# Prostate Cancer Canada Network – NEWMARKET

**Volume 21, Issue 8** **April 15, 2016**

A support group that provides understanding, hope and information to prostate cancer patients and their families.

*Topic for the April meeting…*

## State of the Art in Image-Guided Treatment for Prostate Cancer

**Andrew Loblaw**
BSc MD MSc FRCPC CIP

Dr. Andrew Loblaw is a Radiation Oncologist, Clinician Scientist, and dual Professor in the Department of Radiation Oncology and the Institute of Health Policy Management & Evaluation at the University of Toronto.

He received a Bachelor of Science in Physics from the University of British Columbia and his Doctor of Medicine from Queen's University. He completed his specialty training in Radiation Oncology concurrent with a Masters degree in Clinical Epidemiology to graduate from Royal College's Clinician Investigator Program all at the University of Toronto.

Dr. Loblaw's clinical practice and research interest focus on improving outcomes for men with prostate cancer and the healthcare system. He has a particularly interest in the design and conduct of clinical trials, the generation and dissemination of evidence-based guidelines and in image-guided radiotherapy.

Dr. Loblaw is an Ontario Association of Radiation Oncology Clinician Scientist and a Scientist at the Sunnybrook Research Institute. He is the Co-Chair of the American Society of Clinical Oncology's Genitourinary Advisory Group and Co-Chair of the GU group for Cancer Care Ontario's Program in Evidence-Based Care. He has authored over 190 peer-reviewed papers and has been awarded grant funding of over $17M.

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| **Meeting Date:** | **Thursday, April 21, 2016** |
| **Place:** | **Newmarket Seniors Meeting Place**<br>**474 Davis Drive, Newmarket** |
| **Time:** | **6:30 pm to 9:00 pm** |

**Prostate Cancer Canada Network – Newmarket**
**Newmarket, ON**

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*The Newmarket Prostate Cancer Support Group does not recommend products, treatment modalities, medications, or physicians. All information is, however, freely shared.*

For the month of March, our support group opted for a peer to peer discussion. The turnout was reasonably good with 13 attending and valuable information was shared.

Editor's note: With the exception of some of the support group executive, member names have been kept confidential in order to preserve the privacy of the individual participants.

NOTE: This was a discussion among peers and NOT medical professionals. Please do not interpret general layman opinions for medical recommendations or advice. Please seek professional advice as needed.This is an edited transcript of the discussion.

# Peer-to-Peer Discussions

*by*
*Mike McMaster, Copy Editor*
*March 17, 2016*

*Photography by Daniel Ho*

**Walt (our support group Chairman):** Welcome everyone, we'll just go with the flow this evening and when we finish, we finish.

In my case, I had a radical prostatectomy after dealing with an enlarged prostate for years. I was on Flomax and Avodart to try and keep the swelling of the prostate down. The medication reduced the libido so I wanted to get off it. But shortly after I stopped taking it my PSA started to go up, so there came a point where they needed to do a biopsy.

The results of the biopsy were positive (5% positive in one of the 12 core samples, the rest were clear) with Gleason 6, and based on my family history – my mother had passed away in her 30's from cervical cancer – I decided to have my prostate removed. I was advised that surgery wasn't a panacea, there could be leakage, but I was pretty flippant at the time, so I said let's get it out of there and I'll deal with the consequences.

I went ahead and had the surgery. I did 100 Kegels a day prior to surgery.

**Q:** What are Kegels?

**Walt**: Kegel exercises are done to strengthen the sphincter muscle that controls urination. When you go pee and try and stop the flow that is the muscle you want to exercise. I used to do them when I was driving back and forth to work. You pull the muscle in, count to ten, and then relax. You

can do them anytime; I do them when I brush my teeth.

When they removed the prostate, they removed one of the sphincters that control urine flow, so you have to strengthen the one that is left to prevent leaking.

**A new member offered:** I was told after 70 I didn't have to worry about rising PSA and prostate cancer anymore, so I didn't. Now, at seventy-five, I had my PSA tested recently and it is three hundred and forty-seven! My doctor was surprised because when he did the digital rectal exam, he didn't feel anything abnormal, and said if it hadn't been for the PSA reading, he would have passed me. So far, I have had no treatment, I have just been put on some pills and I get my first hormone injection next week. The side effects scare me.

**Walt**: Mike has been on hormone treatment.

**Mike**: Yes, my story is a little different than Walt's. I wound up having treatment that involved three elements – hormone treatment, High Dose Rate Brachytherapy and external beam radiation. The adverse effects of the hormone treatment were minimal and I am pleased with the overall results of the treatment.

I was first diagnosed as I hit my 63rd birthday. It was a routine physical and the doctor didn't like what he felt, and that, combined with my PSA result which was 5.7, was a concern, so off to the urologist I went.

The urologist said that, given my family history and the preliminary results from my family doctor, the probability that I had prostate cancer was greater than 60%. The next thing we did was move on to the biopsy to find out for certain.

He took seventeen core samples. Seven of the seventeen core samples were positive at Gleason 9. Now, we are on to the bone scan and the CT scan and the ultrasound and the x-rays to see if the cancer had spread. Fortunately for me, it was detected early and still confined to the prostate. On the TNM scale, it was T2b, which means the cancer is still confined to the prostate.

*[Editor's note: TNM Classification for Prostate Cancer http://emedicine.medscape.com/article/2007051-overview ]*

After the results were in, I told my urologist I didn't want surgery. He said that given my Gleason score, which indicates high risk prostate cancer, he highly recommended High Dose Rate Brachytherapy at Sunnybrook. The HDR Brachytherapy procedure involves inserting little tubes through the perineum (the space between the scrotum and the anus) into the prostate and irradiating the tumours with a seed that is then removed. It is day surgery – no hospital stay, no catheters and the recovery period is 48 hours, not 3 to 4 months, as it is with surgery.

So my treatment was multi-modal, it started with one month on Casodex followed by a Lupron injection. One month after that came the High Dose Rate Brachytherapy procedure. Two weeks after that came 5 weeks of external beam radiation. The Lupron prescription was for two years and the injections stopped 18 months ago.

I go to Sunnybrook every six months and so far the blood tests indicate I am doing well. They test the testosterone and the PSA levels. The PSA is 0.49 which is still acceptable, and the testosterone is over 10 which is higher than it was before I started all this.

**Another support group member offered**: I have been on hormone treatment for a year and I am finished now, so they are allowing the testosterone to go back up. With hormone treatment, you will be able to compare notes with females about hot flashes, and my breasts enlarged a bit, but other than that there was really no problem.

Hormone treatment does stop the testosterone. What I found interesting is how much testosterone drives men, when you are without it you have no interest in sex at all.

**Q**: Were there any other side effects like indigestion?

**A**: No, just what I mentioned. No indigestion.

**The new member asked**: Mike, why did they suggest hormone treatment along with radiation?

**Mike**: The treatment regime they suggested at Sunnybrook had been tested on hundreds of patients before me and that was their formula.

**One member offered**: I had treatment last year and they started with the hormone treatment, and then after a couple of months, they hit it with the radiation because they find that to be most effective. Hormone treatment first, then external beam radiation – the prostate is still there. The cancer had metastasized to three spots on my spine.

**Mike**: I believe I had the three therapies because my Gleason score was so high.

**Our new member asked**: Have you ever heard of anyone with PSA 347?

**Mike**: No, that is beyond anything I have heard.

**Walt**: I believe Frank had PSA readings above 500.

**Mike**: I didn't know that, I remember he once announced to the group a reading of 260, but he had an interesting approach: Instead of initially going with hormone treatment, like Lupron or Zoladex, he instead chose to take Casodex, a pill once a day. Lupron and Zoladex block production of testosterone by affecting the

pituitary gland which sends signals to the testicles to stop production, while Casodex blocks the uptake of testosterone by the cancer cells. He wanted to preserve the production of testosterone to keep his muscles strong.

If you haven't heard of Frank Kennedy, he was an august member of the group who joined the group at the very beginning along with Derek Lawrence (the founder) twenty years ago. Frank passed away just a couple of months ago at 84.

**Another member offered**: The hormones are used for a limited time because the cancer learns to get around it.

**One of the group said**: I am on ADT (Androgen Deprivation Therapy) for life now. They switched me from Lupron to Zoladex and next month they will switch me to another drug. Prostate cancer can become resistant to certain drugs, so they go back and forth.

**Walt**: The hormones stop the testosterone which feeds the cancer, so if they can stop the testosterone they can kill the cancer.

**Another member offered**: One advantage of the hormone therapy – I lost the hair on my back.

**Another**: And the hair gets thicker on the head. My brother (who is on hormone therapy) had his hair about 85% gone, now it is only 30% gone, and he lost all his body hair.

**Walt**: Maybe I should look into hormone treatments *(as he rubs his head.) (Group laughs.)*

**Mike**: The other good thing about hormone treatment is that it can stop, and things can return to normal. The erectile dysfunction side effect disappears – Mr. Happy is back, so to speak. Each of the six injections I had lasted for 4 months, so about six months after the last injection, things started to happen.

**Walt**: Does hormone treatment affect the bones?

**Mike**: Yes, you have to take calcium supplements to reduce bone loss.

**Q**: Walt, with such a low volume of cancer and such a low Gleason score, why not just say, to heck with it and go for active surveillance?

**Walt**: Based on my family history, my mindset was that if there was any cancer there, I wanted it out.

**Q**: Walt, has there been any "buyer's remorse?"

**Walt**: Because of the enlarged prostate, technologies like HIFU (High Intensity Focused Ultrasound) and arthroscopic surgery would not work. All the research I did on cryogenics and the like were ruled out because of the enlarged prostate. So, I was left with radiation or a radical.

Based on some of the presentations here, I took away that I could have a radical and then radiation if it came back, but not radiation and then surgery. Initially, I was told I was Stage 1 with Gleason 6, after the surgery they said it was Stage 2 with Gleason 7, so it was probably a good decision to have it removed.

The member commented: It just seems that more and more these days, if you don't have high risk, they are recommending active surveillance or watchful waiting.

*[Editor's note: Differences between "Active Surveillance" vs. "Watchful Waiting". These two terms are not equivalent.* [http://www.prostatecancer.ca/Prostate-Cancer/Treatment/Active-Surveillance](http://www.prostatecancer.ca/Prostate-Cancer/Treatment/Active-Surveillance) ]

**One member of the group offered**: With regard to erectile dysfunction and the inconvenience of penile injections, there is a new drug that comes in a cream form called Vitaros. It is available in many European countries but not in Canada yet, even though it is made here.

*[Editor's note: Additional information regarding Vitaros from Ontario Mens' Health* [http://www.ontariomenshealth.ca/vitaros-for-toronto-men](http://www.ontariomenshealth.ca/vitaros-for-toronto-men) ]

**Another new member offered**: About 18 months ago my PSA started to rise so I was referred to a urologist. The results of my biopsy were Gleason 6 and the TNM was T1. According to my urologist the recommended strategy is watchful waiting, but I am 70 years of age and concerned about what options will be available to me in the future since I may be past the point where they can operate.

**Another member of the group**: I found a lump on my neck and my doctor sent me for a biopsy and they removed four lymph nodes from my neck. I am now waiting for the results of the biopsy to see what can be done.

**Another member responded**: There is a firm in Mississauga that does PET scans (Positron Emission Tomography) and they are far more accurate than a CT scan at finding metastasis. It is not covered by OHIP and runs around $2,200 but you can get it for nothing if you are approved on compassionate grounds. I am not sure of the name but if you Google "PET scan Mississauga" I am sure you will find it.

The hospitals are limited in the solutions that they can offer so, if you want alternative treatment, you have to do significant research.

*[Editor's note: The result of the search was KMH Cardiology & Diagnostic Centres in Mississauga.* [http://kmhlabs.com/about-us/services/](http://kmhlabs.com/about-us/services/) ]

**A member asked**: I am wondering about the side effects of some of the drugs, in particular, Avodart and Flomax, and what some of you may have experienced?

My journey started about 12 to 14 years ago, PSA of 4, it slowly progressed up. I had six biopsies, 12 cores per biopsy, and they finally detected some cancer on the 12th core of the sixth biopsy. I could have gone external beam but I decided on Brachytherapy. I found it very acceptable in terms of side effects.

I have pulled myself off Flomax and now want off Avodart. My PSA was 12 and after the operation it was 0.6, my last reading was 0.31. The doctor was concerned about the doubling effect if I stopped Avodart, and I said I can live with 0.62. So we will see what the PSA reading is at my next appointment next month.

**Question to one of the new members**: Have you talked to your doctor about improving your immune system?

**New member**: Not as yet, he suggests that I am in pretty good shape so hopefully we can overcome it. So far, I have stuck with pomegranate juice and lots of vitamin C & D and other dietary recommendations he has made, like no red meat.

Mike McMaster

**One of the group**: We had a specialist here and as part of his presentation he stated that we develop cancer cells everyday and that it is our immune system that kills them. It was interesting for me because I had not thought of cancer in that way before.

**Mike**: Within the last couple of weeks, there was an article in the Toronto Star that focused on the immune system and a slew of new drugs, at least four, that are used to treat 17 different cancers including prostate cancer. So, the bottom line, there is that it is another tool in the bag to be used in conjunction with other treatments. My hope is that this type of therapy will hold off future metastases. In my case, with Gleason 9, you know that in the future the cancer may return. So with the new immunotherapy drugs you can potentially stave off that result.

**New member**: My concern is that if it were not for the lump on my neck, we never would have known I had a problem because I had no symptoms.

**Another Member**: Yes, that is something I had a hard time getting used to, because you walk into a doctor's office and they tell you you're sick, but you don't feel sick.

**Mike**: Right, because you are asymptomatic, and generally, feel pretty healthy. That was my thing, if it wasn't for the routine physical and the abnormal DRE and the high PSA, I could be in a completely different situation today.

**One of the group asked one of the new members**: Are you concerned that your treatment options are reduced because of your age?

**Answer**: Probably, because my doctor seemed to be concerned.

**Another response**: One of the doctors who recently presented here said that it was more complicated than just age; it had just as much to do with the physical shape that you are in.

**Mike**: But, in general, from what I remember from those remarks, for the normal man, it is harder to bounce back from a radical prostatectomy when you are seventy years old because you just don't have the muscle tone to stop all this random leaking, so in terms of recovery from surgery, the younger you are the better. But in terms of radiation, the younger you are, the more reluctant they are to recommend radiation because they know radiation causes cancer, so over a fifty year period the chance of reoccur-rence is greater. However, if you are 70, or 75, or 80 then radiation is still an option for you.

**Response**: If it was local to just the prostate, then maybe they could still operate but if it has metastasized, they have to prevent it from spreading some more.

**Mike**: We mentioned a couple of guys earlier on, Frank

Kennedy and Derek Lawrence, who founded the group, with both of them, the plan was to have a radical prostatectomy. But they opened them up and found the cancer had spread so they closed them right back up again and said you've got to go with a different option. So neither Frank nor Derek had their prostates removed. Frank lived for 20 or more years and Derek is still going strong.

**Member**: The latest thing they do is combine hormone treatment and chemotherapy at same time. They say they have tripled their success rate. My cancer had metastasized but now I am clear.

**Q**: Are you cured?

**Response**: The cancer is in remission but I have to stay on the medication.

**Mike**: In the very first meeting I attended, the presenter, Dr. Tom Morton, an urologist from Lakeridge Health, said to look at prostate cancer as chronic condition – something that is going to stay with you for the rest of your life - it will be in abeyance at times, but it can recur.

**Q**: What is it caused by?

**Walt**: Most of the time the body can fight radiation off – the sun, the earth, certain foods we eat. It may not have been anything specific that you did.

**Member**: Most men get prostate cancer or have prostate cancer cells. With regard to radiation, there was the old story from twenty years ago of the radar guns the police used - they used to rest them on their laps when not in use and many developed testicular cancer.

*[Editor's note: Veracity of this story is unclear. "Health effects of occupational radar use have not been widely studied, and further research into a possible association with testicular cancer is warranted."* http://www.ncbi.nlm.nih.gov/pubmed/8213849 *]*

**Mike**: When I first got the news I asked my urologist if there was anything I had done to bring this on, like lifestyle or anything else. He said: "No, don't blame yourself, this is largely genetic. Unfortunately, you can't pick your parents." There may be some environmental factors but no one thing you can put your finger on.

**Walt**: Most men die with prostate cancer, not of it.

**Mike**: Be proactive, early detection is key. At the outset, there are basically two tools in the box, DRE and PSA, use them.

A suggestion was made that getting a second opinion was a good thing and the group agreed.

**Walt** closed by thanking everyone for their participation.

## ~ ~ ~ Notes from The Chair ~ ~ ~

I really enjoyed our peer-to-peer session last month. We set it up as a round table discussion with the topics completely open. We had some great discussions as you can read from the newsletter.

Our end of season June meeting is coming up fast. As we have been advising this will be a peer-to-peer session with a barbecue to celebrate 20 years of support. We are hoping to see members from current and past years even if you haven't been out recently. We will be sending out an e-mail asking for an RSVP so we can start the planning in earnest and estimate the cost. We would also like to see if anyone may be able to help with the organization, set-up, cooking, etc. We are looking forward to a great evening and will need lots of hands on to help make it a success. Depending on the numbers and corresponding cost, we may also look for an entry fee to help offset the expense. We will be asking for your thoughts on that aspect as well.

This month looks like a great session with Dr. Andrew Loblaw. I will be interested to hear more about the latest radiation treatment options.

Next month we will be having Dr. Vlade Gagovski present to the group. He will discuss the types of nutritional infusions to treat cancers, insulin use in low-dose cancer treatment as well as the newest types of medications that are on the market. For October, our speaker will be Dr. Frank Bailey who has significant province-wide credentials. He will speak about erectile dysfunction and impotence

Please stay tuned for more details on the 20th anniversary celebration of the support group in June. We will be looking for suggestions and trying to get an idea of how many will attend.

*Walt Klywak*

Chairman