

ABSTRACT

Navigating cancer is an experience that begins with a diagnosis and then lasts a lifetime. The volume of information and innumerable health care teams encountered along the journey are astounding. As a patient, partnering with one's wellness team is essential to surviving the psychosocial, physical and spiritual toll. This partnership is one step in living on the other side of cancer. While the surgeons work on the cancer from the outside in, pharmacists are masters at strangling cancer from the inside out. And with the continued support from the nurses, nutritionists, technicians, and alternative medicine and specialty physicians my hope grew daily. In addition to the healing professionals, having a social support team and positive mindset are critical to recovery. Within this triad—the healthcare team, the social support team or one's positive mindset—who is the boss when it comes to making decisions? Along the way the healthcare team executes, the social support team coaches and inspires, yet ultimately the positive patient mindset is the essential ingredient in managing these life challenges. Join me on my experience, navigating the disease and providing hope to others.

Joint Decision Making: Who's The Boss?

By Deborah DeNure, Patient Advocate

Diagnosis

My day began like many others, routinely actually, when my cell phone rang. "It's Linda," she says, "from UW Breast Center" (routine call, I think; as I have received many calls from the center over the last 15 years with benign cysts and negative breast scans). This call was anything but routine. Today was different.

Today, I start a new journey, learning to navigate through and around a stage II 1.3 cm (breast) and 2 cm (node) cT1 cN1 cM0 infiltrating carcinoma (IDC) I learned that while there are over 400 types of breast cancer, I was diagnosed with ER-PR- Her2+ with a positive axillary lymph node. I thought, I am prepared; after all I have served for years on the education committee for Susan G. Komen, my educational consulting practice specialized in patient-centric initiatives which focused on an integrated care model including providers, nurses and pharmacists, and I personally knew many "survivors". I actually said "Why not me?", as statically a woman is diagnosed with breast cancer every three minutes and someone dies every 13 minutes.

Knowledge is power and I knew I would need different types of help at different times. Over the next 15 months, my care and support teams, along with my positive mindset, helped me navigate cancer. We proceeded to make decisions as a team, each person accountable for a step or action in my wellness plan, having responsibility and authority to fully accept the logical consequence for those actions. My work began, building my support team.

Accountability: Care Team Approach

Within 48 hours of my life-changing call I met with my UW Hospital Care Team, Dr. Lee Wilke (Surgery) and Dr. Amye Tevaarwerk (Oncology). Early in the conversation, knowing that UW is a teaching hospital approaching wellness through the lens of joint-decision making and team accountability, I asked who would be on my care team. It was an enlightening discussion, as I learned more about each stage of my treatment. This approach created a shift in my thinking. My focus moved from the "Why me?"—looking backward as a cancer

patient in a disease state to the “Why not?” – looking forward to building my well-being team. I thought to myself, life decisions have been preparing me for this exact moment.

One of the first questions Dr. Wilke asked, “How do you like to learn?” was an essential question and foundational principal that I ask in my profession. “I am visual,” I said. Both Dr. Wilke and Dr. Tevaarwerk proceeded to draw and illustrate the process--were the cancer was located, how the treatments worked and listed out a few next steps. I still have those drawings today.

They walked my family and me through all the options—the stages of treatment, radiation, chemotherapy and surgery. I thought, “I am prepared (after all I consulted with pharmacists and nurses for over ten years, helping to transform their professions to team-based care models). I have doctors that understand my style of learning and communicate clearly. I have resources to help navigate my drug regimen, I am partnering with trusted professionals who demonstrated patient partnership, reviewed the latest treatment options and spoke in a commanding way to fight for a resolve.” My team confidently began to build a treatment plan, mapping out my survival strategy.

Treatment. Joint Decision-making

On October 21st, 2010 my treatment began with a well-mapped plan to oversee and manage my care appointments, In addition to UW Hospital’s pharmacological review, I reached out to Lynnae, a friend and trusted pharmacy advisor as well as Amy, my local retail pharmacist. My pharmacy team provided me with the latest research on my new drug plan. I felt well-prepared to move on to my next chapter.

The following drugs saved my life. I started on AC-TH, which consisted of four drugs. Phase one was Adriamycin/cyclophosphamide (AC) administered intravenously for four, 90 minute treatments over an 8 week period. After the AC round, I received taxol/herceptin (TH) IV 120 minutes per week for 12 weeks. I then moved on to phase three, 13 doses of Herceptin via infusion every 3 weeks for about 90 minutes for the remaining 40 weeks of the year. The treatment was overwhelming and scary.

It is important to have moments to connect. UW Hospital is a teaching hospital so I had the privilege of weekly visits with UW Pharmacy residents to discuss the type of drugs, side-affects and adherence. At first the Residents would “just check in” yet by the end of my treatment, they were more consultative than prescriptive. As a patient I feel using consultative behaviors for engagement and discussion is critical to wellness. Although the pharmacists have lots of patients to see and a shortage of time, I always viewed those exchanges as teachable moments. After all nurses must wear protective gear when administering the chemo-cocktails, I realized these drugs could just as easily kill me. And yet I couldn’t live without THEM.

One memorable day, our country was experiencing a shortage of a treatment drug I needed. The pharmacist and my oncologist needed an alternative plan, so my care team consulted with me, provided options, weighed the pros and cons, and we jointly decided on a course of action. In my experience, pharmacists are often viewed as an ancillary group and not an essential care team member. I have come to appreciate their input and in fact insisted on consultation with every drug I take. The next step in my journey was surgery and I needed to update my support system.

I created a website called Warrior Woman on [Caring Bridge](#). It is free to patients of any disease and informed my social network of my progress and let me connect with other survivors. I provided great encouragement in every message. Often video's, relaxation ideas and medication ideas were posted to keep me spiritually aligned. In March of 2011, a new treatment plan was kicked in gear. I was now managing my recovery from a bi-lateral mastectomy. The surgery required additional decision making skills, breast reconstruction or not, the social impacts of not having reconstruction. I had no idea the number of prosthetics and gear available to me. I elected not to have reconstruction and [Careware](#), the retail store at UWBC was instrumental in helping me figure out my new shape. After receiving the pathology results, my Physician stated, "The tumor bed was identified and without residual carcinoma. Resolved! This is a word I will never forget. The chemo killed the cancer cells, surgery removed a part of my body that was harming me and I continued my rounds of Herceptin, slowly getting back to my routine. My medical treatment ended on December 9, 2011. Routine life began again!

Survivorship: Patient Survivor Advocate

Now what? I no longer had standing doctor's appointments. I had ended the drug regime that was keeping me alive. Time was on my side, my hair was growing back and I continued to work as I had throughout treatment. With the encouragement of my professional and personal support team I began to talk more about my experience as a patient, both informally and formally. First, my professional wellness team became the focus. The most memorable experiences were leading workshops at American Society of Health-System Pharmacists (ASHP), instructing a class at the UW Pharmacy School, facilitating an Art of Collaboration course for integrated care professionals at the Veterans' Hospital in Madison and a keynote for UW Oshkosh School of Nursing. Each venue provided a forum to talk about a fraction of my experience. I am prepared! My cancer experience had shifted from disease management to patient advocacy.

Second, [UW Hospital Breast Center](#) (UWBC) launched a Patient Survivor Advocacy (PSA) program with the support of the [South Central Wisconsin Affiliate of Susan G. Komen](#). This peer-to-peer support program pairs newly diagnosed patients with peers who are at least one year beyond complete of their treatment. This program is open to referral from UWBC providers who identify candidates for peer support in their clinical practices. To date, 25 new patients have been matched to advocate peers in the PSA program selected on the basis of shared diagnosis and common life factors. Major themes underlying the psychosocial support shared by these patient-advocate pairs include management of emotions and uncertainty related to breast cancer, the realities of breast cancer treatment, and how to integrate breast cancer care into one's life. Newly diagnosed patients receive support from other women who have experienced breast cancer first hand, and in turn advocates describe their participation in the program as a form of "giving back" from which they derive a sense of achievement. New patients also find that this peer support system helps them with making treatment decisions, and discussing their breast cancer with their loved ones

Finally, becoming a mentor for breast cancer patients was the next step in my journey. In partnership with the [After Breast Cancer Diagnoses](#) organization and UWBC, I became a certified mentor. The UWBC continues to expanded this essential service and build the PSA program today. The PSA program poster was presented at the [San Antonio Breast Cancer Symposium](#) in December 2014 and can be [viewed online](#) by searching breast cancer survivor advocacy. ABCD has a 24 hour hotline for breast cancer patients to connect with a mentor when they have questions. I continue to

draw on my experiences with my pharmacists and physicians as I provide insights into the navigating the disease with those I mentor. My greatest reward has been talking with patients about the social and emotional impacts of the disease, and more importantly, my greatest value has been sharing the steps needed to reframe the experience into a wellness journey. It is a mindset that takes fortitude of personal accountability and joint decision-making. I am prepared! Beyond diagnoses.

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Thank You

There are many people that have helped me along my journey and many more that I will encounter over the years to come. It is a pleasure and honor to share my story and inspire others to live beyond breast cancer. I would like to thank; The University of Wisconsin Breast Center, South Central Wisconsin Affiliate Susan G Komen, Patient Survivor Advocate Program, Careware, After Breast Cancer Diagnoses, San Antonio Breast Cancer Symposium research team and my article support crew; Julie, Stef, Patti, Mary and Jennifer. You guys rock.

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