

Unflagging Courage

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which I had no real symptoms: stage four esophageal cancer.

There were dark moments that were both paralytic and full of deep ache. I remember shopping with my sister one day. A few outfits caught my eye, but somehow they made me cry too, because I figured the jeans with the sparkly pockets would outlive me. Similarly, I literally said goodbye to the beach where we regularly vacationed — I did not think I'd make it to the next season.

When you are 43 and told by your doctors to get your affairs in order and to enjoy the next few months with your three young kids, it quickly commits you to either submission or defiance. It's a fight or flight time. My kids needed me — I knew what it was like to no longer have a mom. Besides, I had bought those jeans with sparkles on the pockets, and I wanted to wear them.

I knew with the poor prognosis that surviving could not be a passive endeavor — that left too much to chance. For me, it required a mix of tenacity, muscle, humility, vulnerability, competitiveness, and a high level of organization to manage my family, work, and a full-time schedule for treatment, not always feeling great.

I decided that while cancer was bigger than me in many ways, I still had the power, and that's what I think is most important.

Even when you don't think you do or think you can, I learned that there's always a small lever you can pull to keep the gears moving. You can make a choice to control something every day. It can be a big thing like getting up to exercise or go to work, or a little thing like making sure you take that supplement that you believe in or meditating your way through very real physical discomfort and emotional despair.

Staying engaged and staying vocal about

WHAT PHARMA CAN LEARN FROM ME:

When providers, pharma, and researchers tap into the power of advocacy groups that concentrate on the patient voice, an entirely new perspective can be exposed that ultimately may improve outcomes. Physicians are not the only specialists. Patients and caregivers are, too. They are the ones who have walked the walk. Their experiences and words represent an entirely new data set that can't be found in the lab.

As both a caregiver and a patient, I've had lots of on-the-job training.

It started when I was 32, with young kids, my mom (who was an RN) was diagnosed at age 61 with stage four colon cancer. She only lived for another six weeks and those six weeks were fraught with gut-wrenching pain, smells that I will never forget, and uncoordinated care. While it was too late to make a difference in the outcome, I learned quickly the importance of advocacy.

Soon after that, my mom's 90+ year old parents — my grandparents, my rocks — battled various maladies of old age, including some cancer, though nothing quite as evil as my mom's. They were otherwise active and vibrant, and I worked hard for several years to make sure they had the best care possible. Securing the care that I knew they deserved, versus accepting the somewhat patronizing care that the system was conditioned to deliver to near-centenarians was my challenge. The loss of their only child, my mom, was devastating, but they drew on their strength and faith to be present, able, and available for my young family. There were constant surprises and setbacks like life-threatening falls and fractures, pneumonia, gastric issues, and more. Their courage and zest for life galvanized my efforts to find compassionate, personalized care. While nothing came easily, I felt satisfied knowing that their quality of life was the best it could be for many years.

Fast forward a year or two, I found myself feeling tired and not like my usual, energetic self. After some inaccurate diagnoses, I was facing my most formidable foe yet, and one for

your health is one less thing that cancer can have. No matter how bad I felt, I could mitigate it by getting up, exercising in some way, and getting dressed for the day. It became a habit and a mantra — never do less than you did yesterday and dress like you want to feel and be treated. And, importantly, be your own advocate. Read and ask lots of questions. Get involved. Connect with people. You never know what you will learn.

One of the most important things that I try to emphasize to patients and caregivers, whether they are newly diagnosed or back in the ring, is the gift of connection. It really can be the difference between life and death, both emotionally and physically.

Illness, whether chronic or acute, can be one of the most isolating, scary places you will ever be. When you are in that despair, that pain, where you are in the center of the merry-go-round and life is twirling around you — the laughter, the colors, the noises — as if nothing is wrong, there is little that can break the field like the words of someone who has been there.

That is what happened to me. Through adversity, I also found opportunity. But that only happened because my own connections, self-advocacy, research, skilled physicians, and some luck, kept me alive until my breakthrough was available. That breakthrough was immunotherapy, and while I know the future is never certain, I know I would have not had the past five years without it. **PV**