

FORWARD

FALL 2015

LIVING YOUR BEST LIFE WITH CANCER AND BEYOND

Caring Connections

Online support groups help cancer survivors

Supporting Healthy Partnerships

Companionship throughout the cancer journey

Childhood Cancers

Long-term followup for adults with late effects

Todd Wong

Cultural activist, dragon boat paddler and accordion enthusiast, this 26-year cancer survivor takes his greatest pleasure in “living out loud”



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If you have a topic that you would like to see covered in a future issue of *Forward*, please let us know by emailing us at forward@bccancer.bc.ca.



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Our Journey Together

The road to success, whether in life or in the pursuit of health and well-being, is never travelled alone. Over the past two years, it has been our privilege at the BC Cancer Agency, through our publication *Forward*, to inform, support, uplift and inspire you on your journey through cancer – from diagnosis and treatment to healthy survivorship and beyond.

In this issue's cover story (page 10), we meet cultural activist, dragon boat paddler and accordionist Todd Wong, a 26-year cancer survivor whose infectious smile and joyful zest for life is an inspiration to us all. Once faced with a life-threatening cancer diagnosis, Todd is living proof that you can survive cancer and live well – both in body and soul.

Doctors have long known that laughter is very good medicine. Sports reporter Steve Ewen shares the story of how he used his own humour-infused blog, *Crush the Tumour with Humour* (page 8), to share his take on the cancer experience with others going through cancer – and to help him heal.

Steve's story reminds us of how important it is to be connected to others, which brings us to our story on how online support groups (page 16) can make the journey easier for people in survivorship. No one understands the cancer experience better than someone who is going through it. Together they are stronger.

Adults who were treated for cancer in childhood are at significant risk for developing late effects. This special group of cancer survivors now has the support of an exciting new initiative – the Adult Childhood Cancer Survivors Program (page 18). This groundbreaking program will help identify at-risk patients as they enter adulthood and provide much-needed support to adults experiencing post-cancer medical problems.

In addition to our features, we examine a new breakthrough in childhood sarcoma research, highlight a helpful resource for cancer survivors who are returning to work, and examine the importance of remaining co-supportive partners through cancer.

We have much to share with you, and hope you enjoy this very special issue of *Forward*.



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Healthy Smile, Healthy Body

Oral health is important for everyone, but it is even more critical for people with cancer

Good oral hygiene, before or even after cancer treatment, can make a huge difference to the quality of your recovery, including how well you are able to eat and speak. By contrast, poor oral health not only has the potential to compromise your health and quality of life, it could also affect your ability to complete a planned cancer treatment.

“The mouth is the most common area of the body for untreated infections,” says Dr. Allan Hovan, provincial professional practice leader (Dentistry, BC Cancer Agency).

“There are so many people out there with untreated gum disease or untreated dental decay,” observes Hovan. “If you’re healthy, your body can often take care of these chronic infections – at least until it gets really bad. However, the rules can change when you start immunosuppressive chemotherapy.”

The issues don’t just affect patients with head and neck cancers, where treatments often take place inside the mouth. Radiotherapy or chemotherapy aimed at cancers in other parts of the body can also compromise the immune system. For example, chemotherapy for breast cancer can lower a patient’s white blood cell count, which in turn reduces their immunity to infection for a period of time after the treatment.

“With chemotherapy, the natural defence system in your body can be altered,” says Hovan.

If an oral health problem flares up while a patient is undergoing chemotherapy,

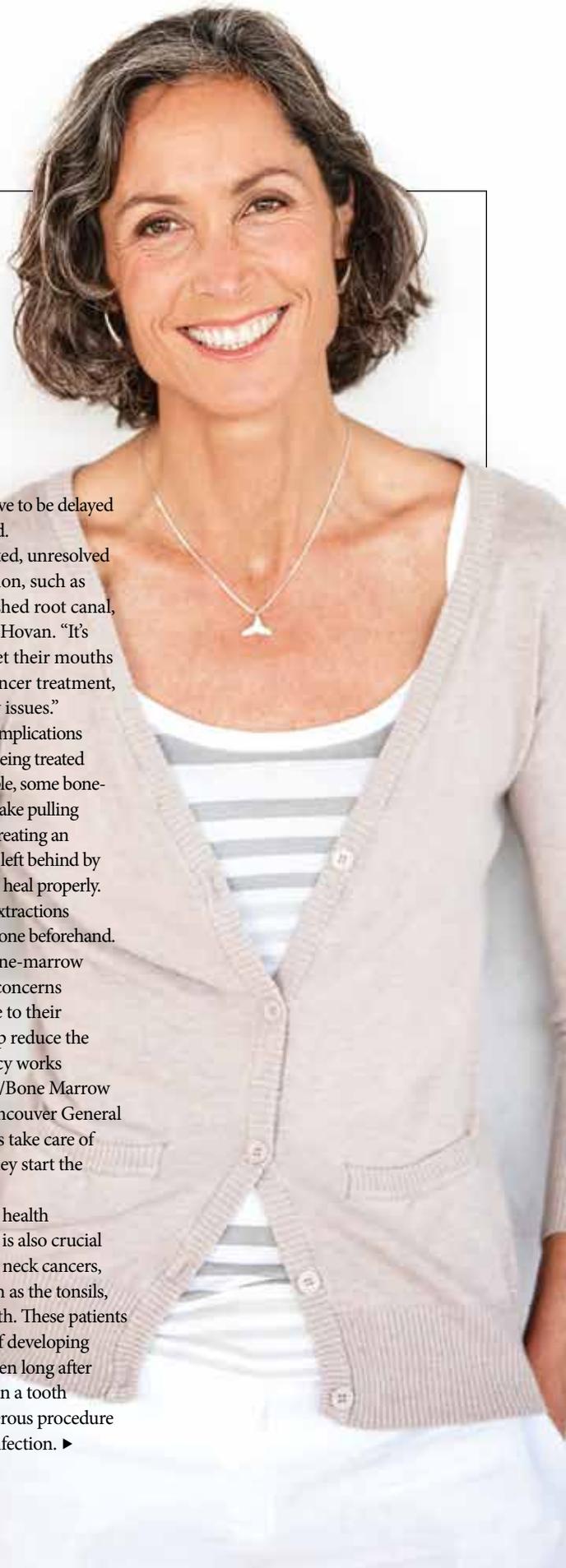
cancer treatment might have to be delayed until the infection is treated.

“If you have an untreated, unresolved pre-existing dental infection, such as gum disease or an unfinished root canal, it can be a problem,” says Hovan. “It’s important that patients get their mouths in good shape before a cancer treatment, so they don’t run into any issues.”

Hovan says that oral complications can also occur in patients being treated for bone cancer. For example, some bone-strengthening drugs can make pulling a tooth very problematic, creating an increased risk that the hole left behind by the extracted tooth will not heal properly. Patients who need dental extractions should always have them done beforehand.

Patients receiving a bone-marrow transplant have the same concerns around oral infections due to their lowered immunity. To help reduce the risk, the BC Cancer Agency works closely with the Leukemia/Bone Marrow Transplant program at Vancouver General Hospital to ensure patients take care of any dental issues before they start the transplant process.

Maintaining good oral health before and after treatment is also crucial for patients with head and neck cancers, which can affect areas such as the tonsils, throat and inside the mouth. These patients are also at increased risk of developing cavities or gum disease, even long after treatment is complete. Even a tooth extraction is a more dangerous procedure due to the higher risk of infection. ▶





continued from page 5

Dental care after cancer

Doctors and dental professionals are well-equipped to guide patients in how to maintain good oral health over the long-term once their cancer treatment has finished. Doctors and dental professionals can also help patients address common side-effects of cancer

treatment, like xerostomia (dry mouth) and oral mucositis (mouth sores).

The BC Cancer Agency works with community dentists to improve their understanding of how to best treat cancer survivors. That includes how past cancer treatments may affect a patient's oral health and future dental treatments.

The BC Cancer Agency hosts numerous information workshops at dental schools, dental and medical conferences, and in the local community. Oncologists also work with dentists on recommended long-term care for individual patients.

Long-term impacts

Sometimes patients who have had oral cancer believe there are no permanent changes in their mouth. However, this is not the case.

“Even though the tissue in the mouth might look normal, it's forever changed once a person has had something like radiotherapy in the head and neck,” says Hovan.

The BC Cancer Agency recommends that

dentists treat these patients with extra care even when doing a standard cleaning, since the tissue is more fragile.

Hovan recommends that everyone – whether or not they have been diagnosed with cancer – receive regular dental checkups. This is important, not only to keep up your oral health, but also so dentists can detect oral cancer at an early stage, which increases the chances of successful treatment and survival.

The BC Cancer Agency pioneered two early detection tools that are now used by dental and oncology professionals worldwide. The first is the toluidine blue stain used on patients to identify high-risk oral lesions. The second is the VELscope fluorescence technology, where a special blue light is used to scan the mouth and identify abnormal tissues.

“At the end of the day, nothing replaces a good old-fashioned dental checkup,” says Hovan. “Doctors and dentists can only do an early diagnosis if they're allowed to have a look.” ■

Healthy Smile Habits

If you remember nothing else about comedian Mike Meyers' endearing 1960s secret agent Austin Powers, you almost certainly remember his teeth. Crooked, crowded and impossibly stained, it was obvious Austin's teeth rarely saw a toothbrush, let alone dental floss. Austin became the poster boy for bad oral hygiene, casting the spotlight on the importance of a healthy smile. Here are our TOP 5 TIPS for supporting healthy teeth and gums.

- 1** Brush your teeth and tongue at least twice a day using a soft-bristle toothbrush and non-abrasive fluoride toothpaste. Also, change your toothbrush every two months.
- 2** Consider using an electric toothbrush. The advantage here is that the head is constantly moving, and many feature a timer that ensures you brush for at least two minutes.
- 3** Floss your teeth twice daily. If you can't floss, use a floss pick or rinse your mouth with an alcohol-free mouthwash that contains an antimicrobial agent, such as chlorhexidine. Chewing sugar-free gum containing xylitol can be your default to help keep your mouth clean. Sugarless gum stimulates the production of saliva – nature's way of washing away acids in the mouth.
- 4** Avoid sugary and highly acidic foods (see opposite page). Sugar feeds the bacteria in your mouth, causing them to produce acid. This acid erodes tooth enamel.
- 5** Wait at least 30 minutes before brushing your teeth after consuming acidic foods and beverages. Brushing too soon can erode tooth enamel, while waiting 30 minutes allows saliva to neutralize the acid. ■





Bad for Your Teeth

Here are **SEVEN COMMON FOODS** that are known to cause problems. While you don't need to eliminate them from your diet completely, try to limit their consumption, and be sure to rinse or brush at least 30 minutes after you eat.

- 1** Citrus fruits (e.g., grapefruit, lemon juice, pineapple) are highly acidic and can erode tooth enamel over time.
- 2** Sticky, chewy candies, (e.g., toffee, sour candies) are loaded with sugar that sticks firmly to the teeth. They can also pull out your fillings.
- 3** Hard candies not only fill the mouth with acid-promoting sugar, biting down on them can fracture teeth.
- 4** Pickled foods (which contain vinegar) can erode tooth enamel.
- 5** Carbonated soft drinks (e.g., cola) and sports drinks are highly acidic and can erode tooth enamel.
- 6** Coffee tends to stain the teeth quite easily.

7 Red wine and black tea both contain high concentrations of tannins, which can stain the teeth.

To help promote good oral health

drink lots of water, as it helps wash harmful sugars and acids off your teeth. Also, eat lots of dairy products, as they are an excellent source of calcium – one of the key building blocks for strengthening teeth and bones.

High-fibre foods, like leafy green vegetables, are another great choice for promoting oral health. These foods (e.g., a fresh kale or spinach salad) require lots of chewing, which stimulates saliva production and helps scrub the teeth.

FALL RECIPE

Warm Maple Cinnamon Butternut Squash and Arugula Salad

This quick and healthy recipe incorporates the best of fall's fresh vegetables. Butternut squash is rich in carotenoids, which are potent antioxidants, while arugula is part of the cancer-fighting cruciferous vegetable family, packed with glucosinolates, which seem to lower inflammation.

INGREDIENTS

- 1 -1.5 lbs./400 g package frozen cubed butternut squash, or small fresh butternut squash
- 1 Tbsp. olive oil (plus 2 tsp. set aside to drizzle on the salad)
- 1 Tbsp. maple syrup
- 1/2 tsp. cinnamon
- 1/8-1/4 tsp. cayenne (optional)
- 1/8 tsp. kosher or sea salt
- 1/8 tsp. pepper
- 4 cups arugula, washed
- 1/4 cup dried cranberries

DIRECTIONS

Preheat oven to 425°F.

Place cubed butternut squash on a foil-lined baking sheet. In a small bowl, mix together the olive oil, maple syrup, cinnamon, cayenne, salt and pepper. Drizzle over butternut squash and toss to coat evenly.

Cook butternut squash for 20 to 30 minutes until you see the edges browning, turning once halfway (the larger the cubes, the longer they take).

Pile arugula on a large platter. Top with warm butternut squash, dried cranberries and a drizzle of olive oil.

Add fresh ground pepper and a pinch of sea salt or kosher salt, if desired. Serve.

Recipe courtesy of the BC Cancer Agency

“You really need to focus on what’s directly ahead of you, and find the humour in the moment. That’s paramount.”

—Steve Ewen



Healing With Humour

Sports reporter Steve Ewen turned to laughter to help him cope and recover during treatment for a rare cancer

Sometimes you have to laugh to keep from crying. That was certainly the case for Steve Ewen. Ewen freely admits he cried several times a day for six months during his cancer treatment and rehabilitation, but he also credits humour with helping him to not only survive, but thrive.

Ewen shared his trials, and his humour, through a blog called *Crush the Tumour with Humour* (www.crushthetumourwithhumour.blogspot.com), posting his first missive less than two weeks after being diagnosed with a rare solitary plasmacytoma in his T-2 vertebrae. “Part of the reason that we’re moving forward right now is that we are belly-laughing as much as sobbing, if not more,” he wrote in his first entry.

At that point in his treatment Ewen had no idea that he would go on to face 20 radiation treatments, eight surgeries (including two to rebuild his back with titanium rods and screws, and four to deal with three serious infections), and months of rehabilitation to relearn how to walk.

As a sports reporter, Ewen was accustomed to writing, but says, “This was easily the most ‘I’-centric thing I’d ever done – the closest to home.” But he saw a need for it.

“There’s such a fear, such trepidation and lack of understanding of cancer out there. This was a chance for me to give some people some knowledge, so they would know more if this happened to them or someone close to them. I didn’t understand cancer, or what radiation was.

“That was hugely important to me – to give back. I just wanted to talk about it, to hear from other people.”

Ewen has mentioned more than once in the five years of blogging, “To steal a premise

from my buddy Bob Mercer, ‘Cancer is one of the scariest things in the world, but it might be THE scariest word in the world.’”

While Ewen’s reliance on his dry, self-deprecating humour was instinctive, the medical community has long understood that humour has healing qualities. As early as the 14th century, French surgeon Henri de Mondeville used humour therapy to aid patients in their recovery from surgery.

Current literature asserts that laughter reduces pain, strengthens the body’s immune function and decreases stress. There’s even a name – gelotology – for the study of laughter and its effects on the body.

According to Dr. Hunter Doherty “Patch” Adams, perhaps the most famous proponent of laughter’s healing properties, “Humour is an antidote to all ills.” In the book *Gesundheit! Good Health is a Laughing Matter*, which he co-authored with Maureen Mylander, Adams describes his thinking as “the philosophy that art, fun and connectedness are as important to health as CAT scans and IVs.”

But Ewen just knew instinctively that finding the humour in his situation helped him – and those around him – deal with it. He was, and remains, inspired by the number of people who stepped up to help him and his wife, Carol-Ann. When he once commented on how many people had come to visit, a friend responded, “Dude, your funeral’s gonna be packed!”

Another friend told him early in his journey, “You can’t future surf, because you don’t know what’s going to happen.”

“You really need to focus on what’s directly ahead of you, and find the humour in the moment. That’s paramount,” Ewen

says. He recalls a point in his journey when he and Carol-Ann only allowed themselves to think in four-hour intervals, “but we would try to have the best four hours we could have.”

They still laugh about many things that happened – simple events like having trouble getting his wheelchair into places, or the fear that he would fall into the toilet from the chair.

They also celebrated small victories: the first time he could stand on one foot for 10 seconds or put his socks on by himself.

Ewen’s commitment to giving back continues. He trained with a former rehab therapist-turned-trainer so he could ride in this year’s Ride to Conquer Cancer, an annual two-day, 200-kilometre bicycle ride to benefit the BC Cancer Foundation.

Earlier this summer, he wrote, “I had lost so much balance from the operations and the hospital stay that my wife, Carol-Ann, and I weren’t even sure if I could ride a bike at all when we bought one in preparation to take part in last year’s event.

“‘We could sell it,’ I thought. ‘It would have to go at a severely reduced price from all the scratches that I’m bound to get from crashing,’ I rationalized, but we could sell this.”

Self-described as “ridiculously stubborn,” Ewen rode for 150 km in last year’s ride.

After four years of being cancer-free, Ewen still has some after-effects, such as not being able to tilt his head up, but he also still has his sense of humour.

When he missed catching a pop fly in a recent slo-pitch game, the pitcher asked him, “Did the sun get in your eyes?” To which Ewen replied, “No, cancer did.” ■



Cultural activist, passionate volunteer, dragon boat paddler and accordionist, this 26-year cancer survivor takes his greatest pleasure in “living out loud”



W Todd Wong

On a rainy Saturday evening in January, in Vancouver's Chinatown, one might catch a glimpse of a character known in some circles as Toddish McWong. He'd be dressed in a kilt, and might be chatting with Mayor Gregor Robertson before preparing to carry a haggis into a roomful of hungry guests ready to celebrate the city's cultural diversity. Usually held sometime around Robbie Burns Day and the Chinese Lunar New Year, Gung Haggis Fat Choy is an event founded by Todd Wong, a fifth-generation Chinese Canadian who is also involved in many other cultural projects in the city. Many don't realize that Todd is also a cancer survivor.

The passage of 26 years has not dulled Todd's memory of the spring of 1989, when back pain and difficulty breathing eventually led to the discovery of a grapefruit-sized tumour in his chest. As he reflects on that time, he nods toward his mother Betty, now 83, as he recalls missing first Mother's Day, and then being very sick on Father's Day, that fateful spring.

Traditional and complementary medicine: then and now

Having grown up with family-practised Traditional Chinese Medicine, and after months of not feeling well, Todd had seen an energy healer who observed a "blockage in his heart." With a relationship in a rocky state, Todd was told he was "not letting enough love in." While that may have also been the case, the blockage turned out to be a malignant germ cell tumour so intrusive that it was displacing his vital organs by pushing on his vena cava, restricting the flow of blood returning to his heart.

On June 21, 1989, "the longest day of the year became my longest night," recalls Todd of the day he was admitted to emergency, and his parents and girlfriend were called to the hospital in shock.

His mother was told chemotherapy would give him a 60-per-cent chance to live; without treatment he could expect to live only two weeks. Todd began a course of chemotherapy that would last

five months and leave him with a temporary condition known as "flat affect," a severe reduction in emotional expressiveness, as well as other long-term side-effects. But the treatment also saved his life. After months of a regular routine of eating, sleeping, visualizations and affirmations for health, folding origami, and playing his accordion, Todd, like many, found a new gratitude.

Looking back almost three decades, he still remembers aspects of his experience that shaped his life choices. Todd had grown up with cultural traditions that included herbal remedies and visits to Chinatown for various treatments, so the family assumed that his mother, a therapeutic touch practitioner and later Reiki master, would contribute to his healing through hands-on touch sessions. But, health-care practices were different in those days and alternative therapies less accepted. Still, Todd's mother found a way to sneak in therapeutic touch treatments, which Todd credits with playing a role in his recovery. He also acknowledges that attitudes have since changed: "Health-care professionals are now so much more open to culturally diverse practices and traditions."

Calling in the coach

Only a few months after his treatment ended, Todd was back at Simon Fraser University ("probably too soon," he admits), but with a new focus for his learning.

"I devoted my studies to anything to do with health," he recalls. From health psychology to a course in Illness and Culture, Todd was interested in the social support systems in place for patients and survivors.

"In Canada, the only time the word 'coach' is used in health-care scenarios is primarily in terms of a birth coach," observes Todd. "Why don't we coach people through other health experiences?"



Todd Wong (left and below left), a devotee of the accordion since age 11, has devoted his life to community service, building bridges and promoting cross-cultural understanding.

Todd still paddles today; one of many self-fulfilling activities around which he has built a life as a cultural activist and volunteer, and that have earned him acknowledgement as “one of the 150 most fascinating people in British Columbia” by visitors to the Royal British Columbia Museum in 2008, celebrating the 150th anniversary of the province.

Outside his job at the Hastings Branch of Vancouver Public Library, Todd, now 55, keeps busy with Gung Haggis Fat Choy event planning, and many other literary and community events and organizations, as well as a spin-off CBC-TV documentary on the Gung Haggis Fat Choy event. In the years since he survived cancer, Todd has chaired the campaign to help save author Joy Kogawa’s historic childhood home in Vancouver, and has served for many years as a board and committee member for the Asian Canadian Writers Workshop, The Land Conservancy of BC and the Alcan Dragon Boat Festival Race Committee. He also helped start up the Vancouver Taiwanese Dragon Boat Race in 2003.

A disciple of the accordion since age 11, Todd also plays with the Vancouver Squeezebox Circle, and has a particular passion for Celtic céilidh music (and its accompanying taste for Scotch whisky).

He has been recognized for his community and cultural contributions with the Terry Fox Gold Medal, and the BC Community Achievement Award for his “devotion to community service, building bridges and cross-cultural understanding.”



“I’m still standing”

Asked if, almost 30 years later, he still identifies as a cancer survivor, Todd is quick to say yes. He is brimming with conviction when he says, “We can create the kind of world we want to be in. As cancer survivors, we know how precious our time and energy is.”

Todd says he feels a kinship with fellow survivors, and over the years, he has channeled that into volunteer work with teens for cancer, as well as ongoing work with the Terry Fox runs.

“When I first started speaking at runs in 1993, I would ask how many people in the crowd knew someone with cancer. Back then, maybe a third would put their hands up. Now, they all put their hands up.

“It’s important to show that there are survivors,” says Todd, crediting research and the work of societies and support groups with giving patients more hope now than ever before. “When I was diagnosed in ’89, it was still ‘the C-word’ and my mother didn’t tell anyone at work.”

As a veteran cancer survivor, Todd has a valuable message for those who are on the same journey.

“When we stand up for whatever we believe in – whether it’s promoting racial and cultural harmony with an event like Gung Haggis Fat Choy, or as a cancer survivor, or even as an underappreciated accordion player, it’s all important,” he says, with the quiet promise of a smile. “Things are going to be better than you ever imagined.” ■

In the meantime, guided by the post-cancer philosophy that “you can’t live your life waiting for things to happen,” Todd married and divorced over the space of five years. To combat growing bouts of post-trauma depression, and seeking the rebalancing power of endorphins, he took up running, which led to his first Terry Fox Run, an activity that evolved into dragon boat paddling.

Hope floats

It would be another five years before dragon boat paddling for cancer survivors would be made popular by UBC sports medicine specialist Don McKenzie, whose Abreast in a Boat initiative proved what Todd also knew.

“They discovered the power of the social support groups these experiences provide,” Todd says, along with the many valuable connections between health and sports psychology, such as visualization, self-talk and positive affirmations.

Sarcoma Research Breakthroughs

Research by Dr. Poul Sorensen and his team at the BC Cancer Agency has led to a major breakthrough in high-risk childhood sarcomas. These diseases have seen little or no improvements in outcome in the last 20 years, and Sorensen's research provides much-needed hope for new treatments.

Sarcomas are malignant (cancerous) tumours of the connective tissues, including bones and muscles. They are more common in children and can be extremely difficult to treat because they have a high tendency to metastasize, or spread. Up until now, very little has been known about the mechanism behind the spread of sarcoma cells to other organs.

Comparing tumour types

Building on previous research studying a protein called YB1 and its capacity to make breast cancer cells (which are of epithelial origin; i.e., cells that make up organs) more like connective tissue cells and increase breast cancer metastasis, the team began to ask questions about the relationship YB1 has with sarcoma cells (which are of mesenchymal origin; i.e., cells that form connective tissues). Sorensen, a distinguished scientist at the BC Cancer Agency and Johal Chair in Childhood Cancer Research at the University of British Columbia (UBC) says, "I like to study scenarios where what we learn from one tumour type can apply to others. We knew that YB1 made epithelial breast cells more like mesenchymal cells, so our original question for this study was 'What might YB1 be doing in tumour cells that are already mesenchymal, such as sarcoma cells?'"

By conducting tissue experiments and studies with mice and zebra fish,

the research team, with key experiments performed in the laboratory by Dr. Amal El-Naggar, was able to determine what happens in the pathway between YB1 and HIF1 α – a key protein in how tumour cells survive under low oxygen levels and become more metastatic. They found that YB1 acts as a stimulant for HIF1 α , making sarcoma cells stronger and more invasive. By blocking the ability of YB1 to induce HIF1 α , tumours are less able to spread and are more receptive to drug therapy.

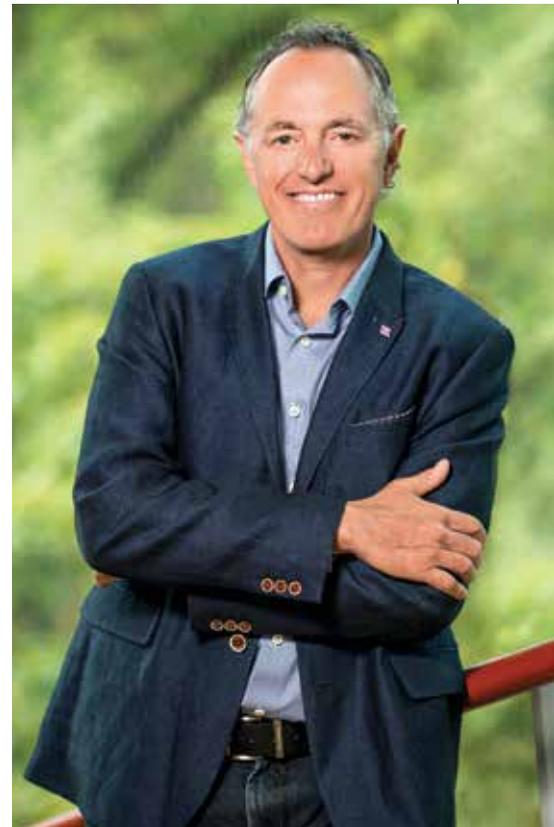
"It is a very good feeling to know that what we figured out is really important," says Sorensen. "The good news, as well, is that our next steps with the research include determining what drug therapies that already exist might work given our findings.

"We're exploring this re-purposing strategy right now, and it means there would be a much shorter time frame bringing them to patients than if a whole new drug therapy had to be created."

Support for the study

Sorensen is grateful for the community support that enabled this study to take place: "There was some funding through grants, but the vast majority of it was local. Much of it came through the BC Cancer Foundation's Ride to Conquer Cancer and Team Finn (Team Finn was started by the Sullivan family and friends of Finn Sullivan, a young boy who died of rhabdomyosarcoma, a particularly aggressive type of sarcoma primarily seen in children).

"We are also fortunate to have a very good Molecular Oncology department here, and due to the foresight of UBC and the BC Cancer Agency, clinician scientists are able to focus on their



Dr. Poul Sorensen, distinguished scientist at the BC Cancer Agency and Johal Chair in Childhood Cancer Research at UBC.

research work without being pulled in a number of directions, and that makes a difference," adds Sorensen.

Even though this study was focused on a childhood cancer, Sorensen says it has wide-ranging applications: "Metastatic spread is the single biggest determinant of outcome in most cancers. This is a biology study at its core – how tumour cells spread. What we have learned is really important, because the findings can be applied broadly across different types of cancer, including epithelial malignancies such as breast cancer." ■

Supporting Healthy Partnerships

It's important for couples facing cancer to remain co-supportive partners throughout the cancer journey

Our personal partnerships often reach into every aspect of our lives: at home, at work, with family and friends and, of course, in the bedroom. But when one partner is diagnosed with cancer, things shift. Immediately one partner becomes a patient, while the other takes on the new and unanticipated role of caregiver.

Cancer diagnoses and treatments present enormous challenges for any couple. While human instinct prompts a primal desire to take care of those we love, falling into the caregiver role can seriously strain an intimate relationship says Richard Wassersug, PhD and adjunct professor, UBC Department of Urologic Sciences.

This can happen whether the partner provides physical care or just psychological support. The effects on a couple's relationship from a cancer diagnosis can be devastating for both partners. The imbalance in the relationship brought on by the shift in roles can erode the partnership. This happens too often says Wassersug, when all the attention is on the needs of the patient, and either the patient or the partner is unaware (or unaccepting) of the load on the partner.

"In the cancer world, we often use the words 'patient' and 'caregiver' as if we are somehow honouring the caregiver by acknowledging the good thing the partner is doing for the patient," says Wassersug. "Unfortunately, when we accept those labels, you have implicitly redefined



a co-supportive couple into a dynamic where one partner (the 'caregiver') now carries the burden of having to not only care for themselves, but also the patient. That is stressful, and often very difficult."

Wassersug believes that we need to do more to recognize that cancer burdens both partners in an intimate relationship, even though only one partner has the cancer. Also, men and women react differently to that burden.

"In male/female relationships, talking about problems often helps women feel less isolated," says Wassersug. "Men need to understand that. At the same time, women need to understand that what's best for some men, when faced with new challenges, is not to talk too much about them. In the cancer world both patients

and caregivers need support, but the support they need can differ.

"We must strive to keep patients and partners in a co-supportive relationship. But that requires understanding each partner's needs. And we need to be careful about the labels we use. Overuse of the word 'caregiver' can take away from keeping the partners in true partnerships. It's not just the person who has had cancer who needs care. It is the partner too."

Wassersug encourages partners to reach out to the counselling services offered by the BC Cancer Agency. ■

BC Cancer Agency Patient and Family Counselling: <http://www.bccancer.bc.ca/our-services/services/patient-family-counselling>

Helping with Returning to Work After Cancer

Maureen Parkinson,
vocational and
rehabilitation
counsellor at the
BC Cancer Agency,
answers questions
about the Return to
Work program.

Returning to work after cancer can be a challenging transition for survivors, as well as their health-care providers and employers. To help them, in 2012, the BC Cancer Agency published the first edition of *Cancer and Returning to Work: A Practical Guide for Cancer Patients*. Maureen Parkinson talked about the newly launched second edition of the handbook.

Q: How did the second edition of the handbook come about?

A: We sought feedback on the first edition from almost 60 patients, health-care providers, human resources specialists and employer representatives from different backgrounds and a variety of occupations and industries. We were happy to see that the handbook was well received and reflects what we heard from survivors.

Q: What other resources are available for survivors returning to work?

A: The Vocational Rehabilitation program is available to patients across BC, either in person or by phone. The handbook can be used as a companion to the Return to Work group, and it's also used as a stand-alone resource. We also have a variety of online resources. In January, we will offer a return to work session via video link to Kelowna. The *Cancer and Returning to Work* handbook is about returning to the previous job, but we also realize some people don't have that option. To help them, we're creating a job search group and developing online information and tools, such as resumé writing.

Q: What is one of the most helpful tools for patients considering returning to their former workplace?

A: Our job analysis tool. It allows patients to gauge the physical, cognitive and emotional requirements of their job, and informs the dialogue with the physician to assess job readiness.

Q: What is your key advice to patients about returning to work?

A: It's important to plan early. Often patients don't realize there are things they can do to anticipate challenges, and get ready physically and emotionally. We encourage patients to take control of the process early, to educate themselves and problem-solve around the obstacles. They will be better prepared when they do return to work.

Resources: The *Cancer and Returning to Work* handbook is available on the BC Cancer Agency website at <http://www.bccancer.bc.ca/health-info/coping-with-cancer/practical-support/work-school> or for sale at the C&W Bookstore. ■

Visit the Cancer & Work website at
<http://apps.desouzainstitute.com/cancerandwork>





Caring Connections

How online support groups can make
survivorship easier



“Friends would ask me, ‘when are you going to be normal? When are you going to be able to go on hikes and dance like we used to?’”

Devon Jones, a 35-year-old massage therapist from Victoria, reflects on the questions she was asked after she finished an 18-month treatment for leukemia; treatment that not only involved heavy chemotherapy, radiation and stem cell replacement, but also uprooted Jones and her husband from their Pender Island home so she could be treated in Vancouver.

“Your friends and family don’t always remember or understand that even though you have finished the treatment, your body is still recovering,” says Jones. “And that can take quite some time.”

Jones’s experience is common, according to Heather Rennie, clinical co-ordinator, Provincial Psychosocial Oncology Program, BC Cancer Agency.

“At some point, your natural support network just may not want to hear about [your cancer] anymore,” says Rennie. “Since you are done with treatment, they are ready to move on.”

“When patients reach the end of treatment, there is this expectation they are going to move rather quickly into post-cancer life and back to some sort of new normal.”

—Heather Rennie, clinical co-ordinator, Provincial Psychosocial Oncology Program, BC Cancer Agency

“When patients reach the end of treatment, there is this expectation they are going to move rather quickly into post-cancer life and back to some sort of new normal,” she explains. “Often people who have not gone through the experience don’t understand how challenging this transition is.”

Moreover, says Rennie, survivors themselves often underestimate the lingering effects of treatment: “It is one of the top two or three things I hear from people going into post-treatment: just how difficult the transition from treatment to survivorship is, that it’s not a matter of easily slipping back into a pre-cancer life, and perhaps even impossible to ever go back to a pre-cancer life.”

Cancer survivors know better than anyone what cancer survivors are experiencing. This is why many turn to both in-person and online support groups, where they can discuss the challenges of survivorship with others who have had similar experiences.

Devon Jones is one of these people, and she found the virtual CancerChatCanada support groups (operated by the BC Cancer Agency, where Heather Rennie is program lead) enormously helpful.

“During treatment in Vancouver, I had a support group of fellow patients,” says Jones. “But now we are far away from each other, and I don’t get to talk to them very often, and there aren’t a lot of support groups for leukemia survivors around Victoria.

“But on CancerChat, I found a support group consisting of ladies across Canada who were all facing the same issues in transitioning to post-cancer life.”

CancerChatCanada’s support groups are private and structured. Each group is modelled around a topic that is discussed over a 10-week period, with a weekly online text chat of 90 minutes between participants.

Between chats, CancerChatCanada sends reading material and links, so that participants have a starting point for each week. At the end of the 10 weeks, participants can either roll into a new online support group, or form their own using email or private Facebook groups.

“The goal of our group was coping with survivorship,” says Jones. “About finding the new normal. About being okay with not being able to always do all the things you want to do, and sharing the frustration that so many of us feel about not being able to go back to the way our lives were before we had cancer.”

Jones says that while one advantage of her online support group was finding other survivors who had gone through the same treatment, another was being able to communicate from the safety of home: “You don’t have to go anywhere. You don’t even have to get out of bed if you can’t that day. Yet you feel you still have people there for you. It can be hard to share emotion online, but you can feel free to be as emotional as you need to be in your own place and still express what you need to other people.”

Jones found the chat room concept let her develop her thoughts more fully than would be possible in a face-to-face setting: “Sometimes, in person, it can be hard to express what you are really feeling because it all comes out in an emotional blur.”

Rennie notes that online support groups can also ease the strain that cancer treatment and post-treatment can put on couples. She notes that during treatment and during the lingering side-effects after treatment, a spouse or partner takes on greater household and family responsibilities, and may even take on an extra job. By seeking a support group, the survivor does not have to rely on their partner as their only source of emotional support. ■

Learn more about online support groups at:

BC Cancer Agency
<http://www.bccancer.bc.ca/>

CancerChatCanada
<https://cancerchatcanada.ca/>

CancerConnection.ca
<http://cancerconnection.ca/home>

Continuity of Cancer Care

The Adult Childhood Cancer Survivors Program provides ongoing support to adults dealing with late effects from cancer treatment received in childhood

Days after she celebrated her 13th birthday, Ashley Turner was diagnosed with a rare form of kidney cancer known as Wilms' tumour. This cancer most often manifests in very young children, so Turner's rare case prompted doctors at BC Children's Hospital to monitor her closely, not only during her treatment – which included radiation and chemotherapy – but also through her regular followup checkups to age 21.

"I had such an amazing medical team," says Turner, now 29, as she reflects on her experience as a survivor of childhood cancer. "Everyone who has to go through something like this should have my experience."

As an adult, Turner continues to monitor her health for so-called "late effects" of the cancer treatment she received growing up. For Turner, these late effects include cardiomyopathy (a weakened heart muscle) that she says is the result of the cancer-fighting drugs she received as a teen.

She is one of about 3,400 adult survivors of childhood cancer in BC who will now receive ongoing support for their existing and potential post-cancer medical conditions through the Adult Childhood Cancer Survivors Program. Childhood cancer survivors are being encouraged to learn more about the new provincial program, and how they can stay on top of their health and potential late effects. (For adult survivorship information, please email survivorship@bccancer.bc.ca.)



Karen Goddard, director of Pediatric Radiation Oncology at the BC Cancer Agency and medical lead for the new program.

Many adult survivors of childhood cancer don't realize that their risk of developing late effects increases, not decreases, over time and that the health problems that sometimes emerge decades later are a direct result of the treatment they received to cure their cancer in childhood.

Children treated with radiation therapy and intensive chemotherapy have an 80-per-cent chance of developing significant health concerns by the time they turn 40. That's largely because they were treated at a time when their bodies and organs were still developing.

"Adult childhood cancer survivors have very unique needs that are different from other cancer survivors," says

Each year, about 120 new adult survivors of childhood cancer transition from pediatric to adult care in BC. The program builds on the existing expertise and resources of BC Children's Hospital, the BC Cancer Agency and primary care providers, and includes:

- Improved services for cancer survivors moving from pediatric to adult care to ensure a seamless transition for lifelong followup care;
- A registry to track patients based on their levels of risk associated with past treatments, the patient's age and their diagnosis to ensure they receive appropriate long-term support;
- Recall of past patients who were treated when there was limited information about the effects of treatment during childhood so they can receive followup care over their lifetime as needed;
- Research and evaluation to ensure the program is meeting the needs of survivors and their families;
- A designated clinic to support and care for high-risk and complex cases;
- And consultation and advisory to primary care providers who are caring for adult survivors.



“Childhood cancer survivors are more at-risk for developing other health issues, such as heart disease and damage to the central nervous system, as well as anxiety and depression.”

— Karen Goddard

Karen Blain, provincial director of the Survivorship and Primary Care Program at the BC Cancer Agency and administrative leader for the Adult Childhood Cancer Survivors Program.

Childhood cancer survivors are more at-risk for developing other health issues, such as heart disease and damage to the central nervous system, as well as anxiety and depression, says Karen Goddard, director of Pediatric Radiation Oncology at the BC Cancer Agency and medical lead for the new program.

“It’s important to follow up with those children when they become adults and see how they’re doing,” says Goddard, who adds that current and past patients need to be assessed for their level of risk and receive ongoing followup care from the appropriate medical professionals.

The program was developed by a working group of local experts from across BC, which included patients and families

from the Pediatric Cancers Survivorship Society of BC (PCSSBC). Financial support for the program is coming from the Ministry of Health, Provincial Health Services Authority, BC Children’s Hospital, BC Children’s Hospital Foundation, the BC Cancer Agency and BC Cancer Foundation.

PCSSBC president and co-founder Carolyn Vacheresse is pleased the program is being implemented. Her daughter Danielle, 21, is transitioning out of BC Children’s Hospital after years of complex care. Danielle received heavy doses of radiation and chemotherapy as a child to stem the growth of a brain tumour. It was after speaking with other parents of children with cancer that Vacheresse began to hear and understand more about late effects of cancer, including those experienced by her daughter.

“My vision is to establish programs and support networks to assist all adult childhood

cancer survivors, inclusive of family members who have been touched by childhood cancer, in addressing the long-term needs of this unique population, who only now are being recognized as suffering from late effects 20 and 30 years later as a result of their original treatment,” says Vacheresse, whose organization was instrumental in raising awareness of these issues.

She also wanted to ensure childhood cancer survivors don’t fall through the cracks once they transition to the adult health-care system.

“The program, through its education programs, will assist general practitioners, specialists, patients and families in understanding and co-ordinating care for childhood cancer survivors,” she says. “It will include a research component in documenting late effects outcomes (quality of life), including analytical data for improvement of sustainable care necessary for this unique population.” ■

A portrait of Dr. Stuart Peacock, a middle-aged man with short brown hair, smiling warmly. He is wearing a dark blue blazer over a light blue collared shirt. The background is a blurred outdoor setting with stone steps.

Dr. Stuart Peacock, newly appointed
Chair of the Leslie Diamond Chair in
Cancer Survivorship.

The Leslie Diamond Chair in Cancer Survivorship

A new Chair, made possible thanks to a \$3.5-million
commitment from the BC Cancer Foundation, is set
to expand cancer survivorship research in BC.

BC has a growing new community of over 185,000 people. However, it's not your typical community defined by a geographic location. This is a group bound by a common experience of being diagnosed with cancer, and, most importantly, surviving.

With advancements in early detection, diagnostics and treatments, the number of cancer survivors in British Columbia is expected to grow exponentially in the coming years. This year alone, it's expected that 25,400 people will be diagnosed with cancer and many, like Sarah Simpson, will have years – if not decades – to look forward to.

Sarah was diagnosed with a rare abdominal cancer called pseudomyxoma peritonei more than nine years ago. She underwent a special procedure, followed by HIPEC- hyperthermic intraperitoneal chemotherapy (where the organs are essentially bathed in a chemo solution). She also underwent numerous surgeries. Most importantly, Sarah is part of the growing cohort of cancer survivors – a population that has opened up a critical new area of research in survivorship.

Chair Set to Make a Difference

The BC Cancer Foundation is committed to supporting research with the most promise to positively impact cancer patients in BC. The new Leslie Diamond Chair in Cancer Survivorship at Simon Fraser University (SFU) was made possible thanks to a \$3.5-million commitment from the BC Cancer Foundation, including Gordon Diamond's incredible \$1-million gift, honouring his wife Leslie's nearly 30 years of cancer survivorship.

Dr. Stuart Peacock was recently appointed Chair of the program, taking the lead in co-ordinating life-enhancing research efforts across BC. Under his leadership, research efforts will aim to improve survivorship, meaning healthier futures ahead for British Columbians facing a cancer diagnosis.

For Sarah, a decade in survivorship has included four recurrences and consequential cancer treatments. However, cancer hasn't

slowed her down. She's kept her marketing career on track and taken on exciting physical challenges, like hiking Mount Kilimanjaro and racing in a half-marathon and triathlon: "You can live with cancer," she says. "And I can have the same life, if not a better life."

While every cancer experience is unique, the reality is that after undergoing chemotherapy many people will face new health challenges, including heart disease, psychosocial and fertility issues, and the gnawing fear of cancer recurrence.



**This year alone,
it's expected that 25,400
people will be diagnosed
with cancer and many, like
Sarah Simpson (above),
will have years –
if not decades – to look
forward to.**

Sarah hasn't escaped challenges along the way. However, she's taken a proactive approach to her own well-being, and accessed specialists in nutrition and hormonal balance to counteract side-effects from her treatment.

With Peacock taking the helm of survivorship research in BC, the landscape will start to shift for those impacted by cancer in the near future.

"I am excited and humbled to have the opportunity to lead the new cancer survivorship research to foster innovative, world-class research to improve the well-being of cancer survivors and their families," says Peacock.

His primary goal is to lead multi-disciplinary research that will help develop better access to more effective cancer services, so that British Columbians who have had a cancer diagnosis can continue to thrive and enjoy their healthiest lives possible.

Part of Peacock's research will work in tandem with the BC Cancer Agency's Survivorship and Primary Care Program, with a focus on building better transitions and collaboration between family physicians and oncologists: "This work will help address many broad issues cancer survivors face as they disconnect with the cancer system and rely on their family doctor, who may not necessarily have the same level of expertise in dealing with cancer-related issues."

Peacock is appointed within SFU's Faculty of Health Sciences and will work within the BC Cancer Agency's Cancer Control Research program, which has a rich history in survivorship research. The provincial and collaborative approach to this research will ultimately help to improve the overall health and well-being of those impacted by cancer in the years to come. ■

The BC Cancer Foundation is the direct fundraising partner of the BC Cancer Agency. To learn more about the research initiatives we support, visit bccancerfoundation.com and join us online [@bccancer](https://twitter.com/bccancer).



FOR A CURRENT LISTING OF EVENTS...

go to www.bccancer.bc.ca and scroll down to Upcoming Events.

Nutrition Advice for Prostate Cancer Patients

DATE: December 2, 2015

TIME: 6 pm

DURATION: 1.5 hours

To REGISTER: If you are interested in finding out more about this session, or you would like to join it, please contact: PCSC program co-ordinator, Vancouver Prostate Centre at 604-875-4485, or e-mail PCSC@vch.ca

Brain Tumour Support Group

DATE: First Wednesday of every month

TIME: 9:30 am to 11 am

LOCATIONS: BC Cancer Agency, Vancouver Centre (600 West 10th Avenue, Vancouver), John Jambor Room, 1st floor.

DESCRIPTION: This group allows members to share experiences and obtain factual

information from health-care professionals. Current and former brain tumour patients, their families and friends are welcome. Every other month we break into two sub-groups; one for patients and another for caregivers/loved ones. This allows members of each group to support each other around their unique challenges.



Partners of Patients with Metastatic Disease or Receiving Palliative Care

DATE: Fourth Thursday of each month

TIME: 5:30 pm to 7 pm

LOCATION: BC Cancer Agency, Vancouver Island Centre (2410 Lee Avenue, Victoria).

DESCRIPTION: This group is for partners of patients dealing with metastatic cancer. It is a safe place to share thoughts and feelings, and connect with others who are also dealing with the complexity of a life-threatening illness.

FOR MORE INFORMATION: Call 250-519-5525



2016 Workout to Conquer Cancer

DATE: April 2, 2016

LOCATION: Richmond Olympic Oval, Richmond, BC

DESCRIPTION: Get ready to lunge, stretch and sweat towards a world free from cancer! Join in the fun of this full day of fitness fun sessions to raise funds for breakthrough cancer research.

To REGISTER: Sign up as an individual or as a team at www.workouttoconquercancer.ca

FOR MORE INFORMATION: Call 604-877-6040 or

1-888-906-2873, or

e-mail workout@bccancer.bc.ca.

**WORKOUT
TO CONQUER
CANCER**

2016 Ride to Conquer Cancer

DATE: August 27-28, 2016

LOCATION: Vancouver start

DESCRIPTION: The Ride to Conquer Cancer, presented by Silver Wheaton benefiting the BC Cancer Foundation, is a unique two-day cycling event that will take place on August 27 and 28, 2016. During this bold cycling journey, you will ride for two days through picturesque scenery from Vancouver to Seattle. Our vision is clear – A World Free From Cancer.

FOR MORE INFORMATION OR TO REGISTER: Visit www.conquercancer.ca or call 1-888-771-BIKE (2453).

Health and Wellness Resources

Whether you are newly diagnosed with cancer, are living with cancer, or are a cancer survivor, it's important you live as healthy a lifestyle as you can. At a time when your life may seem fraught with uncertainties, what you eat, how much you exercise, how you think and how you live can make a tremendous difference to your overall health and well-being. What's more, these things are completely within your control.

The Internet is an excellent place to access helpful information on health and wellness topics. However, it's important to recognize that not all websites are created equal and that you need to be thoughtful about whose advice you're going to take, especially where your health is concerned.

To help you navigate, here is a listing of some of the Internet's top health websites, as reviewed and evaluated by BC Cancer Agency librarians.

US National Institutes of Health – www.health.nih.gov

This top website contains quality information on a wide range of health- and wellness-related topics, including nutrition, exercise and mental health. It also provides links to a broad network of NIH-recommended online resources on subjects that range from achieving a healthy weight or better weight control, to advice on how to successfully increase your level of physical activity.

HealthLink BC – www.healthlink.bc.ca

This site, which features medically approved information on more than 5,000 health topics, offers excellent advice on maintaining a healthy lifestyle. The Healthy Eating section includes specific advice regarding nutrition as it relates to various types of cancer and weight control. It also provides excellent links to exercise and stress



management information, and provides health advice specific to men and to women.

MedlinePlus

– www.nlm.nih.gov/medlineplus/
Another service of the US National Institutes of Health, this easy-to-navigate site provides fast access to a specific series of health and wellness topics, including fitness and exercise, food and nutrition, personal health issues, sexual health issues, social and family issues, and wellness and lifestyle.

Health Canada – www.hc-sc.gc.ca

This official Government of Canada site, which covers the full spectrum of Canadian health concerns, includes a helpful subsection on healthy living, with links to healthy eating, mental health, oral health, physical activity and other relevant topics. The site also links readers to other resources and downloadable PDFs.

NetWellness

– www.netwellness.org
Experts from three leading universities contribute content to this comprehensive, reader-friendly site. The site allows you to scan a full listing of health topics. Clicking on the desired subject pulls up a large list of related articles, each of which is written by a contributing medical expert. Doctors on this site are also available to respond to questions.

Additional Websites: The Consumer and Patient Health Information Section of the Medical Library Association (CAPHIS) has produced the Top 100 List: Health Websites You Can Trust. To access this site, go to caphis.mlanget.org/consumer/index.html. ■

For more information and resources, go to the BC Cancer Agency Library page, <http://www.bccancer.bc.ca/our-services/services/library>, which offers a number of excellent pathfinders on a variety of topics.



I'm still here
to see my kids grow up

I'm still here because of cancer research.

The BC Cancer Foundation is the largest funder of cancer research in B.C. To learn more or to make a donation, please visit bccancerfoundation.com or call 604.877.6040.

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Supporting the BC Cancer Agency