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# Conflicts

- Malecare
- New York State Prostate Cancer Coalition
- DOD - PCRP
- Consultant - Dendreon

## What is Cancer



- **I wish  
cancer  
got  
cancer  
and  
died**

Never assume that your audience has even what you believe is basic knowledge. Cancer is a term used to describe many different diseases in which abnormal cells grow without any sort of control. These abnormal cells are able to invade other tissues.



A recent Harris Poll Found that  
the Most Feared Disease in the  
United States is:

**CANCER**

In this poll 41% of those polled listed cancer at the top of their fears

So, it is not surprising that when a person is given a cancer diagnosis they have a major emotional response.

That word cancer always strikes fear into everyone. Some people have great difficulty even saying the word, CANCER.



## The Problem



Men do a terrible job of taking care of themselves. They do not go to the doctor, they are often dishonest about their physical condition. As a result men die 5 years younger than women. The problem stems all the way back to our childhood. Men are taught that “Big Boys Don’t Cry.” And the problems compound from there.

# The PC Problem



- There are many options to treat PC.
- All treatments come with side effects.
- No matter what treatment is chosen 1 in 3 men will still have a recurrence.

1- Happily there are many options to treat prostate cancer and a man will need to make some very important decisions about treatment when faced with a diagnosis.

2- No matter what the treatment decision are made there will be some side effects to contend with post treatment. The specific nature of the side effects and the level of severity of the side effects are unpredictable.

3- Despite what treatment is chosen 1 in every 3 men will have some type of recurrence of their cancer. There is no way to predict who will have a recurrence and who will not have one.

1- Confusion is very common when deciding on a primary treatment for stage 1 or stage 2 cancer

2- And it is also true for men deciding on treatment for metastatic, or stage 3 and stage 4 cancers

## An Empowered Patient



- We all can be patients, but.....
- You must become an EMPOWERED PATIENT  
The CEO or superhero of your medical care

It is no big deal to be a patient, we all can and will become patients.

1- To best deal with our diagnosis we must learn to become empowered, educated patients

Empowered patients are those who become partners along with their doctors' in making their own health care decisions. Empowered patients have educated themselves about their disease and are full participants along with their doctors in managing their medical care.

## How to Be An Empowered Patient

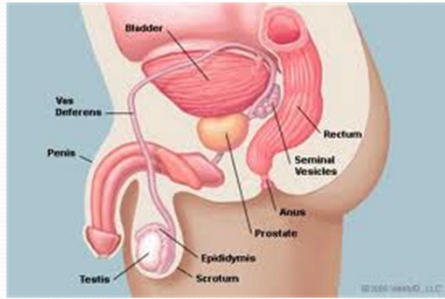


- Educate yourself about your disease. Use the internet, talk to people, go to seminars, participate in support groups.

Since Dr. Wellbe and Dr.Kildare have all retired and are not taking new patients you need to step into their shoes. You must learn as much as possible about your disease and its treatments. Then, you must take personal responsibility along with your doctor in directing your own personal care.



# What is the Prostate Gland?



- Note the geography of the prostate gland and its relationship to:

- 1- The urethra
- 2- the bladder
- 3- the rectum
- 4- The nerve bundles

As part of the male reproductive system, the prostate gland's primary function is to secrete a fluid which during male climax (orgasm), the muscular structure of the gland helps to propel the prostate fluid, along with the sperm that was produced in the testicles, into the urethra. The semen then leaves the body out through the tip of the penis during ejaculation.....

By observing the anatomy you can easily see why any type of treatment for prostate cancer can cause significant side effects.

The urethra runs through the gland, both the bladder and the rectum are very close to the gland. It is easy to see how any of these could be accidentally damaged with any of our current treatments.

There are nerve bundles on both sides of the gland which can also be damaged causing some degree of erectile



dysfunction.

## Know Your Cancer



- Initial treatment decisions should rely on seven considerations

PSA, DRE, BIOPSY, GLEASON SCORE, STAGING

## Consultations with Doctors



- 2<sup>nd</sup> and 3<sup>rd</sup> opinions from different practice areas are vital when making decisions

Make sure that you have seen 2<sup>nd</sup> and 3<sup>rd</sup> opinions from different doctors in both the same and in different practice areas. Mull over what each of them have said. Read about their recommendations and consider which treatment seems to fit you and your cancer

## Personal Feelings



- Listen to your heart and your gut.

Some people can be tolerant with the risk of active surveillance in exchange for avoiding the side effects, others can not tolerate knowing that there is cancer inside them. This is a very personal issue. However, if you do decide to have a treatment you must understand that you will have some level of side effect, how much and what type is unpredictable.

## Making Decisions



- Take your time to make decisions, understand the upside and the possible downside of each treatment.

Remember, what ever your decision you will be effected by it for the rest of your life.



## Making Decisions



- When making treatment decisions remember that your cancer is unique just like you: you are unique.

Your cancer and you are both unique

## Making Decisions



- Team Work –Learn from other survivors.
- However, remember we are each individuals with different values and a different cancers.

## Making Decisions



- Statistics are important only when you are trying to make a decision.
- Once you have made your choices the only statistic that matters is the statistic of one, **YOU**

1- However, statistics have a significant limitation. Statistics may predict your fate, but there is no individual guarantee. Statistics only predicts group trends, they do not predict how you, as an individual will respond.

## Finding the Right Doctor



- Go to the best possible doctors at the best possible health facility.

Research has shown that the more experienced the doctor the better the eventual outcomes.

## Finding the Right Doctor



- Cancer = Big Business
- Ask questions

Cancer care is big business for the doctor and the hospital. When talking with a doctor always remember that a small number of doctors will be influenced by personal gain, not your medical condition.

Take advantage of the many options that are available to us all, especially in the Metro area, seek 2<sup>nd</sup> opinions from different doctors from different practice areas

1-Ask about what the doctors treatment goals might be for you do they match with your values? Find out how much experience the doctor has using this treatment.

2- Make sure that the doctor and you are on the same page about treatments, quality of life and about your role in your medical care decisions.



## Finding the Right Doctor



- Can you be a member of the team?
- Communications in between meetings?
- Tape recording a session or bringing a friend?

Develop a team of healthcare providers that support your role as an empowered patient.

1- Find out how you can communicate with the doctor and does this system work for you?

Telephone, email? What is their policy on communications, will you communicate with the doctor, the nurse, a resident?

2- Will they permit you to tape an office visit and bring a friend with you?

3- What is their philosophy on pain management?

## Finding the Right Doctor



- Experienced treating men with prostate cancer?
- Off label drugs
- Clinical trials
- Picking the treatment plan

Find doctors who have extensive experience treating men with prostate cancer. There is a lot of evidence that the more experienced doctors have better outcomes.

1- Does the doctor have the experience and knowledge about the use of “off label” drugs.....this only comes from experience

2- Does the doctor stay informed about clinical trials and will the doctor help you to identify appropriate trials?

3- Make sure that you learn about all the possible treatment options available to you, including when appropriate active surveillance. Learn about surgery, including open, laparoscopic, robotic and Cryosurgery. Learn about radiation including IMRT, External beam, seeds and Proton. Learn about active surveillance if it is appropriate for you. Learn about the side effects possible from each of these therapies. Unless you have a high Gleason and unless you have a large number of biopsy cores that have a lot of positive tissue you have time to decide what treatment will be best for yourself.....

\*\*\*\*\*An important question to ask a potential doctor is, After I listen to

your treatment plan, may I choose what I believe is best for me?

## Managing Your Doctor & Insurance Company



- Make yourself human to your doctor.
- Make yourself human and a fighter to your insurance company.

Make yourself human to your doctor. Give them your life story and make sure they know that you are loved and cared for by others. Remind them that you have a family and that you are an important part of the world. Share your personal accomplishments and how you have effected the world or your neighborhood

1- Let your insurance company know you are a human being and that you will fight when necessary to preserve your life. Remember, it is your life.

## How To Be An Empowered Patient



- **Surgery Bait-and-Switch - Who Will Perform Your Surgery? Its in the consent**
- **You can change your mind until you are asleep.**

For any test or surgery you have a right to know and to expect one specific doctor to perform it.

Make sure that the consent form specifies who is going to do the surgery, not a member of the team, or it is anticipated that .... will perform the surgery.



# How To Be An Empowered Patient



- Get copies of all your medical records
- Read them and understand them.
- Ask questions and ask more questions.

Keep your medical records in a binder or file. Your records belong to you. This way if you need to go to a new doctor or if you need to map out some of your disease progression such as changes in PSA or changes on scans you will already have the information. – This will save time.

1-- Read and understand your medical records as well as all your test results.

2- Ask questions and then ask more questions until you understand them. Remember, your medical records provide facts, details and specifics that illuminate the characteristics of your cancer.....

\*\*\*\*The quality of your understanding of your records will shape the quality of your questions, and the quality of your questions will determine the quality of your answers.

## How To Be An Empowered Patient



- support groups
- Call : 1-800-4 cancer
- Go to lectures/seminars and learn about PC
- Become an expert

On-line and face to face support groups provide you with an opportunity to meet other men who share your experience and your feelings. They can be a great resource, but be aware of men who are negative, they can not help you.

## How to be An Empowered Patient



- Younger men should think about sperm banking

For some reason sperm banking is almost never discussed. Treatments for prostate cancer will leave a man infertile, if there is any possibility that you want to have children in the future, sperm banking needs to happen prior to treatment.

## How To Be An Empowered Patient

- Evaluate Web Information
- Develop a best practices guideline to evaluate good from bad websites.  
Remember, anyone can publish anything on the web.
- It's up to you to know what is good and what is bad on the Web.

One of the first response many of us make is to go to the internet o learn about a new diagnosis. Learn to evaluate the information you read on-line.

Trust your intuition – anyone can write anything true or false on the internet.

### **Stick with well respected health websites**

Learn to **separate fact from opinion.**

### **Analyze any advertising to help assess the site's credibility**

Be cautious **of pharmaceutical or device websites.** **If you are not sure who has put out a website** dig a little deeper, you'll find the information. Scroll to the very bottom of the homepage, or study the "About Us" or "Contact Us" page to see who put the site online.

### **Testimonials are suspect.**

Make sure the information you find is the most current available. Often you will find that studies conflict each other, or newer information trumps older information.



# How To Be An Empowered Patient



- Malecare.org
- Malecare.org/advanced-prostate-cancer-program/
- Ustoo.org
- PCRI.org
- US government sites
- Medscape.com

Learn how to tell good sites from bad sites. Here is a list of just some of the to be trusted sites on prostate cancer. This is not a complete list, just a few samples of some sites.

Government sites - National Cancer Institute (NCI); CDC; Departments of Health, National Institute of Health (NIH); Food and Drug Administration (FDA)



## Clinical Trial

- Who should participate in a clinical trial?
- What needs to be thought about before joining a trial?
- What are the possible risks?
- Where can you find out about clinical trials?

Some people participate in clinical trials because they have exhausted standard (approved) treatment options - which either did not work for them, or they were unable to tolerate certain side effects. Clinical trials may provide another option when standard therapy has failed.

Other people participate in trials because they want to contribute to the advancement of medical knowledge.

1- People should learn as much as possible about the clinical trials that interest them. They should discuss their questions and concerns with members of their health care team. Prospective participants should understand what happens during the trial, the type of health care they will receive, and any costs to them - which may or may not include the cost of the product, costs associated with administering the product, or supportive care. Some insurance companies cover clinical trial costs, others do not... so ask your insurance company about their policy.

2- Anyone considering a clinical trial should know that there are benefits and risks associated with participating.

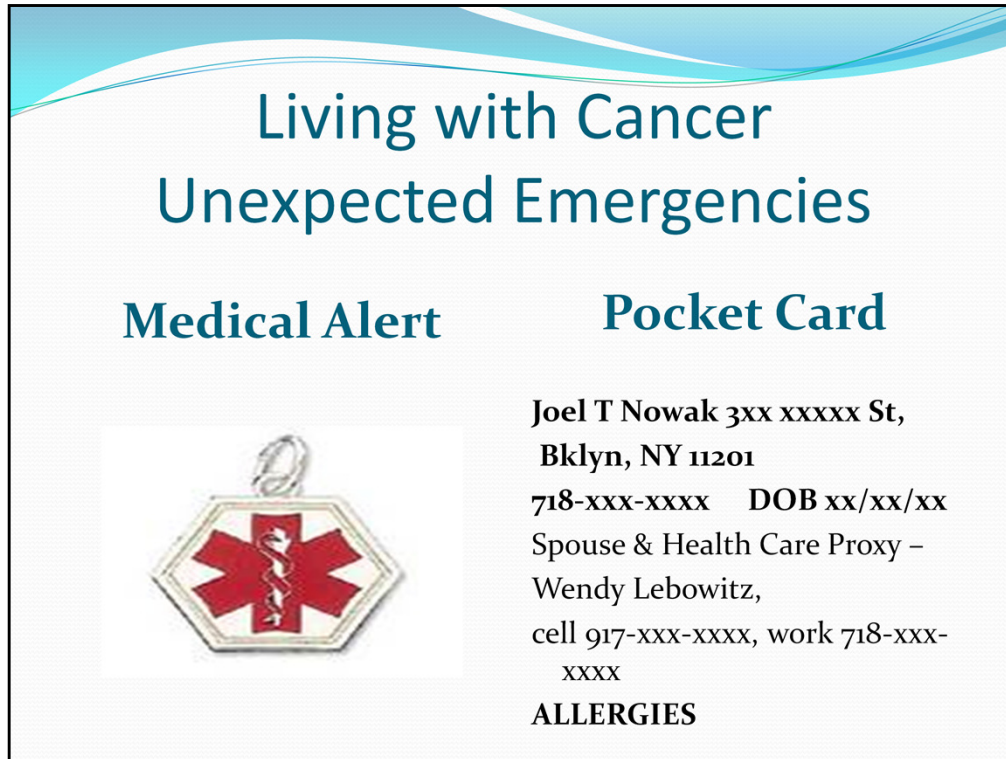
There are generally known and unknown risks associated with clinical trials, such as: unpleasant, serious, or even life-threatening side effects resulting from the treatment.

the treatment may not be effective for the participant and

the protocol may require more of the participant's time and attention than a standard treatment.

However, the trial might also make a huge difference in someone's disease status.

3- [clinicaltrials.gov](https://clinicaltrials.gov) and Malecare has a special arrangement with Center Watch where you can plug in your requests and when a trial opens meeting your criteria you will get an email



We never know when we are going to have some sort of emergency, so we need to always be prepared. The best way to quickly convey important information, especially if you are unconscious is either with one of the commercial Medic Alert services or with a self made pocket card.

My pocket card includes: My name , address, phone, Spouse and Healthcare proxy, contact information, my medications along with dosages, supplements I take, Medical History with doctor names and contacts, and allergies.

## Living With Cancer

- Having cancer is NOT a punishment.
- Remember you are still alive- so live your life.
- Use what is working, don't struggle with what isn't working

For many people there still remains a left over feeling that having cancer is a punishment. This just is not true. Having a cold, having the flue or having cancer is not a punishment. It is just a reality of living your life.

2- Live your life, don't waste it. My wife and I are working on my bucket list. I want to see the aurora borealis, so we went to Iceland. In August we are taking our family to Alaska. What ever is important, do it, don't delay. My goal is to do everything on my bucket list so that I will just have to make a new one to work on.

3- Take advantage of your strengths. Remember the adage, "you can not teach a horse new tricks, so practice the good old stand bys.

## Living with Cancer

- You did not choose to have cancer, but you do.
- Cancer is something you have, it is not who you are.
- Have a daily goal. Stay in the present – the further out we go the more stressful.

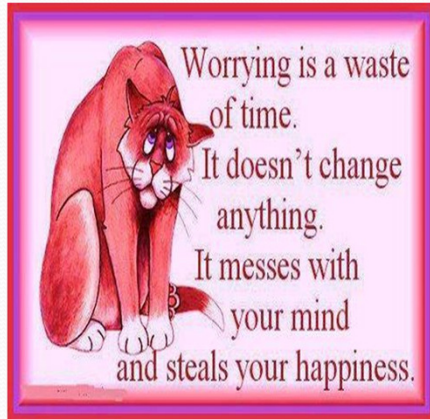
So, you have cancer, but you are still a human, a grandparent, a parent, a brother, and a friend. You are now a grandparent, a parent, a brother and a friend with prostate cancer, that the only change.

1- Don't worry about yesterday, it is already past. Tomorrow may happen, or maybe it will not. What is the difference.

It is today that counts because you know that today is happening.



## Living with Cancer



- Listen To Your Body.
- Finish unfinished business and eliminate stress from today.
- Find a positive in your diagnosis.

Listen to your body – tell Melanoma story

1- Eliminate stress – Tell stock broker story

2- Find a positive in your diagnosis – Tell story  
incidental finding of renal cancer-



## Living with Cancer

- You always have choices, choose to **always** be positive.
- This has to be a very conscious decision.
- Interrupt negative thoughts – your brain can only handle one thought at a time.

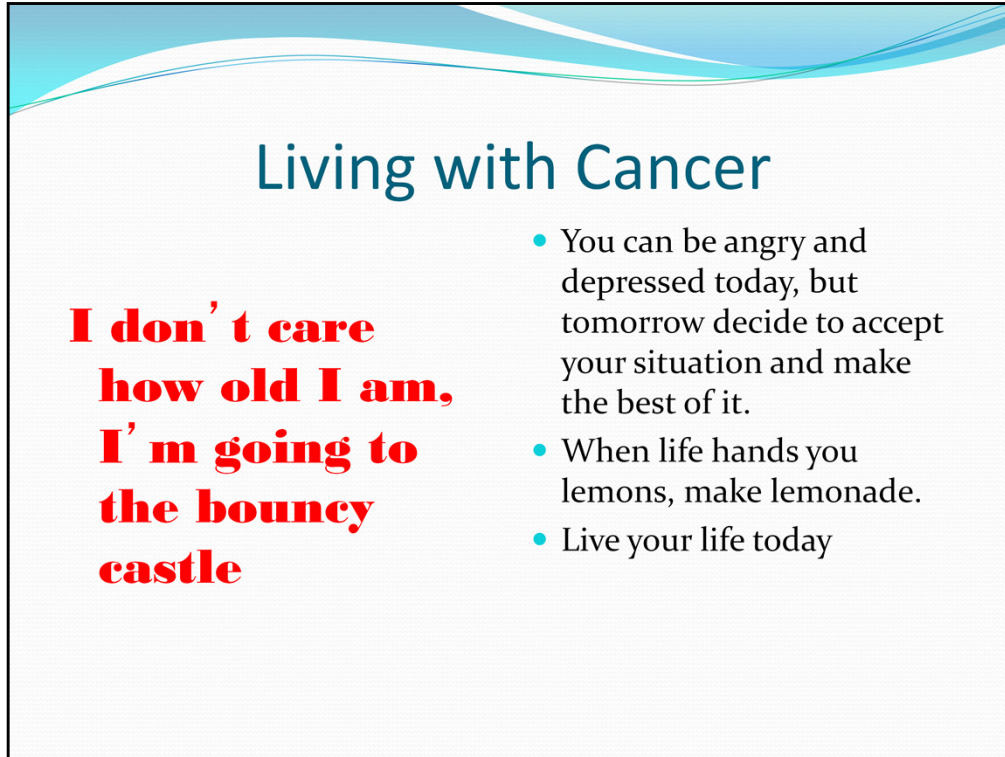
Tell story of my anger and my decision to stop being angry and make a contribution to the world.



## Living with Cancer

- When you executed a decision, NEVER look back.
- Remember, if you followed this guide, you made the best decision you could have made. There is never room for should have or could' have.

This is why it is important to not move ahead without taking the time needed to make the best decision for who you are given your clinical status.



## Living with Cancer

**I don't care  
how old I am,  
I'm going to  
the bouncy  
castle**

- 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

Some people confuse acceptance with apathy but there's all the difference in the world. Apathy fails to distinguish what can and cannot be helped; acceptance makes the distinction. Apathy paralyzes the will-to-action; acceptance frees it by relieving it of impossible burdens.

- Arthur Gordon

## Living with Cancer



- Surround yourself with positive people.
- Wrap yourself in a blanket of love.





## Living with Cancer

- Be honest with yourself about your feelings. Saying them out loud helps.
- Then consciously decide to move on and live your life.
- Don't do what you can not do, but do what you can.

I believe that expressing your feelings, even out loud so that you can hear them, often helps you to accept your feelings.

1- Moving on by making a conscious decision to live your life while you also deal with any barriers that come across while living your life.

2- Know your limits, ask for help when you need to and do for yourself what you are able to do.

## Living with Cancer



- Consider advocacy as a way to shift your personal focus away from your personal struggle to a larger fight against the disease.

Refocus your attention on educating others is one way to convert your fear into empowerment. The more you learn the more you can teach and the more you can control how you feel.

## Living with Cancer

- Set up a web presence to report your progress
- CaringBridge.org
- CarePages.com
- Blogger.com
- Facebook.com
- Twitter.com
- LotsAHelpingHands.com

Caringbridge is a free personalized website that supports and connects loved ones during critical illness, treatment and recovery

CarePages is a free patient blog place that connects friends and families during a health crisis

Blogger has free blogging tools and templates

FaceBook a popular social networking site that offers quick and easy communication to a broad group of people

Twitter can be used to disseminate brief updates quickly to your friends and family

LotsAHelpingHands is a tool to help assist individuals assist anyone needing support due to illness, infirmity, financial need, military leave etc.



## Living with Cancer

- Get those feel good endorphins circulating.
- Exercise everyday for at least 30 mins.
- Walk when you can (get a dog, I did).

Exercise is vital. It has a significant effect on your mental health and on your ability to deal with possible side effects of treatments.

## Living with Cancer

Epigenetics – The study of environmental influences that can mitigate gene output.

- Stress is immunosuppressive.
- Use psychotherapy & antidepressants if needed.
- Use energy medicine – TiChi, Yoga prayer, biofeedback, etc.

It is very clear that our environment does influence our health and well being. Living with stress will not only influence your quality of life, but it could kill you!

2- There is no shame in getting help to deal with your life and your diagnosis. Well trained therapist and the proper medications, if needed, will enhance your well being and the well being of your family.

3- Ask your doctor about help in locating energy medicine programs that are geared to people with cancer. There are many available and they will also improve both your quality of life and your physical well being.





## Living with Cancer

- You are not any sicker or closer to death because you were diagnosed.
- Being diagnosed can extend your life because you can now start the battle against your disease.



## Living with Cancer

- Believe in the strength of your prayers
- Believe in the strength of your faith
- Believe in miracles, they do happen
- Never lose hope

## The Truth



- Not All Facts Are Knowledge

T.S. Eliot

Becoming an empowered patient is not easy. There are pitfalls, confusion and discrepancies through out our journey. Our job is to sort out the noise, the mistakes and the misnomers.

## The Truth

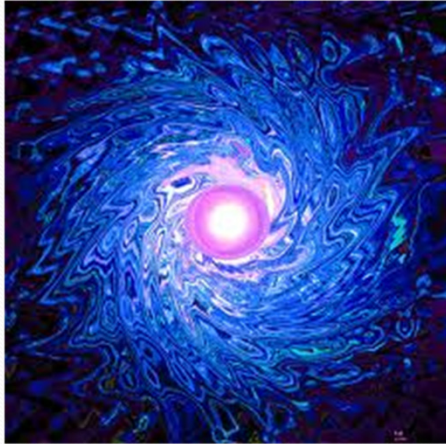


- Not All Knowledge Is Wisdom

Bart Kamen, M.D., Ph.D.

We need to figure out what is correct for ourselves,  
what is our own personal wisdom

## Your Job



- It is your job to sort out the facts, the knowledge and most importantly, the wisdom