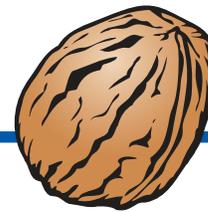


The Walnut



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

AUTUMN, 2017

Caregivers



Men with prostate cancer rely on their doctors, nurses and other professional caregivers. But what of family, friends and others in our lives who provide care and support?

The journey belongs to the patient. Still, everyone needs someone to listen, to help explore treatment options and decisions – to help research issues, work through the medical system, clarifying medication issues, and dealing with any lifestyle changes that happen, either because of choice, or because of circumstances.

In this issue, we look at how caregivers can help to meet the psycho-social needs of patients as part of a comprehensive treatment approach. We look at the impact on families and friends, and explore how caregivers can find support themselves to continue the crucial and sometimes difficult roles they play. ■

Monthly Meetings

We meet the 3rd Thursday of each month at St. Stephen's Anglican Church, 930 Watson Street, off Pinecrest, north of the Queensway. Parking is at the rear. Please bring a contribution for the St. Stephen's food bank.

MARK YOUR CALENDAR!

• 19 October 2017 • 16 November 2017

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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

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Vice-Chair	Chuck Graham
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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.

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.

In Memoriam

BLACKADAR, Robert M.A. Ph.D

PCCNO member since 2001. Bob passed away June 12, 2017, at the age of 89. Bob was the son of the late E. Gordon and Myrtle (Norman) Blackadar. He began his association with the Geological Survey in 1947, and participated in or directed four major helicopter-supported reconnaissance programs, which mapped thousands of square kilometres and laid the foundation for subsequent mineral exploration by private industry. Bob is survived by his cousins in Ontario and in the United States.

Leroux, Joseph Bruno

Passed away on Sunday, August 27, 2017 at age 86. Beloved husband of Suzanne. Loving father of Julie (Glen) and Sylvain. Grandpa to Taylor, Kayleigh and Carter. Son of the late Hormidas Leroux (Henrietta). Dear brother of Laurent (Madeleine) and predeceased by Edgard (Desneiges) and sister Thérèse (Robert). Bruno also leaves behind many dear family and friends. Proudly served for over 40 years with Canadian National Rail – Superintendent of transportation.

MANCHIP, Robert J.

PCCNO member since 2003, Robert passed away peacefully at his home in Ottawa on Easter Sunday, April 16, 2017, after a 14-year battle with prostate cancer. After achieving his professional accounting designation, Bob spent his career with the internal audit branches of the Federal departments of National Defence and Revenue Canada – Customs & Excise. He was an avid cyclist and enjoyed fishing, cross-country skiing and snowshoeing. The family would like to thank the doctors and nurses of the Ottawa Regional Cancer Clinic for their care and compassion since Bob’s cancer diagnosis.

MORIN, Moose “Rene”

Moose (Rene) Morin passed away in May, 2017 at the age of 80. He was a man of strong faith with a huge heart, a love for all things ‘zesty’ in life, a deep commitment to family and friends and an unmistakable laugh. A proud University of Alberta alum, he earned his engineering degree in 1959 and enjoyed a long and notable career. Moose loved to travel. He and Doris spent the past twenty years checking destinations off their bucket list. They enjoyed spending winter months in Mexico where their families and friends would join them. He leaves behind his wife and best friend of nearly 43 years Doris (Amadori), his children Marc, Carla and Paul; his children-in-law, Jess, Matthew and Lara. ■

Events

CCSN and PCCNO Meet with Ottawa Mayor, Jim Watson

<http://survivornet.ca/ccsn-meets-ottawa-mayor-jim-watson/>

On June 7, 2017, members of the Canadian Cancer Survivor Network and Prostate Cancer Canada Network Ottawa met with Jim Watson, Mayor of the City of Ottawa to receive the Mayor's official proclamation declaring June as National Cancer Survivors Month in Ottawa.

The proclamation states,

"Whereas a 'cancer survivor' is defined as anyone living with a history of cancer – from the moment of diagnosis through the remainder of their life; and whereas, an estimated 202,400 new cancer cases will be diagnosed in Canada this year, increased access to quality cancer care, screening, and prevention must be a top priority in our community; and whereas, the great city of Ottawa

has an active and productive cancer survivor population; and whereas, hundreds of communities worldwide will be celebrating life this month; therefore, I Jim Watson, Mayor of the City of Ottawa, do hereby proclaim June 2017 as National Cancer Survivors Month in Ottawa, and urge citizens to join in this joyous celebration of life".

It was a very positive day of celebrating survivorship and those who have survived cancer.



PCCNO Conference: Discover the Future



From left to right: Dr Chris Morash, Dr Ilias Cagiannos, Dr Christina Canil, Dr Rodney Breau, and Dr Scott Morgan shared some of the latest innovations and ideas at The Ottawa Hospital to help address prostate cancer, including screening, surgery, clinical trials, treatment options and more.

The Prostate Cancer Canada Network Ottawa (PCCNO) brought 120 experts and advocates together for 'Prostate Cancer – Discover the Future' at the Ottawa Convention and Event Centre September 14–15.

Working in partnership with Prostate Cancer Canada and The Ottawa Hospital, the conference featured leading medical specialists in prostate cancer treatment, as well as individuals involved in integrative care and complementary treatments.

Dr. Chris Morash, Medical Director of The Ottawa Hospital's Prostate Cancer Assessment Centre and a team of urology/oncology specialists addressed 120 advocates and experts representing many parts of Ontario and Quebec.

"We were just thrilled to have six of Ottawa's best prostate cancer specialists from The Ottawa Hospital sharing the stage for over two hours to provide important insights about innovations and new technologies for those affected by a prostate cancer diagnosis," said Larry Peckford, Chair of the local Ottawa Prostate Cancer network.

Jennifer Van Noort, Vice-President, Philanthropy and Leadership Giving at The Ottawa Hospital Foundation who moderated a panel discussion with the medical specialists remarked:

"I hope the Ottawa community is reassured of the world class caliber of prostate cancer care and research here at The Ottawa Hospital. Dr Chris Morash, Dr Rodney Breau, Dr Ilias Cagiannos, Dr Luke Lavallee, Dr Scott Morgan and Dr Christina Canil shared some of the latest innovations and ideas at The Ottawa Hospital to help address countless aspects of prostate cancer, including screening, surgery, clinical trials, treatment options and more."

The Walnut will feature more details about the conference later this fall. ■

Spouses / Partners / Family



Adapted from: <http://www.ustoo.org/Spouses-Partners-Family>

Although prostate cancer strikes only men, a diagnosis of prostate cancer can have a profound impact on a patient's spouse/partner and family.

It's natural for the prostate cancer patient/survivor and loved ones/caregivers to feel many emotions including anxiety, fear and frustration, it's also important to take charge of managing the disease and to recognize that knowledge is power. You can help your loved one to cope with the physical and emotional impact of cancer and its treatment by:

- ▶ Helping him stick to his normal routine as much as possible
- ▶ Making sure that he eats a heart healthy diet with enough calories to support his ideal weight
- ▶ Making sure he gets plenty of rest
- ▶ Encouraging him to pursue activities that will improve his emotional well-being
- ▶ Activities that are purposeful and meaningful – going back to work, playing with his children or grandchildren
- ▶ Recreational activities – taking trips, golfing
- ▶ Exercise – improving both physical and emotional well-being

- ▶ Anticipating and implementing changes in his lifestyle due to side effects of treatment
- ▶ Incontinence – sit at the back of the movie theater, choose aisle seating in airplanes
- ▶ Erectile dysfunction – seek out sexual contact and re-establish intimacy
- ▶ Seeking out support from other friends and family members
- ▶ Encouraging him to join a support group
- ▶ Becoming an advocate for prostate cancer research and awareness

Find Support

It can be very beneficial for the patient and the spouse/partner/caregiver to talk with others who are having or have had the same experiences. As the Chinese proverb says, "To know the path ahead ask someone coming back." Collaborating with your peers can provide emotional support as well as valuable treatment information, advice and tips from others who have "been there and done that." There are many support groups for patients/survivors, spouse/partners and family members of patients with prostate cancer. One local support in Ottawa is Cancer Coaching. ■

A Caregiver Guide

Ottawa Public Health has adapted the Caregiver Compass with permission from Saint Elizabeth to create the Ottawa Public Health Caregiver Guide.

This guide will help if you are a full-time or part-time caregiver and even if you are caring for a person who lives far away. It will give you tips and ideas to help you care for your loved one and yourself.

The Caregiver Guide has five chapters:

Chapter 1:
Caregiver Responsibilities

Chapter 2:
Finding Your Way Through the System

Chapter 3:
Caring For You...The Caregiver

Chapter 4:
Caring for an Older Adult

Chapter 5:
Providing Care at End-of-Life

See: <http://ottawa.ca/en/residents/public-health/healthy-living/caregiver-guide> for more information.

The Caregiver as Advocate

Source: http://www.caregiverexchange.ca/51/Why_autonomy_matters

For caregivers, the demands of direct care – getting to doctors’ appointments, filling prescriptions, helping with shopping, cooking, eating and housekeeping, and more – can seem overwhelming. But there is another role that can be just as important – that of patient advocate.

Here are some of the ways you can be an effective advocate.

- ▶ Begin by checking with the person that they’re comfortable with you speaking on their behalf with care providers.
- ▶ Ensure that the person continues to be involved and understands his condition and options.
- ▶ Get to know the care team and keep communication open.

Medical appointments:

- ▶ Schedule appointments at the best time of day for the person with the health condition.
- ▶ Go prepared, with a list of medications and supplements, any changes in symptoms or behaviour, and any specific questions or concerns.
- ▶ Help the person communicate with the health providers, but don’t take over.
- ▶ Ask questions and take notes. When you see a blank look, probe further.

With home care providers:

- ▶ Let them know the person’s likes and dislikes.
- ▶ Ensure they know you are the go-to person and can reach you at any time.
- ▶ Monitor care. Don’t hesitate to raise concerns. And don’t forget to express appreciation when things go well.

In the hospital:

- ▶ Provide vital information including a health card, a list of medications, advanced directives, and doctors’ contact information.
- ▶ Bring the person’s glasses, hearing aid and dentures.
- ▶ Ensure that providers know that you are the go-to person and can reach you at any time.
- ▶ If the person is acting more confused than normal, let the medical team know immediately. Be aware of the signs of delirium.
- ▶ If new medications are prescribed, ask why and what the possible side effects are.
- ▶ Ask questions and take notes. Ask providers for their business cards, so you have their names and contact information.
- ▶ Be calm and positive, but firm. As www.workingdaughter.com puts it, “You are not at the hospital to make friends: you are there to get your parent the best care for them.” ■

Keep yourself from “running out of gas” as a caregiver

Adapted from: <http://www.caregiverexchange.ca/39/>

Paying attention to your own needs isn’t selfish

If you find yourself spending a lot of time looking after someone, it can be easy to ignore the toll that it may be taking on you.

Routinely placing someone else’s needs ahead of your own can have a negative impact on your health. Remember: if you get sick, you’ll be of little use to the person you’re trying to help. Paying attention to your own needs isn’t selfish; it actually makes you a better, more resilient caregiver.

Finding support services in your community

Because people typically don’t plan on becoming caregivers, they’re often unaware of the community supports that can help them lighten their load when they find themselves looking after someone. Terms like “respite care” or “adult day program” may be alien to them. They may assume that getting help will be expensive. That’s not always the case.

Thehealthline.ca provides a comprehensive, up-to-date listing of health and community services provided across Ontario, including programs specifically designed to support caregivers. Many programs are offered at little or no cost.

Involving people you know

Family members can play a role as well. Another option is to enlist the support of friends and/or neighbours. It’s often surprising how helpful people who aren’t family members can be when asked.

My Prostate Cancer Story

Dalton McIntyre,
PCCNO member

Born in Ottawa, Dalton grew up in the west end, attended St. George's School, St. Patrick's College and two years of college before attending Queen's University which he put on hold to serve his country.

Dalton served on the minesweeper the Nipigon, the escort carrier HMS Nabob, and the destroyer the Restigouche, first as a stoker, and finally as an Engine Room Artificer (ERA). His rank upon retirement was Chief Petty Officer (Engineer Branch).

After the war, Dalton was finally able to complete his Mechanical Engineering degree at Queen's on a Veteran's allowance, and he obtained a job in the Heating and Air Conditioning field, first in Windsor and then in Montreal where he joined the ASHRAE society which dominated this field. In 2005, at the age of 84 years, Mr. McIntyre made the decision to volunteer at the Perley and Rideau Veterans' Health Centre. In November of 2014 he received investiture in the Order of St. George for service in the Second World War.

Dalton was married for 63 years to a beautiful Montreal woman and had four sons and a daughter who in turn have given fifteen wonderful grandchildren. They participated in curling, skiing, skating, tennis, swimming, as well as taking many trips some of which are stories unto themselves. His wife passed away last year with all the immediate family present.

My experience with Prostate Cancer began in April 2001 when my Family Doctor found that my PSA had risen to 4.86 and sent me to an Urologist whom I visited

in June, and he reported no sign of Cancer. In October 2003, the PSA had risen to 8.54 and my FD advised me that there was a 10% chance that I had Cancer of the Prostate. At the time, I was under the impression that such cancers grew very slowly so I did not do anything about it. In June 2004, my PSA had risen to 23.5, so my FD arranged for me to go to the same Urologist whom I saw on Oct 13. This time it was determined that I did have Cancer and thus began a series of X-rays including a CT scan.

During the same time period a sciatic pain developed in my left leg originating in my buttock. When it started, I stopped playing tennis, and later had to stop bicycling. I tried all kinds of Physio-therapy and even a Chiropractor to relieve the pain to no relief. In Sept. my wife and I took a 16 day pilgrimage tour of Eastern Europe where I had to walk with a cane and sit down wherever possible.

On Dec. 1st 2004, my Oncologist confirmed that I had Prostate Cancer class T3. On Dec. 6th he showed me on the CT scan that it had spread to at least three lymph nodes and pointed to one that he thought was causing the sciatic pain. My PSA was up to 90.85. I was given prescriptions for Casodex pills for a month during which the sciatic pain disappeared. He also gave me a prescription for Zolodex injections to be taken every three months for the rest of my life starting Dec. 22. He also arranged for 15 radiation treatments which began on Jan. 6th 2004. Most of those taking radiation treatment were given 30, but mine were apparently stronger. My PSA dropped to about 5 by the end of Jan. and continued to drop to

below 0.1 by April 2008. It has been in the range of 0.05 since Oct. 2008

My wife who passed away last year was with me for many of these meetings with the doctors. I did get back to playing tennis till June 1st 2015 when I fell on the courts and broke my hip bone. Later while bicycling, I passed out and hit a post and broke my wrist, so no more tennis or bicycling. We moved into a senior's residence 5 years ago, and it is now my home. I take all the exercise classes and go for walks almost every day. Just before Easter this year I took a river Boat Cruise from Switzerland to Holland with one of my sons. For someone who will be 96 in July, I think I am doing well. I am thankful for the care that has been and is still being provided everywhere I go. ■

What is Cancer Coaching?

Cancer Coaching, launched in 2011 by the Ottawa Regional Cancer Foundation, is comprehensive care focused on what matters to patients, their families and caregivers.

Cancer Coaching focuses on your physical, informational, emotional and practical needs. Cancer Coaching exists to help men and their families meet the challenges of cancer, and improve quality of life.

Cancer coaches are health and social care professionals who help each person address their physical, emotional, informational, navigational, financial and spiritual needs. With cancer coaches as partners in care, patients, families and caregivers are reporting a better experience, a greater feeling of empowerment and better health outcomes. For more information about their services, go to:

<http://www.ottawacancer.ca/how-can-we-help-you/cancer-coaching/cancercoaching/>



Mindfulness

Mindfulness therapy “aims to help individuals change the ways in which they relate to their thoughts rather than changing their thoughts”. – Mindful Caring, Article in Journal of Psychosocial Oncology November 2014.

This, and many other articles and research reports, suggest that mindfulness practices can help both caregivers and their loved ones maintain their emotional well-being. Strong emotional well-being is a good defense against such stress-related problems as depression and anxiety.

“Mindfulness is about being fully awake in our lives. It is about perceiving the exquisite vividness of each moment. We also gain immediate access to our own powerful inner resources for insight, transformation, and healing.”

– Jon Kabat-Zinn

Research findings also indicate that caregivers often experience higher levels of distress than the person they are providing care for. Results from a 2003 investigation examining the distress on caregivers and cancer survivors indicated that caregivers reported greater psychological distress and fear regarding cancer diagnosis when compared to the cancer survivors themselves (Matthews, 2003).

Mindfulness is about learning to focus and live in the “now” with intentional awareness. This sounds a bit abstract, but really in our rushed lives and busy routines, many of us do not manage to experience tasks as we do them and merely perform them in an automatic or reactive manner.

The practice is not about trying to restructure your thoughts, fight your inner battles or try to get to settle the rights and wrongs of your life’s stressors.

Kabat-Zinn explains that the aim of mindfulness is to nurture an inner balance that allows you to face life situations with greater stability, clarity, understanding and wisdom. This ultimately allows you to respond in a more effective, clear and understanding way. This may ultimately help you

deal with your family issues in a more productive way.

Janet Murchison, an occupational therapist who leads mindfulness groups at Baycrest Health Sciences in Toronto says that people are all too often “distracted by thoughts of the past or the future, worrying about what did, could or should happen, reacting to those scenarios as though they were really happening. While we are lost in thought, we miss the very moment in which we live life.”

More information about their resources can be found at: www.mindfulnessstoronto.net/mindfulness-courses-toronto/

The Ottawa Mindfulness Clinic is one local resource: <https://ottawamindfulnessclinic.com/> that offers programs and support in Ottawa and surrounding area.

Algonquin College also offers course in mindfulness: <http://www.algonquincollege.com/ccol/courses/an-introduction-to-mindfulness-based-stress-reduction-mbsr/> as does the University of Ottawa: <https://www.uottawa.ca/mindfulness/mindfulness-meditation-classes>

Please let us know at The Walnut if you have any experiences with these, or other local resources. ■



The Road Together

The web site My Prostate Cancer Roadmap has resources intended to support you. The site offers guidance for family members and friends facing the stresses associated for caring for a loved one. More information is available at: <https://www.myprostatecancerroadmap.com/road-together>

Caregiver Tips

Foster Open Communications

Health discussions between you and your loved one can be a minefield, as complicated as fights about finances or asking for directions. For many men used to being strong and feeling in charge, facing medical fears can be overwhelming, especially when it comes to advanced prostate cancer. Be prepared to do a lot of the heavy lifting, such as scheduling the appointments, supporting your loved one during follow-up with physicians' offices and implementing physicians' advice at home.

- ▶ **Speak Up When Something Seems Off:** As a caregiver, you may be the first to notice when your loved one is not feeling well, even if he is not willing to admit it, or might not even see it. Pay attention to what is going on with your loved one's health and do not be afraid to gently ask questions and, if needed, be insistent.
- ▶ **Do Not Get Righteous:** Instead of attempting to single-handedly "fix" and "save" your loved one, work together on a health plan that works for you both.
- ▶ **Quietly Flip the Script:** If you want to change the way your loved one eats, work with him to make grocery lists that include fresh, healthy foods. Explore recipes for lower-fat, lower-sodium versions of meals. Try new restaurants that serve healthier options – ask restaurant staff about alternative menu items that are healthier.
- ▶ **Lead by Example:** When finding the energy to care for loved ones, you also need to nurture your own health and well-being. Make time to keep yourself healthy and strong. ■

In the Next Issue

November 2017

PROSTATE CANCER

Discover the Future >



Highlights from the Prostate Cancer Conference held September 15 –16, 2017 at the Ottawa Conference and Event Centre, 200 Coventry Road, Ottawa.

We explored the remarkable advances in surgical, radiation and pharmaceutical therapies and examined the role of alternative and holistic approaches in cancer treatment.

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. ■