

# The Walnut



NEWSLETTER OF PROSTATE CANCER CANADA NETWORK OTTAWA  
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SUMMER, 2017

## Values and Preferences as Part of Treatment Decisions



**U**nderstanding and assessing patient values and treatment preferences is critical for both health care providers and for men diagnosed with prostate cancer.

Patient centered care that encompasses informed decision-making can improve treatment choice and quality of care.

In this issue, we begin with a look at the “big picture” of values and our health system. We also explore the perspectives of health care providers, and how vital it is that treatment and care take into account the individual needs, preferences and values of men facing treatment decisions. We encourage you to explore the importance of conversations around goals of care, in particular when a man’s condition changes or advances. ■

### 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!** • 21 September 2017 •  
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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Outreach/Awareness	Vacant
Volunteer Coordinator	Bernie Murphey
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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.

**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.

# Patient-Centred Care

What does it mean to be patient-centred? Many of us have heard the term, but what does it really mean? And what does it have to do with values and preferences in the provision of health care?

Research conducted by the Picker Institute and Harvard Medical School provides some insights, and emphasizes the need to consider values and preferences in treatment choices.

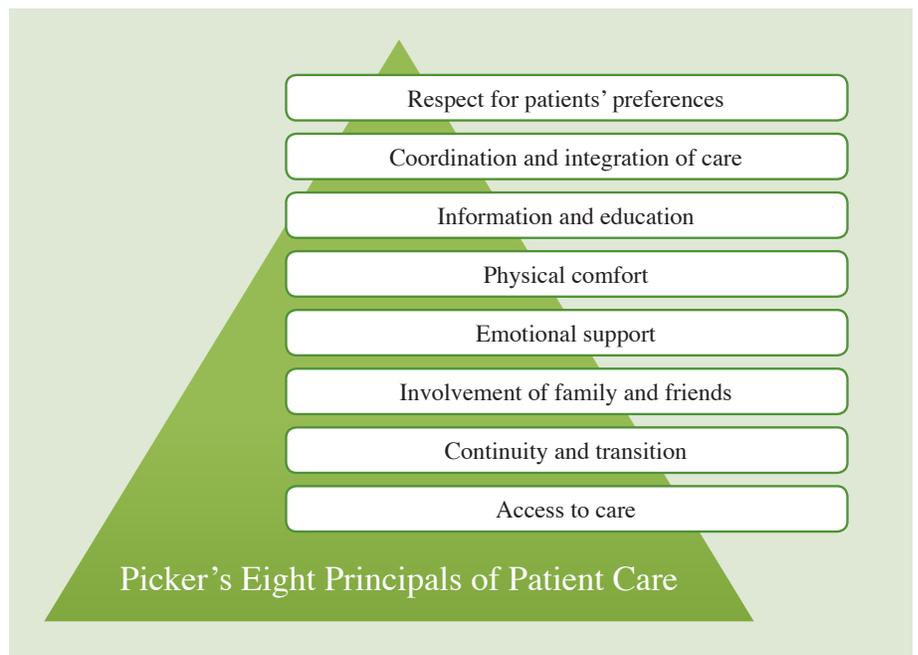
## Defining Patient-centred Care

Patient-centred care is the practice of caring for patients (and their families) in ways that are meaningful and valuable to the individual patient. It includes listening to, informing and involving patients in their care. The IOM (Institute of Medicine) defines patient-centred care as: “Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.”

Using a wide range of focus groups—recently discharged patients, family members, physicians and non-physician hospital staff—combined with a review of pertinent literature, researchers from Harvard Medical School, on behalf of Picker Institute and The Commonwealth Fund, defined seven primary dimensions of patient-centred care. These principles were later expanded to include an eighth—access to care.

Number one in their definition is “Respect for patients’ values, preferences and expressed needs”, which they describe as: “Involve patients in decision-making, recognizing they are individuals with their own unique values and preferences. Treat patients with dignity, respect and sensitivity to his/her cultural values and autonomy.”

Their patient centred care model is illustrated here, and more information is available at: <http://www.oneviewhealthcare.com/the-eight-principles-of-patient-centered-care/> ■



# Upcoming Events

## PROSTATE CANCER

*Discover the Future >*

### Registration now open!

Prostate Cancer Canada Network Ottawa (PCCNO) will be hosting a Prostate Cancer Conference September 15 -16 to be held at the Ottawa Conference and Event Centre, 200 Coventry Road, Ottawa.

Join us to explore the interconnected web of care that influences body, mind and spirit. We will showcase the remarkable advances in surgical, radiation and pharmaceutical therapies and examine the role of alternative and holistic approaches in cancer treatment.

This event will:

- ▶ Demonstrate the progress in prostate cancer treatment and research
- ▶ Provide a forum to enrich prostate cancer practices and innovation
- ▶ Discuss transformative technologies in prostate cancer treatment

The conference begins on **Friday evening, September 15** with registration and an opening reception. On **Saturday, September 16** we will have a full day program with a catered breakfast and lunch. This will be an exceptional learning opportunity! For more details: <http://pccnottawa.ca/news/2017-pccno-conference-agenda>

## PCCNO Annual BBQ

Please join us for our annual event!

Everyone welcome – your wife, partner, significant other, friends and family. Lawn chairs a good idea!

**When?** 16th June, 2017 starting at 4:00 pm; food served from 5:00 pm

**Where?** [Maplesoft Centre](#), 1500 Alta Vista Drive at Industrial, across from Canada Post.

**RSVP** to [events@pccnottawa.ca](mailto:events@pccnottawa.ca) to advise if you and a guest(s) are coming, and to tell us your preference of burgers for each. Burgers, beverages, and snacks will be supplied by PCCNO. The grill team is raring to go! ■

# Past Events

## Harvey Nuelle awarded the Sovereign's Medal of Honour



As part of National Volunteer Week, Her Excellency Sharon Johnston and His Worship Jim Watson, Mayor of the City of Ottawa, presented the Sovereign's Medal for Volunteers to 64 exceptional volunteers from Canada's Capital Region during a ceremony at Ottawa City Hall, on April 28, 2017.

The Sovereign's Medal for Volunteers recognizes the remarkable volunteer achievements of Canadians from across the country in a wide range of fields. As an official Canadian honour, the Medal pays tribute to the dedication and exemplary commitment of volunteers.

Harvey Nuelle (on the right in this photo), PCCNO Director and Peer Support Coordinator, has been active for many years with the PCCNO, mentoring and supporting those newly diagnosed. As well, he has volunteered for more than 15 years with the Bruyère Continuing Care Helpline, an outreach service that promotes independent living for vulnerable individuals living alone in Ottawa and the Outaouais areas. ■

# Preferences, Values and Histories



In an essay in Longwoods publishing, “Advancing the Art of Healthcare through Shared Leadership and Cultural Transformation”, the authors talk about how the most effective delivery of healthcare is founded on a holistic view of the patient as a unique individual who needs to be recognized as such.

They make some thoughtful and thought-provoking points. See full article at: <http://www.longwoods.com/content/23770>

A holistic perspective entails acknowledging the values and knowledge that each person involved in a healthcare encounter brings to that situation, including the patient, their family members and their care providers, all of whom should be allowed to speak and be heard.

This view requires a re-visioning of the relationships among all people involved in a healthcare encounter as integral to that encounter, with the patient and their experience at the centre, as the focus of concern.

## Viewing patients as more than the sum of their symptoms.

In 1904, pioneering Canadian physician Dr. William Osler wrote... “It is much more important to know what type of patient has a disease than what sort of disease the patient has.”

Patients have preferences, values, and histories that need to be acknowledged and respected.

They also have families, live in communities, and contribute to society. The system of tomorrow needs to see the whole patient, recognize their place within their family and community, and link them to the resources they need for maintaining their health – regardless of whether those are within or outside of the formal health system. Expanding our view of health services to encompass a more multi-disciplinary, community-based model is one way to help support the treatment of whole patients.

## The importance of relationships

“Healthcare is a touch business. It’s all about relationships.” (Macleod et al. 2013)

In the relationship between patients and care providers as it typically exists today, there is a significant imbalance of power. A patient, coming under the authoritative care of a health professional, may feel vulnerable and ill equipped to advocate for herself. This is a time when the patient experience should be of primary concern for the healthcare provider.

“When you enter a doctor’s office or hospital there is a profound shift in power. You give up your body and power to a team of professionals, a team of strangers. This experience is quite different than any other service sector where you have the power to walk away and never return. In a healthcare environment, you don’t get to vote with your wallet... More than just “fixing” the immediate “complaint,” patient empowerment involves taking the initiative to advise patients - how to best manage their condition(s) and the risks and symptoms they may encounter from complications.” (Cox and MacLeod 2014)

Addressing this power imbalance starts with putting ourselves into the position of the other, establishing a relationship of mutual trust and respect. Communication is key and must be encouraged and allowed to occur freely in both directions, with multiple opportunities for feedback. Patient engagement or communication is a vital process that must be built into the everyday operation of our healthcare system.

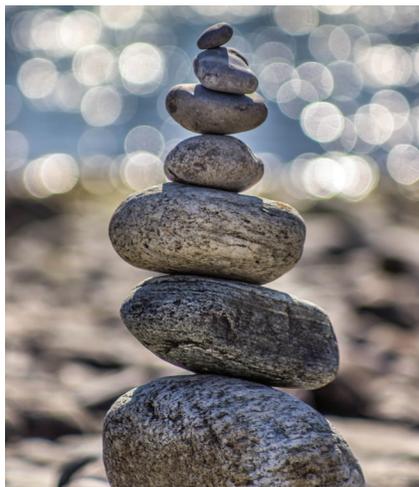
The authors, Cox and MacLeod state: “Far too many healthcare organizations view patient experience as (just) making and keeping patients happy. This misses the point – patient experience is also about a hospital’s philosophy for the delivery of care.” ■

# Making the “Right” Health Care Decisions: Why Values Matter

Adapted from: <http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000136>

Shared decision making in health care can be defined as the process of “...defining problems, presenting options, and providing high-quality information so patients can participate more actively in care...” This model of decision making is rooted in several core principles of medical ethics, but perhaps most strongly that of patient autonomy.

Autonomy—the right to self-determination—entails a process of informed and meaningful consent to the care a patient is to receive. The idea of informed consent clearly goes beyond a simple procedure of form-filling, and requires that the nature of an intervention, the potential alternatives, the likely risks and benefits, and the implications are clearly laid out and mutually understood before a patient and clinician can agree on the course of action to be undertaken. In a Policy Forum published in *PLoS Medicine*, Michael Wilkes and Margaret Johns set out four characteristics of the types of decisions that best lend themselves to shared decision making: those where “effectiveness of the outcome is uncertain; ... where the risks and benefits are sizeable or nearly equal; ... where the patient is able and willing to participate; ...[and] where the patient can understand the trade-offs.” An obvious requirement for the fourth characteristic—the understanding of trade-offs—is that a patient interprets data regarding risk and can integrate that data into their own system of values.



## Framing the data

A key challenge, however, to the premise of shared decision making is the observation that a patient’s choice of their preferred treatment will change *depending on the way that key data are presented*. For example, survival data can be represented in a “positive frame”—chance of survival—or a “negative frame”—chance of dying. A patient’s choice regarding treatment options will change, depending on which type of presentation is given, even if the actual data are equivalent. However, little research has been done to explore the dependencies between the way that key statistics are presented, and a patient’s choice in relation to their own prior values.

In order for shared decision making to support patient autonomy, health care providers must recognize the role of their own values and understand and respect those of the patient, in the decision that is ultimately made. ■

## Values and Men with Prostate Cancer

### The healthcare provider perspective

Clinicians face some very big questions when making treatment decisions: How can we find ways to support the incorporation of patient values into treatment discussions and decisions? How can we identify what is important to each patient when making healthcare decisions? How do we establish patients’ treatment preferences in the doctor-patient relationship? How can we support men to clarify the personal beliefs that make certain aspects of any one treatment more or less attractive?

### The patient perspective

Men who are diagnosed with prostate cancer also face some very big questions, especially when looking into the sometimes bewildering constellation of treatment options. Most of these options provide similar chances of survival, so the optimal choice for any particular individual is crucially dependent on the strength of his preferences for various clinical and non-clinical treatment characteristics. As part of informed decision making to choose the “optimal treatment”, men need to examine their values and preferences when faced with these difficult choices.

*How clear are you on what values matter most to you? How have you discussed and established your preferences and priorities in your relationships with doctors and other health care providers? PCCNO and The Walnut would be interested in hearing your thoughts, perspectives and stories on this important topic.*

# Cancer Care and a Person – Centered Perspective



## Why measure this?

In people with cancer, distress is generally defined as an unpleasant emotional experience or experiences. It is related to psychological, social, spiritual, practical or physical concerns that may negatively affect a person's ability to cope with cancer and its treatment. Late identification of distress in cancer patients has been associated with negative outcomes, including poorer adherence to treatment recommendations, lower levels of satisfaction with care and poorer self-reported quality of life.

Screening for distress at various points in the patient journey can be useful in customizing interventions that address patients' changing needs, which may improve quality of life.

## Why do these findings matter?

Routine screening for distress can help identify cancer patients' psychological, social, spiritual, practical or physical concerns. The **Edmonton Symptom Assessment System (ESAS)** is the most frequently used self-report screening instrument in Canada. It measures nine commonly reported symptoms (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, lack of well-being and shortness of breath). Another tool in common use to screen for problems or concerns of cancer patients is the **Canadian Problem Checklist**.

To have a positive impact on patient well-being, screening must be accompanied by adequate follow-up and intervention as required (e.g., further assessment, change in care plans, physical and psychosocial intervention, referral to another practitioner and ongoing monitoring of symptoms). ■

The Canadian Partnership Against Cancer (<http://www.partnershipagainstcancer.ca/>) is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. The Partnership works with cancer experts, charitable organizations, governments, cancer agencies, national health organizations, patients, survivors and others to implement Canada's cancer control strategy. They recently produced their seventh *Cancer System Performance Report* measuring cancer system performance across Canada.

Chapter 5 of the report, "Person-Centred Perspective" talks about how, in recent years, there has been an emphasis on transforming the health system from delivering disease-centred care to a more person-centred model. An excerpt follows; the full report is available at: <http://www.systemperformance.ca/reports/>

The core components of person-centred care are dignity, respect, communication and information sharing, collaboration and participation. As it is currently defined within the health care system, person-centred care is driven by the individual needs, values and priorities of those receiving the care and their families/caregivers, within the parameters of clinical evidence and quality. Embedding the person-centred perspective into cancer care involves intentional planning and delivery of care based on the experiences and perspectives of people affected by cancer.

## Screening for distress

In particular, the report talks about the use of a standardized "screening for distress" tool. The introduction of this measurement tool is the initial step in identifying distress and implementing an appropriate response to the distress scores. This type of program reflects efforts within provinces to achieve more person-centred cancer care.

# Values in Health Care



**H**ealthy Debate [www.healthydebate.ca](http://www.healthydebate.ca) is a Canadian web site led by a team that includes patients, doctors, nurses, pharmacists, paramedics, physician assistants, journalists, business leaders, managers, policy advisors and researchers.

Their mission is to provide accurate, accessible information about health care to the public, practitioners, journalists, students, managers and policy makers. In their [Opinions](#) section, Dr. Mark McLeod, an orthopedic surgeon and the past president of the Ontario Medical Association, shared his thoughts about the importance of values in our health care system. It starts this issue's exploration of values. See excerpt below; you can find his complete article here: <http://healthydebate.ca/opinions/values-in-health-care>

The language of health care has had dramatic change – we now commonly use terms like patient centred care, quality outcomes, accountability, and so on in our description of a current or desired state for health care systems and the delivery of care.

One discussion I do not hear frequently enough is a discussion of values in health care. I'm not talking about values of individual patients or values of practitioners or values of funders, but a discussion of the values of the health care system itself. The values that determine how we conduct ourselves as a system, how we make difficult decisions, and how we approach the increasing number of dilemmas our system faces.

Our system doesn't really have clear values. The Canada Health Act lays out five conditions for federal funding of health care (public administration, comprehensiveness, universality, portability and accessibility), but these aren't values, they're legal conditions for the transfer of dollars.

I'm also not talking about value for money, nor the need to work within fixed funding envelopes or adhere to budgets; these are not values, they are constraints within which our values must operate. Instead, values help us determine whether we want a hospital-based health care system.

*See Values in Health Care on page 8*

## In Memoriam

### Don Atkinson

ATKINSON, D.G. (Don) Retired Colonel, RCAF/Canadian Forces. PCCNO member since 1991.

With family by his side, Don passed away on November 19, 2016 at the age of 86. Don was born and raised in Saskatchewan, where he studied at the University of Saskatchewan, graduating with a B. Comm. He subsequently earned an M.B.A. at Michigan State University. He spent 34 years in the RCAF/ Canadian Forces, serving in a number of locations across Canada, and in Germany, Africa, and the USA.

### Daniel James Faber

PCCNO member and leader of the Warriors + 1 support group. Dan died peacefully in the presence of his wife, Michelle née Boisvert Faber, at Ottawa, Ontario on Thursday, May 4, 2017, at the age of 84 years. He was married to Joanne née Stenson Faber for 54 years.

He was member of the American Military for a period of four years while completing his Masters Degree in the state of Rhode Island. After graduating from the University of Wisconsin with a Ph.D., he began his biological career which included ground breaking research through the Ontario Department of Lands and Forests, the National Museum of Natural Sciences and was appointed scientific director of the Canadian Oceanographic Identification Centre (COIC) which included the development of the Faber Light Trap. He has received the Commemorative Medal for the 125th Anniversary of the Confederation of Canada from the Governor General. Many PCCNO members attended his memorial service.

Of course we already have a large, expensive, hospital based system and those practices, as much as the hospitals themselves, are solid, difficult to repurpose or change, and have been created at great expense. Clear shared values can help us with the enormously difficult task of changing course, if that's what we decide needs to happen.

I think we need a thoughtful discussion of values, where we clearly articulate shared values that we can rely on to inform decision making, can assist us to cut through the morass of conflict when encounter difficult or troubling decisions, and can use to backstop our decisions when we have made them.

This discussion won't be an easy one. It transcends individual preferences, political demands, provider wants – all of them.

If we do not start defining the values of the health care system, the courts will make the decisions. We have seen the courts intervene in a number of circumstances and those decisions, independent of the reasons for their original filing, and independent of the benefit to the patient, may or may not be helpful or healthy for the health care system. ■

## The Patient as Person — and as Stakeholder

An excerpt from an article by Bob Tufts, presenting his thoughts from the perspective of a cancer patient. He stresses the importance of engaging patients in treatment decisions, and take into account their values and priorities.

Source: [http://www.huffingtonpost.com/bob-tufts/the-patient-as-person-and\\_b\\_5448281.html](http://www.huffingtonpost.com/bob-tufts/the-patient-as-person-and_b_5448281.html)

“We want to be treated as individuals, not as mere data points. We want it acknowledged that many of us can and will live beyond mathematically estimated standard deviations on a computer's spread sheet. There is no average cancer, treatment, response or recovery. Treatments that “only” slightly improve life span for some may drastically increase the life span of others. We patients will fight, survive, thrive and contribute to society thanks to transformative and incremental innovations in medical care. And we know that even these small changes will result in further advances... We want to be involved when ethics and the edges of life issues are discussed.” ■

## In the Next Issue

### 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. And 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.

## Share Your Story

**The Walnut** will be focusing in an upcoming issue on 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](mailto:thewalnut@pccnottawa.ca) and we will include your stories in the caregiving issue of **The Walnut!** ■