



WELLNESS

How we find hope at the end of life

By Rosemary Cashman, Nurse Practitioner, Vancouver Cancer Centre, from an interview with two nursing leaders in cancer care.



Janie Brown (left) is the Executive Director and Founder of Callanish Society and author of *Radical Acts of Love: How We Find Hope at the End of Life*.

Dr. Tracy Truant, (right) former BC Cancer Professional Practice Leader and Provincial Director, Research, Education and Innovation, was diagnosed with a glioblastoma in 2018.

RC: You two worked at BC Cancer many years ago. What was that like?

JB: Tracy and I met on the 5th floor of BC Cancer where we were both nurses in the 1980s. I think of that period as the high point of my bedside nursing career. We had a shared vision for nursing care that was holistic and centred on the patient and family. The nurses truly cared about their patients. I still remember those patients. This was in the early days of bone marrow transplants and we lost a lot of patients. Nurses grieved together when our patients died and celebrated together when they were doing well. I think back to meeting

Tracy, who was truly a visionary. Her optimism, clarity and positivity had a big impact on me.

TT: Patients and families were always at the centre of our care. We saw our patients as individuals, not just as people with cancer. I was a new nurse and Janie was a clinical nurse specialist and a great mentor to me. She helped to create an environment of learning where nurses were encouraged to reflect on patients' experiences and improve their quality of life.

RC: What led you to the paths you chose in cancer care?

JB: Callanish was developed as a way of reconnecting individuals to their strengths rather than focusing solely on the cancer and its treatment. Seeing individuals only through the lens of cancer is too limiting. Callanish offers a shift in perspective, so that the person is seen in all aspects of their humanity. We don't ignore the cancer, but we also acknowledge other aspects of patients' lives, such as family and community. We try to help people see what they can do, rather than only what they can't do. Hope is a crucial part of this. When cancer is viewed as one experience in a life of many experiences, hope becomes more focused on how to make life meaningful every day.

TT: Hope is different for everyone. Although my path started with patient-centred care, I saw that the health care system sometimes was organized around what worked for the system, rather than what was important for patients and families. I wanted to focus my doctoral research on understanding the barriers to and the benefits of that individualized care in our health care system.

RC: What has the experience of Callanish been like for each of you?

TT: I have been drawn to Callanish as a nurse and as a patient. As a nurse, Callanish was a wonderful resource that I could recommend to patients. As a patient, I have participated in several Callanish programs including an amazing Callanish retreat. Janie and the other staff are so authentic, supportive and open. I wanted to explore my own heart, mind and soul as I faced the challenges of my diagnosis. The Callanish program honoured my feelings and allowed me to discover joy, compassion and grace as I reflected on my future.

JB: People who are most drawn to the Callanish program are those who are trying to live with purpose and meaning. People who ask, what am I going to do with my life and how am I going to live it, rather than just waiting to die. We help them to plan for life—and to live fully—rather than planning only for death. The retreats allow individuals to explore their sense of purpose because without purpose there is despair. Our discussions help people to reconnect to the desire to be of use throughout life.

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**COMING SOON –
Support groups for
brain tumour patients
and families by zoom**

If you are interested in participating, you must contact rcashman@bccancer.bc.ca for a zoom invite.

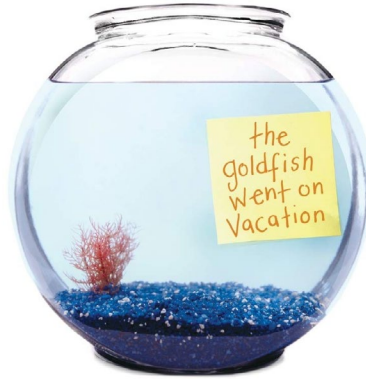
The Goldfish Went on Vacation by Patty Dann

By Yaron Butterfield

WHILE BROWSING THROUGH my bookshelf I came across a memoir by Patty Dann called *The Butterfly Hours—Transforming Memories into Memoir*. In this book, she mentions that her husband had passed away from brain cancer. That led me to search online for other books that Patty Dann had written, and I found *The Goldfish Went on Vacation*, which I purchased immediately. I was interested in this book because I am writing a memoir about my own brain cancer experience.

The book is a four-part narrative with short chapters, some only a few pages long, so it's an easy read. The fact that the book is written from Patty's perspective was new for me, as the other brain cancer books I've read were written by the person with cancer.

The memoir recounts how Patty and Willem met in a New York synagogue, married and then adopted a baby boy from Lithuania named Jake. When Jake was 3 years old, Willem was diagnosed with a glioblastoma (the same diagnosis I have). We learn how Patty dealt with many challenges and emotions as she cared for her husband and son.



A MEMOIR OF LOSS
(and Learning to Tell the Truth about It)
Patty Dann

This book gave me some insight into the effects that a serious illness diagnosis can have on a family and how difficult this can be for family caregivers. I found myself recalling my attempts at humour when I was diagnosed, and how these fell flat as my family struggled with their fears and anxiety. I wondered if I could have been as strong as my twin brother if he'd been diagnosed with cancer, and I had been his caregiver. I learned a lot from this book and was able to appreciate how much my family had to conceal their own feelings so that they could show me love, strength and positivity. As I read this book, I sometimes

wondered if the author was in denial about her husband's illness, but then I realized she had to remain calm and focused on overcoming her fears. She had to summon up the courage to support her dying husband and prepare her young son for the impending loss of his father.

Throughout her memoir, Patty showed me that when a person gets cancer, it has profound effects on their loved ones. Patty cared for her husband even though he was a different person, with changes in his personality, speech, memory and thinking. She had to balance caring for him with caring for her son. And she also had to care for herself in all of this.

I recommend this book to anyone interested in learning how one deals with a loved one's serious illness, especially when it's brain cancer. It is an excellent book for caregivers because it demonstrates how you can find strength in hardship and accept a terrible situation.

Hardcover: 144 pages
Publisher: Trumpeter; 1 edition (Jan. 9 2007)
Language: English
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ISBN-13: 978-1590304280
Product Dimensions: 13.6 x 1.9 x 19.8 cm
Shipping Weight: 272 g

BC Cancer Library re-opening update

By Chantalle Jack, Provincial Library Leader, Vancouver Centre

The BC Cancer's sudden closure of library sites in March affected many people.

While our library spaces remain closed to the public, we are carefully resuming the circulation of physical materials, and following recommended guidelines for public health and staff safety.

Borrowing Materials

Vancouver Library ONLY: Public borrowing of books, media, and other physical materials from BC Cancer has resumed! Items may be picked up "curbside" outside of our Vancouver Library location. Please note that borrowed materials cannot enter clinical areas.

Not in Vancouver? Don't want to come all that way to get your books? No problem! Library materials can be delivered via postal mail.

1. Visit the library website at libraries.phsa.ca/bcca to search what we have. Patients and public, remember to select *Recommended for Patients or All Patient Public Items* to find resources tailored to you!
2. Add items to your list > view My List > Borrow and fill out the contact information. Library staff will follow up with your request. OR...
3. Email library@bccancer.bc.ca or call 604 675 8001 with your requests.

Returning Materials

We encourage you to return items you have borrowed and there are many ways you can do so.

- If your item(s) were delivered by mail, you should have received a free return postage label. Simply package up your items, stick on the postage label, and slip the package into the mail.
- If you have an existing BC Cancer appointment at any of our regional sites, you can find a library drop box to return your items. Visit our website for our locations and contact information.
- Lost your mailing label or don't want to come to the library?

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Boney Music Memorial Invitational Bag Pipe Competition and Recital

By Rosemary Cashman, Nurse Practitioner, Vancouver Cancer Centre

THE BONEY MUSIC MEMORIAL INVITATIONAL is an annual piping competition and recital to benefit brain cancer research. The competition was initiated in 2016 by celebrated piper, BC Pipers Association (BCPA) member and glioblastoma patient, Andrew Bonar. It is being continued by BCPA at Andrew's request following his passing in October 2017.

The top five pipers in the annual BCPA Open Piping Grand Aggregate standing and the previous year's winner of the Boney Music Memorial Invitational each perform a medley of various musical styles. The

best performance receives the Boney Music Memorial Invitational trophy.

Admission is by donation, and ALL donations go to BC Cancer to support brain tumour research.

The 2020 competition in February was held at the Seaforth Armoury and raised an incredible \$3,087. It was thrilling to hear the pipers in this historic heritage building and home of the Seaforth Highlanders. seaforthhighlanders.ca



PHOTO: PHIL EDGE

Boney Music Memorial pipers with Andrew Bonar's family.

We thank the family of Andrew Bonar for their incredible generosity and support for our patients!

To read more about the Boney Music Memorial invitational, see bcpipers.org/programs/boney-music-memorial-invitational

BC Cancer Library re-opening update continued from page 2

Email library@bccancer.bc.ca or call 604 675 8001 and we can send you a return mailing label.

Virtual Services

The library is fully open online and we can answer your questions via phone or email,

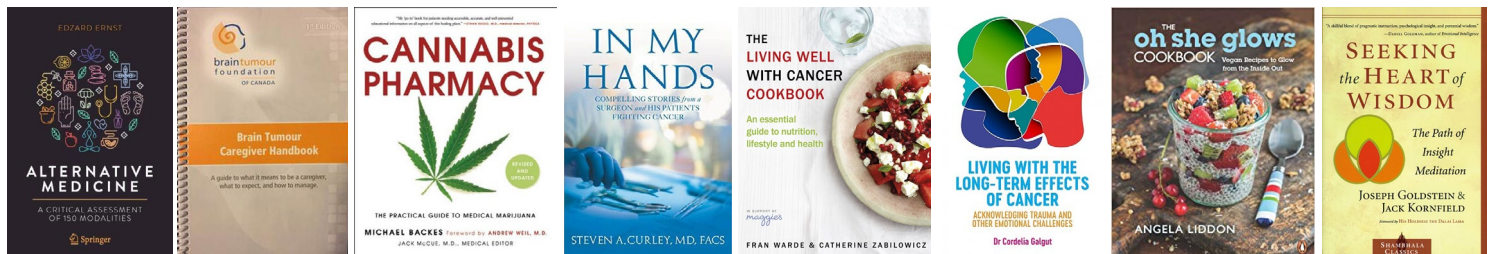
and offer you access to numerous eBook resources. Explore a wealth of great online cancer resources on our library website and contact us today for your information needs.

NEW Information Request Form

If you live in BC or the Yukon, you can now request information from home using our new online Information Request

form, available on the Library Website. Use this form to request cancer information customized to your needs and interests. Select cancer stage and type, treatment type, and topics such as clinical trials, coping with cancer, fatigue, nutrition, complementary therapies, talking to children, and much more. Librarians will search for and compile your information and send it to you via mail or email.

Here is a selection of recent acquisitions available now from BC Cancer Library



BOOK IMAGES COURTESY OF OPENLIBRARY, GOOGLE IMAGES, AMAZON

- Alternative medicine : a critical assessment of 150 modalities / 2019
- Brain tumour caregiver handbook : a guide to what it means to be a caregiver, what to expect, and how to manage / 2019
- Cannabis pharmacy : the practical guide to medical marijuana / 2017
- In my hands : compelling stories from a surgeon and his patients fighting cancer / 2018
- Living well with cancer cookbook : an essential guide to nutrition, lifestyle and health / 2016
- Living with the long-term effects of cancer : acknowledging trauma and other emotional challenges / 2020
- Oh she glows cookbook : vegan recipes to glow from the inside out / 2014
- Seeking the heart of wisdom : the path of insight meditation / 2001

View a complete list of new titles at bccancer.bc.ca/library-site/Documents/New_Titles_PP.pdf

Clinical Trials update

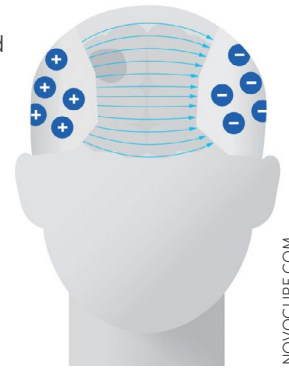
By Dr. Brian Thiessen, Neuro-oncologist, BC Cancer – Vancouver

CURRENTLY AT BC CANCER, we have two active trials for primary brain tumour patients. For newly diagnosed glioblastoma patients, we are participating in the MIRAGE trial which is studying the benefits of marizomib, a therapy that targets the proteasome in cancer cells. Proteasomes are the garbage collectors in the cancer cell. Blocking their function leads to toxic buildup in cancer cells, which eventually causes the cancer cells to die. The study drug is used in combination with standard radiotherapy and temozolomide chemotherapy. For oligodendroglioma tumours, we have the CODEL trial, which is comparing the effectiveness of temozolomide chemotherapy versus a 3 drug combination of procarbazine, lomustine and vincristine (PCV). Both chemotherapy regimens are used following radiotherapy. There is another trial in the works, the INDIGO trial, which we are hoping to

open in the fall of 2020. This trial is for newly diagnosed low grade gliomas harbouring the IDH mutation that is typical in this disease. For IDH-mutated low grade tumours after surgery, this study will randomize patients to receive an IDH inhibitor, AG-881, versus a placebo. The intent is to see if a targeted therapy against the IDH mutation can delay the time until further treatment is needed with radiation and chemotherapy. The hope is that if this medication (which appears to be well tolerated) can control the disease and delay the start of more toxic therapies, we can prolong survival and prevent or delay late toxicities from radiotherapy and chemotherapy. Eligible patients will be required to have had surgery (biopsy or resection), but no prior treatment with radiotherapy or chemotherapy.

Further on the horizon, there is tentative work underway to open another study for glioblastoma patients, the TRIDENT study. This study is investigating the use of the Optune device in glioblastoma patients

undergoing radiotherapy and chemotherapy. This portable device uses local electromagnetic fields to disrupt the ability of cancer cells to divide. The study will try to determine if it is safe and effective to use the device during radiotherapy and chemotherapy, rather than only for maintenance after treatment. Local discussions regarding this trial are still in the early stages, and we don't yet have a timeline for initiation of the study.



NOVOCURE.COM

Stay tuned for more information about these and other studies in future issues of Headlines.

For general information about clinical trials, see the Headlines **Winter 19** issue.

How we find hope

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RC: Janie, what prompted you to write your book?

JB: Three things. First, over 30 years of working in oncology, I have learned so much from patients and families, and I wanted to share some of that wisdom by telling 20 stories about people I have met. Second, I wanted to provide some reassurance for people that although death scares us all, it can be a positive experience, and it can be peaceful. And third, I wanted to empower families to have courageous conversations about death. Talking about death can help the person who is dying and ease the grief of bereaved families.

RC: What can health care providers do to better support patients and families who are living with a brain tumour?

JB: We can be better listeners. Health care providers can be very directive and need to be more receptive. We should not consider

ourselves experts in someone else's life and need to make space to hear what patients and families are feeling and what they need.

TT: I never feel like just a patient. I also think about the concepts that helped my patients when I was a nurse. Health care providers should help patients build and connect to their strengths. Don't just focus on the medical aspects of treatments. Help them find meaning through creative and spiritual activities like poetry, meditation and art. And ensure that they feel supported at every step of their illness, from diagnosis, through treatment and right up to the end of life.

For more information about the Callanish program, see callanish.org

Janie's book, *Radical Acts of Love: How We Find Hope at the End of Life*, is available at bookstores and through Amazon. You can read more about Janie and her book here: janiebrown.com

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For more information about how you can support enhanced patient care, patient information and brain tumour research, please contact Vanessa Stevens, Development Officer BC Cancer Foundation.

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Editions of *Headlines* are also available as a pdf download on our website at: www.bccancer.bc.ca/headlines

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).