

## **Our Journey with Prostate Cancer; A Wife's Perspective**

By Kathy Parnay (May 2014)

It's amazing how quickly your world changes when someone you love receives the dreaded cancer diagnosis. Everything stops. What was once important becomes insignificant as your world narrows into a single focus: "The cancer".

On October 16, 2012, at the age of 47, my husband, Stefan, got the call at work. His Urologist had been watching Stefan's PSA slowly rise over the last three years. Due to his father's history of prostate cancer, Stefan was in the high-risk category. His doctor had been pushing a biopsy for over a year before Stefan finally agreed to the procedure. The results were now available. Stefan's busy day at the office was abruptly interrupted with the earth shattering news, "I'm sorry, but you have cancer". Stefan's diagnosis was aggressive prostate cancer (T1c, Gleason 8, PSA 4.1, 3 out of 12 samples positive).

Upon receiving the results, his doctor proclaimed the need for urgency; surgery within three months was essential, sooner if possible. His doctor cautioned us that this aggressive cancer could spread quickly to other areas of my husband's body, if it hadn't already. We were in a state of disbelief. Agreeing to the biopsy had been merely an act to appease a concerned doctor. Stefan was healthy, physically fit and extremely active. Besides, his PSA was not alarmingly high nor had the increase been significant over time. We truly had not suspected he actually had cancer.

Needing to gain a sense of control over this unimaginable situation, I channeled my fear into seeking knowledge. Stefan has a demanding job where he commutes one hour each way to work. He didn't have time to devote to searching through the vast amounts of information about prostate cancer and treatment options. Since I worked part-time and took care of our two teenage daughters, it was natural for me to take on the role as advocate.

Of course, my first instinct was to Google prostate cancer. As I am sure you are aware, the amount of information on the web is overwhelming and it is very difficult to tell the difference between fact, fiction and exaggeration. In order to gain clarity, I began to pull out common threads from the material I was reading: sugar feeds tumor growth, meat and dairy may contribute to cancer, and fresh fruits and vegetables have cancer-fighting properties. This information was not new to us; we had heard bits and pieces over the years about healthy eating playing an important role in fighting and preventing cancer. It made logical sense as a way to increase Stefan's odds of winning this battle.

Consequently, that very day, we eliminated sugar, meat, dairy, and all processed foods from his diet and began juicing vegetables every day. Excluding meat and dairy was not a hardship; we typically ate meat only once a week. Stefan would miss cheese, but it was a bearable sacrifice. Sugar, however, was more difficult. As a proclaimed chocoholic, giving up dark chocolate and dessert was the first hard sacrifice Stefan made. Additionally, removing processed foods left a huge void in his daily snacking. But these steps made us feel like we were taking positive action, gaining a small amount of control over what seemed uncontrollable.

Although the temptation to jump on the “hurry up and cut it out” bandwagon was strong, we needed to gain a clear understanding of the severity of Stefan’s cancer before we could feel comfortable committing to a permanent life changing procedure. Armed with several pages of notes, we went back to the doctor with a litany of questions, such as:

- 1) How many tumors are suspected?
- 2) How much of each sample was cancerous?
- 3) What is the size of the tumor(s)?
- 4) What is the rate of error for a Gleason score since it is a visual determination?
- 5) Where is the tumor located?
- 6) How can you tell if the cancer is metabolically aggressive?

We also requested a second and then a third opinion of the Gleason score. Much to our dismay, each diagnosis came back the same: Gleason 8 (4+4). However, the good news was that there appeared to be only one tumor, approximately 5 millimeters in size that was contained within the walls of the prostate. We chose to view this news as encouraging; the cancer was small and contained. We have time to consider our options. But the doctor continued to push the urgency of surgery, claiming that it was only a matter of time before this cancer went out of control.

In response to the pressure for urgency, I frantically began seeking information about radical prostatectomies. The information out there was discouraging. The more we learned the more we realized that western medicine was not offering a cure, but an “out of sight, out of mind” approach that does not address the root cause of the cancer. We learned that, for Gleasons 8 or higher cancers, statistically, reoccurrences were common after treatment and that surgery was likely to only extend a patient’s life for five years. We also learned that, for the first year after surgery, all patients are impotent and have some level of incontinence. If normal function eventually returns, it is likely to decline again several years post treatment. Of course, we were told, there are surgeries and medical devices that can help with these unpleasant side effects, however none have the ability to return the patient to completely normal functioning.

There is something you need to know about Stefan. He is an eternal optimist. When he was first diagnosed with cancer his initial response was not “oh my god, I’m going to die”, but rather, “okay, what are my options?” His calm and proactive temperament helped focus my anxiety and fear on the search for that needle in the haystack of healing alternatives.

Not wanting to waste a single moment, I immediately expanded my search for other conventional treatments. I began charting the pros and cons for all the different procedures available, from cryotherapy to radioactive seed implantation. When we finally stepped back to view the options, a deep sigh of hopelessness escaped my heart. All of the options were far from perfect, leaving Stefan’s body damaged in some way. These facts pointed to the depressing truth; Stefan’s quality of life would be very different after any western medical treatment, affecting both Stefan’s relationship with his body and our relationship with each other. What were we going to do?

I have a hard time defying authority. The pressure from the medical world and loved ones with “good intentions” was overwhelming. Fortunately, early in my quest for knowledge I ran across the book “Invasion of the Prostate Snatchers” by Ralph Blum and Dr. Mark Scholz. This book confirmed our reservations, giving us the courage we needed to question the doctors and seek options outside of western medicine. I had heard that there were encouraging studies on the effect of diet on Gleason 6 cancers. The one important question we could not find an answer to was: could nutrition and lifestyle changes reduce or eliminate a Gleason 8 cancer? Since the current western medicine protocol for aggressive prostate cancer is immediate treatment (i.e. surgery or radiation) and “active surveillance” is still a fairly new practice for lower grade prostate cancer, there was no research data available to us.

Although we were making positive changes to Stefan’s diet, a battle was raging inside me. On the one hand, I was concerned that we weren’t doing enough; we were missing an important component to healing that was just out of reach. On the other hand, that nagging voice inside my head kept whispering, “You’re wasting precious time! Schedule that surgery now!” As far as we knew, no one diagnosed with Gleason 8 prostate cancer had ever tried using nutrition as a vehicle to healing. I was out of my league. I desperately recognized we needed someone to guide us. As a result, I began interviewing holistic doctors. I quickly learned that most are skilled in helping to lessen the side effects of western treatments and could not offer us an alternate course with the confidence of a proven success record.

As I continued my search, a name kept coming up from different sources, a nutritionist who focused on cancer patients. He practiced about an hour away from our home and had been very successful helping other cancer patients manage their disease. I called his office to schedule a consultation for November 8, 2012. Before our meeting, he asked that we send him a biography of Stefan that included his medical history, cancer diagnosis, test results, and what our goals were. Stefan and I spent hours summarizing his situation, the questions we had about food and nutrition, and the direction we wanted to take. We made it very clear that we were looking for help in boosting Stefan’s immune system and making his body inhospitable to cancer.

During our first appointment, the nutritionist walked in, introduced himself and then proceeded to share a fountain of research and data for the next two and a half hours nonstop. I sat in my chair feverishly filling a notebook with his golden bits of information. He had been thoroughly prepared for our meeting, taking very seriously our questions, concerns, and wishes. We left his office with both a sense of relief and excitement. We felt validated and now had some concrete tools to work with in Stefan’s fight with cancer. The nutritionist prescribed a comprehensive supplement protocol along with suggestions for exercise and meditation that would be adjusted every four months. Although our medical bills were now skyrocketing (the supplements alone were \$500 a month!), we were committed.

So began a very time consuming and isolating journey for us. Not everyone in our circle of friends and family supported this unconventional approach. We tried to tune out their judgments, but the pressure to justify our decision was exhausting. We had no way to prove that defying the medical community’s protocol for treatment would end in anything but more suffering. There was no proven research to support our decision, no clinical trials.

Thankfully, synchronicity continued to provide us with hope. At this time, Stefan and I were completely overwhelmed. Stefan was trying to manage his stressful job and his newfound health issue along with the typical drama of a family with two teenage daughters and a very exhausted and stressed wife. In order to give us a break, my parents gifted us with a weekend at the coast for our 20<sup>th</sup> Anniversary (November 9, 2012). As I was looking for some reading material to take on our trip, I ran across a book on disc at the library called “Never Fear Cancer Again” by Raymond Francis and Harvey Diamond. This book changed our lives. We listened to most of the discs that weekend, captivated and empowered by the information it revealed. It educated us about the science behind what cancer is and offered empowering ways to combat it. It also reaffirmed what we had already begun to do, concentrating our healing efforts on denying the cancer what it loves and boosting Stefan’s immune system so it can effectively eliminate the cancer on its own.

We tried to share all the information we had obtained and the steps we were taking with Stefan’s Urologist, but he was not easily convinced. He indicated that, in all his years of practice, he had never heard of a patient with aggressive prostate cancer successfully curing his disease through diet and lifestyle changes. Yet, we remained firm. We intended to try this approach first before proceeding with surgery. Grudgingly, knowing he could not change our minds, he agreed to approve routine blood work to check Stefan’s nutrient levels and further PSA monitoring every three months as long as Stefan agreed to a second biopsy around his six month anniversary from the original one. He also ordered a bone scan in order to determine if the cancer had spread outside the prostate and made it very clear, in no uncertain terms, that Stefan’s cancer was a ticking time bomb. We hadn’t won him over, but at least he was willing to work with us.

Thankfully, on November 16, 2012, the bone scan was negative, confirming that the cancer had not yet spread.

Both Stefan’s doctor and nutritionist recommended that we seek consultations with a local Surgeon, Radiologist and a prostate cancer specialist at UCSF for professional advice on conventional treatments; that way we could completely understand the options we were refusing. When we met the surgeon on December 3, 2012, we were not shocked by what he told us. Everything he said confirmed what we already knew about radical prostatectomies. On December 12, 2012, we met with a local radiologist. Much to our surprise, the Radiologist informed us that he did not recommend radiation therapy for someone of Stefan’s age because, within ten years, he would develop another kind of cancer caused by the radiation therapy he would have undergone.

Nevertheless, we were not discouraged. We held tightly to the hope that Stefan’s lifestyle changes were having a positive impact on his healing process. Three months after we began making these changes, we received some promising news. On February 1, 2012, Stefan had his blood drawn. His PSA was reported at 3.4 (a 0.7 drop)! However, his doctor did not share our enthusiasm, explaining that the results could indicate that Stefan’s cancer had progressed to where it was now not recognizable as prostate cells and no longer gave off PSA. He would not back down, warning us that surgery was our best option.

Due to the complexity of getting Stefan's medical records and obtaining an available appointment, we were not able to meet with a doctor from the Cancer Urology Department at UCSF until February 12, 2013. When that day finally arrived, we were excited. We hoped that this doctor, representing the medical institution that pioneered "active surveillance" and who had access to a vast amount of research, would be open to discussing the effect Stefan's diet has had on his PSA and the possibility of nutrition acting as a vehicle for healing. We were grossly mistaken. The doctor gave us a mere five minutes of his time to let us know that surgery, and soon, was his only recommendation. It was not open for discussion.

Although disappointed by the UCSF doctor's response, it seemed to us that the medical experts we consulted with had tunnel vision when it came to their specialties. We couldn't understand why they did not view the healing process holistically as a "whole person" experience, balancing the physical, mental and nutritional elements. Our bodies are made up of complex interrelated parts and systems, why shouldn't one affect the other? We needed to give this approach a chance, otherwise we would always wonder "what if".

Around the time of our appointment with the nutritionist, my sister-in-law had introduced Stefan to a book called "The pH Miracle". The method of alkalizing the body described was overwhelming; I just couldn't grasp how to implement such a rigid cleansing routine in our already busy lives. I had read in many different sources how cancer loves an acidic environment and cannot thrive in an alkaline one. I wondered if there was another way to go about this. I began researching the pH of foods and formulated a plan to create alkaline meals. Stefan was eager to try this new approach, but first I needed to learn where to purchase these unusual foods (e.g., buckwheat, millet, quinoa, etc.), and how to transform them into edible meals. So began our alkalizing experiment.

Unlike my Italian mother, I do not have a natural love for cooking, preferring to spend time reading or in the garden than in the kitchen. I now found myself continually surrounded by recipe books and dirty dishes. Meal preparations alone took several hours each day as I was forced to become more creative. Over the course of several weeks, I strategically created alkaline meals; removing all acid foods from Stefan's diet, including grains, breads and sugar of any kind (even fruit and high glycemic vegetables). In order to monitor the effect on his body, we purchased pH strips and Stefan began testing his levels with urine a few times a day while adjusting his diet. It took him several weeks to get his pH out of the unhealthy acidic range.

Our world became very small as our days filled with one mission, defeating cancer. Time was marked by the taking of supplements four times a day and the rigid schedule of work, food preparations, eating, exercising, meditating, and sleep... repeat. Stefan, a slender athletic man, quickly became gaunt as he lost body fat he couldn't afford to lose (about 12 lbs). In order to sustain his caloric intake, he ate all the time, grazing from meal to meal.

Through this process, we quickly discovered how important the role of food is in our society and how very sensitive others are about their food choices and judgmental about food restrictions. Because Stefan wasn't comfortable openly sharing his newfound diagnosis with his staff and colleagues, it became hard for him to maneuver around lunch meetings. It took determination and inner strength for him to bring his own lunch while others enjoyed the catered

buffet offered. On these occasions, I took extra care to prepare a special meal in an attempt to make the situation easier for him.

It was also incredibly difficult for us to socialize. Stefan's diet, consisting of "strange" foods (e.g., millet, buckwheat, sprouts, tofu, etc.) and lacking typical American fare (meat, dairy, bread, sugar), did not elicit the warm, congenial feelings of comfort, fun and friendship that bring people together. Not wanting to offend any hosts with the denial of their offerings or subject Stefan to feeling deprived from delicious foods being served, it was just easier to avoid social gatherings altogether. If it weren't for the help from family members to incorporate Stefan's diet into holiday meals and family gatherings, we would have been completely isolated. For us, food became an essential vehicle for healing. There was no leniency and Stefan never once deviated from this strict protocol.

Consequently, our relationships with others became strained. We were getting tired of continually fending off the concerns from friends and family. "Without fats and carbs he's all skin and bones", "He can't get enough protein without meat" and "Are you sure he's getting enough to eat" were common criticisms. We tried to be patient, answering, "Thank you for your concern. Stefan's doctor and nutritionist are carefully monitoring him." But the stress of our situation was becoming a heavy burden.

Fortunately, not all aspects of this new lifestyle were difficult to incorporate into our lives. Exercise and visualizations came naturally. Stefan, an avid backpacker and runner, had always enjoyed daily exercise. His exercise routine now became a vehicle to help oxygenate the cells in his body so they would be inhospitable to cancer. In addition, soon after his diagnosis, we began meditating daily to relieve stress. My sister-in-law had introduced us to Caroline Cory's Omnium Universe guided healing meditations. Together, we spent between 20 – 40 minutes a day visualizing the healing process.

The schedule of supplements, however, was another story. Stefan had never liked taking pills and was now taking up to 34 per day. Our kitchen table was littered with different colored pillboxes for breakfast, lunch, dinner, and bedtime. Each one had it's own requirement for ingesting. Some needed to be taken on an empty stomach and others with food. He even had a couple of powders that needed to be mixed with water before consuming. It was challenging to organize this new protocol.

We remained positive by repeating over and over to each other the healing potential of all the changes we had made. We used the fact that there were gaps in western medicine's one-size-fits-all protocol of care that left room for hope that other unconventional options could be a path towards healing.

As the weeks passed, we held tightly to the belief that Stefan's body was healing. Although fully accepting the importance of this new diet, after almost six months, this strict regiment was beginning to take its toll. It was hard for Stefan to find pleasure in eating now that the purpose of food was purely medicinal. I tried to find ways to create variety in his limited diet. I pulled out our dehydrator, trying my hand at making raw crackers from the limited approved food list. One day, much to Stefan's relief, I discovered a recipe for raw pizza that, although it was in an

entirely different experience than American pizza, it was quite delicious. We held these small successes close to our hearts.

However, much to our frustration, our fragile bubble of hope burst when the results from Stefan's May 1, 2013, blood work came back and we learned first hand about the inconsistency of PSA testing. In order to additionally test his free PSA, his blood was processed simultaneously on two different machines. The resulting variance in score was concerning. One machine read 3.7 the other 4.4. Which one should we believe? How was Stefan really doing? We were told that this variance in score was common. We now realized that the PSA test was an extremely poor indicator that we could not depend on.

Finally the day of reckoning arrived. On May 11, 2013, Stefan had his second biopsy. Stefan, the eternal optimist, felt sure he was cancer free. Me, I needed proof. I prayed that, at the very least, the tumor hadn't grown. I worried about what it would mean if Stefan were now forced to undergo surgery. For two weeks we anxiously waited with no word from the doctor. We should have received the results in 5-7 days; what was taking so long? When the doctor finally contacted Stefan, we learned the incredible news; there was no sign of cancer! Every sample was negative! The lab had been meticulously comparing the samples with the first biopsy, concerned that there was some kind of mistake. They had wanted to be absolutely certain before sharing this news.

We were ecstatic! After only six months on this rigid protocol Stefan was cancer free! Of course, the ever-skeptical doctor was not impressed. He claimed that he might have missed the cancer in his sampling and strongly urged Stefan to have another biopsy in six months. Although Stefan believed he was cancer free, we didn't want to leave any seeds of doubt. Thus, Stefan agreed. In the interim, he wanted to continue with his restrictive protocol, just in case.

On August 14, 2013, Stefan's PSA dropped to 2.5 and then on October 11, 2013, it was recorded at 2.6. Although, excited that his PSA was now leveling off in a more "normal" range, we questioned the validity and significance of the PSA test, knowing that it was not a reliable cancer indicator.

Finally, on November 1, 2013, Stefan had his third biopsy. Even though we were both feeling optimistic, I couldn't ignore the anxious "what ifs" that continued to hum in the back of my mind. Thankfully, it only took a few days to get the results back and, once again, Stefan was cancer free! Stefan's doctor was speechless. His western medical training could not provide any answers.

On January 17, 2014, three months from the last PSA test, Stefan's PSA was 2.9, still considered close enough to "normal" range to not warrant a concern.

I have heard it said that you cannot walk away from cancer unchanged. Today, May 11, 2014 (one year after Stefan's first cancer free biopsy), our family is not the same. Not only have our relationships with each other deepened, but we have also gained an incredible inner strength that can only come from facing a challenge that appears to be insurmountable.

Much to Stefan’s relief, his diet is not as restrictive. After we learned the wonderful news, we began to slowly reintroduce some of the foods he had been missing (whole grains, fruit, etc.) We still maintain a vegan diet and eat very little processed foods and no refined sugars. I have become an avid label reader in the grocery store, limiting our purchases to foods with natural and organic ingredients. We exercise regularly and still meditate daily. Our meditation practice has broadened from guided visualizations focused on healing to other forms (sitting in silence, repeating mantras, walking meditations). Stefan still takes supplements, but only a few a day that are designed to fill the gaps that diet alone cannot meet. The structure of our lives has changed drastically from life before cancer.

Do we worry that his cancer will return? Stefan says he’s not afraid of getting cancer again and believes that, as long as he maintains this new lifestyle and is always mindful of making healthy choices, he will remain cancer free. I know, however, that I will be entertaining those scary “what ifs” until we have a few cancer free years behind us. Until then, when I feel overwhelmed, Stefan reminds me that, together, we can get through anything.

I believe that there are many paths to wellness. Each person is unique with different physiological and emotional needs that create the balance required for perfect health. We hope our story provided you with some inspiration as you continue on your search for that balance. Wishing you many blessings as you travel on your healing path.

STEFAN’S PSA HISTORY	
Date	Result
12/21/2009	4.8
03/12/2010	2.9
12/09/2010	3.5
04/29/2011	3.6
09/02/2011	4.0
01/06/2012	3.9
06/15/2012	4.1
09/28/2012	4.1
02/01/2013	3.4
05/01/2013	3.7/4.4
08/14/2013	2.5
10/11/2013	2.6
01/17/2014	2.9

TIMELINE OF STEFAN’S HEALING PROCESS	
Date	Event
October 11, 2012	First biopsy (results: Gleason 8, PSA 4.1, 3 out of 12 samples positive)
October 16, 2012	Received biopsy results and began initial diet eliminations: no meat, dairy, sugar or processed foods and began meditation practice
November 8, 2012	Consulted with nutritionist and began supplement protocol along with daily meditation practice and exercise routine as suggested by nutritionist
November 16, 2012	Bone scan (results: negative)
Mid – late November, 2012	Began alkaline diet
December 3, 2012	Consulted with surgeon
December 12, 2012	Consulted with radiologist
February 1, 2013	PSA 3.4
February 12, 2013	Consulted with doctor at UCSF
May 1, 2013	PSA reported as both 3.7 and 4.4
May 11, 2013	Second biopsy (results: negative for cancer)
August 14, 2013	PSA 2.5
October 11, 2013	PSA 2.6
November 1, 2013	Third biopsy (results: negative for cancer)
January 17, 2014	PSA 2.9