My Mother’s Daughter

Sarah A. Banks

When I first began creating work-sheets to organize my mother’s chemotherapy treatment, people would ask me how I found time to focus on all the details of her care. The question surprised me because the answer was simple—how could I not? I am my mother’s daughter. An RN for about four decades, my mom set an example of what it meant to put others first. Whether she was treating patients in a hospital or teaching them about chronic conditions in a classroom, she didn’t give up. I watched firsthand as a child how she transformed from mom to an RN at a moment’s notice. She took classes with me for childhood asthma, gave cardiopulmonary resuscitation to my little sister, Carmelle, after a seizure, and she would stop by the side of the road if there had been an accident. Still, I was too young to develop a true appreciation for what she did day in and day out. To me, she was simply “mom.” She knew what to do and when to do it. Whether I needed a bandage or a hand to squeeze before a flu shot, she’s the one I trusted. My mom had an exceptional ability to make things better, and that is exactly what she did. When she became a caregiver to my grandparents and several beloved family members later in life, I finally began to see how much she gave of herself to others.

So, in 2006, when she told my sister and I that she had been diagnosed with pancreatic cancer, we instinctively followed in her footsteps. My sister and I became caregivers for the most important person in our lives, our mom. She would come first, and all the lessons she’d taught us about integrity, dedication, and unconditional love would come to fruition.

My mom, Jane Dorr-Banks, was given six months to live—but she fought pancreatic cancer for a remarkable two and a half years. She was diagnosed at the young age of 56, and we fought the disease as a team and refused to treat her like a statistic. My sister and I moved home full-time so my mom wouldn’t be alone, and, to this day, we have no regrets. The three of us approached my mom’s treatment as individualized care. We didn’t want an exorbitant amount of information from the Internet; it was confusing and the information that was available applied to the general population—we wanted to think outside the box. From day one, her body’s reaction to the nine-hour surgery and subsequent chemotherapy was a rollercoaster ride. But there was a pattern to many of the symptoms she presented if you looked close enough. I began to journal her side effects, everything from medications she took to the food she ate. It quickly became clear that each survivor’s experience is unique. Like so many family caregivers, my sister and I didn’t have any training, we just wanted to save her. The learning curve was steep and time was of the essence. We were only in our mid-20s, and I had never been so responsible for the well-being of another person before. I had been witnessing my mom overcoming crises my entire life, and she had made it look effortless. But it wasn’t effortless at all. I began to see a glimpse of what it
meant to be a nurse through her eyes. I understand now that, for her, the title of nurse had become synonymous with a healthy respect for wellness, caregiving, and a selfless outpouring of compassion.

In the next two and a half years, the three of us discovered that learning how to maneuver through this new normal would be key to managing the disease rather than allowing the disease to manage us. Her doctor, specialists, and oncologist wanted the detailed accounts of her symptoms and side effects at each appointment. Within the first weeks after her Whipple surgery (a procedure that removes part of the bile duct, gall bladder, head of the pancreas, and the duodenum), we were lugging around bags of notes, laboratory results, scans, and business cards from countless medical professionals. One frenzied evening, weeks after surgery, her temperature had spiked, she experienced intense nausea, and had unexpected chest congestion, and was feeling increased pain. This was all before chemotherapy had begun! I found myself that night with a telephone on each ear consulting with her doctors. I had been tracking her side effects by the hour on an envelope I found on the bedside table, the closest piece of paper I could reach for. There had to be a better way for us. After that night, I was in need of something specific and not another plain notebook or the back of an educational pamphlet. I felt a sense of urgency to be a knowledgeable advocate for her and rigorously cut through any red tape.

I began designing simple worksheets organized to meet our needs through multiple treatment cycles. I included a thorough health profile, appointment question and answer worksheets, a medication log, symptom management worksheets, and even business card sheets. They were vital components for managing care at home and beyond the doors of the oncologist’s office. Thanks to feedback from survivors, caregivers, loved ones, and members of the oncology community, I finalized the workbook to be as easy, efficient, and effective as possible. Nancy Jo Bush, RN, MN, MA, ONP, a member of the Oncology Nursing Society’s Greater Los Angeles Chapter, and huge supporter, contributed a heartfelt quote.

As a three-time cancer survivor and oncology nurse, I believe communication between patients and their healthcare team aids both physical recovery and coping. The symptom management workbook offers a system for patients to document the challenges they face on their journey by preparing them to become informed participants in their own health care. Caregivers can address patients’ individualized care and their healthcare team feels directed and compassionate.

I began sharing the symptom management workbook with the goal of empowering, motivating, and improving the quality of life for other patients and caregivers. We no longer had to shuffle from our home to appointments with cluttered stacks of notes, appointments cards, and frantically scribbled questions. Being her caregiver didn’t have to be so confusing, and her healthcare team could flip through her workbook and know what she was facing on any given day with a clear account.

We felt more prepared and could focus on other things as well. My sister and I were my mom’s advocates when she was weak, and she could find pleasure in the small things like buying pizza for the nurses on the hospital’s oncology floor. Chemotherapy appointments were followed up with popsicles. Side effects were treated with medications and hugs. Hospital stays included morning laps around the nurse’s station, which she insisted on. On occasion, the end of total parenteral nutrition was rewarded with the long-awaited chocolate malt. Her strength inspired us to push forward and her resilience inspired me to take that envelope with scribbled notes and create the symptom management workbook. She deserved the best quality of life we could offer her.

When the Hirshberg Foundation for Pancreatic Cancer Research reached out to us, it felt only natural to team up with an organization dedicated to patient support and research for a cure. It was a brilliant balance of passionately educating and supporting families while fearlessly pursuing the science. With the help of an educational grant from the foundation, we customized a workbook specifically for pancreatic cancer. Today, they generously gift symptom management workbook kits for patients with pancreatic cancer to families like mine. The support we have received from the medical and cancer healthcare community has been remarkable. Our family has made it a priority to fight this disease in our own way as well. Whether we are fundraising, volunteering, or speaking to representatives on Capitol Hill, with so many people in our corner, I had a renewed sense of hope.

In May 2009, my mom was coming to the end of her journey. We had arranged home care and had an amazing RN in the evenings who paid my mom nearly as much attention as I did. I’d been secretly hoping and bargaining with God that she would live a little longer. Could she have eight more months for one last Christmas? Days passed and I hoped she’d make it seven months to Thanksgiving. If she made it five more months she’d reach her 60th birthday in September. As time dwindled down, I even wished she could last two months for her 30th birthday in July. Now, in May, I was just hoping for one last Mother’s Day. Strong willed as she was, she told my sister that she wouldn’t die this day, or the next, or the next. She held on for 10 more days, making it past Mother’s Day. It was just long enough to read her a Mother’s Day card and say our goodbyes.

Every story contains struggles and triumphs, love and sadness. In our case, there was the heroism of a beautiful single mother, a sister, daughter, friend, and a nurse. There always would be memories in writing and in hearts that couldn’t be erased, not by chemo brain, not by grief, and, most certainly, not by cancer.

The author dedicates this article to Jane Dorr-Banks, Farah Ebrahimi, Cheryl Kay Jacobson, Camille Simeone, and Cecelia Solis, all beloved mothers of close friends and all taken by cancer far too soon.

**Symptom Management Workbook Available**

For more information about the Care Chronicles Symptom Management Workbook for patients, please contact Sarah A. Banks at sbanks.bellahcc@gmail.com, or visit the Hirshberg Foundation for Pancreatic Cancer Research at [www.pancreatic.org](http://www.pancreatic.org).