

It's Personal By Torrie Fields
End Well Symposium, December 7, 2017

Start of Transcript

“Neither the life of an individual nor the history of a society can be understood without understanding both.” It was 2005 when those words first resonated with me. Now I had studied sociology and was deeply rooted in the sociological imagination where this comes from. But I couldn't quite understand the intersection that it discussed, the individual and society until 2005.

I was newly married to my best friend who somehow had just signed the major record deal. I married a rock star. [Chuckles] I was working a great job managing quality improvement at a leading healthcare system and I finally knew what I wanted [00:01:00] to do with my life. I wanted to dedicate my life to suicide prevention, to helping aide people through grief, and helping survivor's loss — people who were lost. My sister had just reached the third trimester of pregnancy after a year's long battle with uterine cancer. And we were going to the Pacific Northwest to be closer to her and to chase our dreams. Me in medical school, and him on tour. We had big dreams but I had a secret. When we were packing our final boxes after we quit our jobs, I received a call giving me my test results. I had been diagnosed with [00:02:00] cervical cancer. I had been battling complications from HPV for over five years at this time. We knew a lot less about HPV then when I was diagnosed. We knew that it was a sexually transmitted disease so my fault. And it was one letter off from HIV. No treatment. We also know that it caused cervical cancer... and my number was up. I won! I was diagnosed with cancer the day I lost my health insurance.

When we were moving, we had already packed our boxes, we had already made these plans and our drive was supposed to be our drive toward a new life together as newlyweds. As [00:03:00] young professionals. People who had figured out their lives. That drive ended up becoming a winding road full of questions and few answers. How long had I had cancer? Was I dying? Was it my fault? As a healthcare administrator you learn two things: one that healthcare is exorbitantly expensive and there is no way to be able to access it without health insurance, which I did not have. And that most health systems have access to services when you can't afford them. So I ended up finding my local breast and cervical cancer program. Now I knew that they existed because I had set one up [00:04:00] in my previous health systems so I knew most academic medical centres had a free clinic that can screen you for breast or cervical cancer and then treat you.

So about a month after we settled into our new home, I went to the free Friday and then I presented my case. “Hi, I'm Torrie. I've been diagnosed with cervical cancer. I lost, I don't have a job anymore and I need treatment.” The social worker sat me down and told me that unfortunately the way that this law was ruled out, you couldn't actually have everybody get treatment if they were unemployed or couldn't afford it. So only those people who were diagnosed with cervical cancer from the program were eligible for treatment. I didn't qualify. [Chuckles] I'm a planner. I had no plan [00:05:00] for this, I panicked. I thought I was going to be able to just go and get treatment and be done. We had dreams. This wasn't in the plan. This wasn't part of it.

So I got practical. I withdrew my application for med school and I got a job. It took me about three months to get a job and I started teaching tax law for the federal government. [Chuckles] That was not medical school, that was teaching tax law. I learned a lot about economics! And the process... but I had to lie to get this job. Let's be clear. I didn't know how to teach tax law. But I did know that if you get a job at the federal government you get health insurance on your

first day of work and [00:06:00] and that's all that mattered. I had cancer. And I needed it treated. It took about four months going through the process of finding a doctor, getting an appointment, getting diagnosed, to the point where I actually could get staged to find out how bad it was. I was staged with 2B cervical cancer which meant that it was — it had spread from my cervix but still local enough to be contained to do something about it.

When I found out that I had Stage 2B cancer, I also found out that my surgery was next Wednesday. I've just been scheduled. I still had a lot of questions. There were a lot of statistics thrown at me like I had a 57% chance of survival after 5 years and [00:07:00] that absolutely made no sense to me. To be honest, it still sort of doesn't make a lot of sense to me how those statistics are calculated. I had no understanding of my treatment options or my prognosis. I still had no answer to whether or not I was going to die, but it had been a year since I was diagnosed and someone just presented me with an option. I had a lot of questions but I thought that by asking them, I was getting in the way of my own treatment. And I'd already spent a year waiting. And my husband had spent a year in agony with me. I could catch up later. I could ask questions later.

So I had my first appointment with a surgeon from my surgery that next Wednesday and what I thought was that everything would be fine and after the first surgery [00:08:00]. What we found out was that I was put on that medical conveyor belt that lasted seven surgeries over three years. We hadn't planned for this. My husband broke his record deal, didn't go on tour so he could be my caregiver and I never went to medical school. I put myself in the body of a patient and I didn't think about anything else. I needed to get the cancer gone. In my last appointment with my oncologist, she told me my edges are finally clear, that my labs were showing that I was responding to treatment and that unfortunately I could no longer have children.

This was a big part of our [00:09:00] future together and unfortunately it ended our marriage. My husband had plans too. And this wasn't the future that he dreamt of either. Those dreams changed for us and I had to step back into that position from being a patient to a person and he, from being a caregiver, to a husband. I felt deceived by my physician, I wished she had told me earlier about all of the side effects of these choices. I felt deceived by my body. And I'd lost my dreams. I didn't know what my future held. So I quit my job. Clearly, I'm not teaching [00:10:00] tax law. [Chuckles] That job, it served me well and it was done and I was very happy to say goodbye to that.

I actually applied to a program in Public Health. What I wanted to understand was what change was possible, what levers can you pull to make an experience better for people so that they're not surprised by their outcome. I had just had my dreams taken from me. I didn't want that to happen to anyone else. When I learned that there were systems that could be improved, that there were things like continuous quality improvement and this term the "Triple Aim" or patient-centered care, I woke up. This was not the treatment that I had received and I had just found out that I could've had it better. I got angry. There has to be a better way [00:11:00]. Other people should not be blindsided like I was. So I ended up getting a job at the place where I had my treatment. I was really interested in changing that place. [Crowd Laughing and Applauding]

So I sent in an internal email to Dr. Berlin who was the Director of the Breast and Cervical Cancer program and [Chuckles] that place that turned me away four years before, I was now her colleague, I wasn't a patient. And I had a story and she needed to hear it. So we sat down and surprisingly to me, she had no idea of the eligibility requirements for the Breast and Cervical Cancer program. And she was as angry as I was [00:12:00]. There had to be a better way. So we reached out, we organized. For the first time in my life I met more people like me. I met young people who had survived cancer — cervical cancer — and there were a lot of us. A lot of people with HPV-related cancers. And we went to congress. And we changed that law!

[Crowd Applauding]

That's when I found my voice and the voices of others, too. What I found in that process was policy makers mean well for the most part and they want to implement ideas that are going to improve people's lives... for the most part. But the devil's in the details. It's really in the implementation of policies where things go wrong, where people [00:13:00] like me get stuck in the process. And I knew more than most people! I had been a health administrator. So I started implement large scale programs. I changed that system and I was patting myself on the back. I thought that I was done. Good job, Torrie! You changed things! [Chuckles] I got complacent. I thought I was a success, you know, in my 20s. And luckily I was given a second chance to wake up again.

On March 1st, 2015, I as diagnosed again with cervical cancer. This time I needed a lot more treatment and a lot more care and I was alone. I didn't have that rockstar husband of mine to lean on. I went to the same cancer [00:14:00] center. I had the same oncologist and I had the same nurse. Really the only reason I came back coz she treated me like a person and not a patient. And she sat down with me and talked with me. Nothing in this process changed. Nothing in that system changed. I was scheduled for surgery the day I found out that I had Stage 3 cancer and that it had gotten to my lymph nodes. Nothing changed except for me. I knew a better way. I asked for a palliative care consult. I told somebody what my goals were in life. I found out that I actually was not going to die and that there were treatment options and we made the right decisions that were right for me, for my future, for my life. I got what I wanted despite never being offered it [00:15:00].

As a survivor, as an administrator, as a policy maker, I have a responsibility. Cancer is the best thing that ever happened to me. It changed my life and it gave me a new dream. That dream is to create a system that responds to my future needs and to those of others. Does your system reflects yours? Your neighbors? Your parents? Let's design a system with patients, with survivors, with caregivers, not just for them. Let's design a better experience, a better system... Let's design a better ending. Thank you.

[Crowd Applauding]

End of Transcript