

3rd Annual Prostate Cancer Forum

Malecare – The Empowered Patient

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Malecare, Inc.**

I. Overview

The goal of Malecare, Inc. is to help men deal with cancer. Studies have shown that men are dying nearly five years earlier than women, and this difference is even more pronounced for African American men. In addition to a shorter lifespan, men are almost twice as likely as women to die of heart disease.

I. Prostate Cancer – A Killer of Men

Prostate cancer will strike one in six men, and prostate cancer is the second largest cancer killer of men in the U.S. In fact, 33,720 men will die of prostate cancer in 2011, and this number is growing each year. Often we hear broad statements that are asserted with such authority that we assume that there is real scientific research behind them, but too often we find that this may not be the case. We all can be patients, but we must learn to become empowered patients. Empowered patients are those who become 100% partners in their care decisions with their doctors. Patients must become the CEO of their medical care, and that begins with self-education.

III. The Empowered Patient

1. How?

Empowered patients are those who become 100% partners in their care decisions with their doctors. Patients must become the CEO of their medical care, and that begins with educating one's self.

2. Finding the Right Doctor

Cancer care is big business for the doctor and the hospital, but you are hiring a professional, so get different opinions from different doctors. Ask questions about your disease and about treatment goals. Does the doctor share your values and your goals? Ask them about their experience in treating men

with prostate cancer. What is their practice with regard to off-label drug use and clinical trials? Perhaps the most important question is the following: After I listen to your treatment plan, may I choose what I believe is best for me? Find out how you can communicate with them and whether their system works for you. Will they permit you to tape an office visit and bring a friend with you? Find out what their philosophy is on pain management.

1. Managing Your Doctor & Insurance Company

Make yourself human to your doctor. Give him or her your life story, and make sure they know that you are loved and cared for by others. Let your insurance company know too that you are a human being and that you will fight when necessary to preserve your life.

IV. Support

Find face-to-face and/or on-line support groups that you can be a part of. Ask your doctor and other survivors, and they can put you in touch with groups. Unfortunately, many doctors don't believe in support groups so that can make it difficult. Use the Internet.

VI. What to Do

- Listen to your body.
- Have a goal for everyday.
- Finish unfinished business and eliminate stress from today.
- Find a positive in your diagnosis.

VII. Making Decisions

Decisions need to be made about treatment, and there are many options, all of which have positives and negatives. Remember that there are no automatically correct answers. Statistics are important only when you are trying to make a decision. Once you have made your choice, the only statistic that matters is the statistic of one, which is you. Your cancer is unique just like you are. Take the time that you need to make decisions, and use the time to become comfortable with your decision. Always get second and even third opinions, and always get copies of your medical records. Read them and understand them, and ask questions when you need to. Talk with other survivors and ask them to share their experiences and feelings, but remember we are each individuals and we have different values.

VIII. Living with Cancer

You did not choose to have cancer, but you have it. Cancer is something you have, but it is not who you are. Stay in the present because the further out you try to go the more stressful it becomes. You always have choices; always make the choice to be positive. It has to be a conscious decision. Interrupt negative thoughts. Your brain can only handle one thought at a time so make it a positive one. When you are comfortable with a decision, once you have made it, don't look back. Remember, you made the

best decision you could make. There is no room for second guessing yourself. You can be angry and depressed today, but tomorrow decide to accept your situation and make the best of it. When life hands you lemons, make lemonade. Live your life today.

Wrap yourself in a blanket of love, and surround yourself with positive people. Learn how to receive from others; learn how to be taken care of. Be honest about your feelings and share them; saying them out loud can help. Once you have done that, consciously decide to move on and live your life. Don't do what you cannot do, but do what you can. Learn to say no when you need to or want to. You may want to set up a web page to report your progress so that you don't have to answer the same questions over and over. Having cancer is not a punishment, and remember that you are still alive. Live your life. Use what is working, and don't struggle with what isn't working. Exercise everyday for at least 30 minutes. Walk when you can, and maybe that means getting a dog to walk with.

Use psychotherapy and antidepressants if you need to, and use energy medicine if it helps. Be involved with support groups, and share your experience with fellow survivors; they know how you feel. Avoid toxic people; put a sign on your door that says, "Don't come in if you cannot be positive." You are not any sicker or closer to death because you were diagnosed today. Actually, being diagnosed can extend your life because now you can start the battle against your disease. Never lose your faith. Never lose your hope. Believe in the strength of your prayers and the strength of your faith. Believe in miracles; they do happen.

Panel Discussion

I. Support Groups

Joel Nowak, MA, MSW

Support groups become an active intervention just like surgery or radiation around the construct of active surveillance. Without a support group, men don't get their PSAs done in a timely fashion, and they almost put the prostate cancer out of their head. Patients need the ideas of availability and ownership. Support groups are a vital piece of prostate cancer treatment.

Participant

It is very important for newly diagnosed men to see that there are a whole bunch of prostate cancer survivors who are alive, happy and living a full life many years after their diagnosis.

II. New Diagnosis

Participant

As a newly diagnosed patient, I didn't realize that there were so many options. I want to do my due diligence to make sure that I feel comfortable with my decision. My urologist has suggested surgery, but I need to continue to educate myself.

Joel Nowak, MA, MSW

You are at the hardest place right now, but you will break through. One day you will wake up, and you will know what you need to do. No one can tell you how to get there, but it will happen.

Participant

I had 22 separate consultations with 22 separate doctors before I made my treatment decision. I have three binders full of information that I gathered, but it came down to when I was in a support group and I saw a man who had come out of surgery the week before. He looked great and he was healthy; that was my moment.

Participant

The other side of the coin is that 99% of active surveillance is knowing when to pull the trigger.

Participant

You should be congratulated because you have taken the reins, and you are steering the horse. That is to be commended because many men don't do that.

III. Proton Beam Therapy

Participant

It is hard to know what is actual factual information and what is marketing information. For instance, I just learned about proton beam therapy, but Dr. Katz said to be careful with that. Is that true?

Participant

Proton therapy has a place in radiation, but it has been used primarily in head and neck cancers in terms of having a proof of benefit. Those same benefits have not been shown in prostate cancer. It has a lot of marketing behind it, and it has a huge price tag. There is no proven benefit. IMRT radiation has equally good results if it is done at a experienced center.

Participant

The guys who do the proton beam therapy are the biggest evangelists for it. Men tend to be evangelists for what they have used or been a part of.

Participant

At Mass General, they use the IMRT radiation prior to utilizing the proton beam radiation. They are hopeful that it is going to be a terrific thing, but at the moment they are not pushing it.

Participant

Another difference between men and women is men generally take ownership in what they have chosen for themselves. Women tend to share the various options with fellow patients.