Prostate Cancer Canada Network – NEWMARKET

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December 15, 2015

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

Support Night & Christmas Dessert Pot Luck

Our December meeting will be an evening of sharing and fellowship with a potluck dessert table. At this busy time of year, we probably don't need the extra calories, but if you can please bring a few sweets or desserts for all to share. We often end up with too much, so just enough for five or six others and we'll have a great sampling of all the season has to offer. The group will supply coffee and juices, as usual. Then we can sit and share our memories with others on the same journey.

Please bring a donation for the Newmarket Food Bank... remember others not as fortunate!

Meeting Date: Thursday, December 17, 2015

Place: Newmarket Seniors Meeting Place

474 Davis Drive, Newmarket (Side Entrance)

Time: 7:00 PM to 9:00 PM

Prostate Cancer Canada Network – Newmarket Newmarket, ON

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Assisted by

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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.

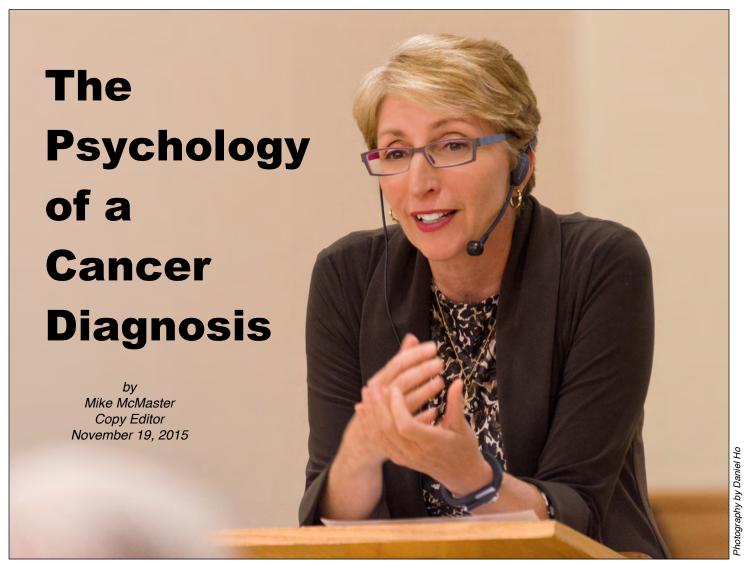
Dr. Michelle Flax is a registered psychologist and psychoanalyst in private practice, specializing in relationship issues and personal well-being.

For over 25 years, she has been providing psychotherapy to individuals and couples, helping them with life and relationship problems and challenges.

Dr. Flax began her career in South Africa, where she completed her Masters degree in clinical psychology. When she came to Canada, she worked at a youth counselling agency and went on to complete her Ph.D. at York University. She is a registered psychologist (College of Psychologists of Ontario #2115) and has been in private practice since 1987.

Post Ph.D., she completed her psychoanalytic training at the Toronto Institute of Contemporary Psychoanalysis and is a supervising psychoanalyst and member of the faculty at the T.I.C.P. She is currently a member of the board of directors at the Advanced Training Program for Psychoanalytic Psychotherapy at the Toronto Institute of Psychoanalysis.

Dr. Flax spoke at our November meeting. This is what she had to say.



I am delighted to have been invited to talk with you tonight. I hope we can learn from one another. You are already taking advantage of one of the most important coping strategies and that is reaching out to others for support and using these supports that the community has to offer.

In tonight's talk I plan to talk about what happens psychologically when one is diagnosed and treated for prostate cancer. And I hope to give you some strategies to help you make your way through this time.

My family is no stranger to prostate cancer – my husband (an urologist)

works with prostate cancer everyday – but other than that, my father was diagnosed with prostate cancer when he was 68. The first we knew of it was when he was told his PSA was over 50 and he would need a biopsy. What was most helpful for me was learning about the illness, the treatments and the

consequences.

My father decided on a radical prostatectomy and he recovered well. He lived fully and happily to age 86 and he died a few years ago of an illness completely unrelated to prostate cancer.

Twelve years ago my 50-year-old brother was also diagnosed with prostate cancer. He too, chose to have a radical prostatectomy, and you can imagine our relief that he too recovered well with few complications,

A diagnosis of cancer affects not only the person given the diagnosis but also those that love and care for him. The incidents of mortality from prostate cancer are low but it is really hard to find the good in a cancer diagnosis when it happens. It is life changing. The diagnosis and treatment places huge stresses on those diagnosed and their family members.

First, I am going to talk about the psychological stresses you face as you go through the various stages of the journey through prostate cancer. And after, I am going to outline some of the coping strategies - from the simple strategies of anxiety relief to the much more complex strategies of dealing with family and making meaning of what is happening to you.

Psychological Phases of a **Prostate Cancer Diagnosis**

I want you to take a moment and think back over the whole sequence of your diagnosis. You might all be at different phases but I imagine it is still very fresh for many of you.

Phase One: Diagnosis

I suspect you remember well the first stage - going to your doctor and having the PSA test done and the digital rectal exam - and then on to further testing the biopsy and the pain and discomfort associated with that and the anxiety associated with waiting for the results and finally, the meeting with the doctor and the shock of hearing the word cancer.

You may have experienced denial, perhaps even anger. There is no right - taking the situation in slowly and processing it.

Phase Two: Treatment Decision

In the second phase there is the overwhelming process of understanding and making your way through your treatment options. Some know immediately how they want to proceed but for many this is a time of confusion while you weigh your options.



The emotions you experience may be confusion. You may feel overwhelmed or scared. At this point you are gathering information and making a decision. Sometimes you may feel you have not enough time, but sometimes you may feel there is too much time while waiting for a procedure or second guessing your choices.

Phase Three: Treatment Process

The third phases is finding a way to live well with active surveillance or proceeding to a treatment option.

You may feel fears of mortality and other anxieties. At the same time there is often quite a bit of relief in finally being able to move forward. Family and friend support is often very present and helpful at this point.

Phase Four: Convalescence and Recovery

A period of convalescence follows in

reaction, there is only getting through it the fourth phase. This is a time where many men begin to feel the full impact of both the treatment and the diagnosis.

> Dealing with the side effects and the worry of persistent side effects are often part of this phase. Because of incontinence some men may withdraw and not want to go out or be intimate for fear that you may smell of urine. These are matters that can be worked through and they don't need to become a major obstacle.

> The possibility of erectile dysfunction is usually the biggest worry and waiting to see what degree of erectile dysfunction you have been left with is a very stressful matter for most prostate cancer sufferers and their partners. Intimacy issues often come to the fore at this phase. Managing your feelings can be a complicated matter.

Career worries can come in at any phase and you wonder whether you will be able to work as well as you did prior to your illness. Your concentration, your memory, your focus are often quite poor in this phase and you wonder if they will ever improve. People are often required to take time off work and this can place an enormous stress on people.

Time consuming insurance paperwork and the financial burden of the cost of medications can add to your stress during this phase.

You may feel shaken, fragile, vulnerable and anxious. Some men take to addictive behaviours to control their anxiety.

Marriages can suffer quite a lot during this period but there is often this sense of gratitude, an appreciation for being alive, and having this loving support.

Phase Five: Living with Cancer / Fear of Re-occurrence

The fifth phase is about living, and living with cancer. And it's about the fear of reoccurrence as well. This phase is about trying to shape your life in a way that the cancer is part of the background rather than the foreground - to live with a new normal as best you

If the treatment failed to stop the

cancer then symptom relief and quality of life issues are at the foreground - that is what is in focus. If you are on active surveillance your task is trying to live well and fully between PSA tests. Health, nutrition and exercise are part of this phase.

This is the time where we try to make sense of the cancer and the devastation to our lives as well as the positives that have come about because of having cancer. It may sound strange but there are some positives that can come about.

Some people talk about seeing the world completely differently because they have had a life threatening disease. You learn not to take anything for granted. You learn to appreciate friends and family in a new way and find a newfound respect for the strength and frailty of the human condition.

Coping Mechanisms

Let us turn to some of the coping mechanisms that could be helpful to you as you make your way through these phases.

Coping Mechanism One: Manage your Anxiety

The first one, of course, is dealing with anxiety. No one of you will have escaped the anxiety that goes with all of this. You are not alone in having a wide variety of feelings, especially in terms of fear and anxiety. When we talk about coping we really mean how you are managing the anxiety that comes with all of this. Anxiety is a signal from your mind that there is a danger that you have to deal with. There is no greater threat than a physical threat to our survival.

I want to say a few words about handling anxiety and give you some ways to keep yourself a bit calmer through the phases.

a.) Distinguish between useful worrying and useless worrying

Useless worrying is worrying when there isn't anything you can do as a result – it doesn't lead anywhere, there is no plan. Useful worrying leads to decisions and actions – creating a list



of things to do or a set of questions for your doctor.

b.) Delaying worrying

If you find yourself worrying anyway, delay the worrying - make an appointment with yourself during the day to limit the time you spend worrying.

c.) Exhalations

Breathing is a calming mechanism. What we have to do to calm ourselves is to breathe out – to focus on the exhalations. Breathe out and count to 5 or 7 or 9. Breathe with the diaphragm. You want the oxygen to go into your body. Do this before any procedures.

d.) Normalize

Do what you can to put this stuff in the background – go on with regular life to the extent you can.

e.) Seek support

One of the best things you can do for yourself is to seek out support – to talk, to have a community. This is your rainy day. This is a time when you are entitled to some special attention.

Coping Mechanism Two: Make Friends with your Emotions

Accept your feelings and the frailties of being human. Be non-judgmental of your own emotions. Getting prostate cancer is not your fault. Turn self-pity into self-compassion. Seek out support – talk to a survivor.

Coping Mechanism Three: Stay in the Present

Staying in the present means being here, now. Staying in the present protects you from worrying about news you have not yet had. Find small pockets of pleasure daily. One approach that helps us stay present is mindful meditation – a program generally of eight sessions, sometimes offered by your hospital – it has an enormous influence on lowering your stress response.

Coping Mechanism Four: Examine your own Theories

I want you to take a moment to think about your ideas about why you or your loved one got this cancer. Look at how you are making meaning of what is happening to you. Human beings are hard wired to make meaning of what is happening to us and we are constantly making up theories to explain events.

We are complicated human beings. Do not hesitate to seek out (professional) help if you think it may be helpful.

Coping Mechanism Five: Be mindful of your Partner and Family

There are many studies in psychology that show that illness in the family can be a cause or a consequence of family dysfunction. When there is illness in the family there is often a marked increase in strained family relationships. Your partner can feel over protective and worry about you being ill. They can feel depression and anger. They can become ill themselves.

Problems that have been long standing can be drawn into the whole illness scenario and families can go back to old ways of functioning that are quite dysfunctional. Sometimes family rituals or important occasions can be disrupted because a person cannot fully participate because of illness or time commitments - treatment schedules, doctors' visits and the like.

The research shows that more serious illnesses also force couples into a closer more intense relationship – which is a good thing. But realize there is no way to be a perfect partner in this situation. Try to normalize the life of the ill person as much as possible and keep routines and enjoyments in place. The most helpful stance is to maintain hope. Above all, the most important skill you have as a couple is to define this as "our problem."

Coping Mechanism Six: Mourn your losses, Celebrate what Remains.

Any life crisis closes some doors even as it might open other doors. Mourning our losses is a necessary part of psychological health – especially if you can come out on the other side and appreciate and celebrate not only what we still have, but also what we have learned and gained.

Relationships are like tapestries – hundreds of woven threads that tell a story rich in colour and detail.

Conclusion

In conclusion, I have learned so much from my patients with cancer. Being able to find gratitude is life affirming – and helpful to both you and those around you. My patients have taught me that being thankful to be alive is the deepest gratitude of all.

Embracing the love and support of those around us when there is a threat to our existence is a gift that continually gives back. Being grateful does not mean never being angry or resentful, rather, it's keeping perspective to know that it is only part of what you are feeling – remaining open to new possibilities including new treatments.

The fact that you are all here tonight means that you have opened yourself to ask questions, to work in a proactive way with your cancer, to work toward gratitude and to allow yourself the benefit of support through this very significant crisis in your life.

Q: I was surprised about the focus you had on loss of sexual life. I know there are just stages of life where you are at – we now cuddle differently, shall we say – but it's never been our priority. Just being able to go to the cottage next summer has been one of my main thoughts.

A: I think you are right to link it to age, or not necessarily to age, but to where you, as a couple, are in your sexual life. For some, there is a worry



about the change in sexual function but, this is what I say about life being a tapestry, to place too much emphasis on sexuality is to do a disservice to the other elements of the relationship. You just try to get the balance right for each relationship.

Q: There is a Joni Mitchell song—"Both Sides Now"—there is a line that says, "Something's lost but something's gained in living everyday." And so, all of us woke up green side up—we can enjoy the moment, wake up, see the cardinals and the blue jays, hear the traffic and play with the grandkids.

A: Yes, that's what you want to get to. Thank you for the Joni Mitchell reference. You know that cancer used to be this dreaded disease. Now, "the big C" stands for chronic – living with a chronic illness. Or, in some cases, the "C" stands for convalescing or the "C" in recovery. It is no longer the signal for our expiration date. You don't want to deny the anxiety and the losses that you face with this but you do want to embrace the possibilities of living as fully as you can.



Feedback from Members

I'm afraid that I'm one of those who just came to the meetings to get an idea about what choice to make. A friend (Ulli Baumhard) told me about the group. He had given me an excellent book to read that led me to strongly consider Brachytherapy.

Dr. Morton from Sunnybrook hospital was the guest speaker at the first meeting my wife and I attended. His presentation confirmed for us that Brachytherapy was the treatment that I would choose.

I have attended a few meetings over the last 6 years when a topic was of interest to me. I realize that all of this may seem selfish and perhaps it is, but the Prostate group can be a benefit to people on different levels.

Even though I attend infrequently, I would be happy to share my experiences with anyone considering the Brachytherapy option and you have my permission to give out my phone number. I guess the only issue might be that given my procedure was 6 years ago, my information may not be relevant when comparing it to recent advances in other forms of treatment.

For your information, I have been very pleased with my decision to have the Brachytherapy treatment. Side effects have not altered my life to any significant degree at this point. PSA levels almost nonexistent.

Hope this has been helpful.

- Gordon (Tom) Ironside -

~~~ Notes from The Chair ~~~

Where has the year gone? I trust you have all been proactive and completed your Christmas shopping. After all, it isn't like it creeps up on us - it happens the same time every year. Unfortunately, I am sure I am not alone and may see some of you for that last-minute dash through the mall.

Hopefully, you will have all received a survey from us in your email. We hope you will take the time to complete the survey. We are hoping the results will help us tailor our meetings to better serve your needs. Please let me know if you are unable to access the survey on your computer. We tried a new Google Docs survey form and I may have messed up the programming. We have had several people answer the survey. A few people have indicated they have had a problem opening it and some were unable to enter data for the last question, so they sent me their reply by email.

When Dan took over the newsletter, he thought it would be a good idea to have a "Notes from The Chair" section. I think it was his way of trying to distribute the workload and help him fill a page. When I wrote the piece for last month, we were hoping it would spark a response from members. We got a terrific email from Tom Ironside and that got Dan thinking about the workload again. This time he suggested it would make the newsletter more enlightening if we were to include a reader response section. What a great idea! We would like to encourage all our members to send us a note/email to let us know your thoughts, good or bad, as well as any recommendations on how we can improve the group to make it more meaningful. With any luck, Dan is hoping for an overwhelming response so he does not have to create a newsletter (*just kidding Dan*)! It would be nice if we could include your response and/or suggestions in an upcoming newsletter. If you wish to remain anonymous, just let us know when you send us the information.

With this meeting being held during the Christmas season, we are setting it up as a social gathering. In the past, we have tried to steer the discussion by having tables set up to suit different topics. This year we decided to keep the evening totally topic-free. That does not mean we won't be discussing prostate issues. On the contrary, the topics are totally open and will be driven by the conversation. After all, we are a support group and that is the reason for the meeting. As always, spouses are encouraged to attend. We have suggested this will be a dessert potluck meeting. You do not need to bring anything to attend. Should you choose to participate, a dessert item would be well received. I am sure Ivan will be bringing his world-famous cream puffs so you may want to get to the meeting early!! Speaking of which, since this is a social meeting, we have adjusted our start time from the usual 6:30 to 7:00 PM.

If possible, please bring along a donation for the food bank. At this time of year, we feel it is really important to support the local food bank so any and all donations will be well received. Thanks,

Walt Klywak