



Never too young for prostate cancer:

A Couple's Path to Education and Empowerment

By Rikki and Terry Robinson

I distinctly remember our lives before cancer.

Last year, we spent a beautiful October afternoon on the waterfront, celebrating my grandmother's 80th birthday. Life felt good. I thought it would be a great time to get my family together to snap a photograph.

Looking back, I realize I was oblivious to the turn of events about to take place in our lives. Little did I know, our seemingly peaceful world was about to be turned upside-down and rocked at its core.

In an instant, our lives began to change. My mom and I were sitting by each other on the couch when my husband, Terry, walked in and sat between us. He explained that he had received a phone call from his physician regarding the results of blood work he had submitted the day before. She told him his PSA blood test was elevated at 17.2, and that he would need to see a urologist. She explained that it didn't necessarily mean anything serious, but definitely warranted further investigation. Terry looked at me and said, "This could mean Prostate Cancer". My first thought was, my husband is going to die. I saw our lives with our young children flash before my eyes.

I didn't really know much of prostate cancer at the time. Coincidentally, I had read an article about the PSA screening controversy about one month prior. The article itself was interesting, but I quickly tucked it away mentally, thinking to myself, *why would I need to know about prostate cancer, my husband was only 45 years old.*

We saw Terry's urologist, a great doctor with a calming disposition. He explained that a PSA of 17 was high for a man Terry's age. It could mean cancer, or it could be something else. He performed a digital rectal exam (DRE), and we received a bit of good news: he didn't feel a lump, but thought the prostate felt a tad firm, which may be suspicious. He gave Terry's PSA two weeks to come down.

Two weeks later, Terry went back for a second PSA test. His doctor called him with the results, and explained that Terry's numbers didn't go down - in fact, they went up to 18 - and he would need a biopsy. Terry called me to break the news, and I broke down and cried. At this point, nothing was going our way.

While we waited on biopsy results, I began an unending search to educate ourselves on all things prostate cancer. I was up all day and all night to the point of insanity. I couldn't stop. The first thing that struck me was Terry's PSA. Some organizations state that the normal range for a man of his age (45) was 2.5 and below. Terry's PSA of 18, if proven to be prostate cancer, could in fact be very serious. At times, this new reality felt like more than I could bear. Still, I pressed on.

Faith Kicks In

It's strange, but I had a deep knowing that my husband had prostate cancer. We couldn't reconcile his elevated PSA, and at that point knew too much about the disease to convince ourselves otherwise - but beyond that, we knew.

We also knew, however, that in the darkest moment of our lives, and in spite of our immense fear and anxiety, God was there. Every second of every day, both of us felt God's presence stronger than any other time in my life, and it provided me with a peace beyond comprehension.

We learned that prostate cancer tends to be a non-aggressive, slow-growing cancer with a majority of men being diagnosed with low-risk disease. Often, men in this category can opt to watch their cancer, rather than treat it right away. For the men that fall into the category of intermediate or high-risk disease, prostate cancer can behave very unpredictably, be more aggressive, and require treatment. Terry's PSA continued to worry us. We prayed that his cancer was treatable.

Why would I need to know about prostate cancer? My husband was only 45 years old!

It was two days before Christmas when we learned Terry had cancer. He called me on the phone, and his voice sounded sad and empty. He painfully uttered the words, "I have cancer". We both sat in silence for a moment. We were shaken and scared to death.

High-risk disease is a Gleason 4+4, and Terry's pathology showed a Gleason 4+3, which was intermediate risk [1]. In that moment, I realized the PSA test may have saved his life. Like a red engine light in a car that flashes when something needs to be checked, it didn't indicate cancer, but rather, pointed out that something wasn't quite right and that we needed to investigate further. The test provided us with very important information about my husband's body, and afforded us the opportunity to do something about it. Although we didn't catch Terry's cancer as early as possible, we did catch it just in time. For this reason,

we support a baseline PSA test for all men starting at age 40.

There is no "one size fits all" treatment for prostate cancer. Men who choose to treat their cancer usually need to decide between surgery and some form of radiation. It can be a complicated process, with no one telling you what to do. You will receive recommendations from doctors for the best course of treatment, but at the end of the day, the decision rests on your shoulders, and that is pretty overwhelming. This is why extensive research as well as a waiting period is necessary to avoid making an overly emotional decision. This is your chance to get it right, so you want to feel as confident as you can about your choice.

After much research and consideration, and based on Terry's young age and numbers, we opted for surgery. We met with an awesome surgeon who explained the details and side effects of surgery to us. Our most important goal was to strive to cure his cancer first, deal with incontinence second, and erectile dysfunction last. Psychologically, we felt comfortable with upfront side effects that would gradually improve over an extended period of time. One last bone and CT scan were performed, and they came back clear. We were given the green light for surgery.

Finally, some good news!

I met Terry's surgeon in the waiting room, who said his surgery went great. I returned to my family in the waiting room and sobbed like a baby. Words cannot express the relief I felt in that moment.

Even better, Terry's post-op pathology confirmed a 4+3 Gleason, with clear margins and negative lymph node involvement. His post-op PSA was undetectable, his surgery was a success.

Life Moves Forward

There is a stigma that comes with prostate cancer. Most men don't want to talk about it, especially because it involves *that* part of the body. Couple that with someone so young, and the silence is deafening. We decided early on, not only would we be advocates and educators, but we would also be open about the side effects. Terry never felt ashamed. Our hope is that the next generation of men and women will use their voice to help raise awareness. Yes, there is much work that still needs to be done, and we lag behind other major cancer awareness campaigns. Still, we are hopeful, and can't help but feel major breakthroughs headed our way in terms of medical research and social awareness.

Attitude is everything during the healing process. We managed to laugh quite a bit through cancer, probably to keep from crying. We even laughed the day Terry had to put on a diaper following catheter removal. He snapped a picture of himself in the doctor's office with a big smile on his face. He was completely dry within six weeks of surgery.

Terry's doctor prescribed him Levitra as part of his penile rehabilitation plan. It didn't do anything for us sexually at first, but we understood why. I guess it's at this exact juncture couples get tripped up sexually. When you focus on the part of the body that isn't working, you stay stuck right there, and hinder the healing process both physically and emotionally. The key for us was acknowledging sex as different, but not broken.

We encourage all men and couples to talk openly and honestly about the issue first, to come up with a sexual rehabilitation plan beforehand.

We stayed light about the subject of ED (erectile dysfunction), because we knew from the beginning that he needed time to heal. With a ton of physical and emotional love for each other, help of supportive doctors, a solid sexual rehab plan in place which included an arsenal of medication, we persistently and successfully pushed forward, with amazing results. What a team!

The truth is, sexual side effects from surgery can wreak havoc on an already unstable marriage, and be a major blow to a man's ego.

Even if a couple is stable, a mere lack of communication and poor understanding of the healing process and side effects can be detrimental to a marriage. We encourage all men and couples to talk openly and honestly about the issue first, to come up with a sexual rehabilitation plan beforehand, and most importantly, to stay positive and never give up hope.

Cancer will steal your joy if you let it. Even after a successful treatment, anxiety about recurrence is real. I am learning to live fully present in the moment, and not worry about tomorrow. If cancer gives you anything, it is a realization that life is precious. I adore my husband. He is the hero in this story. He's working through prostate cancer like a warrior. His positive attitude truly sets the tone for our healing process post-surgery. He's confident with his body's ability to heal itself, and is always willing to be open and honest about his experience.

Prostate cancer has been stressful, but we manage to love and support each other through the hardest of times, and as a result, we are stronger. With our faith in God, hope, support from family and friends, and most importantly, our love for each other, we persevere.

To understand your prostate cancer risk category, including questions to ask your urologist, see the article in the August 2012 issue of PCRI Insights, titled Newly Diagnosed Prostate Cancer: Understanding Your Risk.

1) NCCN Guidelines Version 3.2012 Prostate Cancer