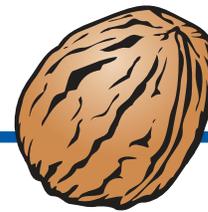


The Walnut



NEWSLETTER OF PROSTATE CANCER CANADA NETWORK OTTAWA
P.O. Box 23122, Ottawa, ON K2A 4E2 • (613) 828-0762 • info@pccnottawa.ca

SPRING, 2019

Wellbeing



In this issue, we examine the physical, emotional and social wellbeing needs of men with prostate cancer. We look at a range of issues, including dealing with anxiety, fatigue, side effects of treatment, loss of libido and sexual function, impact on relationships.

And because many men do not take a pro-active approach to take responsibility for our health, using self-reflection and reinvention to become more proactive and becoming an architect of our own health. ■

“You are not your illness. You have an individual story to tell. You have a name, a history, a personality. Staying yourself is part of the battle.”

– Julian Seifte MD. Author, *After the Diagnosis, a heartfelt and moving lesson on the art of living well through serious illness.*

The content in The Walnut is taken from reputable sources. However, it is not intended nor recommended as a substitute for medical advice, diagnosis, or treatment. Always seek the advice of your own physician or other qualified health care professional regarding any medical questions or conditions.

Monthly Meetings

We meet the 3rd Thursday of each month (except July and August) at St. Stephen’s Anglican Church, 930 Watson Street, off Pinecrest, north of the Queensway. Parking is at the rear. A contribution for the St. Stephen’s food bank is always appreciated. Meetings open at 6:30 and run from 7:00 pm to 9:00 pm. Free parking is available at the rear of the church.

Our monthly meetings are dedicated to providing information, fellowship and support to all who have been touched by prostate cancer. Come join us anytime—we hope to see you soon!

MARK YOUR CALENDAR! • 18 April 2019 •
• 16 May 2019 • 20 June 2019 •

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PCCN OTTAWA is a volunteer organization of prostate cancer survivors and caregivers. Our purpose is to support newly-diagnosed, current, and continuing patients and their caregivers. PCCN Ottawa is a member of the Prostate Cancer Canada Network.

Executive Officers

Chair Larry Peckford
 Vice-Chair Doug Nugent
 Treasurer Jim Thomson
 Secretary Michelle Faber

Board of Directors

Larry Peckford, Chuck Graham, David Cook, David Brittain, Jim Thomson, Jim Chittenden, John Dugan, Harvey Nuelle, Hal Floysvik, Norman MacDonald, Gary Sealey, John Kirk, Kenneth Sanford, Doug Nugent, Michelle Faber.

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Sympathy cards	Joyce McInnis

PCCN Ottawa does not assume responsibility or liability for the contents or opinions expressed in this newsletter. The views or opinions expressed are solely for the information of our members and are not intended for self-diagnosis or as an alternative to medical advice and care.

As a registered charity, we rely on the generosity of donors and volunteers to support our mission. Your donation helps protect men and their families from prostate cancer. You'll be supporting the most promising research projects and providing men with care and support when they need it most. Thank you for your generosity!

PCCN Ottawa Mission Statement

The mission of Prostate Cancer Canada Network Ottawa (hereafter PCCNO), both for individuals and in the interests of the wider community, is to promote and deliver personal support, education, awareness and health advocacy on behalf of all men and their families that are affected by prostate cancer and to better prepare them to deal with their diagnosis and treatment in a positive and effective manner.

Why Language is Important

“Language is very powerful. Language does not just describe reality. Language creates the reality it describes.”

– Desmond Tutu

The language we use to describe our experience is important. Language can mold our perspective on life.

Language not only describes our reality but helps shape it. There is a reciprocal relationship between the language we use and the reality we are living.

Language describes the world as we see it but language has a further function. Language also constructs new meaning in the world as we see it and as we experience it.

Metaphors are very useful in this regard. “Metaphors” are created when we bring words together in creative ways to express new ideas and new relationships. They describe what actually “is” but also deepen our understanding of whatever we are describing. In connecting ideas through metaphors we create new ways of looking at, and being in, our world.

Do we use hope-filled language when looking down the road after an initial diagnosis of cancer or during a time of remission? Or, do we use language of despair and worry? We can choose to emphasize one over the other and thus help shape our lived experience accordingly.

This is because meaning in language is virtual (language points to something beyond itself) and there exists the potentiality of this meaning to become event in our lives. Thinking a particular way can help experience being that way. This is the power of language and it can serve us well when dealing with discouraging or upsetting news about our health.

Language won’t cure what ails us but it can foster a sense of hope and meaning when we find ourselves in places of relative peace and calm as well as in stress and trouble.

David B. Perrin, Ph.D. Full Professor, St. Jerome’s University at the University of Waterloo, Waterloo, ON. teaches ethics. Dr. Perrin is an academic speaker, author, as well as a popular workshop and retreat director. ■

Battle, fight, win — you hear these words describe cancer all the time, but medical experts are now re-thinking how we characterize the disease because of the emotional ramifications. “It has the potential to be detrimental to patients, to their overall sense of well-being,” said Dr. Elie Isenberg-Grzeda, a psycho-social oncologist at Sunnybrook Health Sciences Centre in Toronto. “[Cancer] is sort of the antithesis of what we envision when we think of a fighter, or a warrior, or bravery.”

Source: Amara McLaughlin – CBC News



Events

Heads Up for April meeting!

We meet on April 18 at the Auditorium of The Ottawa Hospital, General Campus, 501 Smythe Road.

Dr. Chris Morash, Site Chief, Urological Oncology at the General Campus is our guest speaker. We expect Ride for Dad representatives attending as well as other invited guests. The meeting begins at 6:30 PM with light snacks and beverages. Dr. Morash will begin his talk at approximately 7:00 PM.

Picture of our booth which we displayed at the annual Ottawa Boat Show held at the EY Centre February 21 – 24. PCCNO joined forces with Ride for Dad who was able to access a booth at the Show. L to R: Don Helman and Roger Cavanaugh of Ride for Dad, Doug Nugent PCCNO



Donation to PCCNO

Harvey Nuelle (left) on behalf of Bell Canada presents to PCCN Ottawa a cheque of \$2,500. This is the ninth grant that Harvey has donated from Bell to PCCNO.

Receiving the cheque at the AGM, are Larry Peckford, President (centre) and Jim Thomson, Treasurer (right).



Coffee and Conversation

PCCNO member Bill Lee coordinates regular informal get-togethers to share in conversation and make new connections.

One is held at 10:00 am the first Monday of each month at the McDonalds restaurant at Billings Bridge, and the other in the Food Court at Carlingwood Mall on the second Monday of each month, also at 10:00 am. If a Monday is a holiday, then they meet on Tuesdays. Anyone interested can contact Bill at 613-825-1186 or leewillum@rogers.com

The Walnut Needs a New Editor

Our current editor will be ending his assignment at the end of 2019, after four years of contribution. PCCNO is looking for a new volunteer – or team of volunteers – to take on this role.

What is involved?

- ▶ Identify topics of interest to men with prostate cancer and their families.
- ▶ Plan, curate and organize content – information about prostate cancer, news and social events of interest to PCCNO members and their families.
- ▶ Collaborate with our formatting and distribution team.
- ▶ Collaborate with PCCNO team with the goal of improving content quality.

Contact us to find out more:

info@pccnottawa.ca

613-828-0762

PCCNO Conference:

4-5 October, 2019

at the RA Centre,

2451 Riverside Dr, Ottawa, ON

“Living with Prostate Cancer”

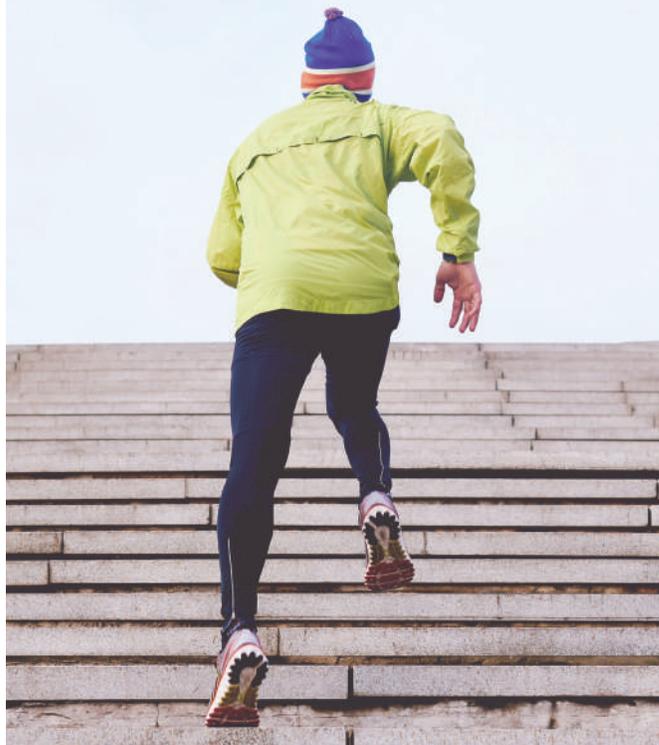
This conference brings together experts to present and to discuss prostate cancer treatment, prevention, survivorship and scientific progress.

Preliminary agenda includes:

- ▶ Intimacy and sex after prostate cancer
- ▶ Erectile Dysfunction: Penile injections and Prosthesis
- ▶ Physiotherapy – Pelvic Floor exercised and other treatments
- ▶ Cancer coaching
- ▶ Naturopathic care
- ▶ Dietary and lifestyle changes that improve quality of life
- ▶ Clinical Counselling & Group Workshops

Go to <http://pccnottawa.ca/> for updates. ■

The Role of Exercise



Source: <https://www.harvardprostateknowledge.org/exercise-and-prostate-cancer>

We’ve all heard about the value of exercise in maintaining good health.

What may come as a surprise is that regular physical activity may actually help prevent some prostate disorders and improve prostate health. Emerging scientific evidence suggests that engaging in a few hours of exercise a week may help keep prostate tumors from advancing — or prevent them from developing in the first place.

Importantly, researchers have found that the exercise need not be vigorous to offer benefits. Scottish researchers determined that moderate-intensity walking produced a significant improvement in physical functioning with no significant increase in fatigue. Improved physical functioning, they wrote, may be necessary to combat the fatigue that comes with radiation therapy.

Exercise is beneficial, too, for men on androgen deprivation therapy (hormone therapy) for advanced prostate cancer. ■

Strategies for Preserving Emotional Wellbeing

A study conducted by Anneliese Levy & Tina Cartwright in Psychology & Health, interviewed men with advanced prostate cancers to learn about their own practices for promoting and maintaining emotional well-being. These interviews provided detailed personal accounts of their experiences of diagnosis, treatment and the physical and emotional impact of cancer.

Within rich narratives of lost and regained well-being, two super-ordinate themes emerged – “living with an imminent and uncertain death” and “holding on to life.”

Holding on to life

The men interviewed talked about coping strategies. There was inevitable variation between participants – since well-being is personal and individual.

Themes that emerged here included how they revealed and contained emotions, how they tried to “live in the now” by being more present through leisure pursuits, hobbies, socializing and family time. For some, this was through activities that emphasized mindful awareness and sensory pleasure in the moment, whilst also reinforcing their sense of self and remaining physical ability through existing hobbies.

As well, they talked about how they strove to move forward and survive in an active and goal-orientated way.

Taking care of their families emerged as a strong motivator. Some used normalization as a strategy in the face of the psychological turmoil caused by advanced cancer and facing death, they worked to protect their identities as family men – fathers and partners with a duty to look after their loved ones. For some, this was achieved through taking control of communication about their cancer and the prospect of their death with their families. One facet of this was making financial and practical plans around death.

By channeling thoughts of their own death towards their family’s future well-being, the men were able to maintain their role as head of the family even after their death, thereby enhancing this role in the present.

Renegotiating purpose

Having a purpose through employment was an important facet of all of the participant’s pre-illness sense of self. Yet their diagnosis of advanced cancer meant they all had to give up their employment and risked losing their sense of purpose. However, all participants had renegotiated their sense of who they were through meaningful activity. Even though they are living with the fear of limited lifespan, they reassessed their new lives as having more meaning and vitality.

The benefits of new activities such as volunteering were multi-faceted; they enabled the men to achieve a sense of belonging in the world, and social connection to counteract the feelings of separation that their “between life and death” state entailed.

The findings of this study add weight to the evidence base for the potential value of psychological interventions such as cognitive behaviour therapy and mindfulness in men with prostate cancer.

The full research report is available here: <https://www.ncbi.nlm.nih.gov/pubmed/25871263> ■

Share Your Story

Knowing about other people’s personal experience of prostate cancer can be a source of support and inspiration when you or someone you love is going through cancer treatment.

What is your experience in dealing with prostate cancer? What has this journey been like?

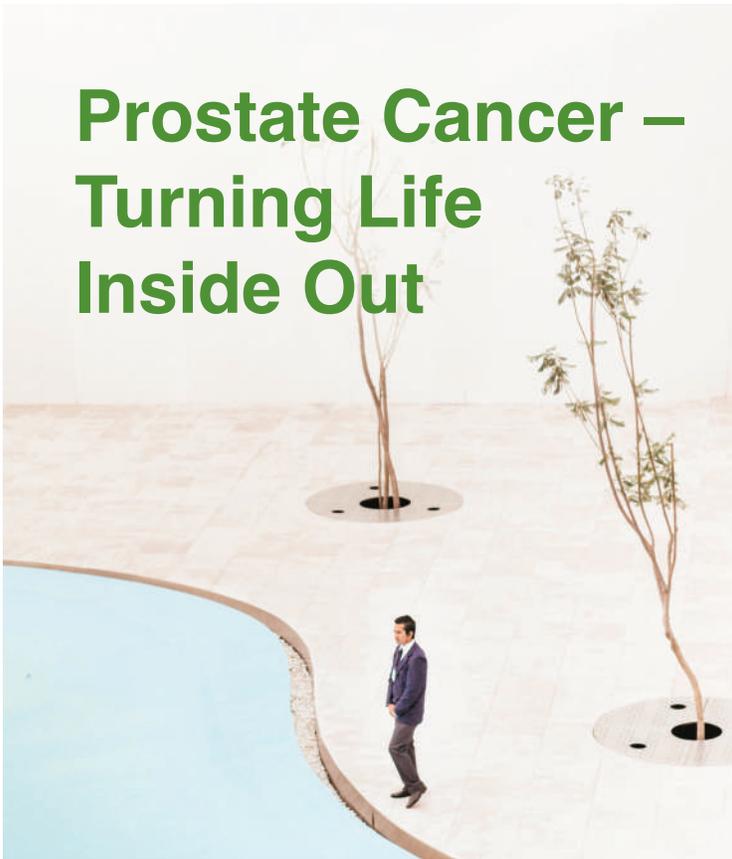
What insights can you share with those about to make, or in the middle of making, important decisions and choices?

If you are the spouse, partner or family member of a prostate cancer patient what experiences can you share to benefit others?

Your stories can support the work of PCCN Ottawa to promote and deliver personal support, education, awareness and health advocacy on behalf of all men and their families that are affected by prostate cancer.

Write us, and we will include your stories in the next issue of The Walnut! We cannot promise we will publish every story we receive, but we will share as many as we can.

Prostate Cancer – Turning Life Inside Out



Source: <https://prostatecancer.net/infographic/life-inside-out/>

Each man’s prostate cancer journey is different. Treatment experiences and challenges may not be the same. Yet there are plenty of stories that let us know that common elements of the journey also exist. In order to garner a better understanding of both the similarities and the points of divergence of men living with prostate cancer, a survey was conducted online in 2018 by Health Union LLC.

Here are some highlights of what men living with prostate cancer had to say.

Of the 928 men who completed the survey, 61% were not symptomatic at diagnosis. They had gone to their healthcare provider for an appointment that was for another medical reason. Thus it is no surprise that men may be shocked and not prepared for test results that indicate a potential problem with their prostate.

Similar to other types of cancer, men who are diagnosed with prostate cancer are diagnosed at various stages of cancer, from early stage or localized to advanced.

After diagnosis, men with prostate cancer begin a discussion of treatment options with their health care team. The typical prostate cancer journey doesn’t end with treatment, however. While 38% of men who took the survey are in remission (they have no evidence of disease or an undetectable PSA level), 14% have had at least one recurrence of prostate cancer since their original diagnosis.

Impact on quality of life pervasive & overwhelming

In order to determine if the prostate cancer treatment has been successful, and to monitor for potential cancer spread, 71% of men had follow-up tests and scans at least twice a year. This level of follow-up is obviously important; yet it also means that the fear of cancer progression or recurrence is always in the back of the mind of men with prostate cancer.

In addition to the fear of cancer progression or recurrence, men often struggle with a lack of energy, problems with sex life, and feeling sad. The side effects of prostate cancer treatment can be significant, and pain can keep men from doing things they want to do.

What frustrates you the most?

When asked in the survey “what frustrates you the most,” not surprisingly, men cited sexual problems as the number one concern, followed by bladder or bowel issues, fear of not knowing the future, and no longer feeling like a man. Other frustrations that were identified by men who completed the survey include dealing with pain, fatigue, and difficulty with doctors.

“Not feeling like a man” is a big part of men having to grapple with a “different self” post-diagnosis. Questioning one’s identity and how one feels may be a new experience for many men. Most men will need time to resolve the emotional aspects with how they are feeling physically, and how they relate to others like a spouse or family members.

Prostate cancer in a word

Men who took the survey were also asked, “if you could describe prostate cancer in ONE WORD, what would that one word be?” The most frequent responses are shown in the graphic here. ■



Who Should Take Responsibility for Your Health and Wellness?

Sources: <http://timothyasher.com/responsibility-control-health/>,
<https://michaelhyatt.com/not-architect-life/>

Personal responsibility for health is a complex issue and more and more emphasis is placed on how individuals can influence both health decisions and health outcomes.

People who come to physicians and say: “I have this problem; fix me,” sometimes don’t have great results because they aren’t taking responsibility for their health issues. Energetically and symbolically, they are putting all of the healing power in the hands of the doctor.

Patient as architect

Think about our built environment. Architects must design our homes and workplaces with variables like winds, earthquakes, communication, traffic, and the surrounding environment in mind.

It’s impossible to imagine building one without architectural plans. But here’s the thing: The lives of everyone working inside those towers are infinitely more complex.

Our daily existence requires coordinating a million variables: just think of all the personal and professional obligations and aspirations we constantly juggle. Yet most of us do so without a plan.

Instead, we cobble bricks together, hoping nothing will jostle them down. But it’s a constant struggle, and we usually have few long-term goals for our activity.

How are we supposed to bring structure to all the external demands and requests so they integrate with our internal desires and hopes, especially when dealing with a disease like prostate cancer? One solution is to become the architects of our own lives. We can start getting the balance and direction we need with a Health and Wellness Plan.

To architect our own lives, we need to keep three elements in mind.

1. Our Vision

Architects start with a vision. They can imagine how the different elements and materials will come together for the



final effect. It’s the compelling picture of the completed building that inspires and informs the plans that follow.

A health and wellness plan works exactly the same way. Find your vision: Make a list of all the reasons why you want to have a healthy body.

2. Our Priorities

Whatever the vision, an architect must work in a particular setting on a particular site.

A great architect can find inspiration within these constraints. It’s the same for us. We have certain realities and commitments already in place. Some are essential to what we’re building. Others we can work around. Some we can change.

Rank your priorities in order of importance. How important is your career compared to your family, for instance? Or your finances compared to your health?

3. Our Actions

Once you have a vision for your life and can prioritize what goes into it, you can set relevant, actionable goals. What are the steps you need to take to enact your priorities?

What lifestyle habits do you need to implement to improve your health? Once you have a plan, make sure you keep a journal to keep yourself in check.

Get help. Taking personal responsibility and control of your health doesn’t mean you can’t ask for help. If you need guidance or someone to keep you accountable, make sure you reach out to someone who can help.

What matters is our determination to follow through with our vision. “An architect must hold strong convictions in order to create,” says Rybczynski. That goes for life architects too.

Finally, laugh a bit more: Happy people live longer. Our bodies respond well when we are positive, so make time for a bit of fun every day! ■



Wellbeing for Partners and Caregivers

This resource booklet, developed by Prostate Cancer Canada, is designed to help caregivers better understand how you can support your family member or friend as they face prostate cancer.

When a man is diagnosed with prostate cancer, the emotional responses to the diagnosis may not be predictable and are as wide and varied as the men involved. Family and friends will also feel the impact of the diagnosis. Certainly, the experience for partners may be more intense and may closely match the patient's experiences. The reality is when a man is diagnosed with prostate cancer the attention falls naturally – and often squarely – on him. The critical challenge faced by a caregiver is finding support and taking care of oneself to ultimately maintain personal health and energy levels.

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own wellbeing. This resource includes a Caregiver Distress Checklist that gives you an opportunity to do a self-evaluation about your distress levels, and advice on how to improve your own wellbeing.

This resource is available online: http://www.prostatecancer.ca/getmedia/97fae849-69d0-4152-ab7e-5f2ac631d8b5/PCC_CaregiverBrochure_FINAL_WEB.pdf.aspx

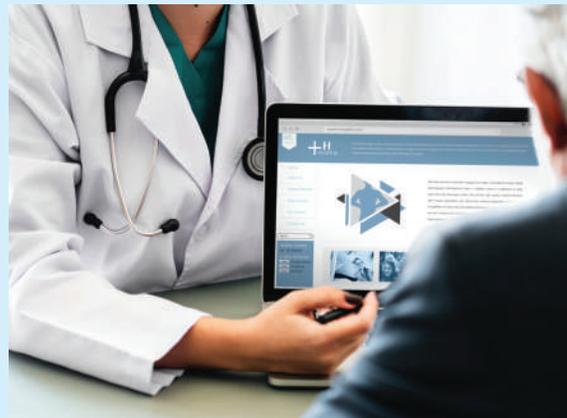
As well, the Prostate Cancer Foundation of Australia has produced a series of four booklets for partners and carers of men affected by prostate cancer. This series of booklets aims to provide information about important issues that partners and carers need to know relating to prostate cancer care and support. The issues are divided into the four separate booklets for ease of access and understanding with each covering a major topic during the cancer journey. The topics covered by the four booklets are:

1) Diagnosis. 2) Treatment. 3) Side Effects. 4) Wellbeing.

It can be found here: <http://www.prostate.org.au/media/430572/Wellbeing.pdf> ■

In the Next Issue

Summer 2019 Advanced Prostate Cancer



In this issue, we explore how prostate cancer spreads, and talk about how this is monitored and treated.

Advanced prostate cancers are not “curable.” However, recent treatment advances offer new hope. New treatments can extend the quality and length of life for men with these types of advanced prostate cancer.

We talk about treatment options, and living with advanced prostate cancer: managing symptoms, managing pain. We also look at how men can find support to deal with psychological distress, treatment distress and quality of life issues.

Join the Team

For many of us, contributing is part of survival. We learn and find comfort by doing things with other survivors.

Participating in the community helps sustain our quality of life. Your help is needed and you'll find it rewarding.

Contact us at info@pccnottawa.ca or use the form on the website to introduce yourself and let us know how you'd like to help out. <http://pccnottawa.ca/volunteers/join-team> ■