that they *truly, utterly* just get it, and they are there for you even if they are strangers *because* they get it. 2) Other people going through this experience have a lot of wisdom to

share and can offer creative solutions and words of reassurance for the practical, everyday issues that come up when your family's life is affected by a brain tumour.

I encourage those caretakers who have not yet attended a support group to try it. It is an emotional experience that you are unlikely to forget.

For more information, or to attend a support group, here is a list of contact names and session times.

In Kelowna

3rd Monday of each month

11:00 am to 12:30 pm

Okanagan Room, Cancer Centre of the Southern Interior

Facilitator: Valerie Colquhoun

250.712.3971 or 250.712.3963

In Vancouver

1st Wednesday of each month

9:30 am to 11:00 pm

John Jambor Room, ground floor

Vancouver Cancer Centre

Facilitators: Douglas Ozier, Rosemary

Cashman, Amy Rappaport

604.877.6000 x 2185, or 604.877.6072,

604.877.6000 x 2813

Every other session is a split support group: one for patients, one for caregivers.

In Victoria

2nd Thursday of each month

11:00 am to 12:30 pm

Wellness Room, 3rd Floor

Vancouver Island Cancer Centre

Facilitator: Catherine Traer-Martinez

250.519.5528

Call for nominations!

The Terry Kennerley Award (inaugural award)

Do you know someone who has made a significant contribution to the brain tumour community? Who has gone that extra mile to support other patients and their families? Or has promoted awareness about the disease? Or has engaged health care professionals to improve care delivery?

Now is your chance to recognize someone who made living with a brain tumour a little easier, a little better, or a little less lonely.

The award recipient's name will be announced during October, Brain Tumour Awareness Month, and will be displayed on a plaque within the BC Cancer Agency.

The deadline for nominations is September 1, 2013.

Please include:

- Your name and contact information
- The name of the person you are nominating
- A short paragraph describing the reason(s) for the nomination

BCCA staff are excluded from receiving this award.

Contact Rosemary Cashman 604.877.6072 rcashman@bccancer.bc.ca

or Colleen Pelletier 604.877.6000 x2418 cpelleti@bccancer.bc.ca

or call toll-free 1.800.663.3333.

For more information about the Terry Kennerley Award see: www.bccancer.bc.ca/PPI/TypesofCancer/BrainnCentralNervousSystem/terrykennerley.htm

My story

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When my daughter was sick I remembered the words of the social worker at Cottage Hospice where Bob had spent his final weeks: "It's really difficult to take care of someone else if you don't take care of yourself." This time I knew better. I continued my yoga practice, and a good friend regularly stole me away for walks in Capilano Canyon, a place to breathe, to move my body away from the demands of caregiving.

Give Them Their Power

Bob was a dying man who was very much alive. By choosing to spare him from all the details of his condition, the day-to-day tasks of running a house and of closing down his business, he felt more alone than

ever. "Beck, I'm not pushing up daisies yet," he'd remind me, "I want you to tell me everything, even if I don't understand it all." Dying people need to participate as much as possible in making choices that will affect them now, and after they're gone.

Assert Yourself

Tell others what you need, and what you don't, even if it feels out of character. Friends at work who organized and dropped off meals to our house knew to bring enough for two servings only, in containers that didn't need returning, to leave them at the front door, and not to ring the doorbell. What initially seemed rather harsh, was essential for my peace of mind.

Go With the Flow

We can't change the reality of a diagnosis,

but we DO have control over how we respond to that reality. Bob rarely got caught up in the 'what-ifs', certain that his copious readings of Krishnamurti helped him live life and approach death with courage and dignity.

Caring for a dying loved one gives us the opportunity to see something in ourselves that we'd like to change. Bob inspired me to take it one day at a time; Rachel reminded me to follow my heart. Thanks to them both, I embrace life as it is, grateful for the blessings of each day. After all, as Ram Dass so beautifully said, "We're all just walking each other home."

For more of Becky Livingston's writing, see:

<http://blivingrock.com/>

<http://facebook.com/joyfulmourning101>

Brain Tumour Foundation of Canada Spring Sprint 2013

Stroll, saunter, walk, jog or run – register today!

When you register for the Spring Sprint you join a nation-wide movement that is transforming the future for brain tumour patients and their families. This means funding critical research into the cause and cure of brain tumours. It also means ensuring that the 55,000 Canadians living with the disease have access to unique support and information programs.

When: Sunday, May 26, 2013

Where: Victoria - Cedar Hill Recreation Centre, 3220 Cedar Hill Road, Victoria
Vancouver - Burnaby Lake Rugby Club, 3760 Sperling Avenue, Burnaby

Registration Time: Victoria 9:30 am, Vancouver 10:00 am

Event start: 11:00 am

Wrap-up: 1:00 pm

For more information, or to register online:

www.braintumour.ca/627/spring-sprint or call 1.800.265.5106



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