

# 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**

Our speaker at our November 20th meeting is Jacqueline Hornick. Jackie is a Registered Dietitian with 22 years of experience. She has been at Southlake Regional Health Centre for over 10 years working in the Cancer Program and Palliative Care. She has also been at the Stronach Regional Cancer Centre since it opened in 2010. Her current areas of practice include systemic, radiation and palliative care in both the hospital and the cancer centre. Her interests include cancer survivorship and nutrition. She has also been involved in the development of a nutrition blog for patients currently receiving treatment at the centre and evaluation of the impact this support has had during their cancer journey. She recently presented this research at the American Institute for Cancer Research annual Food, Nutrition, Physical Activity and Cancer conference in Washington DC.

On November 20th she is planning to discuss the latest recommendations about diet and exercise for cancer survivors paying special attention to pertinent information for prostate cancer. Come and hear what she has to say.

**Meeting Date: November 20th, 2014**

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

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

**Speaker: Jacqueline Hornick, Registered Dietitian**

**Subject: Diet and Exercise for Cancer Survivors**

**Prostate Cancer Canada - Newmarket**  
Newmarket, Ontario. 905-895-2263  
[www.newmarketprostatecancer.com](http://www.newmarketprostatecancer.com)

a member of the



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

## Your Executive

Walt Klywak, *Chairman.* 905-895-1975  
*Communications,*  
Phil Mahon, *Secretary, Website,* 905-473-2688  
Jane & Frank Kennedy,  
*Treasurer and Newsletter,* 905-895-2263  
Dan Ho, *Photos & Membership,* 416-953-8889  
Mike McMaster, *Member at large,* 905-235-7021  
Ivan Martin, *Member at large,* 905-775-7576  
Ulli Baumhard, *Greeter,* 905-806-8842  
Tom Wray, *Photo & Member at large,* 905-939-8064  
Tony Ziolkowski, *Member at large,* 905-836-0328  
Anthony Grech, *Member at large,* 905-862-4053

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

**October Notes . . . Speaker: Amy Brown-Bowers**  
**Subject: Couples, Sexuality and Prostate Cancer**



*While we don't usually introduce our speakers with a big hug, former executive member Doug Bowers took this opportunity to hug his niece as he welcomed her as our October speaker. Amy's talk on sexuality really opened our eyes and minds to so many of the thoughts and feelings we experience when we are first diagnosed with Prostate Cancer. Her talk needs to be a constant reminder to us that we can find ways to help our relationships to flourish.*

Who am I to be talking about prostate cancer? Uncle Doug



mentioned that I am doing my PhD and my research is in this area. I have a background doing research with sexuality, with health and with gender and I have some training as a sex therapist and working with couples as well. I brought these interests and applied for a training experience at Princess Margaret Hospital in their prostate centre. It was supposed to be for about four months but I was there for about two years because I found the work interesting and really enjoyed it. My mentor was Dr. Andrew Matthew, who has spoken to your group, he was my supervisor. I'll talk a little later on about my work there and the services that they offer, because they have a program that was the first of its kind in Canada, to specifically work with couples in a systematic way, on sexuality and helping men recover from side effects. The background for me getting into this research and training is I have some family experiences in this area. That all got me standing here today.

I'm in a shift now to start sharing some ideas from my research. These are researchers who have generally interviewed men, their partners and couples together and what I'm noticing in the research, and I think we're seeing it in clinical treatment as well, is that there's an increasing focus on what happens after cancer treatment. It used to be, "We've cured your cancer, what more do you want from us as clinicians?" The answer increasingly is "We want a heck of lot more." So you're seeing more research focussing on what happens after. That could be things like fatigue, like some of the sexual changes but also how to get on with life. Some of those questions are starting to get more attention. That's part of what my research is about, as well. If any of you have been patients at Princess Margaret or had treatments there, you may have some familiarity.

My work was split in two. I provided counselling, so that would have been one-on-one, sometimes just with men, sometimes I would meet with just the female partners who needed a place to talk and sometimes couples together. They would have been arranged from just after being diagnosed

all the way to, "O.K. I'm supposedly cured but life just isn't really coming together for me, or for us."

I also worked in what was called the Sexual Rehabilitation Clinic, it's now called the Prostate Cancer Rehabilitation Clinic and every man who had a prostatectomy at Princess Margaret was automatically referred to this clinic as part of standard care. We met with people for two years about every three to four months. I worked in that clinic and trained that clinic and part of what we would do was, right from the beginning, soon after surgery, we started talking about, "So what can we do now to help you recover, to give you the best possible chance of recovering from incontinence and to give you the best possible chance of having your erections come back and, if that doesn't happen, how can you adapt to a new normal? I stopped working there about a year and a half ago so I don't know currently what's happening but I'm happy to talk more with any of you about the work that I did there. I was of a psychology background but we had people in urology, we had nurses there, so it was very multi-disciplinary.

I gathered some research on couples dealing with prostate cancer. Prostate cancer is a couple's disease. It happens to "us" rather than individuals — there's this "Us vs them" approach that they seem to adopt, when faced with the diagnosis. In the research, couples talk about pulling together (and sometimes it's a bit of a bumpy pulling together) to face the threat that prostate cancer poses to their lives. Part of that is trying to research and pick treatments and trying to manage the impact of this on their lives. That can be managing the emotional impact; managing other family members: who do we tell, what do we tell them? Managing treatments, managing life at home and managing what happens after as well. Also working together to renegotiate parts of their relationship. That can be, while we're recovering, who's cutting the grass as you're recovering from surgery? and dealing with sexual intimacy, and how do we figure this out? There might be short term changes and there might be long term changes. That's all part of what couples face in the aftermath.

Couples report that prostate cancer crystallizes and reaffirms the relationship, the idea being that they just don't take things for granted any more, this seems to solidify something that they had, something they can focus on. There's a theme of uncertainty which is one of the real challenges of prostate cancer and part of that is picking treatment. In many cases there's not a perfect answer about treatment. You talk to a surgeon and they'll say that surgery is the way to go; you

talk to a radiation oncologist, they'll say that radiation is the path forward and then the uncertainty of will that treatment work? and that emotional up and down every time there's a PSA check. It's ongoing uncertainty. There's also uncertainty about what's recovery going to look like for me? All the stuff that no-one tells you about what it's really going to be like.

I'm going to be sharing some quotes with you today but none of them are from any patient I've actually worked with, I'm pulling quotes from what other researchers have done. I'm protecting confidentiality here. Here's a quote from a man who was treated for prostate cancer: The catheter comes out and they say, "Okay, I'll see you in a couple of weeks when you need your PSA drawn." Nobody tells you about the diapers, nobody tells you how to protect your skin. These are very important issues. Physicians deal with the disease but they don't deal with the consequences of the disease. In my work in the research, there's a lot of worry about the side effects and a lot of questions. Some of them may be expressed and some of them may just rattle around in your mind. "Will I ever have another erection, well we'll see. Will we ever have sex again? Will we make through this together as a couple? Am I going to be able to cope? Is he going to be able to cope? Is she going to be able cope with all that's coming? Will I need to wear pads for the rest of my life? Is this the new normal and what should I be doing to give myself the best chances of recovery? And is there anything I can even do?" Lots of questions, not a lot of them have really clear cut answers.

I'm going to shift now to focus on men in particular and then I'll talk about female partners. I'm going to start by summarizing what is in the research, about what it is like for to cope with changes in sexuality. Then I'll talk about what I have learned from these men, what they have told me and the questions and challenges. One of the first things I'm going to start with is this theme that comes up over and over that men report that the changes in sexuality are experienced as a huge blow to sense of self. Some men say it really challenges my sense of masculinity. We used to think in this field that changes in sexual functioning, changes in erections, directly led to stress. Now the thinking is much more nuanced. There's something in between those two, the threat to who I am as a man, that leads to stress, because there are many men in my work and my research where there are changes in erections but there's not this high level of stress. It seems that if sexual functioning is really intimately tied to sense of self, that can lead to some real challenges and difficulties.

I want to share a couple of quotes with you from men who have been interviewed, talking about this. "I think, probably, for a good part of your life you're either defined by your feelings about your sexuality or it gets defined for you by the popular culture. I mean something might happen, someone might say 'I'm interested in you and you couldn't pull it off, you know?' And I think, you know, this is our manhood we're talking about and it can be pretty hard to deal with this."

This is a second quote: "Well, at this point in my life, I think it's more psychological than anything else. It's the

knowledge that you cannot perform, and it's that knowledge, I think, that's more disturbing than maybe the actual fact. After all, it's a capacity you've had all your life and then suddenly it's gone." Related to this is something I've had come up in my clinical work and also in the research, that men talk about, or their partners talk about pulling back, withdrawing. That's sexual but also pulling back physically, so that changes in sexual functioning can lead to a pulling back and reduction in things like holding hands, holding each other in bed, slapping a bum in the kitchen, flirting, you name it. Those losses are felt profoundly by female partners. So there's withdrawal and pulling back and men talk about it and in some research say, "It's just because I'm going through this really difficult process and it's so painful for me or it's so frustrating that I don't want to open anything up, I don't want to start something that I can't finish." I have a couple of quotes here from men who retreated: "You go to sleep holding hands; it's the best you can do. You sleep in the same bed, and you're afraid to hold each other because somehow you feel like you are starting something that you can't finish, and she's the same way."

Partners also talk about holding back, so it seems it's not just men. They talk about pulling back for a variety of reasons including not wanting to make their husbands or their



partners feel badly, or not wanting to give off the impression that they want to have sex or be sexual, because they don't want to bring up something that's painful or stressful for their partners. Here's a quote from a female partner of a man with prostate cancer: "I think it has caused us to be not as touchy, or as close to touching, or as close as we were. We were, for all the years prior, the sort of couple that would grab hold of each other, and hold each other, and kiss each other any time of the day. That has gone out of the window because I'm frightened of showing it too much in case (my husband) thinks I want more... Now."

This is the last theme I want to talk about for men: Using sexual technologies, and by technologies I mean using medications such as Viagra and Cialis etc., to using injections or pumps, or suppositories, all of those technologies. There's a range of responses: some men talk about being very hopeful that these things exist and that they provide a bridge to a

sexual life that is similar to what it was before prostate cancer and some men report great satisfaction in these technologies. A lot of males have talked about deep disappointment and frustration that they work sometimes, they don't work other times, that it's really hard to wrap my brain around what's involved; the idea of I'm supposed to put a needle where? and that's supposed to be sexy and that's supposed to be comfortable and this just seems so foreign. Also people talk about the frustration of not getting really good information. If somebody gives you Viagra but doesn't tell you that you shouldn't have wine or you need an empty stomach or it's not going to work, or you're not getting the right dose, etc. etc. So there's a mixed response to these.

Men talk about sex using these various technologies as being more mechanical, they talk about missing spontaneity. Then there's communicating with their partner and coordi-



nating around using Viagra or injections. I've talked to men about "Do I tell my partner beforehand so that I can find out if they're interested because, if I take a pill and we have an argument or it's not the right night, well then I've wasted a pill and I'm stuck with a red face and I've spent \$40 and not having sex, so do I incorporate my partner in using these? For some couples the question comes up before using an injection, is that something we do together? Do we make that part of foreplay, is that part of our sexual experience or is that something that is done in the washroom. All these things require a lot of talking, which can be challenging. A couple of quotes. This is a man treated for prostate cancer: "If you use a needle, you go into the bathroom and you've got twenty minutes. You spike yourself and it's going to come up but then, what if your lady says, "Gee honey, I'm not in the mood?"

"Uh, we used the pump thing. It's funny. The first time was a riot. It was like a Woody Allen movie. And when you think about it intellectually, it's really kind of stupid and it's funny. But it works. Who cares, you know? But before that, I was thinking about it. I was kind of worried about it. Not that my wife would reject me or anything like that. Just... it's weird."

I want to wrap up this part focussing on men with just some of the things that I've learned from working with men at Princess Margaret, their challenges, questions and concerns. For one, there's a huge range of emotions: everything from embarrassment to humiliation; fear; anger; frustration; regret, so there's a lot to sort through. And then a lot of questions that don't always have an answer: How long until I am back to normal? (Will I ever be normal?) Is this the end of sex for me? What about pleasure? What about orgasms? How am I going to navigate incontinence and sex, how am I going to figure that out? Will I be able to please and satisfy my partner and what is that going to look like? How do we incorporate rehabilitation into sexual intimacy? How do we talk about all this — for some people when's a good time? That's a big challenge for younger couples who have kids in the house and who have careers. When's a good time to be experimenting with injections and pills? Sex used to make me feel really good. It was something I could count on to be a positive thing and now it does the opposite for me and I mourn that, I miss that. Did I make the right decisions re treatment? There's a lot of "Nobody told me and I'm having a hard time finding someone who will talk to me about it now."

I'm going to continue now about partners and when I say "partners" I mean female partners. There's very little known in my research about male partners, so I am referring to women. Historically it's like partners didn't exist. I think that's starting to change. There's more research, more interest in female partners and this is one of the things that I was really struck by when I worked at PMH, the individual women that I worked with who would come and say that they just needed a place that they could come and talk about some of this stuff. They felt really invisible when they went to the appointments. They were going through this, too. So I'm going to start with a little bit of research and then I'm going to talk about what I've learned when I've worked with women. This is probably no Duh for most of you but, as I said, research is slower to catch up to the real world. Treatment impacts both members of the couple and I thought it was interesting that in a lot of studies, the females experienced a higher level of stress related to the prostate cancer than the men.

Why is that? Researchers have been trying to put their fingers on that and partners in the room here may not be surprised by it. Here are some of the reasons. When we talked to women in the research studies of female partners, these are some of the things that are challenging for them: Adopting a caregiving role can come with challenges, attending to both the physical and emotional needs of their partners (and their own). A lot of women in the studies talk about setting their own fears and emotions aside and then coming back to them later, it's not like they go away, and then they have to deal with both and navigate both; taking on additional responsibilities in day to day life and that can be in the aftermath, maybe, of surgery but also maybe more long term, especially with treatments that are ongoing, like hormone therapy. There's an ongoing negotiation of how do we manage our lives now

that things are changing? Women talk about fear, uncertainty, frustration with the lack of information and a lack of time with caregivers, like surgeons and oncologists - not enough time to ask their questions and be heard. Usually women talk about changes in sexual intimacy being stressful, distressing. Some things in particular, women have talked about feeling less attractive, less wanted. They say, "I don't get that same look in my partners eyes and I really miss that, because something is changing in our relationship," They talk about missing romance, less closeness and really missing the nonsexual physical contact. The holding of hands, just brushing my hair, those small things women have talked about missing.

Partners matter... a lot. Research in the role of female partners in prostate cancer really gives a clear message that partners play a key role in helping men through this process, both in the immediate aftermath and the long term and that partners seem to play a key role in helping men redefine themselves, where they are as a partner and a man. The well-being of female partners is intimately connected with the well-being of men going through prostate cancer. They are deeply connected and, if you look at the well-being of the female partner, that's fairly predictive of how the male with prostate cancer may be doing.

Here's some of what I've learned from the partners I have talked to, either counselled or worked with them in the rehab clinic. Again a mix of challenging emotions and not all of them are bad but I'm talking now about some of the challenging emotions: concern, fear, frustration, grief, and a lot of questions. Some of them are similar to the questions the men have: Is this the end of sex for me and for us? Can he still feel pleasure? How will we be sexually intimate? How do we talk about these things? Talking about missing flirtation, missing a feeling of being pursued or desired. I've had women say to me. "How do I know when he's interested in me or attracted to me, because an erection used to be shorthand, and that's not there any more, so how do I communicate you're desirable? I'm supposed to use my words all of a sudden and that's difficult, too." Questions like, what do I do with my interest now? Not all women are interested but some women say I'm still interested in sex and sexual intimacy, what do I do with that? I don't want to make him feel bad... but .. and that could be anything from "This is hard for me." or "I miss having sex," or Yeah, I miss erections, too. Then questions of am I selfish for... and that question ranged from am I selfish for still wanting sex, or for actually being relieved that there's no pressure any more to have sex? It's a full range of difficult things and what do I do with these questions. And then the big one is how the heck do we do this together? That question stuck with me and is partly why I'm focussing on this in my research, trying to help couples figure this out.

The last chunk here is I want to talk about couples and what we understand in research but also some of what I've learned working with couples about what this is like and what things seem to be helpful to them. There's great variability in couple's process and what I'm learning in working with them

is that this process seems to really highlight the strengths in a relationship but can also highlight the weak points. It's both, you've got both to work with. It's not like your whole history is erased and all of life's problems go away when you've got cancer, it's just added to those, including what may be going on with the relationship around sexual relations but everything else as well.

There's a complex mixture of positive and negative stuff that comes with prostate cancer. I want to share a quote with you that I think epitomizes that there's both gain and loss and I should preface this by telling you that this gentleman is on hormone therapy: (female partner speaking) "My grief has been very deep and at times continues to be profound over the loss of my husband's sexual interest in me. At the same time, I want to stress that prostate cancer has brought a sweetness to our relationship that neither would trade for anything."

Now I want to tell you about some outcomes that people have been sharing for a while. One is people saying, "I'm actually, after going through this, I'm a better lover than I was before; we are more sexually connected than before." Here is a quote of a female partner: "Mouths, hands, toys and occasional porn all help us have enormous fun and fulfillment, and like others on this site, (this was a posting on a support site for partners) we have learned that the quality of our love lives has improved substantially post surgery as the need to talk, understand, take turns to reach out and take time has raised the experience to a much higher plane." And here's a quote from a man: "You might well have some jolly good sex afterwards. I would never have believed them. And yet it happens. Now that is something that I wish someone had told me way back."

A lot of couples I've worked with in the research talked about we have found a way to move beyond sex and we are actually O.K. with this, we've navigated this process. I want to share a quote with you: "We've had our children, they have grown up and gone, we have grandchildren, we're older and we realize it. Now we have moved onto the next stage of our lives, this involves smelling the flowers and friendship with each other and companionship and sharing of interests, and sex is not needed in this relationship." Some couples talk about being closer than ever before, having a deeper connection with each other through this process. "In the long shadow of prostate cancer, I've learned that I married the right woman." (This a man who blogs.)

Here are some final thoughts that may be helpful for you. In part this is from my research and in part from people that I have worked with: Drawing together to figure this out, finding a way to work together on this. Finding a way to communicate and share and talk about the really, really hard things. I recently interviewed a female partner for my dissertation and I said, "Even the really, really hard things?" and she said, "Well you're going to be thinking of them and they're probably going to be impacting your relationship, anyway, so if you can find a way to talk about them, it's probably helpful,".

Redefining sex, closeness and intimacy, in particular

beyond penetration. In human sex there are many ways to define intimacy, it may require figuring out how are we going to get hold of what that used to give us, in a different way. People also talk about humour being really helpful, because some of this is really difficult and some of this can be hilarious, too. Support groups, people talk about them being helpful, they're not for everybody but, in particular, finding a place, a person, a couple where you can talk really frankly about some of this stuff. Finding somebody and it could be a blogger or it could be a friend who's really willing to go to the places you would like to go, in particular to talk about some of the stuff I'm talking about now. A lot of people say to me, I just feel like that's not an open topic. I feel like I can go out and talk about treatment and picking the right surgeon but I just

don't feel like this is a topic I can broach with a lot of people. (*Amy left us a list of books which she has found helpful in researching this topic.*)

The last thing I want to talk about is some of my research. As I mentioned to you, the one thing that really stuck out for me was how the heck do couples do this? I was working with a couple in particular and I started to do some research and I tried to find resources and I wasn't finding much. Over and over couples were telling me that there's not enough information on this, people don't talk very much, so what I'm trying to do in my dissertation is really collect the stories of couples who have gone through this. In part, people who I'm working with in the medical field, or like myself going into psychology, have a more nuanced understanding of what this is like but also so that other couples have more stories to read.

## **To all members:**

As you know, November has become synonymous with the Movember grow a Stache for Prostate Cancer month. We have always encouraged our members to participate in this worthy cause.

This year we have been approached to support a local initiative sponsored by Southlake Regional Health Centre Foundation. As an Executive group, we feel both of these are very worthy causes.

The Movember campaign uses the money raised to support prostate cancer research. It is through this research we may once and for all find a complete cure for this disease that affects you and/or the men in your life.

The hospital campaign provides a more local initiative from which all of us may benefit in the future. I myself have had a cystoscopy done at the hospital and I know several of our members have probably undergone or will undergo this similar experience. The hospital staff have provided our support group with access to several of the physicians and clinicians to provide quality presentations to our support group. The staff continue to make themselves accessible to us for these presentations.

Should you be considering growing a stache this year, or making a donation, we would encourage you to review both causes and make your own decision on where you would want to direct your funds. Both are worthy causes and would be grateful for your participation.

Sincerely,  
Walt Klywak  
Chairman - PCCN Newmarket Support Group

## **Thank you Knights of Columbus**

The Knights of Columbus held a charity golf tournament in September with proceeds donated to support Prostate Cancer in the community. On October 1st a cheque for \$1,850.00 was presented to The Canadian Cancer Society Holland River Unit to support prostate cancer research and on October 16th a cheque for \$1,850.00 was presented to PCCN - Newmarket Prostate Cancer Support Group to assist them in their ongoing support and peer-to-peer mentoring of men affected by prostate cancer. We would like to publicly thank the Knights of Columbus for their time and generosity in support of prostate cancer.