



PCCN REGINA PROSTATE CANCER SUPPORT GROUP INC. NEWSLETTER

The purpose of PCCN Regina is:

1. To increase awareness, knowledge and understanding about prostate cancer in the community we serve.
2. To arrange and conduct regular monthly meetings.
3. To provide education sessions and information to prostate cancer survivors, their families, friends, and the public.
4. To provide for sharing of experiences and concerns.
5. To provide counseling services these counseling services do not include recommendations for treatments, medicines or physicians.
6. To promote courage and hope.
7. To co-operate with other cancer agencies in the fight against cancer.

Our next meeting is on Thursday April 13, 2017

Speaker - Dr. Venugopa from the UofS returns to give us an update on the PCa research project we are partially funding.

Time:

The meeting will start at 7:00 p.m.
and will end at 9:00 p.m.

Place:

Canadian Cancer Society building
located at 1910 McIntyre St, Regina.

McIntyre St. is the next street East of
Albert St. 1910 McIntyre is between
Victoria Ave. and 12th Ave.

Meeting room is on the 2nd floor.

Free evening parking along
McIntyre Street.

Visit our website!

www.pccnregina.ca

Our Mailing Address:

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REGINA, SK S4S 7K4

Please email us at pccn.regina@gmail.com if you have any questions.

PROSTATE HEALTH



Prostate Cancer Treatment: When to Wait

There is an ongoing debate in medicine about whether to treat prostate cancer that is very-low risk to low risk. For men older than 75, who are more likely to die of other causes, the decision is fairly straightforward. But some experts believe that most other men—even if they have low-risk disease—should be treated to eliminate any chance of future cancer progression and possible metastasis.

However, now that large clinical trials have demonstrated the lack of benefit in treating older men with favorable-risk cancer, a growing number of doctors—myself included—believe that a man diagnosed with low-risk cancer over the age of 65 to 70, or any man with serious health issues, should seriously consider surveillance as one option.

During active surveillance, a digital rectal examination, [prostate-specific antigen (PSA) test], and periodic biopsies are used regularly to monitor prostate cancer progression. If these tests ever indicate that cancer is progressing, treatment—surgery or radiation therapy—may be warranted.

A Common Cancer

Prostate cancer is a very prevalent cancer. Doctors know that most men over age 70 harbor some cancerous cells in the prostate. Because the PSA test is not specific for prostate cancer, many of these malignancies are uncovered when a prostate biopsy is performed for a PSA elevation that is unrelated to cancer. I call this serendipity. We also know from countless studies and autopsy reports that most of these small cancers will not cause harm during the lifetime of the patient.

It has been estimated that from 30 percent to 50 percent of prostate cancers detected today with PSA testing would not have been discovered during the patients' lifetime if a biopsy had not been performed. Treating these cancers cannot prolong life but only reduce its quality. If we treat every man that we find to have prostate cancer, overtreatment rates will continue to be unacceptable.

An alternative approach is to recognize that carefully selected men can be monitored, and if their cancer changes, treatment can be undertaken at that time. That is the thinking behind active surveillance as it is practiced at Johns Hopkins and other urology centers around the world. This approach is gaining more interest in the medical community because of the realization that prostate cancer is being overtreated.

Cancer Fears

Prostate cancer has a long, protracted course in most men. Today, in the United States, with widespread PSA screening of men who are free of any noticeable symptoms, prostate cancer is being detected at an extremely early stage in the natural course of the disease.

When compared to men whose cancers are detected the old fashioned way, without PSA screening, most of the cancers discovered today by PSA are of low to moderate risk and unlikely to result in death from prostate cancer in 10 to 15 years if left untreated among men over the age of 65—especially those with other health problems, such as hypertension and cardiovascular disease.

Still, in the absence of definitive tests that can guarantee a man that his cancer will not progress, most men today—even those whose age gives them a life expectancy of less than 15 years—want a solution to their cancer problem. Fearful that cancer will take their lives, they head off to the hospital or radiation center to undergo treatment for their prostate cancer—even though the risks of treatment far surpass the risks posed by the cancer.

It's the fear factor at work. Everyone fears cancer, and no one wants to die from it, so most men will take a pass on active surveillance. They want the cancer out (surgery) or stopped in its tracks (radiation).

Benefits of active surveillance:

- The side effects of surgery or radiation therapy can be avoided.
- Small, indolent cancers do not receive needless treatment.
- Quality of life is retained.

Potential disadvantages:

- Increased anxiety due to living with untreated prostate cancer.
- The need for frequent testing, including digital rectal exam, PSA, and biopsy.

- The uncertain possibility that the cancer will progress or metastasize before treatment can begin and the window for cure will be lost.
- If treatment is eventually needed, the cancer might be more difficult to treat later on.

What Patients Ask

To follow are answers to questions that I regularly get from patients recently diagnosed with prostate cancer who want to know about active surveillance and whether it is a course of action that they should consider.

Q. Who should consider active surveillance for prostate cancer?

A. Active surveillance is an acceptable alternative for carefully selected older men (typically 65 and older) who want to monitor their cancer rather than undergo immediate surgery or radiation. Even though these men have curable disease, they understand that it does not have to be cured right now. Instead they take an alternate course of active surveillance and regular testing, deciding to live with an uncertain future while still maintaining a high quality of life, free from any side effects of cancer surgery or radiation.

Q. Who are the ideal candidates for active surveillance for prostate cancer?

A. There is disagreement among physicians about who are the ideal candidates for surveillance. However, to ensure maximum safety, at Johns Hopkins we recommend this approach mostly for men who have a very-low-risk cancer and are, in general, older than 65. Johns Hopkins pathologist Dr. Jonathan Epstein originally classified very-low-risk prostate cancers as small (less than 0.5cc) and low grade (Gleason score 6 or less) and likely to be present if they have the following features:

- Stage T1c
- PSA density (PSA divided by prostate volume) is below 0.15
- No more than two cores with cancer
- No core with more than 50 percent cancer involvement

Many experts are recommending an MRI (magnetic resonance imaging) of the prostate as an additional means of insuring that no larger more aggressive cancer was missed on a prostate biopsy prior to entering surveillance. However, the value of this is yet to be proven.

A low-risk prostate cancer is defined as:

- Stage T1c or T2a
- A PSA less than 10.0 ng/ml
- A Gleason score of 6 or less

Together, very-low-risk and low-risk prostate cancer are referred to as favorable-risk prostate cancer.

I believe that the safest candidates for active surveillance are men with very-low-risk disease—unless an individual's life expectancy is limited by other health issues, in which case a man's higher-risk disease may also do well with surveillance. But for a man over age 65 who wishes to avoid treatment, studies show that harm is not likely over 15 years without treatment if favorable-risk prostate cancer is present.

In my practice, men with very-low-risk prostate cancer and a life expectancy of less than 20 years are ideal candidates for surveillance. Those with low-risk prostate cancer who have a life expectancy over 15 years can consider surveillance as one option, while men with a life expectancy below 15 years should consider surveillance as a leading option.

Likewise, surveillance should be the recommended strategy for any man in poor health with favorable-risk prostate cancer and a life expectancy of less than 10 years.

Q. What factors should be considered before deciding on active surveillance for low- risk prostate cancer?

A. If you are considering active surveillance, you should first review all other options carefully and understand their benefits and drawbacks. Understand, too, that active surveillance entails close monitoring by a physician on a regular basis. In the Johns Hopkins program, we monitor men with regular PSA measurements and a digital rectal exam twice yearly, as well as an annual or eighteen-month prostate biopsy up until the age of 75.

It goes without saying that if you decide to be monitored, you must stick to the recommended surveillance schedule. Just as important, active surveillance also requires that a man be able to live with the idea that he has cancer and will require long-term testing.



Prostatectomy and Incontinence: What to Expect

Many men, upon receiving a diagnosis of prostate cancer, fail to register anything else their urologist tells them. Thoughts of impending death block out any additional information provided. And if they are to undergo surgery, many men focus on ED as the major complication of radical prostatectomy.

But recovery of urinary control is far more important. If that happens slowly, or never happens at all, incontinence will cast a far greater shadow on their lives than impotence would. Hence, many men are surprised and embarrassed by the urinary incontinence they typically encounter following prostate surgery.

Prostate surgery is a shock to the system, and incontinence—the inability to contain urine—affects both quality of life and self-esteem. Although the incontinence itself isn't life threatening, the stigma attached to wet clothing and offensive odor can have profound consequences that may lead to humiliation and social withdrawal.

Causes of Incontinence

The reason incontinence develops is because the healthy tissue responsible for urinary control is at high risk during a prostate procedure due to its nearness to the prostate itself. Surgically removing the prostate entails separating the part of the urethra that passes through the prostate at the point where it joins the remaining sphincter located just downstream. It also may mean removal of part of the sphincter muscles when the tumor is extensive and possible damage to the nerves that control sphincter action if the operation is difficult to perform because of prostatic size or variations in anatomy.

Depending on how extensive the tumor is, the surgeon may also remove tissue at the bladder neck, which adjoins the prostate. The bladder neck is a tapering ring of muscles that act as shut-off valves, and these muscles funnel down to the urethra and can affect how well the new connections between the bladder and the urethra form. Experienced surgeons are certainly aware of these technical aspects of the surgery and generally keep this in mind when counseling patients about the relative safety of radical prostatectomy as opposed to other forms of treatment for the disease.

After the prostate has been removed, the surgeon reattaches the bladder to the urethra. When the sphincter has been damaged, it remains partially or fully open after healing is complete. Even when the surgery is performed expertly, there may be strain or damage to these muscles and leakage can result.

After Surgery

After almost all prostate surgeries, a urethral catheter is left in place for a few days to a few weeks, depending on the type and nature of surgery. In the first few weeks after removal of the catheter, most patients will experience temporary urinary frequency and incontinence. It doesn't matter whether a robot or a scalpel was used in the surgery. No one escapes from some degree of urinary leakage. A few drops of urine may leak out after getting up from a chair, during a walk in the park, or after lifting a bag of groceries. This is called stress incontinence. Others experience urgency—the sudden need to urinate—with many leaking uncontrollably before making it to the bathroom. A small subset of men experience a combination of stress and urge incontinence.

How common is incontinence following a radical prostatectomy? At medical centers of excellence, incidence of serious incontinence appears to be low, in the 3 percent range. However, if you look at overall national patient survey data, the incontinence numbers are dramatically higher, in the range of 50 to 60 percent.

When Incontinence Persists

Most incontinence, fortunately, is temporary. As the pelvic floor that supports your bladder heals and the external sphincter muscle that controls urine flow becomes more efficient, continence typically returns within a few weeks or months after catheter removal. (Even at this early stage, it is important that your doctor exclude two treatable conditions—urinary tract infection and urinary retention—that may be causing the problem.) The time frame varies, depending on the extent of the surgery, your age, and the surgeon's experience in rebuilding the urinary tract and preserving the urinary sphincter.



Should You Have a Repeat PSA Test?

If your doctor suspects you may have prostate cancer because of an elevated prostate-specific antigen (PSA) level, you might want to ask for a repeat PSA test to confirm the results, says a Canadian study published in Mayo Clinic Proceedings. It could save you from undergoing an unnecessary prostate biopsy that could entail serious complications.

Of 1,268 men who underwent a second PSA test within three months of their first test showing elevated PSA levels, 315 (24.8 percent) had normal results the second time around.

As a result of their findings, published online in December 2015, the researchers recommend that men with elevated PSA levels should repeat the test before undergoing a biopsy. Elevated PSA levels might result from infection, physical activity, or sexual activity.

The American Urological Association already recommends that the decision to undergo a biopsy shouldn't be

based on a single PSA test result. However, other studies reveal that only 16 to 56 percent of primary care physicians ordered a repeat test for patients with abnormal results.

Most experts agree that PSA screening should be used with a digital rectal examination and additional information (such as family history, race, and age) to assess the likelihood of prostate cancer being present. The PSA test should be performed following a discussion with your doctor about its benefits and risks.



Overestimating Prostate Cancer Survival Rates

Overtreatment of localized prostate cancer is an important public health concern, since the survival benefits of surgery or radiation therapy have not been well established.

A 2016 study in the *Annals of Family Medicine* found that most men with localized prostate cancer underestimate their life expectancy without treatment and overestimate their potential gain in life expectancy with surgery or radiation. These misperceptions may lead to overtreatment, decisional regret, and decreased post-treatment quality of life.

To better understand the overtreatment of localized prostate cancer, researchers conducted a cross-sectional survey of 260 black and white men ages 75 or younger in the Detroit area who had newly diagnosed localized prostate cancer. The survey found that 33 percent of respondents expected to live fewer than five years if their cancer was left untreated, 41 percent said five to 10 years, 21 percent said 10 to 20 years, and 5 percent said more than 20 years.

With their chosen treatment (i.e., surgery, radiation or watchful waiting/active surveillance), 3 percent of patients expected to live less than five years, 9 percent said five to 10 years, 33 percent said 10 to 20 years, and 55 percent said more than 20 years. And although the largest and longest-followed active surveillance cohort of men diagnosed with localized prostate cancer actually showed prostate cancer-specific survival rates at 10- and

15-year follow-up of 98 percent and 94 percent, respectively, only 25 percent of all patients in the study expected to live more than 10 years.

Unrealistic patient expectations are concerning because active treatment does not provide a survival advantage compared with men who choose active surveillance when these patients are carefully chosen, and active treatment can be associated with ED and urinary incontinence.

When making a decision, patients with localized prostate cancer should include their doctors in the process to make sure that their expectations and choices support realistic treatment goals.

healthafter50

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A Message from Prostate Cancer Canada

CanDirect is a study funded by the Canadian Cancer Society. It tests a novel approach to helping people manage their mood following cancer treatments. **Anyone over 18 that has completed treatment (surgery, radiation, or chemotherapy) for a non-metastatic cancer is eligible.**



canDIRECT
New study for cancer survivors

Help us test a novel treatment to help cancer survivors

Local researchers:
(Princess Margaret Cancer Centre)
Jennifer Jones, PhD
Madeline Li, MD PhD

Study funded by:



Canadian Cancer Society

Version: August 18, 2016

It is common for people who have had cancer treatment to feel down, worried or stressed.

This study tests a novel approach to help people who have completed their cancer treatments manage their mood.

How might this help me?

Study participants receive a binder containing a workbook, relaxation CDs, a DVD, online tools and other options. These tools include information and exercises designed to develop skills to improve low mood and worry. Telephone support is also available for those who might want it.

The tools are yours to keep at the end of the study.

Can I join the study?

If you are 18 or older and have completed treatments (surgery, radiation, and/or chemotherapy) for a non-metastatic cancer, you may be eligible.

What is involved?

People who are interested in signing-up complete an initial 15 minute screening interview over the telephone to determine if they are eligible.

If you are eligible and decide to sign up, you will be asked to complete 3 questionnaires: one at sign-up, one after 3 months, and a final one after 6 months. Each questionnaire takes about 30 minutes to complete, either on paper or online. Questions ask about your health and mood. You can complete them from your home - you will not be required to come to the study centre at any time.

To learn more...

For additional information about the study, or to sign up, contact:

Mihaela Dirlea
416-581-7652
mihaela.dirlea@uhn.ca

Help us spread the word!

Tell someone you know who might be interested, or share this link through Facebook or Twitter:
www.mcgill.ca/candirect



TAKE NOTE

Two copies of **"PROSTATE FOR DUMMIES"** have been added to our library and are available for takeout by members.

Plans are taking place for an informal public forum in September during Prostate Awareness Month. More later.

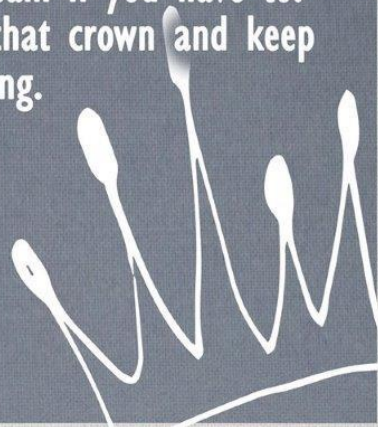
PCCN Regina Support Group has volunteered to help maintain the Cancer Survivor Garden in front of the Allan Blair Centre at the Pasqua Hospital. Volunteers are required from PCCN Regina to work with the Regina Qu'Appelle Health Region to help with acquiring the plants and organize the annual planting/clean up days.

We need your help.

Please contact Jim Odling by e-mail golfer@sasktel.net or by phone **306-522-7590** to volunteer or for more information.

Some Words of Wisdom

There's going to be very painful moments in your life that will change your entire world in a matter of minutes. These moments will change you. Let them make you stronger, smarter, and kinder. But don't you go and become someone that you're not. Cry. Scream if you have to. Then you straighten out that crown and keep on moving.





PCCN REGINA PROSTATE CANCER SUPPORT GROUP INC.

PCCN REGINA PROSTATE CANCER SUPPORT GROUP TAX DEDUCTIBLE DONATION

PCCN Regina is a volunteer support group for men diagnosed with prostate cancer and their families. We are a registered charity that relies on the generosity of its members, supporters and friends to fund its programs. Charitable deduction receipts for income tax purposes are issued for amounts of \$10.00.

You can donate by sending a cheque to:

PCCN – Regina: PO Box 37264

Regina, SK S4S 7K4

Donor's Name: _____

Donor's Address: _____

Postal Code: _____

If this gift is in memory/honor of someone, please provide mailing address information
if you wish us to provide a notification.

This gift is in memory/honor of: _____

Send Notification to:

Name: _____

Address: _____

Postal Code: _____

BOARD STRUCTURE 2016/2017

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2017-2018 MONTHLY PROGRAM DATES

Support Group meeting dates are the second Thursday of each month. Monthly Programs are being developed and will be announced in future newsletters.

2017

**January 12 - Board Members
November 5th Oncology Symposium
Report**

**February 09 - Speaker Dr. Nelson Leong
Radiation Oncologist**

**March 09 - Round Table Member
Discussions**

**April 13 - Dr Venugopa from the UofS
returns to give us an update on the PCa
research we are partially funding.**

**May 11 - Lana Van Dijk of Body Fuel
Organics and Barry Bremner, a PCa
survivor; on the Importance
of Proper Nutrition.**

**June 08
Annual Meeting**

**July and August
No meetings**

Pending for 2017-2018

- UofR RN Professor on PCa Patient Care
- Advance Care Planning Workshop
- Update on UofR PCa Research Program we are partially funding