Prostate Cancer Canada Network - NEWMARKET

Volume 18, Issue 5, January 15, 2014

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

Our speaker for the January 16th meeting is Sandra Robinson RN. Sandra is the Nurse Navigator for the Prostate Assessment Clinic at the Southlake Regional Health Centre. She is coming to our meeting to introduce us to the Diagnostic Assessment Program and all that it entails. She will speak about the Prostate Assessment Clinic, what it is and what you can expect if you visit. Sandra has had a diverse Nursing career. Beginning in Toronto at St. Josephs Health Centre from birthing babies to a decade in the Home Care setting helping individuals in their homes. A large component of her care was to people dealing with their Cancer journey, either actively being treated or in the Palliative state. She joined the Southlake team in 2001 as a Float Nurse which allowed her to continue to nurse a variety of different populations. This new position as Nurse Navigator was created by CCO to target that diagnostic phase. Sandra has been instrumental in setting up the Prostate Clinic at Southlake since its inception in Aug 2012. Come and hear what she has to say

Meeting Date: January 16th, 2014

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

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

Speaker **Sandra Robinson RN, Southlake Regional Health Centre**

Subject: **The Prostate Assessment Clinic at Southlake**

Prostate Cancer Canada - Newmarket
Newmarket, Ontario. 905-895-2263
www.newmarketprostatecancer.com

a member of the

Assisted by the Canadian Cancer Society
Holland River Unit
905-830-0447

Your Executive

Walt Klywak, *Chairman. Communications*,	905-895-1975
Phil Mahon, *Secretary, Website*,	905-473-2688
Jane & Frank Kennedy, *Treasurer and Newsletter,*	905-895-2263
Dan Ho, *Photos & Membership*,	416-953-8889
Doug Bowers, *Member at large*,	905-841-2759
Mike McMaster, *Member at large,*	905-235-7021
Ivan Martin, *Member at large,*	905-775-7576
Ulli Baumhard,*Greeter,*	905-806-8842

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

Lots of Singing and lots of eating at our December 19 Christmas meeting with pot luck refreshments.

Susan reaches the audience with her rendition of **"O Holy Night."**

We welcomed back Susan Ryman to our Christmas (party) meeting. She entertained us with several wonderful solos and then tried to turn us into a Christmas choir. Regardless of how we sounded, we all enjoyed singing a variety of songs, from "Frosty the Snowman" to "Have Yourself a Very Merry Christmas" and beyond. Susan is well known in musical circles and performed in at least 12 concerts over the holiday season.

Our support members enjoyed joining the singing... and in the social time.

We had extra draw prizes for the Christmas party. Derek was one of thelucky winners.

Our pot luck trial was a great success with an abundance and variety of delicious food, as each member seemed to be trying to outdo the others with their individual specialties. We could easily have fed another 30 guests. (and to think the executive was worried about having enough food!)

I want some of everything but my plate's too small. I'll bring a tray for myself next year,

During a song, Susan's one-year old daughter, Holly, joined her mother by conducting the "choir" and was also the first to applaud at the end of each song. Look forward to a duet next year.

Jingle bells, jingle bells,
See our Christmas fun,
With Susan's songs and carolling
And food for everyone.

That boarding house reach comes in handy.

Susan Ryman enjoys sharing music with local artists and has recorded several CD's, including "This is My Story", "Memories of Christmas" and "This is My Song". Now a music teacher at Carol's Music Studio in Newmarket, Susan is dedicated to singing music that awakens memories and inspires the heart. Susan will be performing with many of York Region's talented performers at Wesley United Church, Woodbine Rd. at Aurora Sideroad (Wellington St.) on Jan. 24th at 7 pm. Tickets $15 thru Jane & Frank.

All photos by Dan.

Addendum to October Speaker Notes . . . Dr. Andrew Matthew, Senior Psychologist
Princess Margaret Hospital and the University of Toronto,
Subject: Sexual and Urinary Dysfunction

Our guest speaker at the October meeting was Dr. Andrew Matthew. Dr. Matthew is a Co-Founder and Director of the Health Psychology Clinic and a Staff Psychologist at Princess Margaret Hospital in the Department of Surgery, and the Department of Psychosocial Oncology and Palliative Care. As a principal developer of several hospital-based counselling programs for cancer patients his talk ranged from treatment decision making to sexual rehabilitation, intimacy, quality of life, and survivorship. We covered much of those subjects in our November newsletter but we ran out of space in that issue . The following is his talk on Sexual and Urinary Dysfunction at that meeting. Here is what he had to say.

Sexual and Urinary Dysfunction: I'm going to spend more time on this than any other, just because it happens to be an area where many people experience significant impact on their quality of life. We're looking at 25 to 75% of patients suffer erectile dysfunction. That wide range is because of the various difference in methodologies of the studies, how long they track patients for, what were the risk profiles, were nerve bundles spared and the like. Meta-analysis: 54 long term studies found 75% with erectile dysfunction (ED) at least 2 years post radical prostatectomy (RP). A Stanford Study found 40% to 55% of bilateral nerve sparing patients, from both radiation and surgery, experienced ED at 18 months. If the nerves are spared, the chance of returning to normal function is definitely significantly improved but, even in that group, the return to natural function is still only 40% to 45%. The good news is these people respond well to things like Viagra. In comparison, if we take a look at sexuality, in the average population not prostate cancer patients, 57 to 64 year olds are 73% sexually active; 65 to 74 year olds are 53% active and 75 to 85 year olds are 26% active. Half of this oldest group reported a frequency of 2 - 3 times a month in the general population. So it is clear from these studies and comparisons that the loss of sexual activity after radical prostatectomy or other forms of prostate cancer treatment do substantially influence and reduce sexual activity. This wouldn't be so bothersome if it wasn't so bothersome.

We took a look at not just the fact that they experience the erectile dysfunction and loss of sexual activity but how much did it bother them? The majority of patients that are experiencing it report moderate to extreme distress. In psychology, it is very rare even under very difficult situations that people start to report extreme levels of distress. I know that this sounds uncanny but it is true that this change in both the patient's life, in their relationship with their partner, in the partner's life and in the relationship as a couple, does seem to have much more of a significant impact than we ever originally assumed. Most survivors experience severe and lasting dysfunction. What is sad is that more and more we are diagnosing men at a younger age and treating them at a younger age, hence challenging their regular functioning of sexual activity at a younger age. We're finding that their partners are facing equal or even greater distress than the patient in this regard

. The interesting point is that we have pro-erectile agents and devices for ED post radical prostatectomy and they are quite successful. There are oral medications like Viagra and they are 30 to 60% effective and that could probably grow by learning how to use them more effectively as well. They are much more dependant on nerve bundle status, whether they have been spared or not is very important. Then we take a look at injections. They are very effective. I am very impressed with how effective these are, when you get over the idea of using them. Micro-suppositories (57%) and the vacuum device (80%) are also benficial. The penile implant (85%) is a last resort. I think, if you're getting to that point, if you've done this then you'd better be satisfied.

The problem is that we have high rates of ED but we have a number of different pro-erectile agents and devices that are successful but we don't seem to be solving the problem. That is that these high rates of assisted aids are offset by low rates of uptake and ongoing use. Among men 4-8 years post treatment 50% had never even used pro-erectile agents or devices. Only 30%-40% of men remain sexually active at 1-5 years after a radical prostatectomy, despite attempted use of two or more aids. That's not just the passive "Oh, this has happened to me and I'm not going to do anything about it." That's the couple that's gone out and sought assistance, have tried pro-erectile aids at least twice,

different types and they still weren't successful. Something's going wrong. So we interviewed couples over a two year period and we looked at the stress of adherence. We interviewed the couples as the patient alone, we interviewed the partner alone and then we interviewed them as a couple. We did this three or four times over a two year period and ended up with 225 interviews that were transcribed ... and I'll never do this again. But it did give us some insight. To get a flavour, patients were treated inwardly on their acceptance of difficulties. The patients say, "There are barriers on my side but I can't help it. It's harder to get physically close because I know it's going to reach a "stop". It's difficult to talk about because I have had a hard time dealing with it myself." And they say, ".. basically, this is the way I look at it... if there's no way I'm going to buy anything "downtown" then I'm just not going to go shopping. It's not working and I don't know how to deal with that, so I don't want to initiate anything because it's not going to work."

The partner's experience is far less related to the actual erectile dysfunction but far more related to the stress pertaining to the patient's retreat from intimacy. He has told her the fact that he can't finish it makes him feel bad, so he would just rather not go there. While she understands that and doesn't want him to feel bad, touching and holding and being intimate is still important to her, to them. You can see the perplexity of this.

Of these interviews, we took a look at different themes. The patient/partner stress themes, one is the macro-masculinity. It's quite a prevalent impact. One of my patients said that previously he was not that concerned with his erectile functioning at all. He and his wife had a wonderful relationship, they were both academics, they were not that sexually active but they loved to travel; everything was fine. All they wanted to do was get rid of this cancer and continue with their lives. Then, one year after the treatment, he said to me, "I had no idea how much this would influence me and how upset I am by the fact that I don't have erectile function." He said it made him feel old. I've had women say to me that she felt that she wasn't as attractive to him any more or that she wasn't exciting him very much any more and hence that's why he was struggling. She was not taking into account that this was a physical problem and had nothing to do with her attraction. It can have impact on both members. No matter what happens, there's going to be a change in the sexual response pattern. I've never met a couple that went back to the same experience in terms of their sexual activity after this procedure.

Then, a big one here, and what's very important for myself as a health care practitioner, is you have loss of your usual support. Under these circumstances, we might call this trauma. When any one of us experiences trauma, what we do is go to our support network, our families, our partners, our friends and that helps us through our trauma. Here we have trauma and I think everybody would know that I've just talked about the difficulties couples have talking about it, so, for a man, it's not very likely that he would go our for a beer and wings and talk about the fact that he's not getting an erection. He's not going to go that friendship route. Then, as well, if you have couples over for dinner, you're not going to say, "This roast beef is good. By the way, Mary and I aren't having any sexual activity." It just doesn't happen, right? So it really does isolate couples in this experience and that's why this type of thing is very important to us as health care practitioners to make sure that they have access to care. Part of what we're looking is why non uptake or lack of ongoing use of agents and devices? The loss of naturalness and spontaneity. The patient is thinking: "What do I do. Should I say, okay dear, I'm going to take a tablet of Viagra now, so, I reckon in ... a few hours we should be in bed. That's not exactly romantic, is it? So I didn't know how to handle that." If you're going to take any of these oral medications, you need to wait two hours after a meal. Then it needs to be in the system for an hour, or an hour and half. Then you need to get yourself in a sexual state of mind and you have to be physically stimulated. Now, if you think about that, you come home from work, it's 5.30 P.M.. You get something on the table by 6.30 P.M., you've got to wait two hours until 8.30 P.M., then you've got to take the pill and wait another hour and half until 10 P.M. Then you've got to get in a sexy state of mind and by the time the whole thing's over, it's not very spontaneous and natural. So you need to have strategies to make this easier.

There's a lot of confusion regarding a course of recovery. In a radical prostatectomy you will lose your erections after the procedure, no matter what. Over a two year period you'll have return of function, what level it's very difficult for us to tell and it's based on other different risk factors. In Radiation, your erectile functioning is fine and then it dissipates over a two year period. Where that ends up is also very difficult as it's associated with risk factors.

There is confusion regarding use of pro-erectile therapy. The common belief is that I get my catheter out and two weeks later I'm finally befriending my groin area again after all of its distur-

bance, so I'm just going to take this little blue pill and then I'll be at a movie theatre in the back seat with my wife or something. It doesn't work like that. I can tell you that it's more like 90% of men will have no or little response to Viagra, in the first three months post treatment. There's a lot of trial and error, so we're just looking for blood flow, not erections yet but there can be a lot of frustration around that and those unrealistic expectations. Broadly speaking, in terms of intimacy and relationships between intimacy and sexual activity, the partner often says, "I don't feel like it's as natural, touching used to be a big thing with us, I was very spontaneous and all that. Now I feel uncomfortable because I'm not sure. I'm not sure what it means...like, if I say I love you, what does it mean? You get into a pattern of ships passing in the night... we're coming from a long way apart now." This sounds very sad, but remember, this was before we developed any programming. The nice thing about this is, this type of programming can absolutely prevent any of this type of experience.

We also didn't just look at things that went wrong. We looked at things that went right. Some of our couples did very well and we wanted to know why. Intimacy seemed to be the biggest thing. Intimacy can probably be best described as communication. Which means that in many ways you haven't talked about sex and sexual activity if you've been married for some time or you've been partners for some time and this is actually bringing it back into your regular communication and talking to each other so you can make things work out. The intimacy itself is the best foundation, a sense of closeness and connectiveness. A sense that is best described as being in love is what is the best foundation with which to challenge the erectile functioning and the sexual dysfunction. You can have an orgasm with a completely flaccid penis. That's a good thing because it's a reminder that you haven't changed the actual experience of the organism aside from the orgasm being dry, because there's no ejaculation but the sensory experience is exactly the same. Hence it's a continuation of your previous sexual activity that you experienced. Creativity between the sheets. I'll leave that up to you. A broader perspective of masculinity helps - the idea that I'm not just a penis but I also bring home some money, I'm a husband, I'm a father, I do the lawn, all the masculinity things can be helpful. Humour can be very good as well. In one interview they took the communication, when I was talking about it in terms of intimacy, very specific to sexual activity, so the partner says: "Yes, we're pretty open and we communicate... ask how things are going or what's working, what can you do differently or is good or not, so it's very open and I think we're very comfortable with each other." Then he turns to me and says: "We're talking more during sex than we used to. Less moaning, more talking."

In response to that, we did develope the Rehabilitation Clinic. It's a Bio-Psychosocial clinic, which means that we work from a urologic and social perspective but also from a psychosocial perspective. It's multidisciplinary, we have an urologist, a psychologist, a nurse, a sexual health counsellor who follow you over a 24 month period, seeing you up to about seven times during that period of time. We have a manual and we also collect data so that I can hopefully report back to you on what's working and what's not.

Dr. Matthews then went on to describe the Rehabilitation Clinic's program whose goals are to restore passion (intercourse and outercourse), to restore intimacy (communication) and to restore love.