

Patty

A gardener's hands tell a story of her life and death.
by Brenda

This is a story of Patty, a fifty-seven-year-old woman of the earth. Patty was not yet on hospice, but on home health palliative care. She was still receiving treatment and clinging to the hope of having her life back, which was a life lived in rhythm with the seasons. Patty's life and career were spent as a gardener. Her green thumb could make anything flourish, but her specialty was herbs. She was known in the local farmers market for her many varieties of herbs, especially basil. Other gardeners at the market admired and respected that she was an expert in this arena.

Patty was a pretty woman. Though the consequences of a long term illness and harsh treatments left her with greying hair and some well-placed worry lines, she lacked the adornment of makeup and jewelry that many other women rely on. The picture on the fridge, before her illness, revealed a younger woman with shiny auburn hair, a sun kissed face, and a vitality that only those who touch the earth regularly can obtain. Disease robbed her of some of this outward beauty but not her spirit.

Patty had lower abdominal cancer. This is an especially difficult kind of cancer, and when I met Patty she was suffering. Patients afflicted with tumors low in their belly often describe the feeling as having a bowling ball sitting in their pelvic floor. Tumors in the lower abdominal cavity have a complex set of symptoms. They press on the lower bowel and rectum. This often causes hemorrhoids and pressure on the bladder, which can block proper urination. These tumors can impinge the blood flow to and from the large vessels going to the legs, and cause swelling. It can also cause pressure on the lower spine and hips, which can be excruciatingly painful. This often leads to immobility and even paralysis. For these reasons, and others, tumors in this area can be intense.

I was asked by the home health nurse, who had become quite fond of Patty, to consult on symptom management. Patty was nauseated, constipated, wheelchair bound, anxious, frightened, and in pain. One of the things that sticks in my memory of my first meeting with Patty were her hands. They were strong. These diligent hands had become strong from years of tilling soil and nurturing seeds into being. Her simple

wedding band rested near slightly oversized knuckles that were weathered from years of sun.

I made some suggestions in the hope of giving her some relief. What gave Patty the most comfort the first day was that I not only validated each of her symptoms, I explained why she was having them. Chronic illness is a lonely place. It is hard, if not impossible, for others to understand the impact it has and how it slowly and insidiously robs your life. Her home health nurse was an excellent nurse, but the focus of home health is for treatment and rehabilitation, not comfort. Patty was not yet ready for hospice as she was still pursuing treatment with hope for a cure. But it was at this moment I felt Patty thinking, "Oh my God I think this woman really gets what's going on in my body!" She felt seen and heard by my experience and this is what connected us.

Being a steward of the earth she naturally leaned toward alternative medicine and therapies. Therefore she surfed the web in search of hope of a remedy. This resulted in a box full of supplements that did nothing to help her feel better. If anything it added to her nausea and certainly did not offer a cure. At the same time she swam in the murky waters of traditional medicine trudging to chemo treatments and oncology appointments.

In the same way she grew herbs, Patty had grown a good life for herself and for her family. She was in a long standing and loving marriage that showed itself in the manner in which they treated each other with kindness and respect. She tended greenhouses in her backyard and sold her goods at both local farmers markets and co-ops. Her life revolved around nature, growing and cooking good food, and raising her family.

About two months after I met Patty she was referred to hospice. Her scan showed the tumors growing and spreading. Her body was not responding to treatment, and her increased pain, fatigue and plethora of other unwelcome ailments were evidence of this.

Once the goals of care shift from cure and treatment to comfort and quality, there are more possible treatment options to address discomfort. It is never just one piece that helps people feel better, but a combination that adds up to a patient feeling an improved sense of overall well-being. For me personally, symptom management is like a puzzle. I like bringing all the pieces together to create the bigger picture of an improved life quality. These puzzle pieces are not just physical symptoms, but rather a complex collage of who we are spiritually, emotionally, and physically. This is one of the reasons

it is important to know a person's story, and have a sense of who they are.

Meeting Patty this second time was much different than the first. She had not given up hope, nor was her spirit broken. Being the practical farmer she absorbed the facts and chose a path that made the most sense. And frankly she wanted an escape from the physical suffering. Hospice was her best bet for this so she was looking forward to it. As we sifted through her mounds of medications and she handed me bottle after bottle, I was struck by the difference in our hands. Mine were small and displayed recently smooth lacquered nails. Hers were the same strong, confident hands I remembered from my first visit and her cuticles clung to the nail. This marked just one of the many differences in how we lead our lives. Despite our differences, we were two women, both mothers, both lived our lives with passion and purpose. It is here we met each other and strode toward Patty's well being.

Within a few days of being on hospice, Patty was feeling significantly better and even able to walk a few feet. This is the magic we get to experience with people as they get to reclaim their body and life, even briefly. I was so excited to come in one day to find her holding herself up next to the washing machine doing laundry. She was thrilled to be doing something that felt normal.

Patty was a joy to work with because she allowed me to organize her medication and trusted hospice to manage her symptoms. Because of her willingness to allow me to do what I do best, she did not spend her time bogged down with trying to control all the aspects of her care. Instead she spent her time doing the things she loved, which included making macaroni salad and baking cookies.

As we were chatting one day, she was organizing her many unfinished projects in her knitting basket. Once again it was her hands I noticed. They danced with confidence and knowing through a forest of yarn. They had not yet lost their strength like the rest of her body was doing. She shared the plans she had for each project and where she bought the yarn. I found this act so beautifully human. On one hand she was working on closure and trying to finish some projects. On the other hand, she was living in a place of hope that she would live not to do just these projects, but more. Hope is powerful and we should never give it up. It is true that hope can be a shapeshifter. It changes as our realities change, but the essence of how it makes us feel not only gives us comfort and meaning but something to hold onto. Hope feels much more tangible when you are not spending all your energy trying to survive symptoms that rob you of your physical and emotional energy.

Patty had a good life and she didn't want to leave it, but she knew it was coming to an end. Her husband could see the loss and longing she felt when she looked out to see her empty greenhouses, which she could no longer tend. He simply took them down, so she didn't have to look at them. This was an act of true love. I'm guessing it also served to ease his own sense of loss as well.

Patty had two children in their mid twenties. One lived at home and the other next door. They were a tight knit family, and Patty was still very involved in the daily happenings of their lives. This was the area she found most difficult to face, and to let go. It was clear she was the hub of the wheel in the home, and she worried about what they would do without her. With me she did not try to hold back her grief. While she was strong enough, our usual place to meet and chat was the kitchen table with a view of her garden. It was here I spent much of my time with her, just being there, while she cried. I did not try to fix it or even try to make her feel better. I was the outsider and she did not need to care for me emotionally. Therefore, she felt safe to openly grieve her many losses.

Patty enjoyed almost a month of feeling better and having her life back to a certain degree. She did not spend this time checking off major life events on a bucket list but rather just enjoying the simple life and family she had so attentively grown. Soon after this, she began to decline. This is when I saw, for the first time, her hands give way to a slight tremor. The disease was snowballing and she developed severe pain. It took days of aggressive symptom management to get her pain under control. Her hands clenched in protest to the turmoil the tumors were inflicting on her body. This was traumatic for Patty and her family.

When I have a patient with out-of-control symptoms, I become very focused, intense, and in control. Bossy doesn't adequately describe how intense I can be in situations like these. Internally, I am an anxious and nervous wreck, but on the outside I appear as though I know what the next move or intervention is going to be. This is how I cope, and generally it helps patients and families feel like there is a grown-up present who will make everything better. All hospice nurses find their way and rhythm of practice; it is an expression of who we are. Hospice professionals that stay in the field long-term have a unique set of skills and personality traits. This helps us meld well with the complexity of the job to guide people through the end of life process. Frankly, I find it irritating when people call me an angel. When I hear this I say to myself in my head-- Lucifer was also an angel. There is a misconception that hospice nurses are soft, kind, and sweet people

who sit and hold people's hands while they die. This does not describe me or the nurses with whom I work. We tend to be tough but compassionate, non-judgemental professionals. We are smart, hard working, and must manage many tasks at once which are constantly changing throughout the day. We are also direct and clear communicators who are emotionally intelligent and able to navigate the murky waters of stepping not only into people's lives, but into their homes, but not on their toes. I also like to think we are an especially funny group of people who play well with the dark side of humor. I suspect this is because we see the best and the worst of humans on a daily basis. Along this same vein, when I met Nancy and saw how she practiced, I saw a reflection of myself that I liked.

Back to Patty. Due to the complexity of her disease process, and intense set of symptoms, she was on IV (intravenous) medication to control her pain. These sedating medications contributed to her no longer being awake. I remind people daily, "They are not dying because we are giving medications. We are giving medications because they are dying." Not only was this a relief for Patty, but for her family as well. She was finally comfortable. Her ever loving, strong, dependable hands demonstrated this. They too were finally able to loosen their grip, relax, and be at peace.

Once we had her symptoms managed she lived three more days. When I think of Patty and her family I feel grateful that she did not die while in pain, or even just after getting her symptoms controlled. These three days were long and hard, but they were also a gift. Patty had deep faith and enjoyed her favorite religious radio station that her family kept playing in the background. Now that the crisis was over, they could sit with her, tell stories, look at albums, set up altars, light candles, and hold her quiet hands.

It is being present in moments and rituals like these one comes to accept what is going to happen, and even welcomes it. The whole family was beyond exhausted, and they no longer wanted Patty to hold onto a life in this state that was not her. It is a sweet, yet painful moment when families realize they want their loved one to die and let go of life. Families are then forced to grapple with the guilt of these emotions. This is when I gently explain that what they are feeling is not only a good thing, but it shows what true love really is. To love somebody enough to want them to die so that they no longer struggle is love in a very pure form.

Although Patty was the hub of the wheel in this family, her husband was the strength who gave direction and was clearly in charge of the situation. My brief view into their lives gave me the impression of a good marriage, balanced in both power and respect

for one another. He was taking care of everything and everybody, while she was letting go of the wheel. I don't think for a moment that they were perfect. All marriages have their struggles, I'm sure they had theirs, but the love and care I witnessed was genuine and tender.

Patty's sister-in-law was a nurse, and she came to help her brother take care of Patty. She was competent and supportive and yet stayed on the periphery. She was also a person Patty and her close knit family could let into their nest. Although she was a nurse, she knew she was completely out of her realm clinically. She recognized the complex symptom management taking place. Without questioning the care, she offered Patty her solid skills, as a nurse, which were invaluable, appreciated, and compassionate. She was the one Patty's husband could lean on for comfort and support while he supported his children and dying wife. I felt a kinship with her as a nurse, woman, and mother. We worked together in such an intense way to help Patty and her family as she was dying. As the circumstances changed, we witnessed the family shift from hoping for a longer life, to loving her and letting her go through the process of death.

Patty died in the early hours of the morning with only her husband present. Being with a family and patient as they transition from life to death can be very intimate. Through this process a deep connection can grow between us, our patients, families, and their friends. I respect and honor this, and it is what gives joy and meaning to my work. Although being present does feed my soul, I also realize it is their family and their death. I am merely one of the professionals helping to guide them through this profound loss. From each death we gain a pearl of wisdom.

We bathed and dressed Patty that morning. It honored not only Patty but also her beautiful body that carried her through life. It also honored those of us who cared for her. And it gave her family a last look at her clean and beautifully dressed before leaving her home for the last time. Death is a labor of hard work and I believe patients and families deserve this moment. As I washed her hands I thought of the life time of work, care, and love they provided. Her hands had held her husband's as they vowed to love and care for each other until death do them part. They had bathed and swaddled her babies as they came into this world. They nurtured the earth and grew bounteous food and flowers that shaped her and her family's life. They also cleaned the muck off the kitchen floor and packed hundreds of school lunches. To me, these strong hands were the last to fade as her life bubble shrank and slipped from this life.

I feel touched and fulfilled by my job, and my role in caring for people and their families while somebody dies. However, I do not carry their loss and suffering with me. That is not mine. As I said my goodbyes and left their home, I knew that their grief would be intense and last for quite some time. I also did not worry about them, for they were a loving family. Those who know how to love, know how to heal.

Another thought that struck me was for Patty. She carried within herself the immense worry her children would not know what to do without her. Patty was a devoted mother who put her heart and soul into providing a good life for her children. They were intensely loved and they never had to go without anything. I would not say they were spoiled. In fact, they were hardworking, a trait which their parents modeled for them. But they had not faced this kind of intense loss and suffering in their lives, until now.

Losing their mother at a young age would put them in a deep place of emotional turmoil and loss. Of course this was difficult, but I believe the love they were raised in would see them through the pain. In the end they will be deeper and more compassionate people for it. Even in her death, Patty handed her children and family a gift.