Prostate Cancer and Mental Health

Depression, stress, fatigue, pain and psycho-social factors can all affect men with prostate cancer.

Anxiety may exist both before testing and while awaiting test results. Confusion over choosing from various interventions often adds to anxiety and depression.

Caregivers, including spouses, friends and families may also experience significant psychological turmoil while caring for a man diagnosed with prostate cancer.

We explore what and how men and those who are important in their lives can get support. We also look at the importance of the consultation–liaison relationship between medical professionals (psychiatrists, psychologists, urologists, oncologists) and men and families dealing with prostate cancer.
THE WALNUT • SPRING 2017

PCCN Ottawa

P.O. Box 23122, Ottawa, ON K2A 4E2
613-828-0762 (Voicemail)
Email: info@pccnottawa.ca • pccnottawa.ca

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  Chuck Graham
Treasurer  Jim Thomson
Secretary  Jim Chittenden

Board of Directors
Larry Peckford, Chuck Graham, Jim Thomson, Jim Chittenden, Martin de Leeuw, John Dugan, Harvey Nuelle, Lionel Burns, Dan Faber, Hal Floysvik, David Brittain, Bill Dolan
(Ex-officio member)

Key Functions
Program Director  Vacant
Peer Support Coordinator  Harvey Nuelle
Outreach/Awareness  Vacant
Volunteer Coordinator  Bernie Murphey
Communications Director  Vacant
Newsletter  Editor: Don Briscoe
Layout: Shannon King
Distribution: Andy Proulx, Martien de Leeuw
Admin Support  Mike Cassidy, Martin de Leeuw, Fil Young
Website  Peter Lindstrom
Database  Hal Floysvik
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.

PCCN Ottawa Mission Statement

We provide information on prostate cancer to those in need, gathered from a variety of sources. We participate in events that provide a venue for promoting awareness of prostate cancer through our informed member interaction at public gatherings or as speakers. We collaborate with local organizations such as The Ottawa Hospital, the Ottawa Regional Cancer Foundation, the Canadian Cancer Society, urologists and oncologists for information and support.

One Man’s Story

While each man’s cancer journey is different, there’s value in knowing what other men have gone through. Read what different men did after learning about their diagnosis and what lessons they learned along the way.

These web sites provide different perspectives in stories and videos that we hope you will find interesting and helpful.

http://www.healthline.com/health/prostate-cancer-true-stories#1
http://www.prostatecancermatters.ca/tools-resources/patient-caregiver-stories

(23 March 17) Dan Faber, the esteemed leader of our Warriors+1 group is currently quite ill and has been moved from the Ottawa General Hospital to Palliative Care at 1400 Carling Avenue. Over the last couple of years, and despite dealing with his own health challenges, Dan has successfully revived the flagging Warriors Group, turning it into one of our most unique support services. Dan is also the original inspiration behind our upcoming Prostate Cancer Conference this September, laying the initial groundwork by preparing and presenting a proposal for an Ottawa conference to the Executive Board and then working alongside committee members to get the project rolling. Dan’s tireless efforts on behalf of those affected by prostate cancer are an inspiration to everyone at PCCNO. Please keep Dan and his wife Michelle in your thoughts and prayers.
Conference:

PROSTATE CANCER
Discover the Future

Prostate Cancer Canada Network Ottawa (PCCNO) is pleased to announce the speakers and program outline for its first ever conference to be held in Ottawa, September 15–16, 2017.

Our conference goal is to recognize and promote how the inter-connected web of care across a broad spectrum influences body, mind, and spirit and helps fight this disease, extend life, and improve the overall quality of life. The conference will highlight the remarkable advances in surgical, radiation and pharmaceutical therapies, as well as the benefits of alternative and holistic approaches in the treatment of prostate cancer. With this as the backdrop for the conference, the following speakers are now confirmed.

The PCCNO has been developing the program in collaboration with Dr. Chris Morash, Head of Urologic Oncology and Medical Director of the Prostate Cancer Assessment Centre at The Ottawa Hospital. Ottawa has world class medical practitioners and researchers; our association with The Ottawa Hospital is a cornerstone to the success of the conference. Expert urologic oncology speakers will include Dr. Ilias Cagiannos, Dr. Rodney Breau and Dr. Luke Lavallee. All are nationally and internationally recognized experts in prostate cancer treatment and research and surgeons at The Ottawa Hospital. Topics that will be covered include active surveillance, technological advances in diagnosis and treatment, cutting edge research and the latest in treatment of advanced prostate cancer.

Pamela Fralick, President of Innovative Medicines Canada will deliver a keynote presentation. A proven health care leader and former CEO of the Canadian Cancer Society, Ms Fralick will highlight how the discovery, development and commercialization of innovative medicines are improving the lives of all Canadians.

The conference is oriented to examine the broad spectrum of whole person care that is available to prostate cancer patients and their families. Led by a presentation from the Ottawa Regional Cancer Foundation, conference participants will hear about its Cancer Coaching Health and Social Care Service. Organizers will have a panel join the discussion on the benefits from services that focus on the psycho-social aspects of cancer treatment.

Dr. Dugald Seely, founder and Executive Director of The Ottawa Integrative Cancer Centre’s (OICC) will speak to conference participants about how complementary cancer care offered alongside conventional treatment has become important in the care and well-being of prostate cancer patients and their families. Ottawa Integrative Cancer Centre (OICC) is the first integrative cancer care and research centre of its kind in Central and Eastern Canada.

Dr. Rob Rutledge, a Radiation Oncologist in Halifax, Nova Scotia, specializes in breast, prostate and pediatric cancers. He will deliver our final keynote address. An Associate Professor in the Faculty of Medicine at Dalhousie University, Dr. Rutledge leads the Healing and Cancer Foundation, a Registered Charity that freely offers educational videos, documentaries, and webcasting seminars. Dr. Rutledge brings a message on a mind-body approach to treating prostate cancer.

All conference sessions will feature a Question and Answer opportunity for conference participants.

Registration for the conference will take place in early April. Interested persons should monitor the PCCNO web site for details.

TELUS Motorcycle Ride for Dad

When? June 3, 2017, Ottawa
Where? Canada Aviation Museum
11 Aviation Pkwy
Ottawa, Ontario

Join in for a fun-filled day of riding with a lunch, poker run, prizes and much more all while helping to raise money to fight prostate cancer for our local community.

Don’t ride? Register as a virtual Champion, pledge a rider, make a donation to our fight against prostate cancer, or volunteer! For more information: http://www.ridefordad.ca/
Recent studies point out that 10% to 20% of men with prostate cancer are found to have clinically significant levels of psychological distress. This data comes from studies of quality of life, psychological distress, and specific psychiatric disorders.

The term “distress” is used, with the hope of decreasing the stigma associated with “psychological” problems in cancer patients and increasing awareness and treatment of psychosocial difficulties. The National Comprehensive Cancer Network (NCCN) defines distress as an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness, and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in a spiritual crisis.

Do treatment choices make a difference?

Some studies report that emotional well-being does not differ significantly with different forms of treatment. However, a recent study has shown that different forms of prostate cancer treatment are associated with significant differences in quality of life.

Men who underwent a prostatectomy or received brachytherapy reported a higher overall quality of life. Men who received radiation therapy reported a lower overall quality of life, but they also reported fewer sexual and urinary symptoms. Men who received androgen-deprivation therapy reported the lowest quality of life.

Because of the stigma associated with cancer (and with mental health issues) and widespread lack of understanding, patients are often isolated and unable to feel supported and understood by their loved ones and usual support system. Men with prostate cancer are less likely than other cancer patients to disclose their diagnosis and tend to minimize the impact of the illness on their life and need for support.

Treatment of psychosocial distress

Screening is critical identifying patients who may be having difficulties coping, could use extra support, or could benefit from a referral to a mental health clinician.

With screening comes the responsibility of evaluation. The first step in evaluation is discussion with the care providers. This initial assessment can determine the nature of the distress (having trouble with transportation, marital stresses, depression, or spiritual crises) and facilitate the appropriate referral.

In many cases, treatment of distress begins simply with a referral from the oncology team, which is usually the front line in providing supportive therapy to patients at the time of their diagnosis and throughout their medical treatment. However, other resources outside of the team, including support groups, psychotherapy, and psychopharmacology, may provide additional benefit.

As well, many hospitals and communities have support groups for men with prostate cancer. Support groups are often local groups organized by men with prostate cancer, or national groups such as the various branches of PCCN.

Men with prostate cancer face a variety of psychological challenges that begin at screening for cancer and continue beyond the completion of treatment. Substantial levels of anxiety and depression are present in these men, and this distress should be screened for and treated. Being aware of these challenges may help men to communicate with their health providers and explore support options.
Support Groups

As most readers of the Walnut know, the Prostate Cancer Canada (PCCN) provides a network of local, independent support groups. Group work includes monthly meetings, one-on-one hospital visits, newsletters, awareness sessions, parades, and presentations at health fairs and service clubs like Rotary, Lions and other community organizations. Our local groups enjoy excellent relationships with medical professionals in their community and these men and women give freely of their time and present timely talks to help educate and consult.

While prostate cancer is exclusively a male disease it sometimes has a profound impact on the family unit. Many groups recognize this and facilitate special meetings for women only. These small meetings allow women to share their feelings and concerns in a non-threatening, intimate manner.

In many communities, other kinds of groups can also provide support for men with prostate cancer and their families. These can include religious, service clubs, and community organizations of various types.

Interestingly, groups that provide opportunities for exercise have been shown to be helpful as well.

As a recent article in the Oncology Journal states, participating in supervised group exercise programs not only improves prostate cancer patients’ physical and mental well-being but also provides them with much-needed emotional and social support, according to the results of a recent study.

“Exercise represents an intervention that uniquely fits with traditional masculine characteristics, and is also action-oriented and requires physical prowess,” the authors wrote. “The unique environment of a supervised exercise program provides considerable improvements in health and well-being, as well as extensive psychosocial support, in a manner that is highly acceptable to men with prostate cancer.”

Humour was a key element in fostering a supportive environment, as men felt more comfortable disclosing difficult information or concerns through the use of jokes and lighthearted banter, the authors said.

“Men noted the development of strong camaraderie with other participants, which motivated participants’ continued engagement with the program.” Findings such as this suggest that group exercise programs should be incorporated into supportive care services for men with prostate cancer.

(Source: http://www.cancernetwork.com/oncology-nursing/prostate-cancer-patients-find-support-group-fitness-classes)

A support group affiliated with PCCN is the TrueNTH, a Movember initiative. The goal of their Lifestyle Management Program is to ensure prostate cancer survivors across Canada have access to health professionals and resources needed to live balanced, active lives.

They provide a Canada-wide network of men, and provide information and programs on local physical activity, nutrition, and stress-reduction community programs and wellness professionals.

They offer a health library of resources and interactive, online programs to help track and monitor your healthy living, and provide support through a “circle of care” to keep you motivated.

At our PCCNO meeting on March 16th, Chad Hammond from the Canadian Hospice Palliative Care Association (CHPCA) spoke about Advance Care Planning and their latest initiative, “True NTH Advance Care Planning: Support for Men with Prostate Cancer, their Partners, Families and Caregivers”. Highlights from his talk will be featured in the summer 2017 issue of The Walnut. That issue will focus on “Values and preferences as part of treatment decisions”.

“Men noted the development of strong camaraderie with other participants, which motivated participants’ continued engagement with the program.” Findings such as this suggest that group exercise programs should be incorporated into supportive care services for men with prostate cancer.
For some men, it can be difficult to share their feelings and concerns when it comes to dealing with prostate cancer. In fact, in a survey conducted by the Association of Oncology Social Work, about 50% of men with prostate cancer reported that they kept their diagnosis and their treatments secret, and 59% are concerned about being a burden to their families.

It is important as a caregiver that you give the senior male in your life an opportunity to talk — if they would like to — about their fears and concerns about their cancer. Not everyone will want to talk about it, but knowing that they can in a nonjudgmental way can make a big difference.

One issue many senior men have is that they feel their doctors are not as concerned with the level of discomfort that will be experienced when selecting treatments as they are. As a caregiver, you can play a role in the doctor / patient dynamic by attending doctor visits and, if needed, voicing concerns your loved one might feel too uncomfortable mentioning.

Finally, a vast majority of prostate cancer patients, 78% wish that those around them understood better what they are experiencing and how the treatments affect them.

Read more: http://www.griswoldhomecare.com/blog/prostate-cancer-from-the-perspective-of-older-men-and-caregiver/#ixzz4UtVliif00

Survey Results

Key Points
Almost half of surveyed patients reported that they keep silent about their prostate cancer and treatments, and 59% are concerned about becoming a burden to family and friends, compared to 43% of respondents who have the same level of concern about dying.

Caregivers who participated in the survey expressed a high degree of stress associated with their roles and reported being more concerned about helping their loved one cope than they are about their own physical and emotional health.

Both sets of respondents reported being overwhelmed by the volume of information available to them, suggesting the need for navigation tools that will help guide patients and caregivers to information that is most relevant to them.
We appreciate the following article from Dr. Nick Paterson from The Ottawa Hospital, who shares his own recent experience as a patient, having undergone surgery himself. Some valuable insights!

As a surgical resident physician, I spend a good chunk of my days explaining to patients what to expect after surgery. Those words never took too much meaning until I found myself on the other end of the knife undergoing an emergency abdominal surgery. I’ve tried to compile a few tips to help troubleshoot some of the common hurdles right after a surgery.

**Discharge:** There are a few “milestones” we like to see patients reach prior to being ready to go home. These include: pain that is well controlled on oral pain medications, the ability to eat a full diet, bowels that have woken up and are passing gas or stool and being able to get around at least enough to transfer yourself around from the couch to the bed.

Once you are set for discharge, make sure you have all the necessary information. The most important considerations are:

- Symptoms that should prompt you to come back to hospital for reassessment
- Which new medications are being prescribed – if you do not have insurance/drug plan and finances are tight, this is a good time to speak up. Cheaper alternative medications can sometimes be substituted
- Any restrictions or limitations in physical activity
- If you need a work/sick note, now is the time to get one
- What scheduled follow up has been arranged and the contact information for that office

- If there any written handouts or information sheets that are given out

Once at home, every day gets a little easier than the last... but the first few are the hardest.

**Pain:** Everyone experiences pain differently. At the beginning, the pain plays an important role to let our body know we need to rest and heal those tissues. Who knew you used your core for just about every movement? Managing the pain is best done using a stepwise approach with different classes of medication. You will often have a prescription for opioid pain medications such as hydromorphone or morphine. Consider these last resort drugs. Start with Tylenol and Advil around the clock while you are awake every 4-6 hours and supplement with the heavier stuff as needed. Climbing “up the ladder” ensures you get better pain relief as certain drugs work together synergistically and you avoid the side effects of the more intense pain killers. If you can stay ahead of the pain by regularly taking the lighter medications, you will not need to use as much of the heavy stuff.

**Swelling:** After trauma to the tissues, the body sends in all sorts of healing cells to the area which cause fluid shifts in the tissues so you can expect to feel a few months pregnant. It can be leftover air in the belly from laparoscopic (camera, small incisions) or normal postoperative fluid accumulation. This will typically start to resolve after the first few days. Ice or heat pads can help relieve some of the discomfort associated with the swelling. Loose clothing will be your best friend.

**Bowel movements:** Opioid or narcotic pain medication are notorious for causing constipation. The easiest things that you can control yourself are maintaining adequate fluid intake and fibre in the diet (think fruits, vegetables,
whole grain products, beans etc.). On top of this you may have a stool softener prescribed. Prune juice is a safe natural alternative with laxative properties. Products such as Restoralax (PEG) or Dulcolax are available over the counter. Being on the looser end for the first few days will make life a lot easier as you will not have to strain and engage those sore core muscles.

**Dressings:** These are normally okay to come to come off on the second or third day and let air dry any incision area. You may have staples which come out in around 2 weeks by either your surgeon or family doctor. You may have small incisions closed with dissolvable sutures and Steri-strips on top. The Steri-strips tend to fall off on their own but if they are still on after 7 days, pull them off gently after a warm shower.

**Limitations:** These will be different depending on the extent of the surgery but a good rule of thumb is that you should be off 1-2 weeks completely and after that only return to light duties that don’t require any physical exertion. For 4-6 weeks after surgery it is important not to lift items >10lbs as this can cause increase strain on the sutures that were used to close the abdominal muscles/fascia. Ignoring this recommendation can cause tearing of these structures which can lead to bothersome hernias (and possibly more surgery) down the road.

**Tips for the first few days:**

- A cane or walking stick nearby will help prop you off the couch
- Bring a pillow to the toilet to brace against your abdomen if you need to strain
- Have a good collection of movies ready to roll. I went with Band of Brothers; watching soldiers endure the hardships of WW2 from an artillery-riddled foxhole during the middle of winter in Bastogne helped put things into perspective
- Get out of the hospital as soon as it is safe to; the creature comforts of being home go a long way
- Be as active as your body lets you. Go for small walks, take some deep breaths, gently stretch and even standing will help promote recovery
- Your back may be sore the first week or so as it must work overtime to compensate for the lack of engaging your abdominal muscles. Don’t be alarmed. Ice, heating pads and gentle stretching or massage can help a lot.

Nick Paterson, MD, Urology Resident, The Ottawa Hospital

---

**In the Next Issue**

**Summer 2016: Values and Preferences as Part of Treatment Decisions.**

Patient centered care that encompasses informed decision-making can improve treatment choice and quality of care. Assessing patient treatment preferences is critical for developing an effective decision support system for men diagnosed with prostate cancer.

In this issue, we explore how vital it is that treatment and care take into account the individual needs, preferences and values of men diagnosed with prostate cancer. We explore the importance of conversations around goals of care, in particular when a man’s condition changes or advances.

---

**Share Your Story**

The Walnut will be focusing in an upcoming issue on Caregivers: the role of family, friends and others in our lives who provide care and support.

Knowing about other people’s personal experience of prostate cancer can be a source of support and inspiration for others.

How do you provide support, and what has the impact been on families and friends?

How have you found support for yourself to be able to continue the crucial and sometimes difficult roles you play?

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

What do you wish you had known at the outset of your caregiving journey?

Contact us at thewalnut@pccnottawa.ca and we will include your stories in the caregiving issue of The Walnut!