Prostate Cancer Canada Network - NEWMARKET

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

Special Note, We're returning to the Seniors Centre this month and hopefully from now on for all our meetings. Our speaker for the June 20th meeting is Dr. Sandy Sehdev. Dr. Sehdev. is a medical Oncologist and a Bone specialist at the William Osler Health Centre. His talk will focus on advanced prostate cancer that has spread to the bones. When left untreated, cancer that has spread to the bone can lead to serious and debilitating complications that can cause pain, disability and even death. It's important to have access to the most appropriate bone-targeting treatment at the earliest sign of metastases. Medications such as Zoledronic Acid and Denosumab can then be most helpful. Come and hear what Dr. Sehdev has to say.

Meeting Date: **June 20th, 2013**

Place: **Newmarket Seniors Meeting Place, 474 Davis Drive, Newmarket (Side Entrance)**

Time: **6:30 pm to 9:00 pm**

Speaker **Dr. Sandy Sehdev, Oncologist, William Osler Health Centre**

Subject **"Bone Targeted Therapies"**

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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.

May Speaker Notes . . . Dr. Jerome Green, Urologist, Southlake

Subject: "Dealing with Incontinence after treatment"

Dr. Jerome Green is always one of our favorite guest speakers. His talk to our members at the May meeting was on urinary incontinence a subject that many are now experiencing or almost certainly will have to deal with down the road. Here is what he had to say

I'm going to talk about urinary incontinence tonght. It affects a lot of men, based on their therapy for prostate cancer but this is one topic that also affects women, so they may get something out of this as well. We'll talk about the types of urinary incontinence, as well as its relation to prostate cancer and what we can do to fix up some of these problems. Urinary incontinence means the involuntary loss of urine, it means when you're going about doing whatever you're doing, all of a sudden you get these sudden leaks of urine. There are different types of incontinence. The most common types we see, not necessarily in the general population is the overactive bladder, as men and women get older they tend to develope this overactive bladder. It means you have the urgency, the sudden compelling desire to pee. Everyone has this, if you hold on to your urine long enough, you're obviously going to feel the urge to pee, eventually. But this is where it interferes with your daily activities. You don't have to have leaking, just the urgency associated with it. Usually it's associated with frequency of more than eight times in a 24 hour period and waking up two or more times a night. That is different from what we call stress incontinence., which refers to strenuous activity, not that you're stressed out and should be on anti-depressants. It refers to the fact that when you're doing something strenuous, coughing, sneezing, bending, lifting, running, jumping on the trampoline, that kind of thing. Obviously, you'll have men who have both conditions and you have to treat both. There's total incontinence, which means leaking all the time and that's usually because of sphincter deficiency but this is quite rare. Then there's something called overflow incontinence which tends to happen in men who don't empty their bladder properly and when they're sleeping at night, they tend to be leaking.

So, why am I here talking about it? It's very common, as I'll point out; it is quite debilitating and will affect the quality of life; as physicians we don't do a good enough job diagnosing it — a lot of times we don't ask, a lot of times patients don't tell us or talk about that; and it's also undertreated. If you look at prostate cancer, when we talk to our patients about treatment, the most feared complication out there related to treatment of prostate cancer, is usually urinary incontinence. People have friends who are wearing bags. They don't want to be leaking all the time. This is an important thing to talk about. Talking of the general population, not prostate cancer patients at this point, in a random telephone survey of men and women over 18, we found that overactive bladder was in over 13% of men and about 14% of women. When you look at the numbers, it actually increases with your age. The average age of men was about 44, 5% of them had incontinence, 5% these had the urge but 15% of them had the stress and the urge together. This was a study done in multiple countries, done in 2005. Basically, what it's showing you is that, as you get older, your risk of this overactive bladder, whether it's leaking or not, goes up with age. What you tend to see is that the women outnumber the men until you get to the sixties and that's the effect of the prostate. The work of the prostate wreaks havoc with our bladder. What you typically see is, when you get to your seventies, 20% of men are having problems with overactive bladder. We're not talking about prostate cancer yet.

So, what's the big deal? It is a big deal, we know it affects people's quality of life. We know it restricts a lot of people's activities. People stop going out shopping. A bunch of my patients will now have all their groceries delivered to their house because they're too embarrassed to go to the local Metro and, all of a sudden, get that sudden urge to pee and they may have an accident. So they restrict their activities. 60% of patients who had overactive bladder suffer loss of their self-esteem and some even consider suicide. It does cause social isolation. Obviously, if you're waking up four or five times a night, you're not getting that much sleep and that's difficult for a lot of people. We know it impacts sexual function and it does have a negative impact on personal relationships. So it does impact people's quality of life. Some people actually plan their day based on where the washrooms are around town. They go from place to place to place, when they're going into the city, they need to know where the washrooms are. It also has other detrimental affects. You get these sudden urges to pee and you can't get to the washroom in time and there's a panic, even if you're in your own home. When you get out of bed at night, then you may trip and fall. We've shown that both men and women, as they get older, tend to get out of bed quickly and fall and that leads to fractures. Fractures, unfortunately, lead to hospitals and sometimes death or other complications. This obviously has an impact if you're on hormone therapy because that can weaken your bones. If you're

tripping and you're osteo-anemic or you have lower bone density, this can be an issue as well.

That's just the background on urinary incontinence. If you look at when we talk to patients, and they've done studies, once you're treated for cancer, the most important determinant of quality of life is their urinary function, the second is erectile function. A lot of times the incontinence is the result of the therapy you are getting. That being said, as men get older, their risk of having incontinence goes up. We're dealing with two issues here. There's the base line function and the therapy. It's rare that we see men with advanced disease, more and more men are presenting with earlier stage disease now. With locally advanced disease, certainly you could have severe incontinence or overflow incontinence or total incontinence, which I talked about. That's rare these days, it used to be more predominant before the whole PSA area came about. If you look at the risk factors for incontinence, we talk about age. That's because, as we get older, our muscle function becomes worse for the bladder and the urinary control system. If you had issues with urinary control before you had therapy, it's going to be worse after. It's never going to be better. Then, other patients who have other medical issues, if you've had a stroke, MS, if you have Parkinson's disease, all these things can lead to problems with urine control. Those things aren't going to help you when you go through your therapy. The other problem is, if you have an enlarged prostate in addition to having your prostate cancer, that can affect your bladder function. Our bladder provides two functions. It's supposed to store urine and it's supposed to empty. The storage is in the bladder and it's supposed to nice and pliant, like a big balloon, and it's supposed to stretch. What tends to happen sometimes with radiation is that stretching ability is lost. There's an internal sphincter that sits at the bladder neck and that bladder neck is not under voluntary control, it's working all the time, whether we like it or not. That tends to come out when we take out the prostate and then there's the sphincter that we all control. That control valve is the one that can lead to leakage. If you're leaking, it's either because you can't keep the urine in because the bladder itself as a vessel is not storing, or it's because the outlet, which is supposed to stop the urine, is not working. There are lots of reasons why this may not function: it's because the muscle's damaged; the nerves are damaged; lack of support in the tissues that are there; or a combination of all that.

We're going to talk about the different therapies, in terms of the damage that can be done. W

ith the radical prostatectomy, you take out the prostate, the internal sphincter also comes out from the bladder neck. You rely on the other sphincter at the pelvic floor to do it's job. This is where you're urinary control is. It's very close to the prostate and it can easily be damaged when we remove it. we're talking about millimetres of distance. We take out the prostate, you're left without this control. Your bladder relies on keeping the urine in on this control valve and it can obviously be damaged when we're putting in stitches and reconnecting the bladder to the urethra. A lot of times this leaking is because of damage to this area. The other thing is an overactive bladder. Probably 15 to 20% of men over the age of 50 have some degree of overactive bladder. Before your operation and before you've had your prostate removed, you may not notice that you have an overactive bladder, because the prostate actually also protects an accident from happening. If you remove that obstruction which prevents the urine from leaking, and then you reconnect things, all of a sudden that overactive bladder is obvious and you can have leaking after the operation. Most commonly, men tend to have stress incontinence, it's a big problem but we cannot overlook overactive bladder. Why do men develop stress incontinence? This damage to the sphincter. There are different factors. The two most important factors are age and surgeon experience. The closer you are to 50, the better your urine control is, compared to the closer you are to 70. That's purely muscle function. As we get older, our muscles don't work as well. We tend to reserve surgery for guys under the age of 70, sometimes 72. The problem with that is, as you get over the age of 70 and we start operating on men, the risk of incontinence goes up dramatically. If your surgeon is not experienced, your outcomes are not going to be as good. Surgeons who complete more than 15 prostatectomies per year have excellent results, compared to surgeons who do less than ten. If you have leaking before your operation, there's a very good chance you're going to have leaking after it, unless it's that overflow problem but then you tend to have an overactive bladder. If you've had your prostate scraped because of BPH before your operation, the risk of having incontinence afterwards is higher. If you've had radiation, we tend to not recommend surgery after having radiation, because the risk of incontinence is very, very high. It's better to have surgery first and, if necessary, radiation after but it's not recommended to have radiation first and then surgery.

Not all sphincters are the same. Some men have thicker sphincters than others. We don't know that, there's no way of telling that. Maybe we should do an MRI but they're talking about millimetres of difference on a microscopic level. The problem is, if you're one of these men and we don't know how to identify these men, if you have a very short urethral length, there's a good chance that when we take out your prostate, some of that muscle is going to be damaged. That's why, when we take out your catheter after surgery, most men are leaking initially but get better over time. That's because some of that muscle is damaged initially but, if you don't have much muscle to begin with, then your risk is bound to be much higher. There's a lot of hype out there and I'm not promoting the open versus the laproscopic versus the robotic prostatectomy but lots of studies have shown that there's no difference in urinary control rates in any of these.

Stress incontinence tends to be more common and it varies depending upon what studies you read. I quote men total incontinence at 2 to 3% and 20% will experience some stress incontinence. With stress incontinence, I tell men that

there's a 2 to 3% chance of leaking all the time and those are the men that I offer surgery to. 20% of men may just have enough leaking that they may or may not wear a pad, they're not too bothered about it and they don't necessarily want other treatment. We do know that, after surgery, your leaking gets better over time. I recommend preoperative pelvic floor exercises and that's because it's been shown that you get earlier control if you've done the Kegel exercises before. If you take two people and one does the exercises and one doesn't, the guy who doesn't is going to be leaking longer but, at one year, both of them will be dry. It's just a matter that the guys that do it before get better quicker. About 40% of men that I see in my practice, initially when I see them about three months out, they tend to have an over active bladder, they have this urgency/frequency problem. It tends to go away but a lot of men out there need to be on medication for their bladder. It was probably there before but because their prostate was there acting as a buffer, they really didn't notice it.

Radiation tends to have less affect on urinary control valve and more affect on the bladder. As I said, the bladder is a stretchy organ that's supposed to expand as it fills and contract properly as it empties. What happens with radiation, unfortunately radiation damages tissue and causes the bladder to become stiffer. The neural networks within the bladder don't work properly and so you can develop this overactive bladder and have leaking. It's less common to have the stress incontinence because the radiation tends not to damage the sphincter. Radiation has gotten better and with better precision, we are able to focus simply on the prostate, avoid the rectum and spare the urethra and the bladder. If you've had your prostate removed and you need radiation, the risk of incontinence is higher, especially if you start off with surgery induced incontinence. Radiation specialists may prefer to wait until that is better before initiating radiation therapy.

What about Radical Prostatectomy vs. Brachytherapy vs. External Beam Radiation? Quality of life (QOL) studies show no difference between the 3 treatment modalities and I think that has to do with how educated you are when you get to your therapy. If you're educated to know what to expect, your quality of life hopefully won't be that bad but we know that your quality of life is less than men who have not had prostate therapy. Prostate cancer therapy affects your quality of life, whether we like it as surgeons and radiation oncologists or not. We know that over time things can change so that's why we'll talk about those Kegel exercises and other things, because eventually, if you're fine now, you may have problems down the road.

How do we diagnose incontinence? Well, we have to take the history, we have to ask. Most men physicians don't ask women about their overactive bladders or incontinence. We know that most urologists may not ask their patients about those either. The problem is, if you don't ask, the patient may not tell you. Only about 50% of patients may even seek care. Why? They could be embarrassed, they don't think there will be any good benefits. They prefer to use the available pads. They go to Shoppers or whatever, buy the pads and put up with it.

What about treatment? You have to direct the treatment at the type of incontinence. If you treat someone who has stress incontinence for an overactive bladder, they're not going to get better and vice-versa. A lot of patients have both so you may have to address both issues. We'll talk about the overactive bladder first. This is the frequency/urgency problem, with or without leaking. You're peeing too often. #1 - Conservative treatment, which is lifestyle modification, behavioural therapy, absorbent pads. There is medication and surgery, which is rarely used. The biggest problem I have in my practice with men and women who come in to see me for overactive bladder, forget about prostate cancer, it's caffeine. Caffeine is a bladder irritant, it's not just a diuretic. I'll pick on a man as an example. He comes to my office, I routinely see guys in their 40s and 50s, who think they have prostate problems, they're coming to see me because they're peeing 12 times a day, when they've got to go, they've got to go. They may not make it in time, and I quickly just ask about caffeine intake and they tell me they're having ten cups of coffee a day. They say they can't do without it and I say, "Well, I can't help you. It doesn't matter what I give you, that caffeine is stronger than any medication that we use." Just restricting that alone, 50% of patients improve dramatically.

Then there's behavioural therapy - bladder retraining. I will ask how frequently you need to go. If the answer is every 45 minutes, I will tell you to force yourself to wait for an hour. After a few weeks then you go up to an hour and 15 minutes. What you're doing is passively stretching your bladder and you're turning off that response where it's normally for 45 minutes and we get you up to three or four hours. It takes time but it works. A patient may come in complaining about leaking. I ask how many times he goes to the bathroom and he may say three times a day. So we do the opposite. I say, O.K. so, you're waiting three or four hours before you have to go and then you're leaking. Why not go every two hours. If you stop leaking, go up to two and a half hours and go progressively up. Pelvic floor exercises are important for men and women. As we all get older and we've had any treatments or not, pelvic floor exercises are done. You don't have to be down on your bum, you can be sitting or standing, you just need a reminder to do them. You try to focus on your anus, squeeze it tight, that's a Kegel exercise. Some people just can't get that, despite me trying to explain it, despite us giving out pamphlets, so they need to go on to physiotherapy. Physiotherapists can be a big help in getting you to focus on the right muscle and in keeping you on time. However you do the exercises, the outcome is the same, if you are doing them properly. These exercises take four to six months to work. I tell people ten squeezes, three times a day. Use your meal times to remind yourself to do the exercises.

Then, my friends the pads. Twenty years ago they didn't have male pads, right? Now they have all these different types and patients ask me which pads to use. Well, I try to promote

no pads. Initially, what happens when we take the catheter out, when guys have had surgery, they're going to wear pads until the muscles come back. Which one you wear is up to you, whichever is more comfortable to you. Long term, though, to use these long term, it's something we try to get rid of.

What about medications for the overactive bladder? All medications are designed to cut down the urgency, the leaking and peeing as less often as possible. They work about 80% of the time and they're much better if you take the medication and do the exercise. We know that the exercise alone has about 50% response, the medication has about 80% so you probably have about 90% success if you're using both of them. Surgery for overactive bladder? Botox. Anyone heard about Botox. It gives you a pretty bladder. I haven't used it in men but quite often in women. No reason why not for men. It's an outpatient procedure, which takes about four to five days to take effect. The down side to this is it only lasts six to nine months. There's a cost issue, the procedure is covered but the drug is not. It costs about $800 for the drug but, if you add up the overactive bladder drugs, it costs about the same. It is now covered if you're over 65 or on ODE in Ontario if you have MS or some kind of spinal cord injury but, hopefully overtime, it will be covered for all patients.

Let's move on to treatment for stress incontinence. It really depends on how bad the leakage is and we rely on how many pads you use in a day. Treatment is the same stuff, lifestyle, cut out the caffeine — Caffeine can trigger your bladder to be more irritable. If you do end up coughing or bending, that can lead to leaking. We did talk about pelvic floor exercises. Medications don't work that well, they're more for overactive bladder. Surgery is more for this than the overactive bladder. We use clamps, they do work but they seem kind of archaic. Every time you need to pee, you unclamp it then put it back on. It is cushioned so don't you're not strangling your penis and people are happy with this. They are cheaper in the United States. They're expensive here, about $200 here and only $50 in the U.S. Most of the home help pharmacies will have these. Some men walk around with condom catheters, where they leak into a bag continuously. It's close to wearing pads, which sometimes cause rashes and can lead to skin infections. Medication: the Impramine is the older medication we use that causes a lot of dry mouth. It can help but most people don't tolerate it very well. You take it four times a day and the dryness is pretty severe.

Surgery: we tend to tailor surgery to the degree of incontinence and how much leakage someone is actually having. We used to use urethra bulking agents in women as well but we've abandoned that. The theory behind it was to inject into the wall of the urethra with either collagen or other agents and what we were trying to is bulk up the urethra to create the blockage that it had before. The problem was the durability. It didn't work very quickly early on and seemed to fail after six months. I don't think there's anyone out there doing this now. The next option is the male sling. These are indicated for mild to moderate incontinence, for patients who are wearing about two to three pads a day. The success rate is about 80%. If you're using about two pads a day and your sphincter isn't working as well, by putting this in, the dry rates are about 90-95%. The problem is, we put this piece of meshing in, it's outpatient surgery, you go home the same day. I leave a catheter in for about two days and about less than 5% of patients can't pee afterwards. You say it's horrible, you've gone from leaking to can't pee. I tell my patients that means you're perfectly dry, you can't force anything out of you. Eventually, you've got to learn how to pee again. It takes some time but that's not a bad complication. It's rare for us to have to go in and cut this out.

Then you've got the gold standard, The Artificial Urinary Sphincter. It has three components: it has a pump that sits above the testicles, under the skin so nothing's exposed. There's a cuff, which is like belt, which sits around the urethrae and there's a reservoir balloon that sits near the bladder. Everything's under the skin, nothing is exposed. When it is activated, urine fills up into the bladder and then it acts like a belt when you want to go pee, you just pump on this a few times. It shifts fluid from the cuff through the pump and into the reservoir and that opens up the cuff so you can pee. This is a self-regulating balloon and your on your way again. It gives you about one to two minutes to pee. If you have incontinence and you're wearing one or two pads a day, this is an excellent choice for you.

So, in conclusion, incontinence increases with age so, if you've had treatment or not, it's going to increase with age. Prostate cancer therapy does cause incontinence, both the overactive and stress. We have to treat the cause and we also treat the degree of incontinence. A lot of patients don't want treatment, so we don't force them. Unless you talk to us, unless your doctor talks to you, you're not going to get anywhere.

Word Play

To write with a broken pencil is . . . pointless.

When fish are in schools they sometimes . . . take debate.

A thief who stole a calendar . . . got twelve months.

When the smog lifts in Los Angeles , . . . U.C.L.A.

The professor discovered that her theory of earthquakes . . . was on shaky ground.

The batteries were given out . . . free of charge.

A dentist and a manicurist married. .. . . They fought tooth and nail.

Urinary Incontinence tool a guide from CHealth

Please check on the answer that best describes your experience. This Urinary Incontinence tool is an aid to help speed up the process of assessing the condition of someone who may have urinary incontinence. Before visiting the doctor, take a few moments to answer the following questions. Print out your assessment and take it with you when you see the doctor.

Answer Yes, No, or Unsure for each question.	Yes	No	Unsure
1 Do you leak urine?	⬡	⬡	⬡
2 Do you experience urgency when you need to urinate?	⬡	⬡	⬡
3 Do you leak urine when you cough, laugh, sneeze, or do an activity that strains your pelvis or bladder?	⬡	⬡	⬡
4 When you urinate, is it accompanied by a burning sensation?	⬡	⬡	⬡
5 Have you ever had a urinary tract infection or been diagnosed with an enlarged prostate?	⬡	⬡	⬡
6 Do you leak urine at night?	⬡	⬡	⬡
7 Do you dribble urine even after you've finished urinating?	⬡	⬡	⬡
8 Is it difficult to urinate?	⬡	⬡	⬡
9 Do you make frequent trips to the toilet to avoid "having an accident," i.e., leaking urine?	⬡	⬡	⬡
10 Do you wear anything to absorb urine, such as absorbent products (absorbent pads, briefs, or underwear)?	⬡	⬡	⬡
11 Do you get up more than twice in the night to urinate?	⬡	⬡	⬡
12 Is your sleep affected by urine leakage?	⬡	⬡	⬡
13 Is your ability or desire to exercise or lead an active life affected by urine loss?	⬡	⬡	⬡
14 Do you avoid going shopping or doing other activities outside your home because of urine leakage?	⬡	⬡	⬡
15 Are you taking any medications?	⬡	⬡	⬡
16 Do you have any pain with your bowel movements, or have constipation or diarrhea?	⬡	⬡	⬡
17 Are your personal relationships affected by a frequent need to urinate or urine leakage?	⬡	⬡	⬡