



MY STORY



By Danny Howard

MY NAME IS DANNY. I'm 34 years old and I'm receiving treatment for a glioblastoma, the most malignant brain tumour. I understand that the odds are that I will die of this disease within a year or two. Currently, I have excellent quality of life. I recently went on a three-day rock climbing trip with friends whom I cherish.

I first started having symptoms of my tumour ten years ago while I was living in Malawi, in Southern Africa, working with Engineers Without Borders Canada. While on a hiking vacation, I came down with malaria. Then I started having seizures that eventually prompted an MRI which showed the tumour.

At the time, the doctor explained to me that he still had healthy patients coming to him 20 years after their initial diagnosis of a brain tumour. I wasn't sure how to live with this diagnosis. Could I go back to Malawi? Would it be responsible for me to consider having a family?

Instead of returning to Malawi, I stayed in Canada and began building a really close community in Toronto. My tumour began to grow so I had my first surgery (and was awake throughout the operation) and was home later on the same day. I was back at work at a conference nine days later with staples in my head. Encouragement

came from my community who wanted to support me by sharing my new look. My dad and four great friends spontaneously shaved half of their heads to match my post-surgery hairdo.

The initial pathology from my surgery confirmed that my tumour was an anaplastic astrocytoma, a grade 3 cancer. My follow-up was done at the Princess Margaret Hospital where I have an incredibly diverse team of specialists, support staff, and professionals who provided me with the time, care and broad support I could not have received from cancer specialists alone. More recently, I have spent the winter with my family in Kelowna and have received treatment through the BC Cancer Centre there.

After my first surgery, I was given an estimated prognosis of five to six years. This brought other hard questions. How does one live with only five or six years? With one year to live, I would go and have fun and live for the immediate moments. With decades to live, I would plan for the future, including building a career and family—much like my peers. With five or six years, I really struggled with how to spend my time and live in the best way possible. I wondered how fair it was to include people in my life who might be hurt.

In six years, I had romantic partners, worked hard, crashed, and then worked less hard. I logged many kilometres in a canoe every year with friends, and spent invaluable time with my family. I took stock of my ability to handle stress in my work and figured out how much money I wanted to make and how much time I wanted to invest in my community.

Then my tumour progressed to a size where another surgery was necessary. I had already accepted the reality of my own mortality. It now became important to me to support others in accepting my mortality.



Knowing that the implications of another surgery could mean I might lose the ability to communicate with speech, it became critical to me to communicate to my friends and family how grateful I was for them and how much I loved them. This also created opportunities for others to communicate with me about how they were feeling and gave them a chance to share, understand, celebrate, mourn and heal.

The pathology from my most recent surgery confirmed that my tumour has advanced to a glioblastoma, a grade 4 cancer. My family and I have talked about end-of-life care and considered possible medical scenarios. They know that quality of life is more important for me than quantity.

Looking back over these years, I am confident that, with the support of those I love, I'll figure out how to live a beautiful life.

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Sleep

MOST PEOPLE WOULD AGREE that there are few things as restorative as a good night's sleep. Sleep is vital for our physical and mental health. Those who do not get enough sleep may experience a range of problems including irritability, fatigue, poor memory, decreased concentration, incoordination, increased accidents, reduced motivation and poor coping abilities. Inadequate sleep may inhibit the immune system and make us more vulnerable to illness. Some studies suggest a link between poor sleep and serious medical problems, including heart disease, obesity and early death.

How much sleep is normal?

The optimal amount of daily sleep varies for individuals, and not everyone needs 8 hours. Children and adolescents typically require more sleep than adults.

What are sleep problems?

Sleep difficulties are common in the general population, but a serious medical condition like a brain tumour can create special challenges for sleep. For example, anxiety and depression related to a brain tumour diagnosis may make it hard to sleep well. Some brain tumour treatments

can make you agitated and restless; others make you feel so tired that you nap in the daytime and then don't sleep well at night. Pain, nausea and other physical problems can impact sleep. And worrying about NOT sleeping just makes it harder to sleep.

Sleep problems can be related to an insufficient amount of sleep (usually 6 hours is considered a minimum) or poor quality of sleep (related to the depth of sleep and how many awakenings we experience). It is normal to wake up during the night and normally we don't remember these awakenings. Being worried or distressed can make it more difficult to fall asleep again.

What can you do to improve your sleep quality and quantity?

1. Reduce psychological and physical distress and increase relaxation.
 - Engage in physical activity in the daytime and gentle stretching exercises in the evening.
 - Get support if you are distressed. Talk about what is upsetting you with someone who can help; don't let bedtime become a time to worry and try to solve problems.
 - Learn relaxation techniques.
 - Get help for any physical problems that are affecting your ability to sleep.
2. Develop nighttime strategies to make bedtime calm and relaxing.
 - Consider herbal tea or a warm bath before bed.
 - Avoid stimulating activities just before bed, e.g. strenuous exercise, stressful television or movies, computer work, upsetting conversations with family or friends.
3. Reinforce the stimulus to sleep.
 - Try to go to bed around the same time each night and get up around the same time each morning.
 - Go to bed when you're sleepy and get out of bed if you cannot sleep. Do something relaxing like reading until you're sleepy.
 - Use your bed for sleeping and sex only.
 - Maintain the same routines, mealtimes and activities to facilitate a healthy sleep system.
 - Acknowledge your normal sleep preferences and try to adhere to these. Some people are early risers; others prefer to go to bed late.
 - Avoid napping in the daytime.
4. Avoid sleep disrupters.
 - Limit caffeine or have it early in the day. Besides coffee and tea, caffeine is present in cola drinks, chocolate, cocoa and some pain killers and natural health products.
 - Nicotine and alcohol can also have a negative effect on sleep.
 - Avoid heavy meals and spicy food before going to bed.
 - Avoid drinking too much fluid before going to bed.

For more help in getting good sleep, speak to your health care team and see also:

www.bccancer.bc.ca/health-info/coping-with-cancer/emotional-support

[www.bccancer.bc.ca/coping-and-support-site/Documents/Self-help%20for%20sleep%20problems%20\(insomnia\).pdf](http://www.bccancer.bc.ca/coping-and-support-site/Documents/Self-help%20for%20sleep%20problems%20(insomnia).pdf)

SAVE THE DATE

Brain Tumour Information Day May 5, 2018

BC Cancer Research Centre, 675 West 10th Ave., Vancouver, BC

8:30 Sign in and coffee

FREE to attend

9:00 Program begins

FREE parking

Topics:

Brain tumour treatment: What is the science and where is it going?

Patient and family caregiver perspectives

Health and healing through nutrition

Rehabilitation resources to address changes in abilities after a brain tumour diagnosis

Breakout sessions: CHOICE OF yoga OR support group session

12:30 pm Program ends

Refreshments at morning break but no lunch provided.

Registration: patientexp@bccancer.bc.ca or 604 877 6000 ext 674619

When registering, please indicate whether you would like to attend the yoga session or the support group session.

Ketogenic diet

By Amber Bown-Dahl,
BC Cancer Registered Dietitian

THE KETOGENIC DIET is typically used for weight loss, but has also been used to help treat some kinds of seizures. More recently, there has been interest in using this diet as a possible complementary treatment for cancer and more specifically, for those diagnosed with brain cancer.

Glucose is a carbohydrate which is the body's main source of energy or fuel. The ketogenic diet is composed of calories from high fat, moderate-low protein and very low carbohydrate food sources. It is designed to put the body in a state of ketosis. Ketosis mimics the effect of starvation and fasting as all sources of glucose are depleted within the body. While in this fasted state, fat is released from cells and the liver converts these fats into a new source of energy – ketones. This is the body's second choice for energy after carbohydrates. By forcing the body to burn fat rather than utilize carbohydrates, these ketones become the main fuel for the body's needs.



The current research involving the use of the ketogenic diet in cancer aims to address whether it is possible to selectively “starve” cancer cells by decreasing carbohydrate availability and utilizing

ketones as an alternate fuel source, which cancer cells cannot use. Imagine cancer cells working like a traditional car which runs on gasoline only, and healthy cells operating like a hybrid car with the ability to use either gasoline or electricity to generate power.

Under normal circumstances the brain prefers to use glucose as its main source of energy. If

glucose is not available, the brain can shift to using ketones for energy. Cancer cells in the brain are unable to shift to ketones for energy and mostly rely on glucose. In theory, if the cancer cells' main source of fuel is removed, this may slow or halt further tumour growth.

In terms of the current body of scientific evidence, there have been positive preclinical studies of ketogenic diets inhibiting growth of brain tumours in laboratory animals. There are currently some clinical trials with patients underway,

but unfortunately these are very small studies and participants have found it difficult to adhere to such a very restrictive diet. So, at this point, we do not have sufficient evidence to recommend the ketogenic diet as a treatment for cancer.

There are nutritional concerns for cancer patients who wish to pursue a ketogenic diet. Cancer and its treatments can make eating a challenge at a time when nutrition is critical for health and recovery; a restrictive ketogenic diet may make things worse. Ketogenic diets are considered to be nutritionally inadequate and have their own side effects which include micronutrient deficiency, constipation, elevated cholesterol, weight loss, kidney stones, altered medication absorption and upset stomach.

The ketogenic diet should be guided by health care professionals, with regular monitoring of bloodwork and medications, and consultation with a dietitian to ensure that nutritional needs are met. At the end of the day, there is no one-size-fits-all diet approach for people diagnosed with cancer. Having an open discussion with your health care team, including a registered dietitian, is recommended to help optimize your health and recovery.

Brain Tumour Foundation of Canada 2018 walk

Join the movement to end brain tumours

WALK TO RAISE FUNDS to support the Brain Tumour Foundation of Canada's efforts to support the brain tumour community across the country. These funds go towards life-changing research, support programs, information, advocacy, awareness, and HOPE.

VANCOUVER ISLAND

Date: Sunday, May 27, 2018

Location: Victoria, University of Victoria, 3800 Finnerty Road, Victoria, BC

Time: Registration starts: 8:30 am

Opening ceremonies: 9:45 am

Walk begins: 10:00 am

or

VANCOUVER

Date: Sunday, June 24, 2018

Location: Vancouver, Burnaby Lake Rugby Club, 3760 Sperling Ave, Burnaby, BC

Time: Registration starts: 9:00 am

Opening ceremonies: 10:50 am

Walk begins: 11:00 am



For more information:

btwalkhelp@braintumour.ca or toll free 1.800.265.5106

For a list of the walks see: www.braintumourevents.ca



Nuggets of wisdom

By Yaron Butterfield

IN *NOT THE LAST GOODBYE*, Dr. David Servan-Schreiber describes his experience after the recurrence of the brain cancer he was diagnosed with 19 years earlier. When I picked up *Not the Last Goodbye*, I soon realized it was written by the author of the widely acclaimed book, *Anticancer*, which I had read many years ago. I had followed many of his recommendations on diet and staying healthy. David was a physician, university professor and entrepreneur; after the publication of *Anticancer*, he was also on the book tour circuit promoting his book. In *Anticancer*, which I highly recommend, he describes his journey after his initial diagnosis and all that he did to be healthy and survive cancer.

In *Not the Last Goodbye*, David acknowledges that he didn't necessarily always practice what he preached in *Anticancer*. He writes: "I cared so much about promoting my ideas that I forgot to look after myself." This struck a chord with me. Although it's been 14 years since my diagnosis of glioblastoma and I like to think the cancer is gone, I must continue to be mindful of the need to be healthy in all dimensions. The cancer may be gone, but its physical and mental effects linger, both from the tumour and the treatment, and I want to be as healthy as I can. Also, after my diagnosis in 2004, I tried to identify events and actions that had occurred in the preceding years that may have led to the cancer. In fact, I had a specific event in mind that I felt triggered the cancer. This book helped me believe

that there is no point in regretting the past—that it makes more sense to focus on and treasure what is good in one's life.

Not the Last Goodbye is filled with little nuggets of wisdom. The author made it clear that even though he knew that his illness was terminal, he lived every day fully and with hope. He showed me what I do not want to do, which is to ignore the most important things in life. As I have heard from many others diagnosed with brain cancer, we have a new perspective on life. For me, I tend to see the beauty surrounding us more than I did before my diagnosis. And although sitting at my desk in front of the computer is important

for my work, I also know how important it is to sit amongst the trees on a hill, as this nourishes my soul and that helps me to stay healthy.

Indeed, David believed that there are many things an individual can do to be healthy in addition to conventional medical treatment. The simplest things can have profound positive effects—"spending time in a forest, on a mountain, or a riverbank brings us something that is wonderfully revitalizing...it helps us to align ourselves with the rhythm of the seasons, to find balance and healing within ourselves." I am also mindful of the fact that every one of us has only a certain period of time to enjoy the beauty of life. I've come to realize that the things that used to trigger anxiety, frustration or anger are quite insignificant in the grand scheme of things. So this book really resonated with me.

"We need to nourish our health, our psychological balance, our relationships

with others and the planet around us. Together, all these efforts contribute to protecting us—individually and collectively—from cancer, even if there will never be a 100 percent guarantee." David wrote *Not the Last Goodbye* in April and May, 2011, and it was published in his native France a month later. It went straight to the top of the bestseller lists – just in time: David died on July 24, 2011. Even to the end of his life he taught us valuable lessons about cancer, life, death and healing.

To borrow a copy of these books from the BC Cancer Library, please see the catalogue at: www.bccancer.bc.ca/library or contact: library@bccancer.bc.ca or 604 675 8001 (toll-free 1 888 675 8001 x 8001)

Not the Last Goodbye

Hardcover: 176 pages

Publisher: Collins (Nov. 22 2011)

Language: English

ISBN-10: 1443410888

ISBN-13: 978-1443410885

Product Dimensions: 13.3 x 1.6 x 19 cm

Shipping Weight: 222 g

Average Customer Review: 5.0 out of 5 stars

Anticancer

Paperback: 288 pages

Publisher: Collins (Jan. 4 2009)

Language: English

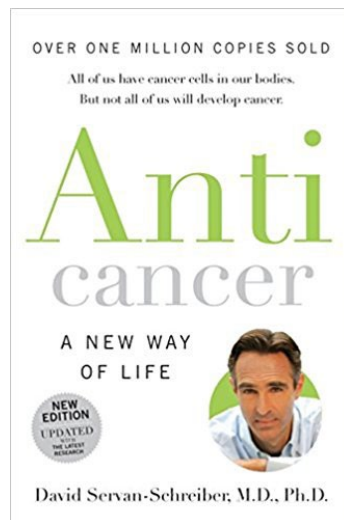
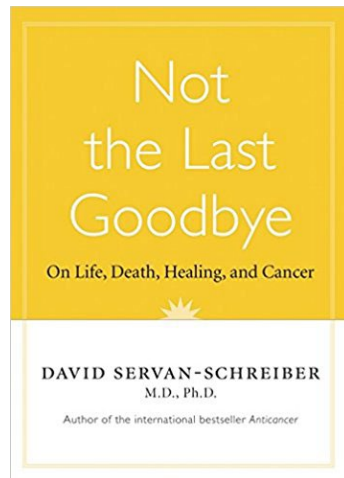
ISBN-10: 1554682223

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Shipping Weight: 386 g

Average Customer Review: 4.8 out of 5 stars



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