A Broken Pot Still Holds Hope

February 24th, 2022 Bela Kienle (https://healthstoriesproject.com/author/belakienle/)
Stories From The Community (https://healthstoriesproject.com/category/stories-from-the-community/)

One winter night in 2000, Kara was involved in a terrible car accident and airlifted to a hospital. Faced with a long and difficult recovery but determined to live the life she'd planned, she worked through the pain caused by the accident for years, without complaint. However, everything shifted drastically again in 2015, when new symptoms surfaced. Even as her pain became unbearable, her primary care physician brushed off her concerns and disregarded her experience. Ultimately, she needed to find a team that would truly listen to and help her — and accept that she needed help. Kara's story is a powerful reminder of the importance of compassion and self-advocacy have in healthcare.

Strong from the Beginning

To better understand Kara's health journey, it's essential to know just how she came into her indomitable nature. She was raised with four siblings in the Midwest. Her younger sister was born eleven months after her, with the umbilical cord wrapped around her neck. Though her sister was given an Apgar score of zero at birth, she pulled through and later became Kara's inspiration and "sunshine." Their mother, however, didn't cope well with the traumatic birth and the difficulties that followed, leaving Kara to pick up the pieces.

As she got older, Kara fell into a caregiver role for her siblings and became the "fixer" of the family. Her childhood helped her become a strong, resilient young woman and her knack for caregiving led her to pursue a career in social work.

While in college, Kara found herself in a marriage beset by domestic violence. After living seven years with her abuser, Kara mustered the courage to leave him and file for divorce. That process was difficult, but in June of 2000, the divorce was finalized. Around Christmas that year, Kara set out to enjoy herself.

"I wanted to finally have my own life. I wanted to do things that I wanted to do," she said.

The Wreck

With a new lease on life, Kara set out for Sedona, Arizona in November 2000. She and a close friend made the trip to enjoy the Christmas lights there, then drove back that evening, well after dark. Around 10:30 PM, their car was hit from behind by a vehicle that had been stolen and was being driven 120 miles per hour. The two thieves inside were accompanied by a 30-pack of beer.

"We went end over end, down a cliff and landed upside down on a tree." Kara recalled. The men took off on foot into the desert, leaving Kara and her friend injured and helpless.

The women were transported by helicopter from the wreckage to a hospital. The damage to Kara's body was extensive. She sustained broken teeth in the back of her jaw; a broken right shoulder; broken brachial plexus, elbows, ribs and neck; and a closed head injury. She had torn muscles in both shoulders and her spine had collapsed, as well.

The Long Road Ahead

As traumatic as Kara's injuries were, her recovery process was much harder. She was discharged at the start of the weekend, just four days after the accident. Rather than sending her to a rehabilitation facility, they sent her straight home. Fortunately, her friends pitched in to take care of her.

For a while, home health care aides came to help Kara with bathing and physical therapy. She quickly found she couldn't do some of the suggested exercises, which prompted her doctors to do more imaging. The results revealed more damage to her body than the initial workup showed. As a result, she started going to pool therapy.

"So much was broken. So many things were wrong," Kara recalled. "I had to go in the pool, one on one with a physical therapist, just to try and get my body moving again."

Kara also participated in speech therapy and occupational therapy. "[The therapist] told me that if your brain is a library, my brain had been through an earthquake. All the books and everything were still in the library, and we had to figure out how to get things put back," she said.

"Survival and Necessity"

The work to heal didn't end there. Kara had multiple dental procedures to address her broken teeth. After the first surgery to fix her shoulder went wrong, she interviewed multiple doctors before settling

on one that would perform three more extensive surgeries. Once these procedures were completed, she had to begin physical therapy all over again.

Despite this long, difficult recovery Kara remained as strong as she ever was. She had a solid support system of friends who stepped up to help her, and her resolve never faltered.

"It was sort of like survival and necessity," Kara said. "This isn't going to be the end of me. I just got out of that horrible relationship and I just now have my life back. I sort of used all of that to say, 'This isn't the end of my story. I want to keep going. I want to overcome this and still have a great life.' So, I wasn't really down at that time."

The most difficult part of recovery for Kara was the loss of momentum in her life. To access the care needed for her shoulder surgeries, she had to leave her apartment and move back in with her parents. She also had to close the social work business she had started prior to the accident, a practice in which she'd specialized in counseling children.

"[Leaving that behind] was the hardest part I think, but I [was] like, 'I can do it again; I did it before. I just need to take care of this stuff for now.' But I did OK through that," Kara said.

Navigating Around Permanent Damage

Even with all the work done to help Kara's body heal, there were some injuries that couldn't be repaired. Her neck was broken, and her spine permanently damaged. Pieces of bone were missing from both shoulders, and if she were to raise her left shoulder over her head, it would dislocate. These injuries hindered Kara in her day-to-day and slowed her down.

Before her accident, Kara worked between 60 and 90 hours a week. The most she could work while continuing to recuperate was every other day. Realizing she had this limit, she booked five people a day and scheduled a half hour between each appointment. During these breaks, she laid on the floor to relieve the pressure sitting put on her back.

Kara was content finding ways to navigate the pain and discomfort she regularly experienced, so long as it meant she got to keep working. She didn't feel the need to share what she had been through with many people. It was more important to her that she was still using her education and moving forward in her career.

"I didn't focus on [my accident]. I was proud of myself that I could still do that much after what I had been through," she said.

Something Was Wrong

In June 2015, Kara had her gallbladder removed, and after that, something changed. "I kept telling my husband something was wrong. I couldn't get out of bed. I couldn't walk up and down the stairs," Kara recalled.

At the time, Kara saw her primary care physician every two to three weeks. Every time she saw him, she tried to express that something wasn't right. After each conversation, however, she felt that her doctor was not taking her concern seriously or factoring her medical history and experience into his approach. Rather than investigate her pain, the doctor prescribed her medications that interacted adversely with her previous head trauma and did little to make her more comfortable. When Kara brought this to his attention, the doctor advised her to exercise more and prescribed her a treatment for nerve-related disorders.

While on that medication, Kara gained weight and experienced confusion. Despite these side effects and Kara's consistent communication, her physician insisted on staying the course. She had never been treated with that sort of disregard before and found the experience surreal.

"I know how tough and stoic I am. To say, 'Hey, something's wrong and I need your help,' and not to be believed, or even be worked up, was really, really upsetting," she said.

Eventually, Kara had enough and sought a rheumatologist to help her find answers. After running various tests, the rheumatologist diagnosed Kara with rheumatoid arthritis, ankylosing spondylitis and osteoporosis. These findings were surprising on their own, but there was more.

"[The rheumatologist] put two fingers on my back and said, 'No wonder you can't move. Your back's broken."

Piecing the Puzzle Together

Knowing Kara was in a great deal of pain, the rheumatologist prescribed her medication immediately. Shortly after Kara's initial appointment, however, the rheumatologist went on maternity leave and Kara had to find a new specialist. The problem was they were all booked out for three months.

A physician's assistant referred her to a pain management specialist, who in turn reached out to a rheumatologist they knew and helped Kara get an appointment the next day. This swift response was a stark contrast to what Kara had experienced with her previous primary doctor.

"There's always good and always bad," Kara said. "Things started turning around significantly once I got the right help."

While Kara and her doctors never pinpointed the cause for her broken back, they were able to start treating her right away. They put her on medication for pain management and began treating her other conditions as well. Finally, she started to feel like the puzzle pieces of her many diagnoses were fitting together to form a clearer picture.

"To have finally figured it out and have a label for it and have a plan for it helped tremendously," she said. "It was so much different. I could move on down the road and figure out what I needed to do."

Flowers Along the Path

As Kara received the treatment she needed, a portrait of her future came together that was vastly different than the one she'd previously had in mind. She had worked very hard to earn her degree, paying for her own schooling along the way. She had started her own business and continued to take care of her little sister. Finally, after decades of being the "fixer" and taking care of everyone else, Kara, at 53, had to accept that she needed help herself.

"Having to switch roles to where I require help and require assistance, that's been very humbling and very hard for me to accept and wrap my head around," she said.

Still, Kara was able to find a new and important perspective. She recalled a story a friend sent her that resonated deeply.

"It was this story about a guy who travels back and forth with two pots on a stick, over his shoulders, every day to get water. He does this every day of his life. At some point, he realizes that one of the pots is broken. The pot feels bad because it's broken and [the man is] doing all of this work to carry water back and forth, but is losing [it] on the way. Well, the guy goes, 'I've known that you are broken. And because of that, I've planted flower seeds along the path. Haven't you noticed all the flowers that have bloomed for me to see on my walk to get the water?""

The story's meaning helped Kara see herself differently and accept that it was okay to ask for help. "It was sort of like I still have value. I still talk to my sister every day; I'm here for my husband; I still have my friendships and my other family members. Just because I'm not accomplishing and doing the things I thought I was going to do, it doesn't mean a broken pot doesn't have value."

"Hope. Hold on. Possibilities exist."

Kara's story can be constructive for patients and healthcare professionals alike. It's a powerful reminder of just how far a little patience and kindness go in a doctor's office. It is essential to consider a patient's lived experience and take their concerns seriously. Simple acts like this can help humanize the treatment process, which can make a world of difference for patients.

"Don't lose sight of your humanity and [your patient's] humanity when you get busy. Don't forget about the human element and that these are people, you know?" Kara suggests.

Kara knows better than most how quickly things can change and just how frightening that can be. For patients experiencing those abrupt and life-altering changes, her story highlights the importance of healthcare advocacy. It is discouraging to be disregarded when you ask for help, but Kara knows that it has nothing to do with who you are as a person when you're treated poorly. It should not prevent you from seeking the treatment you deserve. "You have to be an active participant and look for the answers, look for the help, look for the information. Keep looking; don't give up," she said.

Of the many lessons Kara learned over her health journey, she found that the ability to ask for help was just as critical as the tenacity needed to keep looking. Her determination brought her to good people who could help her, and the relief their aid provided kept her moving forward. "If you know help is coming and things aren't always going to be this bad, it makes it easier to get through it," she said.

As she looked to her next chapter, Kara crafted a mantra to help remind her of the lessons she'd learned. The words come out with confidence, and there is power in them: "Hope. Hold on. Possibilities exist."

Kara Phoenix, AZ Diagnosed with broken back L4/I5, C5/c6 Copyright @ 2022 Heath Stories Project, LLC. All rights reserved.