

The Walnut



NEWSLETTER OF PROSTATE CANCER CANADA NETWORK OTTAWA
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SUMMER, 2019

Advanced Prostate Cancer



Prostate cancer is defined as “advanced” when it spreads outside the prostate gland.

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

**“Tell me, what is it you plan to do
With your one wild and precious
life?”**

– Mary Oliver

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

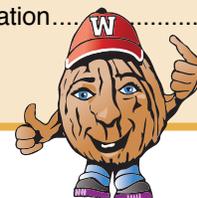
We meet the 3rd Thursday of each month (except July and August) at St. Stephen’s Anglican Church, 930 Watson Street, off Pinecrest, north of the Queensway. Parking is at the rear. A contribution for the St. Stephen’s food bank is always appreciated. Meetings open at 6:30 and run from 7:00 pm to 9:00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

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Vice-Chair	Doug Nugent
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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.

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.

Fast facts on advanced prostate cancer

- ▶ The disease normally has a very good outlook when diagnosed and treated early.
- ▶ Hormone therapy is a treatment option for advanced prostate cancer, as well as chemotherapy and immunotherapy.
- ▶ Prostate cancer can spread to the bones, brain, and lungs.



Development

Advanced prostate cancer is a type that has spread to other organs or tissues.

Prostate cancer occurs when cells in the prostate gland mutate and start to develop abnormally. They will multiply at an uncontrolled rate. In some instances, the cells can spread to other body parts. Cancerous cells can spread through tissue, the blood, or the lymphatic system.

After a doctor diagnoses prostate cancer, they will test to see if the cancer has spread to other areas of the body, or how much of the body the cancer has affected.

A doctor will assign a stage of prostate cancer from stage I to stage IV. Stage IV is the most advanced cancer form.

Stage IV prostate cancer is advanced prostate cancer that has spread to pelvic lymph nodes or is blocking the ureters. The ureters are the tubes that connect the kidneys to the bladder.

Doctors will test any cancerous cells in the body to determine if the additional cells came from the prostate. Even if cancer is detected in the bone, it is still considered prostate cancer if that is where the cancer started.

There are two types of stage IV prostate cancer:

- ▶ Stage IV D1: Prostate cancer has spread to the pelvis, lymph nodes, or surrounding organs. However, the cancer has not spread further.
- ▶ Stage IV D2: Cancers have spread to more distant organs, such as the spine, pelvis, ribs, or other bones. Unfortunately, stage IV D2 prostate cancer is the hardest to cure but is still treatable.

What does it mean for prostate cancer to spread?

Cancer cells can spread to other parts of the body. If this occurs, doctors say the cancer has “metastasized” or spread. ■

More details: <https://www.medicalnewstoday.com/articles/314157.php>

Events

Annual BBQ

Our annual summer barbecue will be held on Thursday June 27. The event is being held once again at the Maplesoft Centre at 1500 Alta Vista Dr., Ottawa. Burgers, beverages, and snacks will be supplied by PCCNO. More details will be posted soon on <https://pccnottawa.ca/site/>

PCCNO Conference:

**4-5 October, 2019
at the RA Centre,
2451 Riverside Dr, Ottawa, ON**

PCCNO is pleased to host another conference in support of men who have either undergone treatment or soon will do so, and their families/friends. Together with a number of our partners we will provide a forum for the exchange of ideas and authoritative views about living with prostate cancer.

A reception will take place on Friday October 4, 2019 followed by a full day of speakers on Saturday October 5, 2019.

Topics planned include:

- ▶ The latest developments in treatment options, and a Q&A session, presented by Dr. Chris Morash from the Ottawa Hospital;
- ▶ The current thoughts and research on Prostate Cancer Genetics by Justin Lorentz, Cancer Genetic Counsellor, Sunnybrook Health Sciences Centre, Toronto;
- ▶ Cancer Coaching services from the Ottawa Regional Cancer Foundation
- ▶ Cancer Navigation - Understanding Available Resources and Choices, from the Ottawa Integrative Cancer Centre (OICC);
- ▶ Pelvic Floor Physiotherapy presented by an Ottawa based Physiotherapist;
- ▶ Use of cannabis to control pain by Apollo Cannabis Clinics;
- ▶ Erectile restoration; and
- ▶ A Break-out session for women attendees to discuss coping with sexual issues experienced from Prostate Cancer.

Registration details will be published in early June on the PCCNO website - <https://pccnottawa.ca/conference/>. Watch the above web page for additional details on the Speakers and the schedule.

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

Contact us to find out more:

info@pccnottawa.ca | 613-828-0762

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.



Treatment Options for Advanced Prostate Cancer

Currently, no treatments can cure advanced/metastatic prostate cancer. However, there are effective ways to help slow its spread, prolong life, and control its symptoms.

Hormone Therapy:

Male hormones, specifically testosterone, support the growth of prostate cancer. By reducing the amount of testosterone in the body, the growth and spread of prostate cancer can be slowed. Hormone therapy, also known as androgen ablation or androgen-deprivation therapy, is the primary approach in the treatment of advanced prostate cancer.

Although hormone therapies are effective in the majority of men, they are not curative and most men progress to what is called hormone-refractory or androgen-independent prostate cancer.

Chemotherapy:

Patients who no longer respond to hormone therapy have other treatment options.

At one time, chemotherapy was used only to relieve symptoms associated with symptomatic metastatic disease. However, since 2004 it has been known that docetaxel (Taxotere) can prolong the lives of men with prostate cancer that no longer respond to hormone therapy and it is now the standard chemotherapy regimen for patients in this setting. Docetaxel is usually taken with prednisone (a steroid), requires an intravenous infusion every three weeks, and works by preventing cancer cells from dividing and growing. Side effects of docetaxel are similar to most chemotherapy drugs and include nausea, hair loss, and bone marrow suppression (the decline or halt of blood cell formation).

Immunotherapy:

Immunologic agents are used to stimulate a patient's own immune system to respond against the cancer.

For patients with advanced prostate cancer, **Provenge** (sipuleucel-T) is an immunotherapy treatment that utilizes the power of the patient's own immune system to identify and target prostate cancer cells. Each dose is manufactured specifically for each patient. The process of making Provenge involves collecting a patient's immune cells in a procedure called leukapheresis, and growing them in the laboratory in the presence of a protein that stimulates the immune cells to recognize prostate-cancer.

Clinical Trials:

Many patients who have no other approved treatment options available often consider participating in clinical trials. Clinical trials test experimental treatments, new combinations of drugs, or new approaches to surgery or radiation therapy.

Clinical trials are commonly classified into several phases, each having a different purpose. In phase I studies, researchers test an experimental drug in a small group of people to determine a safe dose, or to evaluate its safety and side effects. In phase II studies, the treatment is tried in larger groups of patients or in specific diseases to further evaluate its safety and efficacy. Phase III studies are used to compare the efficacy of the new treatment to an existing approved treatment. Placebos, or "sugar pills," may be used as the comparison to the investigational treatment in clinical trials for diseases that have no approved treatment. If the drug successfully passes through all 3 phases, it will usually be approved by the FDA for use in the general population. ■

Source: <http://urology.ucla.edu/prostate-cancer/advanced-prostate-cancer-treatment>



Prognosis and outlook

Prognosis

The prognosis for advanced prostate cancer depends on where the cancer has spread and how aggressively it is growing.

According to the American Cancer Society, survival rates are as follows:

- ▶ Local prostate cancer without spread has a 5-year survival rate at nearly 100 percent.
- ▶ Prostate cancer with local spread also has a 5-year survival rate at nearly 100 percent.
- ▶ Prostate cancer with distant metastasis has a 5-year survival rate of around 29 percent.

These are general statistics; it is important for a person with prostate cancer to speak to their doctor about their specific case.

Outlook

If prostate cancer is diagnosed before it has spread, or if it has only spread to nearby structures, the survival rate is excellent. This makes routine screening and early diagnosis essential in the fight against prostate cancer.

Men over the age of 50 should speak to a healthcare professional about the different screening options and which one is most appropriate for them. ■

Source: <https://www.medicalnewstoday.com/articles/320120.php>

How do I know how long I have left to live?

You might want to know how long you have left to live. This can help you prepare and plan the time you have left. There might be things you want to do or people you want to see. But some men don't want to know how long they have left. Everyone is different.

You can ask your doctor; however, he/she won't be able to give you an exact answer. No-one can know for certain how long you have left because everyone's body and everyone's cancer is different. However, your doctor will be able to give you some idea based on where the cancer has spread to, how you are responding to treatment, how quickly the cancer has spread, and what problems it is causing.

It can be helpful to talk with your family about this. You may not want to upset them but they might have similar questions and thoughts to you.

If you have months or maybe years left to live, it can be difficult for your doctor to say exactly how long you have left. This is because they don't know how you will respond to different treatments. If your treatment stops working so well, there may be other treatments available. Some men may not respond well to one treatment, but may respond better to another.

If you have weeks or days left to live, your doctor may have a better idea of how long you might have left. This is because you may have physical changes that suggest you are nearing the end of your life.

If your doctor does give you some idea of how long you have left, it's important to remember that this is not an exact answer. It can be difficult for you and your family to deal with if you live shorter or longer than they say. For more information:

<https://prostatecanceruk.org/prostate-information/advanced-prostate-cancer/dying-from-prostate-cancer/what-to-expect>

Five questions to ask your doctor



If you or someone in your family is faced with a cancer diagnosis, here are some essential questions to ask your doctor to help ensure you are receiving high-quality care:

What is the goal of my cancer treatment?

A curative treatment seeks to get rid of a cancer completely, whereas a palliative treatment is meant to slow down the cancer or improve symptoms, but not cure.

Understanding this distinction is crucial. Patients are less likely to choose aggressive treatments when goals are palliative and can better plan for the future when they are aware of the goals. An understanding of your treatment goals will help you make more informed decisions.

Can you explain my cancer's stage, using the reports from my scans and biopsy?

A cancer's "stage" describes its size and where it has spread in the body. In the case of prostate cancer, has it spread outside the gland, and to what extent?

The type of treatment a patient receives almost always depends on the cancer's stage. Reviewing this information with your doctor in detail can help ensure that nothing is missed when it comes time to decide upon the best treatment.

What are all the guideline-recommended treatment options for a cancer like mine?

It's difficult for doctors to keep up with all the latest research, so groups of experts create treatment guidelines that doctors can consult. Guidelines tell doctors the options available to treat each cancer, depending on the stage. For example, men with prostate cancer often have several options: surgery, internal radiation, external radiation or close observation. In some parts of Canada, large numbers of men receive treatment with radiation or surgery, with risks of sexual and urinary side effects. In other parts of Canada, the vast majority of men receive close observation. This suggests that many men are not being provided with all the options.

Can you discuss my case at a multidisciplinary tumour board (MDT) meeting?

An MDT meeting is like a team huddle. Cancer doctors get together to review patient cases – often taking a second look at all the scans – and share opinions about treatment. MDT discussions lead to a change in diagnosis or treatment recommendations about 10 per cent to 20 per cent of the time and can be helpful when there is uncertainty about the best treatment.

Are you considered a high-volume provider for my type of cancer?

For many cancers, outcomes are better at high-volume centres, where doctors treat a specific type of cancer frequently. Going to a high-volume centre may require travel and, in such cases, the potential benefits need to be weighed against the downside of leaving home.

Author: Dr. David Palma, a radiation oncologist at the London Health Sciences Centre and a clinician-scientist with the Ontario Institute for Cancer Research. He also runs the patient website <http://www.qualitycancertreatment.com/> ■

Sources: <https://www.theglobeandmail.com/life/health-and-fitness/health/five-questions-to-ask-your-doctor-to-get-the-best-cancer-treatment/article36083372/>

Voices of Caregivers

Metastatic prostate cancer and castrate resistant (mCPCA) bring caregivers closer to death. Caregivers tell us they find it helpful to hear the true experiences and thoughts of other caregivers.

Here are some quotes from interviews and prostate cancer support group attendees.

“Let's just take this more slowly and figure out exactly what's going on before you get rushed into surgery by the urologist.

“I go to every doctor's appointment because I take notes. I advise that for wives or caregivers. Go with him.

“The doctor talks and we hear two different things. He's too freaked to hear the truth. I am the truth-teller of what the doctor says.

“Maybe there are spouses who would want to protect their husbands from stuff but we're just not like that. That's why 100% honestly is kind of critical.

“Every treatment should be looked at through a quality of life filter.

See Five Questions on page 8

Useful resources and information

Prostate Cancer Canada

Prostate Cancer Canada is the leading national foundation dedicated to the elimination of the disease through research, advocacy, education, support and awareness. Prostate Cancer Canada provides up-to-date information, support services and educational resources. Website: www.prostatecancer.ca

Prostate Cancer Information Service

The Prostate Cancer Information Service (PCIS) provides information and support throughout the cancer journey. The PCIS is provided by Prostate Cancer Canada in partnership with the Canadian Cancer Society.

Website: www.prostatecancer.ca/pcis

Prostate Cancer Canada's Expert Angle Webinar Series

Prostate Cancer Canada offers a number of webinars which are delivered by experts in the field. Please look here for recordings of previous webinars and for details of upcoming webinars: www.prostatecancer.ca/expertangle

Prostate Cancer Matters

Prostate Cancer Canada is one of the supporters of Prostate Cancer Matters, which provides additional information on advanced prostate cancer for patients and caregivers and how to cope with its impact on different aspects of one's life. A helpful feature is their list of questions to ask different medical specialists and health professionals, which you can select and then print and/or email to yourself for easy reference.

Website: www.prostatecancermatters.ca

Prostate Cancer Canada Network

The Prostate Cancer Canada Network provides a forum for men (and their loved ones) with prostate cancer to share information and provide practical and emotional support to one another throughout the cancer journey. Support groups provide an opportunity to be with people who know what it is like to have this diagnosis and who can provide empathy. To find a support group in your area, please visit www.prostatecancer.ca/PCCN

Canadian Cancer Society

The Canadian Cancer Society provides information, support and links to other services and resources. Their publication, Living with Advanced Cancer, provides comprehensive information on coping with advanced cancer for the person themselves and their caregivers.

Website: www.cancer.ca

Canadian Virtual Hospice

The Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, healthcare providers, researchers and educators. You can find articles on a range of topics related to palliative care, as well as videos, recommended books, the opportunity to ask a professional a question, etc. Website: www.virtualhospice.ca

Canadian Hospice Palliative Care Association

Hospice palliative care aims to relieve suffering and improve the quality of living and dying. The Canadian Hospice Palliative Care Association is the national voice for Hospice Palliative Care in Canada. You can find information, resources and a national directory of hospice palliative care services.

Website: www.chpca.net

Legacies

Provides publications and resources on caregiving, community development and Canadian history. Publications include books for family and professional caregivers, community and personal development, and recording family histories.

Website: www.legacies.ca

Service Canada

Visit this website to find out how you can qualify for Employment Insurance Sickness Benefits and/or Compassionate Care Benefits.

Website: www.servicecanada.gc.ca/eng/sc/ei/benefits/sickness.shtml

Government of Canada – Seniors Canada

You can find information on advance care planning, wills and estates, services for veterans and caregivers.

Website: www.seniors.gc.ca

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> ■

“We’ve cried about this once and the only time he cried was his concern for me. He was like, “I don’t want you to be alone, I don’t want to leave you.” I was crying too, “You’re right. I’ll be a mess.” That was that. We just live every day.

“Nothing changes your life more than the words stage four prostate cancer.

“I don’t want to live in this disease. One of the women whose husband died, thought about being involved in prostate cancer advocacy and she said her husband told her, I had this disease, you shouldn’t have it for the rest of your life as well.

Source: <https://malecare.org/advanced-prostate-cancer/caregivers-advanced-prostate-cancer/>

In Memoriam

Dolan, Bill

Bill passed away April 30, 2019, at the age of 72. He served as co-chair of PCCNO at a time when new-found leadership was essential. He continued to be present at general and Board meetings until his illness no longer allowed him to do so. Bill possessed good humour and “bon ami” to all whom he met

DRAIN, T. John

PCO member since 2005. Passed away on March 29, 2019 at the age of 79.

John lead a busy and active life:

Past President and Life Member of the Ottawa Kennel Club; Awarded, City of Ottawa Citation for “Outstanding Bravery and Courage” for saving the life of a drowning victim in the icecluttered Rideau River; Member of the Stittsville and District Lions Club for many years.

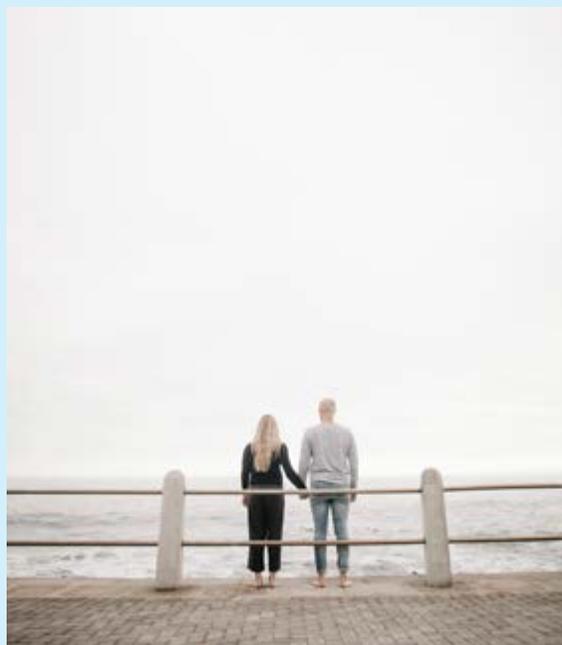
Johnson, Edwin “Ted” Robert

Ted passed away peacefully on April 15, 2019 at the age of 80. Ted was a career diplomat with the Department of Foreign Affairs from 1966-1998 with postings in Washington, D.C., Dar-es-Salaam, San Francisco and Warsaw. From 2005-08 he served as the President of the Prostate Cancer Association of Ottawa working to establish the Do It For Dad Father’s Day Walk and Run. A lifelong supporter of the arts, he returned to printmaking in retirement, exhibiting in the Ottawa area.

McDonald, William

In the Next Issue

Autumn 2019 From a partner’s perspective: living with prostate cancer



What is the impact on partners, families and friends of prostate cancer survivors?

In this issue, we explore the concerns and needs of partners of survivors. Three overarching themes are discussed: 1) coping with life in the face of cancer, 2) encountering difficult emotions related to a partner’s illness, and 3) learning to live with relationship changes.

We look at these at various stages of the prostate cancer “journey”: the process of being diagnosed and treated for prostate cancer and what that experience is like for couples, what they find as helpful, harmful, and surprising throughout the experience, what couples and families need through and following treatment, and how men and women think and respond differently to intimacy and relationship challenges that occur as a result of prostate cancer diagnosis and treatment.