

S P E C I A L I S S U E
Breast Cancer Consortium Quarterly

BY YOUR SIDE: BEING A CAREGIVER



SPECIAL ISSUE EDITORS:

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and

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Breast Cancer Consortium (BCC) is an independent, international organization that promotes collaborative, multi-disciplinary initiatives aimed at increasing understanding of the social, cultural, and system-wide factors affecting breast cancer. We provide information to the public, media, and opinion leaders; develop analyses and conduct research; and share research, tools, and capabilities.

Breast Cancer Consortium Quarterly (BCCQ) is the official publication of Breast Cancer Consortium, published four times per year, and featuring work from members and other contributors. Writers range from social scientists to health advocates and journalists specializing in the social, cultural, and economic aspects of breast cancer. Content includes articles, research briefs, book and film reviews, interviews, social media highlights, public policy updates, literature, photography, and artwork. We highlight academic research, critical advocacy, current news, and personal stories that speak to larger issues.

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The practical and emotional support needed by patients who go through sometimes multiple surgeries, debilitating and prolonged therapies, and in certain cases face metastases, is too un-glamorous to be given space on the cultural landscape. This special issue of the *Breast Cancer Consortium Quarterly* edited by Grazia de Michele and Cinzia Greco shares the voices of caregivers, those who live and love in the wake of another person's cancer diagnosis. The difficulty, grief, and suffering that are part of caregiving are, with rare exceptions, absent from dominant cancer narratives. Here, we give them voice.

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By Your Side: Being A Caregiver

INTRODUCTION by Grazia de Michele and Cinzia Greco

Breast cancer is like an earthquake: it starts in an epicenter, in which the damages are high. Then, inevitably and rapidly, seismic waves hit nearby areas. Cancer not only upsets the lives of those receiving the diagnosis, but also that of parents, daughters and sons, partners, relatives and friends, who suddenly become caregivers. This special issue of the *Breast Cancer Consortium Quarterly* is about them.

In 2014, the *Breast Cancer Consortium Quarterly* published its special issue - Demystifying Breast Cancer – focusing on the experiences of people directly affected by the disease, whose voices are silenced by mainstream representations. This year we make a step forward to include another important aspect of the reality of breast cancer, one deliberately obfuscated by pink ribbon ideology.

The *she-ro* – the stereotyped figure of the female heroine bravely beating the odds - does not experience pain or corporeal damage, and certainly does not see death in her future. The she-ro is a solitary warrior. She is strong, determined and self-sufficient. The care that a breast cancer patient needs is expunged by this narrative, as are the people providing it. Instead, family members and friends are urged to run for the cure, wear a pink ribbon, and donate their money to the cause. The practical and emotional support needed by patients who go through sometimes multiple surgeries, debilitating and prolonged therapies, and in certain cases face metastases is too unglamorous to be given any space on the cultural landscape.

The aim of this special issue is share the experiences of those who act as caregivers and shed light on the difficulties they deal with on a daily basis.

The stories that make up this collection come from the United Kingdom, the United States, and Italy. The authors write in their capacity as partners, mothers, sons and friends. Although two precious contributions come from men, the lion's share of this special issue belongs to women. This is a powerful reminder that care work is still, largely, a woman's affair. Even when they are not affected directly by breast cancer, it is women who pay the highest price to this disease.

If illness is a totalizing experience, that of caregiving is not far from it. Not only did caregivers look after their loved one, with energies and time spent providing assistance, they also attended to the duties of everyday life. In this sense, paraphrasing Susan Sontag, they are *part of the kingdom of the sick and of the kingdom of the well* at the same time. Striking a balance between these two worlds is incredibly demanding. Indeed, one of the common themes in the stories we present is the surprise and lack of preparation the authors experienced when becoming caregivers. They had little idea about what they were in for.

Another recurrent theme is how breast cancer can transform one's personality and sense of self in both constructive and destructive ways. This change can alter one's coping abilities and impact, even if only

temporarily, one's long-term relationships. Though it is certainly true that a life-threatening disease can pull people closer, it can also push them apart. In pink ribbon culture, breast cancer is most commonly depicted as an eye-opening rite of passage that allows those affected to understand what is really important to them, and how beautiful life is. After treatment, they get on with life renewed. Beyond this happily-ever-after narrative is another reality; a disease that can lead to suffering and isolation, and irremediably destroy bonds.

Knowing how one will react to the experience of walking with someone who has been diagnosed with breast cancer and caring for them amid difficulty, pain, trauma, recurrence, or metastasis is not something that can be anticipated. Yet, the sugarcoated image of the upbeat survivor contributes to the astonishment caregivers feel when they suddenly find themselves in the wake of that earthquake that is breast cancer.

The Stories in this Collection...

In *Rolling and Strolling*, Alice Ayers (a pseudonym) narrates how for many years she looked after her partner, who experienced a life-threatening disease - breast cancer, with which she was diagnosed twice - and later a life-ending disease, amyotrophic lateral sclerosis (ALS). In supporting her partner through illness and eventually death she took a practical approach to caregiving, leaving her emotions for another time. She received support from friends and acquaintances who through big and small gestures showed their affection for her and her partner. As a result, a new Alice, cared for by those who love her, has surfaced. Now that her partner is gone, she considers whether she is willing to embrace a new identity.

Marco Peano, an Italian writer, recalls the long journey of taking care of his mother. Peano's mother was diagnosed with breast cancer when he was only 17 years old. The disease was a constant presence in the life of the whole family for a decade, turning Peano and his father into two loving caregivers and forcing them to learn words they never would have wanted to know. It was during the final stages of his mother's illness that Peano started to write about her. Seven years later, he turned this beautiful and heart wrenching story into a novel. *Dictionaries, Cats, Encyclopedias* shares some of Peano's experience taking care of the woman he loved most in the world.

Linda Holden, in *The Wife of a Man with Metastatic Breast Cancer*, describes the effects of her husband's diagnosis with metastatic breast cancer. Twelve years as a caregiver has allowed Holden to understand the importance of being supported by a community of people in the same situation who understand what you're going through and the power of self-education.

The majority of writers in this collection emphasize that while being a caregiver for someone with breast cancer takes a huge toll on them, it does not undermine their feelings of love towards the person. In some cases, though, there is no way to get through the intense hardship of diagnosis, treatment, and long-term care. In *Hard on the Body, Hard on the Soul* Kelly D. (a pseudonym) shares how breast cancer changed the

course of a committed relationship and the lives of a couple to the point that they decided to separate from one another altogether.

In *Caring for our Daughter*, Yvonne Jones-Gill shows the disruption cancer can cause for a single mother with young children. When their daughter was diagnosed with breast cancer at age 35, Yvonne and her husband, both retired, moved into a mobile caravan for months at a time to look after her and her children. The author reflects upon the difficulty of her daughter's treatment, the challenge of trying to "do it all", and the reality of just how many people were needed to care for a single patient. She wonders what happens to patients who cannot rely on such a large network of support.

Anthony M. titles his piece *I Wasn't a Caregiver*. Focusing on the partnership between him and his wife Rachel from the time of her breast cancer diagnosis through her death, his narrative is a testimony to love despite illness and a critique of the optimistic vision of breast cancer that was far from their reality. The author never denies the hard aspects of the disease that took his wife's life and a huge part of his own spirit.

The final piece in our collection, *Diary of a Caregiver*, was put together just a few days before the publication of this special issue. The author, Diane Fine, has been helping her best friend Katherine for the last sixteen months in the wake of Katherine's breast cancer recurrence, a diagnosis of triple negative metastatic breast cancer (MBC). Diane stepped in to take care of her friend when Katherine's family could not. Since Katherine entered hospice in late September, Diane has been sitting at her bedside as well as taking care of business, agitating for change, offering support, feeling exhaustion, grieving impending loss. Diane, a caregiver for her friend — a dancer and activist she has admired since their youth— has been keeping a diary since fateful September and has decided to share some of it with us.

We owe a debt to those who were willing to tell us a part of their caregiving story for this special issue. Their heartfelt contributions offer all of us a deeper understanding of what it means to take care of those we love when they are facing what may be one of the most difficult times in their lives: the love, the labor, the uplifts, the grief, the truth.

ROLLING AND STROLLING by Alice Ayers

Alice Ayers (a pseudonym) writes about being a caregiver of her partner, who was diagnosed with breast cancer at age 41, had a local recurrence three years later, and then was diagnosed with ALS, commonly known as Lou Gehrig's Disease. The lessons she learned about caregiving in those years were many.

It's probably true that nobody signs up for being a caregiver. Maybe parents, when they have children. But certainly not kids, and probably not life partners. For partners, it just isn't what we are thinking about when we get together (unless one of us is already ill). But, really, what do we think will happen as we get older? With age often comes infirmity.

A friend told me that her father died when he was 57 and her mother never got involved with anyone else. The reason: she didn't want to be a caregiver again. It was too hard.

Of course, some of us get to do it twice – or more – with the same partner. My partner was diagnosed with breast cancer at the age of 41 and had a local recurrence three years later. Almost 20 years after that she was diagnosed with ALS, commonly known in the United States as Lou Gehrig's Disease. She died of ALS within three years of her diagnosis.

From these episodes, there are things I learned about being a caregiver.

Most importantly, it isn't about you. The caregiver is not the person who is ill, who has to face his or her mortality head on. As caregivers, we get to stay in the dream of infinite existence, as most others do, until we realize that our lives might end sooner than we think. As my partner's disease progressed, it was hard enough for me to confront the precipitous change in her and, therefore, in our relationship. But it was important to remember that I didn't have cancer, I didn't have ALS, I wasn't the center of this event. My job as caregiver and partner was to be as helpful and supportive as I could be. *And, to that end...*

Eternal vigilance is necessary – but not sufficient. I always tried to be attentive to my partner's physical, emotional, and social needs. But there were events and circumstances I couldn't anticipate. I came to see our life as sort of a soccer game: the goalie, in full possession of the ball, kicks it downfield and may have a plan, but has no real control over what's going to happen once it gets there. If a person's disease is untreatable or fatal, you're never going to get the best of it, no matter what you do. *Which leads me to...*

Feelings of inadequacy can be endless. On any given day things can go wrong, and we can't do anything about them – or we can, but we don't know it. One day, a person who promised my partner would have lunch during chemotherapy didn't show up. Another day, a caregiver's key suddenly didn't work, so she couldn't enter our house while I was away, leaving my partner – who, by that time, was not fully ambulatory – stranded in bed. The feeding tube clogged, and she was unable to take in nutrition. Who

knew that the first line of attack at the emergency room would be to force Coca Cola into the tube? I didn't. *To cope with these and other episodes, another lesson...*

Always have a backup plan. A spare house key, a neighbor to call, some Coke in the fridge. I suppose I should have learned this when my partner was diagnosed with cancer the first time. A good friend, upon hearing about her diagnosis and knowing it's important to take care of the caregivers too, promptly invited me to lunch – and forgot her wallet. (We're still good friends.) Most of attention to backup plans, though, was oriented toward assuring that my partner was in good hands, even when they weren't mine.

Returning to the Idea of “It Isn't About You”



No, it wasn't about me. But I was forced to figure out who I was in relationship with a person I loved who had no time or energy for wondering how I was doing or what I needed – at least, that's how it seemed. Other caregivers for seriously ill partners have echoed this observation: their partners had become highly self-absorbed, and we all had to adjust to this new dynamic in our relationships.

My partner dealt with the business of getting through the day or confronting mortality, a completely absorbing endeavor, leaving me, the caregiver, to take care of all the mundane matters like keeping the household going, getting food to the table (including shopping for it), getting the kitchen cleaned up after meals, paying the bills, doing the laundry, getting the washing machine repaired, and all the other activi-

ties of everyday life. I had to face the possibility that my partner would reevaluate her life, priorities, and goals, and I wouldn't even be included in them.

I've seen many cancer patients go through a period following the end of treatment in which they want to do everything now. They have become acutely aware that their lives are finite, and they just can't afford to defer the pursuit of things they always wanted to do. In their new attention to setting priorities, they might end a relationship with a caregiving partner, either explicitly or implicitly; if implicitly, maybe the physical presence doesn't end, but the emotional presence/involvement may be radically changed.

In the aftermath, the caregiver's relationship is with a new person. Maybe that person has found a new passion and needs to change careers (or not have a career at all). Maybe treatment has destroyed libido, and the future holds little promise of ongoing sexual intimacy. The caregiver is left to figure out whether this new person is one she wants to be in a relationship with, and whether the character of that relationship is one in which she wants to spend the rest of her life. All of which means that a caregiver needs to have a solid sense of self, to know what her goals and priorities are, and whether they can be met in this "new relationship."

Finding the Line Between Taking Care and Taking Over

While the situation might suggest otherwise, the person being cared for – if he or she is an adult – is unlikely to have lost all ability to make decisions. In my case, I was fortunate that my partner was a "take charge" kind of person who took the initiative to conduct a thorough investigation of her disease, from pathologies to treatments to prognoses associated with those treatments, so I didn't have to do that. When I opined that it would be good to have someone come to be sure she had nutrition during the day while she was in chemotherapy and I was working, she organized a network of friends to do that. She arranged rides to chemotherapy and radiation appointments. She did not, however, insist on emptying her drains after her mastectomy. I found in myself the ability to overcome my weak stomach to do that.



When diagnosed with ALS many years later, there wasn't much to investigate about treatment because the options were few. My partner still found whatever there was to find. More importantly, perhaps, I left to her all the things she was still able to do each day: as long as she could, she got her own meals (including taking nutrition through a

feeding tube when she could no longer swallow), maintained personal hygiene (including cleaning the area around the feeding tube), kept her social calendar, took a weekly yoga lesson and Pilates lesson, read the newspaper, did the crossword puzzle, and pursued a path of spiritual inquiry. She found the energy and ability to write perspectives (personal observation/opinion pieces) for our local public radio station and work on writing a book.

What was left for me, then? To think about things that could help her maintain her level of activity: slip-on shoes so she wouldn't have to tie laces, pull-on pants so she wouldn't have to deal with zippers or buttons, a "thing picker-upper" so she wouldn't have to bend to find things she dropped, mitten clips to keep her handkerchief clipped to her clothing so it wouldn't fall to the floor, a head support when her neck weakened, a toilet safety frame when she could no longer stand up from a seated position. And, throughout, initiating what we might think of as extracurricular activities, including excursions out of the house, whether in the neighborhood, the park, or beyond. We called it "rolling and strolling": she in her motorized wheelchair, and I trailing along or hurrying to keep up.



Another part of figuring out who I was: understanding that I shouldn't take personally whatever stresses and strains arose between my partner and me. I quickly understood that I would never – until, perhaps, I face the same situation – understand the dimensions of what she had to confront every minute of every day, either during cancer or during ALS.

Learning How to Maintain Your Identity

As I attempted to figure out who I was I realized that I needed to continue doing activities that were not centered on my partner. During cancer, it was work; during ALS, it was going to the gym every morning, to my volunteer “job” a couple of days a week, and to the college classes that I had begun prior to the diagnosis, as well as socializing with friends over walks, coffee, or meals out. A friend suggested that we audit classes at a local university. When I said I couldn’t add that to my list of activities, we agreed that she would audit the class, I would do the reading, and we would meet every week to discuss. We haven’t “taken” a class lately, but we still meet almost every week.

Gratitude became a keenly tangible part of my consciousness. Gratitude for the people who took care of my partner – friends, home health care aides, hospice staff and volunteers – and those who took care of me. The latter includes my partner, who understood that I would live on after her, and wanted me to maintain my social network so I wouldn’t be alone at sea when she was suddenly gone.

It’s not easy to regain connection to your emotions. My strategy for being a caregiver to a partner who had a life-threatening and, later, a life-ending illness was to treat the entire duration of the illness as a project, recognizing that I’d have time for emotion later. Finding out when “later” begins has been a huge effort – finally precipitated by writing this piece – at least as big as the effort required to dispose of the last items of her clothing, reorganize the shared files, take possession of her desk at home, and attend to the other details of everyday living that distinguish a person who lives alone from one who lives with a partner of many years.

At some point, it’s important to resurface, reconnect, and reciprocate. For me, it wasn’t only the relationship between caregiver and patient that evolved: beyond that, my relationship with the people who took care of me – my real-life social network of friends and acquaintances who kept an eye on my partner and on me, who took me to coffee or lunch or dinner or out for a walk, who brought food and did a million other nurturing things – took on a different character during my partner’s illnesses. In the last few months, more than two years after her passing, I’ve finally become aware that I need to consider whether I’ve allowed that new character (of being cared for) persist, and, if I have, to make a conscious effort to become a fully-reciprocating member of society once again.

DICTIONARIES, CATS, ENCYCLOPEDIAS by Marco Peano

*Marco Peano was born in Turin in 1979. He works for the Italian publisher Einaudi. He won the Volponi Prize for his first novel, *L'invenzione della madre* (The Invention of the Mother, minimum fax, 2015), in which Peano shares the intimate realities of dealing with a mother's long illness, and learning to say goodbye. He shares some of his experience here.*

Lest someone tell it to you, you don't know that you are a caregiver. My father and I, we didn't know. Before cancer broke into everyday life through my mother's body, we had no idea what this word – caregiver – meant. It was one of the many new terms I would discover through my mother's illness, words that would make up a new reality for all of us.

It was 1996 when my mother was diagnosed with cancer in her right breast: she was 45, I was 17; she worked at the post office, I went to high school; she was well aware of her medical situation, I was confused about what "mammary carcinoma" meant.

At the time, we didn't have the Internet on our family computer and Google did not exist. If I'd had an Internet connection, I would have looked for information online. I always found it amusing that the two most popular Italian search engines were named after a mythological character, Arianna¹, and a poet, Virgilio². I had to be content with the more mundane medical encyclopedia to extract data and percentages that did little to clear the fog in my brain.

A few months prior to my mother's diagnosis, we welcomed a kitten of blaze colored fur into our home. I named it Socrates. This little animal, which ended up in our family almost by chance, would keep me and my father company during the hospital stay of the woman we loved the most in the world.

A mastectomy, two courses of chemotherapy and a rather brief convalescence followed. My mother returned to work, but not before undergoing a preventive mastectomy on the left breast.

After all is said and done, everything seems to get back on track. I finish high school, the kitten grows up, but above all my mother is well.



¹ Called Ariadne in Greek, whose thread helped Theseus to find his way out of the labyrinth of the Minotaur.

² Who appears as Dante Alighieri's guide through Hell and Purgatory in the *Divine Comedy*.

Until 2002 when the cancer returns, this time in the cerebellum.

Doctors speak of “cerebellar neoplasm” and there’s me, the one who thought he knew everything about cancer. I quickly find out how much I have to learn. And so we begin again: MRI, hypotheses about surgical treatment and possible permanent damage, fluctuating hopes, tormenting doubts, removal of the mass with no complications, radiotherapy and then, life once more gaining the upper hand.

It is precisely during the radiotherapy sessions that I start, more or less consciously, to reflect upon my role as a companion.

Before being a son, my mother’s son, I am the person driving the car. My father works until late in the evening, and even though he had taken a permit from his job, I know how hard it would be for him to haunt the hospital. I willingly spare him this difficulty. Besides, I’m 23 years old now. I want to demonstrate that I’m grown up and aware, and I gladly attend to such duties.

I drive from the small town where we live to the city where the hospital is located, and I stay in the waiting room, holding my mother’s hand until her name is called. While she receives treatment, I think of her irradiated body. I realize that what is happening inside her is a very powerful narration. I know I will deal with this narration sooner or later, but for now I am here in this waiting room. I look around to see other sons, wives, siblings and friends who, like me, have accompanied someone, a loved one, to this place of waiting. I don’t know that it will take thirteen years for this unfolding narrative to take the form of a book.

In less than two years from that daily trek to the hospital, my mother will fall ill for the last time.

*Meningeal carcinomatosis*³, two words I never wanted to learn. It is a fulminating, inoperable disease, so the doctors say, and this is how one evening – while I am feeding Socrates – I suddenly understand that the cat will survive my mother.

The day I decided to try to tell this small human parable, the first attempt to put it on paper was on April 29th, 2005. She was 54 and was ill; she died within nine months. My father and I – medically and emotionally supported by a charity – set up an area of our home so that my mother could be with us, watched over day and night, during that last stretch of our life together. We had shifts sleeping at her bedside. We had become two helpful and caring nurses. In the meantime, my father had retired and I still didn’t have a stable job. This time, donated to us, gave us a chance to talk to her. She wouldn’t be lucid for long, as the stronger and stronger doses of morphine forced her into a drug-induced oblivion. This was without doubt the most intense time of my life.

³ Cancer in the brain and spinal cord.

April 29th, 2005 was the date everything changed. I know, for I still have that first file in my computer, containing just few lines in which I try to describe how my mother, forced to bed, was snoozing in front of the television. It would take another year and half before I could begin to write seriously about her. But those were the words, that day in April that sowed the seeds of my novel. I haven't stopped writing about my mother, and maybe I never will.

As I wrote about my mother I struggled to understand that, although I was building up facts based upon reality, I wasn't betraying her memory, but I was engraving it on the page forever.

Throughout the writing process, it was hard but necessary to dig out personal and intimate recollections and transform them into narrative material, to devise a plot, develop characters, create dialogues. I was turning a private testimony into a public story that could reach out to as many people as possible.

In the seven years I needed to shape my novel – obsessively erasing and re-writing – other losses followed, including that of my cat, Socrates. My daily duty was to stay planted with my imagination in that room next to my mother, accepting that she had passed away, and knowing at the same time that nobody could take what happened away from me.

Both my father and I, each in our own way, have been caregivers. But we never thought about ourselves in that way until after my mother died, when others used the term to describe our role in those years. We didn't grasp such a word at the time.



What I have come to understand by writing, page after page, is that my mother's body was a dictionary in flesh and blood already containing, since the beginning, all those words.

Photo Credit: Socrates, submitted by the author.

Translation by Grazia de Michele.

THE WIFE OF A MAN WITH METASTATIC BREAST CANCER by Linda Holden

Linda Holden is a native of the San Francisco Bay Area in California. She is a caregiver for her husband Bob, who was diagnosed with metastatic breast cancer 12 years ago. Linda volunteers with her local humane society in their Pet Assisted Therapy program, takes her and Bob's dog Bailey to visit patients, and is a volunteer legislative ambassador with the American Cancer Society's Cancer Action Network.

My husband Bob was diagnosed with stage IV breast cancer, with metastasis to his bones in January 2003. We were dating at the time and had been for seven years. He started chemotherapy treatment. Then he had a mastectomy and radiation therapy. In July 2003, between surgery and radiation, we were married in Hawaii. At the time of Bob's diagnosis, the statistics said he had a two- to five-year life expectancy. It was heartbreaking; he was only 43 years old.

As with any cancer diagnosis our lives were changed forever. Bob hasn't worked since his diagnosis. He was permanently disabled due to chemotherapy-induced neuropathy in his legs and feet and has pain in his bones from the cancer metastasis. He also has some cognitive difficulties and trouble with memory. I definitely believe there is a side effect called *chemo brain*¹. Since I have the memories for both of us, I try to be as patient as I can when he doesn't understand something.

Because Bob is disabled and has memory issues, I became his caregiver.

One of my most important responsibilities as Bob's caregiver is to go to every Doctor's appointment. In the beginning his appointment with his oncologist was every month. Then it went to every two months. At one point we got to six months. Now, Bob sees his oncologist every three months. Going this often takes a toll, with the stress of never knowing what you might hear. But as Bob's caregiver, it is vital that I know about any changes in the disease or adjustments to his treatments or medications. He takes medication for neuropathy, chronic pain, nausea; hormonal therapy to target his particular subtype of metastatic breast cancer (MBC); and medications for blood pressure and other health issues. We organize his medications by week into a pill box to make it easier for him to know what to take and when.



¹ Chemo brain, or chemo fog, is associated with chemotherapy treatment. Patients may have difficulty processing information, concentrating, remembering details of recent events, confusing dates, displacing objects, or fumbling to find the right word or phrase. Symptoms generally fade following the end of chemotherapy treatment, but not always. Importantly, for some cancer patients treatment is lifelong.

It's hard for me as a caregiver and wife to watch this disease cheat my husband out of a full life. He has a great attitude. He gets up almost every day, though there are days when he needs to stay in bed. And I try to make his day as easy as I can. This is where I have a hard time finding the right balance. I know I need to let Bob do as much as he can for himself on the days he is able, but sometimes I get too comfortable doing things for him. Most, if not all, of the household chores are my responsibility. Bob does enjoy cooking though and still cooks dinner. He even does most of the grocery shopping. I think it's important for my husband to participate in the household whenever he can. Sometimes I just need to step back and let him do it.

Over the past twelve years of Bob living with MBC, it's been our social life that has changed the most. In the beginning we went out with friends. But it became hard. Sometimes Bob wanted to come home early. We would never know how he was going to feel. Now, mostly, if we do go out it is for lunch. It's easier.

Being a caregiver for a man living with metastatic breast cancer is especially difficult because there is no cure for stage IV. People with MBC are in treatment for the rest of their lives. I know that someday he will probably die from this disease. I will always have hope. But I understand the prognosis.

Over The Years I've Learned Some Things

I really do have to take it one day at a time. In 2012, Bob had a recurrence of his cancer and he started back on treatment. He was on treatment until 2014 when he had to stop because of side effects. He is now on what they call a treatment "holiday" until he recovers and is strong enough to return to the treatment. Caregivers have to be adaptive in every situation because it changes day to day.

Having support from family, friends, and the medical community is so important to help with care. Support has ebbed and flowed at times. But when dealing with a chronic illness for over twelve years, it is hard to expect everyone to always be there. We just accept when we get support and are thankful for it.

I know how important it is for me to make time for myself and not feel guilty about it. I know if I don't take care of myself I won't be an effective caregiver. I enjoy walking, volunteering, taking cooking classes, anything that gives my mind and body a rest.

I research everything pertaining to breast cancer, especially MBC in men, and connect with others facing similar circumstances. I look up articles online to stay current and reach out to connect with people who have the same interest in breast cancer. Finding support from those in the same situation as Bob and me has given me the most support because they understand. Many people think Bob had treatment, so he is fine, or cured. That is so far from the truth. He will never be cured. We've made so many friends on the same path as us. They are invaluable for their knowledge and support.

I believe this saying to be so true: "knowledge is power".

HARD ON THE BODY, HARD ON THE SOUL by Kelly D.

Kelly D. (a pseudonym) shares the difficulties breast cancer and treatment can create in a loving, long-term relationship.

I don't imagine anyone would say that looking after someone with breast cancer was easy. But in my case, my partner's diagnosis took our relationship into a realm of no return.

Joanne took her diagnosis particularly badly – she was immediately distraught and thought she faced imminent death. Having had some part in looking after my father, brother, and a close friend after their different cancer diagnoses, I knew breast cancer and its treatment could be a long-term ordeal. I also knew that she was scared about having treatment and that there was an emotional and psychological toll from this diagnosis. Whilst I tried to be supportive, tensions between us mounted. I spent many nights crying myself to sleep, as her breast cancer affected our whole relationship.

Pain was a constant feature of my partner's breast cancer treatment.

Initially it was pain from the surgery, then from the side effects of chemotherapy and radiotherapy, and then from treatment-induced menopause that caused searing joint pains. It was hard watching her repeated, stoic, denial of the pain. She would endure it in an increasingly grumpy way, and then snap in fury, swiftly followed by exhaustion and despair.



Many times we would be in some obscure place – on a country walk, in a restaurant, at the cinema – when the pain would strike. Joanne never learned how to manage it, so I started to carry a variety of painkillers wherever we went. Even so, she mostly rejected the drugs out of hand. She thought she could cope. But then it would spiral into the trauma of intolerable pain and we'd have to rush home anyway. She'd be in a fury with everyone, but especially me. I became so exhausted with the stress that we stopped going out much. And socializing separately was equally unsuccessful. I worried about how she would be in my absence given that I'd frequently come home to find her in deep distress.

Dramatic menopause symptoms from the treatment also meant chronic disturbed sleep. Every night, our double quilt would be thrown over to my side of the bed during a hot flash. I'd wake up boiling hot. Then 10 or 15 minutes later, in a shivering and dozy state, Joanne would pull the entire quilt off of me and I'd get freezing cold. Sometimes this quilt tug-of-war repeated every hour and I wouldn't get any sleep at all. This was no good for staying alert the next day at my full time job, so I proposed that we used single

quilts. This helped, but not enough. We had quilts falling off the bed throughout the night. I finally suggested that we sleep in different rooms sometimes – which seemed to work practically for both of us even though I always ended up on the sofa. Looking back, sleeping apart symbolized our strained relationship.



The hardest things for me to deal with as a caregiver and supportive partner were the anger and depression.

Joanne went from banging her head against the wall in the middle of the night to losing her temper throughout the day. This erratic anger could erupt over anything, and it continued for months and into years, getting worse when she was diagnosed with secondary cancer in her bones and had to retire from her job on ill-health grounds. She became intolerant of almost anything I did, so I was constantly running interference, trying to keep the peace, moderating unreasonable demands, deflecting anger, doing whatever I could to avoid being shouted at. It was like walking on eggshells. For some reason, mealtimes became our tensest battles. We started to eat separately – another sign of our deteriorating relationship.

When Joanne's anger turned inward and she became deeply miserable, there was little I could do. She would be despondent for hours, days on end, refusing to see friends or go out. We became hermits. She even asked me to lie about how she was doing. Her friends would become irritated with me because they

only saw Joanne when she was wearing her 'brave face.' To them she *appeared* to be fine, but I saw the other side.

Eventually I persuaded Joanne to talk to a general practitioner who gently diagnosed her depression and suggested that she take part in therapy. Unfortunately, Joanne didn't see how talking would help. She agreed, but railed against the process. She made each discussion theoretical rather than something she could use. Eventually they stopped her therapy – she never understood why. Meanwhile, I got some therapeutic support for myself, a safety valve where I could talk out our issues. I found this helpful, much to Joanne's irritation.

When Joanne's depression got no better, her practitioner prescribed anti-depressants. She eventually took them, and they seemed to take the edge off of both her depression and her anger. After more than 5 years since her initial diagnosis, there were finally times when our life returned to some sort of an even keel. For a couple of years, I started to relax a little, even enjoy our time together. We even had fun sometimes and went on a few short holidays, some of which were pretty good. Some of them were not so good, though, especially when she forgot to bring her medication.

Joanne didn't like some of the side effects of the anti-depressants. She said they made her feel distanced from what was going on. I think she chose to forget to take them sometimes because she wanted to feel her experiences again more fully. After 2 years, she stopped taking them altogether and her emotional reactions returned, seemingly with a vengeance. At this point I could no longer manage her outbursts with the strategies I'd used before. I had no patience left.

Desperately struggling to balance work and home life, I finally told Joanne – as gently as I could – that she was much harder to live with when she was not taking anti-depressants. She promptly said we should stop living together.

Separating was clearly something Joanne had been thinking about, but I was stunned. I couldn't think of anything else to say other than to agree. We immediately started living in the house separately, in a tense but practical stand off. There was no discussion about anything else that could be done. She made her decision. She wanted to move it forward. So we started the formal process of our separation.

We started preparations to sell the house. I started to buy a small flat, and Joanne decided to rent a flat locally. She never discussed why or what sort of relationship she wanted to have with me, but the fact that she chose to rent led me to believe that this would be a temporary arrangement. Her friends rallied around her and helped her move, and she accepted their support.

Just as contracts were about to be exchanged on the house and my flat, I too was diagnosed with cancer.

I was blind-sided. Focused entirely on what needed to be done to move out of the house, I had no time to think about my diagnosis or treatment. At one point Joanne offered to defer the sale of our house and stay and look after me through my treatment. But I knew I wouldn't be able to deal with her moods when I was unwell. With my experience, I was pretty sure I would do better with my treatment and side effects if I were on my own. My surgery took place a few days after I moved, while my flat was still in a state of chaos. Luckily, one of my colleagues from work took a day's leave to construct a bed for me for when I returned home.

Joanne, still lost in her own world, barely saw me at all. One day she phoned to complain to me that I still wasn't supporting her enough. After a few difficult discussions, she hasn't spoken to me since.

Meanwhile I've experienced my own roller coaster of cancer diagnosis and treatment. And, I was pushed out of professional jobs because of my cancer and have been unemployed for significant periods of time. I'm now doing low-paid contract work. I seem to get enough work to get by. And I've become something of a lay expert on pain relief.

Looking back, I can't imagine any way I could have helped Joanne cope better. She needed to find out how to manage her cancer for herself, by herself. But then so did I. So although we managed our emotions about having cancer very differently, perhaps we also have a lot in common.

CARING FOR OUR DAUGHTER by Yvonne Jones-Gill

Yvonne Jones-Gill is 62 years old and lives on The Isle Of Portland, Dorset (UK) with her husband of 45 years, Martin. She has three children. Before her retirement she worked as a senior officer in a day centre for the elderly.

Our daughter Heather is a 35-year-old single mother who lives 300 miles away from us. She is independent, determined, hard working, and now has breast cancer. She still has those admirable aforementioned qualities we've always loved about her. But now, she really needs a lot of support.

Heather had been having tests for a while after she found a lump in her breast. When she finally found out the results, it was hard for us to take in. She had breast cancer. All we could say over and over again was, "She's 35 for goodness sake!" How does this happen?

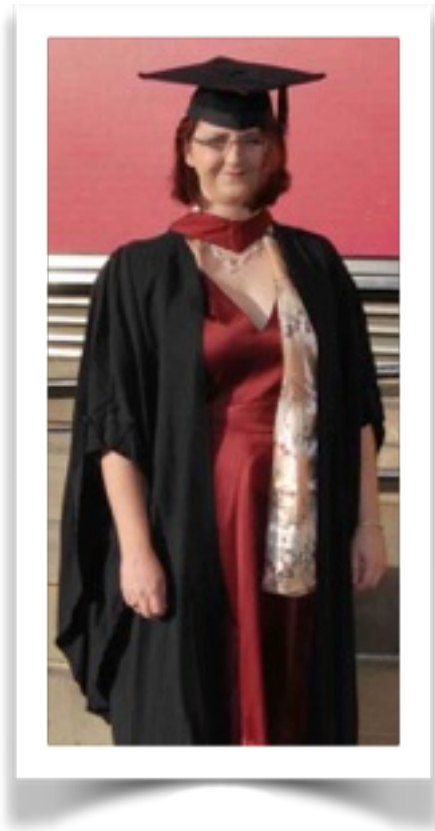
We wanted to help our daughter and grandchildren through this ordeal. At first we considered staying with them over holidays, but we realized it might be easier to buy a static caravan and set up a temporary household nearby. We made arrangements to close our house for a few months, thinking we would return to it after Heather recovered from surgery. The plan changed when we learned that Heather would also be having chemotherapy and radiotherapy for several months because the cancer had spread to five out of 18 lymph nodes.

Luckily, my husband and I have both retired. We were mobile and could be very flexible with how we spent our time. We never imagined we'd be spending it quite in this way, but we were grateful to have the capacity to do it.

We set up our new temporary home about twenty miles away from where Heather lived. This meant we could have some space when she did not need full-time care. When we weren't in the mobile home, we slept on the floor of the lounge at Heather's on a fold out bed. This was challenging in itself when our grandson with ADHD came in at 6 a.m. every morning though he did try to be quiet.

Chemotherapy, A Poisoned Chalice

Since one of the most common side effects of chemotherapy is hair loss, Heather decided to shave her head before getting started. Shaving it all off gave her a sense of control in the midst of a very uncertain situation. It was quite liberating, really, and we thought she looked amazing. We were ready for the



treatment to begin. Killing cancer was all right with us, but we dreaded the treatment at the same time. We knew the side effects could be debilitating.

Chemo treatment one. The day soon arrived for Heather to have the first of six TAC chemotherapy (Taxotere, Adriamycin and cyclophosphamide) treatments. TAC is a cancer-killing drug cocktail that is pretty aggressive. People can have allergic reactions to it, hot flashes, drug leaks outside the vein, and a host of other side effects. When Heather came home, she was bloated from the high dose of steroids she was given in addition to the chemotherapy. Apart from that, she looked the same. We celebrated, one down only 5 more to go! In eighteen weeks, this would all be over.

During the first 10 days of treatment Heather ate, as they say, like a horse. When she wasn't eating, she slept. She needed help with everything. But slowly, after about another 10 days, she could go for a gentle walk, though she became breathless and easily tired.



Chemo treatment two. After what happened the first time around, we looked toward the second treatment date with trepidation. The effects this time were more incapacitating. Her joints and muscles ached so much that she could barely move. She told me one day that she could feel her skeleton, feel her bones. I wasn't sure what that meant. The concoction of drugs she was taking to manage the side effects of TAC had their own side effects. Weight piled on with that large steroid-induced appetite, but her taste buds were off. She craved the strangest foods, and the spicier the better. Ginger, curry, beef broth, anything pungent.

There were times when Heather had to go to the hospital to be checked for infections. At one point, her immune system was *neutropenic* (an abnormally low white blood count), so chances of infection were very high. During the three-week gap between treatments, Heather's breath was so shallow that they ordered an *echocardiogram* (a kind of ultrasound that measures how blood flows through the heart chambers, heart valves, and blood vessels). Heather's heart was functioning at 15 percent below normal. This was a result of the TAC treatment.

The cardiologist prescribed medication to ease Heather's symptoms, which did work, but she now needed to use a wheelchair when going out. It was okay. We went to parks in the country, hired a scooter, and she also used a mobility scooter in shops. She was determined that this setback was not going to stop her.

However, the next TAC treatment was deferred until Heather could get the go-ahead from the cardiologist that her heart could take the next round. This meant that the "end date" for completing treatment,

that date we had all marked in our minds, was postponed. Psychologically, this was devastating. What would happen if she couldn't complete all of the treatments, or couldn't finish as scheduled?

Chemo treatment three. Heather got the authorization to start her next treatment. Her mobility decreased again. And her breathlessness, though improved, was still a problem. After another appointment with the cardiologist, she was prescribed drugs normally used to treat high blood pressure (beta blockers and Ramipril) with the hope that they would impede the chemotherapy's toxicity to the heart. It was a grueling process, but we all still believed chemotherapy offered the best chance of recovery and of the cancer not returning. We moved ahead with the plan.

Chemo treatment four, deferred due to abnormal liver function. This break from treatment gave Heather's body some of the recovery time it needed. But knowing what chemotherapy was doing to her body also made it more difficult for her to subject herself to more poison. Eventually, she had the 4th treatment. But this was her last. Her liver function was worsening due to the treatment, and she needed her liver.



The End of Chemo, An Emotional Time

Just as it had been during earlier treatment delays, stopping chemotherapy before the scheduled end date was psychologically challenging, and none of us knew what it meant for Heather's prognosis. The staff members on her ward were amazing, like none I had ever experienced. They were caring, supportive, and person-centered, seeing patients as individual people. Heather found a support group online. She now writes a blog and has followers. These virtual communities have been an invaluable source of connection and empowerment for her.

Radiation therapy. Even though the chemotherapy ended, Heather was able to move on to the recommended radiotherapy. This entails a 40-minute journey for a 10-minute treatment, then back again, from Monday to Friday, for 20 sessions. The logistics alone are exhausting. Although she's still tired, Heather is able to do more now than she was during her other treatment. Whether this will last as the radiotherapy continues we don't know. But Heather is making the most of it, at times expecting too much of herself.

The light at the end of the treatment tunnel looks a bit brighter at the moment. Heather will soon be half way through this treatment, and that is where she sets her sights. She no longer needs to use a wheelchair and has resumed her mothering role and responsibilities, something she found extremely difficult to give up during her treatment. With all this, we provisionally discussed some dates when we might be able to return to our home.

We're All In This Together, And We All Need Care

It has been challenging looking after our daughter while also being the carers for our grandchildren. Our role has been to support them in all ways when needed, from bathing Heather to cooking, shopping, taking children to and from school, ensuring that birthdays are celebrated and, of course, giving Heather the time, space, and complete allowance to be "ill" and sleep for days if she needs to. At times I wondered if we could, realistically, stay the course. But then we'd get a break. Heather would feel well enough to stay with friends, the children would go to their Dad's, and we'd recuperate at the caravan.



In some ways, I have felt like my husband and I *should* be able to do it all, and I want to whip ourselves because we cannot. The sensible side of me realizes that to fulfill our role as the primary caregivers for Heather and the children we, too, need support. With this amount of mental and physical stress for months at a time, carers also need a break. Heather's friends understood that, and stepped in. I don't

know how we would have fared if they were not there to help. I don't know how people without a strong support network manage at all.

Open lines of communication are the most important part of creating a caring and supportive environment for each other.

One of the most valuable things in all of this is open communication between everyone; Heather, the children and us. Not being afraid to say how we are feeling, needing a cuddle, a cry, or a laugh! We still laugh together and work to overcome obstacles we never thought would exist in our lives. Cancer does change lives and relationships. For us, it is strengthening the already solid relationship we have with our daughter and grandchildren.

But it has been difficult, very difficult, to see our independent daughter using a wheelchair or not being able to do the things we take for granted. The thought of being so far away from her when we return home is daunting. We live by the sea, and I can't imagine living away from it. But we've looked at properties for sale closer to Heather. Who knows? We'll see how we feel after we've returned home.

We thought we knew what it would feel like to be in this situation, but we didn't. Nothing prepares you for it, no matter how much you read or how many films you watch. Dealing with cancer is a personal thing. Not the treatment so much, but the emotional aspects of dealing with the treatment. It feels a bit like childbirth. You can know all the information, but nothing prepares you for the real thing. We are all looking forward to the euphoric feeling of the birth to come.

Photo Credits:

1. Heather at graduation, earning honors in nursing studies and mental health, submitted by the author.
2. Yvonne and Martin, submitted by the author.

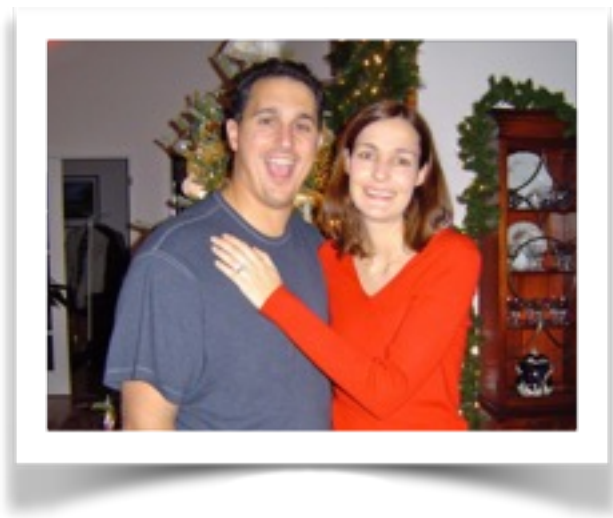
I WASN'T A CAREGIVER by Anthony M.

Anthony M. works for a large New York based financial institution and lives in the same small town on the Jersey Shore where he grew up. Perth, Australia, Rachel's hometown, is literally the farthest city on the planet from it. Anthony shares what it was like to be Rachel's caregiver for eight years, even though he never liked the word.

I asked Rachel to marry me in December 2003 under the Rockefeller Center Christmas Tree. A girl nearby took a Polaroid to capture the moment, gave it to us, and quickly demanded \$20. It was an inauspicious beginning, but only in a New York City kind of way. We were delighted; life was great.

Three months later Rachel found a lump in her breast. Neither of us knew anything about breast cancer. Our next steps were scans, diagnoses, tears, chemotherapy, hosting 200 people at our wedding, double mastectomy, radiation, and multiple reconstructive surgeries. This is not typically what it's like to be a newlywed, but it was all we knew. We had a solid foundation – best friends completely in love. Everything else was noise.

Unfortunately this love story doesn't end well. Rachel died of metastatic breast cancer on February 6th, 2012 at the age of 41.



I start with background to give perspective. Any thoughts I have about being a caregiver are inexorably tainted with grief and loss. I'm not sure how helpful this story will be to anyone looking for comfort.

Caregiver, A Word I Never Liked Hearing

I wasn't a caregiver, that's not what I did. I believed Rachel and I were two halves of a whole; dealing with the adversity that life threw at both of us, not just her. People don't always understand this.

So no, I didn't sign up for this, not that anyone really does. Unlike Rachel, I could have walked away. But I didn't pause for a second. I never thought about our getting married in the wake of her diagnosis as obligatory or the "right thing" to do - it was the only thing I could do. We were already one.

During the eight years Rachel and I were married, we had great times and terrible times. In 2007, we designed and built a house on a hill overlooking the New Jersey shore. In 2010, we rebranded the warm months as the "Summer of Us" and had a three-month-long celebration of our joint 40th birthdays. There was always a feeling of relief when Rachel was feeling well, along with a prevailing optimism that the wellness would continue and we could manage the disease as a chronic condition.

When Rachel wasn't well, life was different. Days stuck at home in various stages of fatigue, the sorrow of shaving her hair before the next round of chemo, the horrible mouth sores, and the nasty orange bile dripping from drains were only some of the challenges.

Nothing in our life was typical. It always depended on the status of the disease.

I Did Learn Something From This Cancer Experience

There is no silver lining to the cancer cloud. Rachel and I tried getting back to our lives after her diagnosis and treatment. This is what the pink-ribbon-wearing, Kumbaya-singing awareness campaigns tell us to do. Breast cancer is "survivable", they say, so we weren't too worried about the long term. But scratch beneath the surface and you'll find a different story. Rachel chronicled the progression of her illness along with the hypocrisy of the pink movement with wit and insight on her blog at <http://cancerculturenow.blogspot.com/>. If you want to know what it's really like to live with metastatic breast cancer and be in a relationship, Rachel wrote about many of our trials and tribulations.



You have to really like each other to spend hours in doctors' offices, hospital rooms, and at home. And we really did. I imagine that a caregiver and his or her ill partner will either bond at a molecular level or grow apart because of vastly divergent life paths. The illness brought Rachel and me closer together than I think would have been possible if we'd both been healthy. When Rachel died, I lost an enormous part of my identity and my spirit.

Perspective is important. What's happening in your life after a cancer diagnosis is not the worst tragedy in the history of humankind, but it may be the worst tragedy that has ever happened to you. Friends and family will decide how much they want to take part in this dreadful drama. The best ones will stay as close as they always were. Others will fade.

Rachel and I liked to use the analogy of the rock thrown into the lake to explain what happens to your circle of support after a cancer diagnosis. The fish under the rock gets hammered; those nearby shaken; and those farther away notice but are less and less affected with time and distance. It's tough for anyone to face his or her own mortality. Being around someone diagnosed with cancer forces the issue, and many aren't up to the task.

Your life will get smaller. Time at home being a caregiver takes away from "normal" life. Rachel and I had to quickly manage the implications of giving up usual things – the ability to have children, various internal and external body parts, most social activities and vacations. Our healthy friends were all collecting things – essentially, they had lives and families - we had cancer.

At some point, you have move on from your grief. I know I can't lock myself in a dark room and run out the clock on my life now that Rachel is gone. I have to move forward. But it's incredibly difficult. I'm dating a great woman, and I'm sure I'm driving her crazy. I don't know how to fully commit to another relationship. I can't imagine voluntarily subjecting myself to being that kind of caregiver ever again. I'm a strong man, but the thought of having to re-live the life of a long-term caregiver to a sick wife or, God forbid, a sick child would likely break me. I know this isn't a healthy attitude. I'm working on it.

Time helps.

Photo Credit: Anthony and Rachel, Christmas 2003, submitted by the author.

DIARY OF A CAREGIVER by Diane Fine

Diane Fine is earning her Master of Social Work and PhD in clinical psychology. At the moment, she has suspended her studies to take care of her friend Katherine who was diagnosed with metastatic breast cancer. Diane has a niece who is like a daughter to her. She lives in Massachusetts.

I met my friend Katherine when I was at a boarding school in New York. A mutual friend introduced me to this nice dance student from Massachusetts. Like many school friends do, we lost contact after awhile. But five years ago we reconnected through Facebook and found out that we only lived an hour and a half away from each other.

Katherine had just gone through a mastectomy for Stage III breast cancer when we caught up with each other. She was still the wonderful dancer and committed person involved in peace and social justice movements that I'd met and admired in our youth. I was so happy to have her back in my life. Our friendship picked up where it left off, as if we hadn't even been apart for all those years.



Unfortunately, 16 months ago, when Katherine was about to mark five years since her diagnosis, she found out that her cancer came back. Triple negative this time, and incurable.

Katherine's family couldn't look after her, so I promised that I would. I've never left her side. I've gone to all of her medical appointments and chemotherapy sessions and given her all of the emotional and practical support I can. During this time, I've seen with my eyes how terrible metastatic breast cancer is.

I joined a newly formed group called MET UP - the Metastatic Breast Cancer (MBC) Exchange To Unleash Power, and in that group I've met so many wonderful people. They have been so kind, and I feel like they are friends. MET UP is dedicated to raising awareness of the devastation of metastatic breast cancer, changing the funding directed to it, and disrupting the breast cancer status quo. Katherine led me to activism years ago, and the people I've met through this group have cemented it.

Taking care of my best friend has been hard and scary, even more so when I started realizing that, being the only person she can rely on, one day I will be in a position of making very difficult decisions. That moment has sadly arrived. Since July, Katherine's health has been deteriorating, and on September 23rd, she went into hospice.

As I'm here at Katherine's bedside, a powerless witness of my friend's impending death, I am keeping a diary. I'd like to share some of it with you.



9/23/2015

Katherine was admitted into hospice today. She wants me to stay with her. I'm exhausted. I feel like my mind is like mush, but I need to give her all of my energies. I promised her I would stay with her until she passes or can leave, and in any case I'll keep campaigning with the MET UP women. I will fight in her name and for the lives of my new friends. I hate cancer.

9/28/2015

The last days have been horrible. Katherine is going down fast. Her stomach is all distended with edema. The nurse says it's her liver that's shutting down. They just increased her meds tonight again to try to contain her pain.

She was up for a few hours today but was mostly vomiting and in pain. I just sat and rubbed her back.

I haven't had a proper meal in four days.

I don't think Katherine's leaving here. She fell last night but thankfully didn't break anything.

I am exhausted. This is a 24/7 job. I'm hoping another friend will stay tomorrow night so I can sleep at home, but I feel guilty knowing she is in such pain that gets worse at night.

9/30/2015

I need to watch Katherine constantly now because she can't get out of bed alone. Besides the hospice staff, I'm the only one looking after her. She doesn't want me to leave even for a second. She's scared that I'm not coming back because I'm tired or mad at her. I think I'm a kind of security blanket for her now.

The doctor asked her, while lucid, if he could invoke my power of attorney so I could make all decisions for her. We will consult her, but if she's too confused to make a decision, I will do it for her. This feels very heavy. I'm doing a deathbed vigil.

10/2/2015

Last night we all thought my beloved Katherine would die. The hospice staff said all the signs were there. They say she's in an active process of dying. But she's still opening her eyes and talking a bit, even though it's nonsense. When I was at the nurses' station, she even managed to get up. She's very confused and agitated.

I kept trying to tell Katherine it was OK to let go. The priest gave her last rites, just in case.

I don't know how she's going on. At least we're keeping ahead of the pain. The doctor said that since she's young and her heart is strong, it might be longer than we thought. She's fighting.

10/3/2015

Katherine seems to be going again, but I'll have to wait and see.

Tonight, a friend of Katherine's visited and made her laugh. Even though she was in and out of lucidity, she actually had some moments of laughter. We massaged her hands and read from a lovely daily inspirational book. Katherine's friend is a lovely Sufi woman who does much of the peace work with Katherine. It helped me to have her here. She's another gentle soul.

I'm watching Katherine's body jerk and again the apnea is starting. I think it will be another sleepless night for me.

I'm so grateful to the kind staff who have been so supportive of me and take such good care of Katherine's body. I'm praying that God, spirit or whatever releases her gentle soul from the devastation that is her body.

I feel horrible. I started having an anxiety attack this morning, and my asthma was acting up. I want to stay strong, but I'm emotionally and physically exhausted. We've been in this nightmare for 16 months, Katherine and me. Others have helped us, but she says she feels safest with me. I need to honor that.

She's fighting so hard. All the staff are amazed.

10/4/2015

I fell asleep at 4 am last night. I had to take something to calm down.

This morning at 7 am, Katherine was already awake. Miraculously, she got up with help and walked to the kitchen sun porch, even sat outside. She then went back to bed.

In the afternoon, some people came to visit. Her sister brought a keyboard from the family room. We all sat listening to her play, and she was dancing with me on the bed (sitting). One of her friends, another peace activist, suggested songs they sang at vigils. We all held hands and sang songs like "This Little Light of Mine," "Down by the Riverside," and "We Shall Overcome." Katherine was singing with us. There was a lot of crying because it felt so nice to have her back.

A day like today makes me think Katherine will be OK, that there's some mistake. I know that's not the case, but it makes me much more aware of how much I'll miss her.



At the same time all this was happening, I was calling the funeral home about cremation costs and sent another friend to Katherine's apartment with a rent check and to tell the landlord that this is the last month. It was surreal doing that while Katherine was lucid. I obviously didn't tell her I was doing it.

I'm worried that today really may have been her last rally. I'm listening closely from my bed to hear her move and breathe. Now, I don't want her to go. I want her to keep being like she was today.

10/6/2015

I went home last night for an appointment and some other stuff. Katherine's sister stayed with her. I didn't like leaving but felt better that at least she wouldn't be alone in the evening. Nights are worse.

Now I feel so guilty, so stupid, like I should have cancelled my appointment. Katherine called me. She kept saying she did something horrible and they were kicking her out. She wanted to know where I was. She said she didn't want to die alone. I felt terrible. I had taken something to help me sleep and knew I couldn't drive. Poor baby... I guess she got really paranoid, agitated and scared. They took her catheter out because she kept pulling on it.

When I arrived this morning Katherine had been up for some time. The staff was glad when I came back. They all recognize that she is calmer when I'm here, and listens to me. A friend and I wheeled her outside.

Katherine keeps looking like she's going to go, but she's fighting. She said she's scared to lie down, afraid she'll die.

I love her. But this is a horrible life. She is a dignified person, and to realize that she's wearing *Depends* would be horrible for her. I wish I could ease her fear of dying. I keep feeling cruel to say it, but I want her at peace.

Photo Credits:

1. Katherine and Diane, submitted by the author
2. Katherine Dancing, submitted by the author.

BIOGRAPHIES

ALICE AYERS (a pseudonym) writes about being a caregiver of her partner, who was diagnosed with breast cancer at age 41, had a local recurrence three years later, and then was diagnosed with ALS, commonly known as Lou Gehrig's Disease. The lessons she learned about caregiving throughout those years were many.

ANTHONY M. works for a large New York based financial institution and lives in the same small town on the Jersey Shore where he grew up. Perth, Australia, his wife Rachel's hometown, is literally the farthest city on the planet from it. Anthony shares what it was like to be Rachel's caregiver for eight years, even though he never liked the word.

CINZIA GRECO, a Breast Cancer Consortium partner, is a PhD candidate at the École des hautes études en sciences sociales (EHESS) and CERMES3 laboratory. She already has degrees in Italian literature and Anthropology from the Universities of Salento and the University of Bologna in Italy, and in Gender studies from EHESS in France. Cinzia's interests focus on the interplay of body, gender and medicine. With a scholarship from the Cancéropôle Île-de-France, her comparative doctoral research, in France and Italy, explores the way patients and doctors view and manage post mastectomy breast reconstruction and cosmetic breast surgery.

DIANE FINE is earning her Master of Social Work and PhD in clinical psychology. At the moment, she has suspended her studies to take care of her friend Katherine who was diagnosed with metastatic breast cancer. Diane has a niece who is like a daughter to her. She lives in Massachusetts.

GAYLE SULIK is founder, executive director, and editor of the Breast Cancer Consortium. She is a medical sociologist and independent scholar affiliated with the University at Albany (SUNY). Best known for her book *Pink Ribbon Blues: How Breast Cancer Culture Undermines Women's Health* (Oxford, 2011), she has published articles, essays, and book chapters on medical consumerism, technology, cancer survivorship, health policy, interdisciplinary community research, and the culture and industry of breast cancer. She writes regularly for *Psychology Today* and other popular outlets. She is a sought-after media spokesperson on breast cancer, advocacy, and women's health. She has been a guest expert on NPR, CNN, Al Jazeera, America's Radio News, Oprah Radio and other outlets, and is frequently quoted in publications such as *The New York Times*, *USA Today*, *Reuters*, *Los Angeles Times*, and others.

GRAZIA DE MICHELE PhD is a Breast Cancer Consortium partner. An Italian-born researcher and historian living in the United Kingdom, Grazia was diagnosed with breast cancer at age 30 during the final year of her doctoral work. She had no family history of the disease or genetic predisposition. In May 2012, Grazia started the Italian blog *Le Amazzoni Furiose* (The Furious Amazons) to raise awareness among Italian women about the need to change the conversation on breast cancer and promote research into systemic issues contributing to the disease.

JENNIFER TIRRELL has been a school librarian for 13 years. She earned her Masters in Library and Information Science from the University of Califor-

nia, Los Angeles and her Bachelors degree in History from the University of Massachusetts, Amherst. She has experience teaching middle school History and English. She has also worked in the retail book business and in public libraries. Jenn serves as associate editor of the BCC Quarterly, the special issue, and other publications.

KAVITHA KOSHY has extensive experience in participatory research, community organizing, and sociology. Before coming to the United States to complete her graduate work in 2005, she worked with Kashtakari Sanghatana (Union of the Hard-working), an indigenous people's organization focusing on women's health collectives in Dahanu, India and Vimochana: Forum for Women's Rights in Bangalore, India, an organization that developed community-level responses to violence against women. She received her Master's of Social Work in Mumbai at the Tata Institute of Social Sciences and graduate degrees in Women's Studies (MA) and Sociology (PhD) from Texas Woman's University. Her graduate work concentrated on cross-cultural misunderstandings, transnational advocacy, development, and globalization. She serves as BCC's managing editor.

KELLY D. (a pseudonym) shares the difficulties breast cancer and treatment can create in a loving, long-term relationship.

LINDA HOLDEN is a native of the San Francisco Bay Area in California. She is a caregiver for her husband Bob, who was diagnosed with metastatic breast cancer 12 years ago. Linda volunteers with her local humane society in their Pet Assisted Therapy program, takes her and Bob's dog Bailey to visit patients, and is a volunteer legislative ambas-

sador with the American Cancer Society's Cancer Action Network.

MARCO PEANO was born in Turin in 1979. He works for the Italian publisher Einaudi. He won the Volponi Prize for his first novel, *L'invenzione della madre (The Invention of the Mother, minimum fax, 2015)*, in which Peano shares the intimate realities of dealing with a mother's long illness, and learning to say goodbye. He shares some of his experience here

YVONNE JONES-GILL is 62 years old and lives on The Isle Of Portland, Dorset (UK) with her husband of 45 years, Martin. She has three children. Before her retirement she worked as a senior officer in a day centre for the elderly.

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