

Journeys of Inspiration



Rolf Benirschke was the placekicker for the San Diego Chargers for 10 seasons, but his career nearly ended because of a difficult battle with ulcerative colitis. He would require ileostomy surgery but returned to play in the NFL and has been educating and encouraging ostomy patients and WOC nurses ever since. His illness led him to start his patient engagement company, Legacy Health Strategies, and author three books, including his autobiography, *Alive & Kicking*. He is married and the father of four children, three with special needs. www.rolfbenirschke.com.

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Every coach has nightmares worrying about their opponent throwing in a trick play and catching them unprepared, especially after carefully crafting what seems like the perfect game plan. Being blindsided by something unexpected that changes the outcome of a game can be devastating. Unfortunately, that's exactly what happened to Nancy Mike, a former high school teacher/coach that led her volleyball team to a New Mexico state championship and was named coach of the year – twice!

At 67 years old, Nancy was still at the top of her game, training for a half marathon and playing in a senior volleyball tournament. In the spring of 2016, she noticed a faint trace of blood in her urine. She wasn't overly concerned, thinking maybe it had something to do with menopause or a possible reaction to some supplements she had been taking. After a visit to her primary care physician, Nancy was immediately referred to a urologist, who prescribed a battery of tests, including a CT scan and a series of blood panels. When she was informed that she had a mass of bladder cancer tumors in her bladder and her blood sample showed precancerous cells she was shocked and remembers thinking, 'Where did this come from? There isn't any cancer in my family.' Suddenly, like every patient dealing with a difficult diagnosis, she wondered if there was something she had done (or not done) to bring this upon herself.

As Nancy came to grips with her diagnosis, she decided to treat it as if she was scouting one of her past opponents by thoroughly researching bladder cancer treatments on the internet, learning as much as she could and finally discussing the options with her doctor. When she was informed that she needed to have the tumors in her bladder removed

immediately, she pushed back. From her standpoint, the timing wasn't good. It was early April, and Nancy was much more concerned about the potential disruption to her students than how her health might be impacted. "It's only another couple of months," she said. "Can't it wait until the end of the school year?" In spite of her protests, Nancy's first cystoscopy procedure was scheduled for the end of April.

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During that summer, Nancy's urologist administered BCG (Bacillus Calmette-Guérin) treatments, the main immunotherapy used

to treat early stage bladder cancer. In her first cystoscopy procedure, the tumors were removed from inside the bladder. After the six treatments of BCG, another cystoscopy procedure showed that the tumors had returned inside the bladder which made the determination that the cancer was very aggressive, and her bladder needed to be removed immediately. Shortly after the operation, the doctors learned that the tumors, while non-invasive, began to form again very quickly. At this point, Nancy's greatest fear became the possibility of having to quit her job and not be able to support herself. Following close behind was the fear of losing her ability to be physically active; something extremely important to her. She was devastated.

It was then that Nancy's three sons; Elijah, King, and Jesse, jumped in and committed to being beside her every step of the way. They would not allow her to dwell on anything negative for very long and became a valuable support team for her. "Anytime I would get weepy or start feeling sorry for myself," she remembers, "they would firmly remind me that there were people facing much greater difficulties than I was."

When Nancy did a lot of reading, she was particularly encouraged by *Changing*

Normal, How I Helped My Husband Beat Cancer written by NYT bestselling author, Marilu Henner, about her husband's battle with bladder and lung cancer. One of Henner's seminal messages was the importance of taking responsibility for your life. This message resonated with Nancy and appealed to her competitive nature. She had no idea how important that mindset would be for her in the challenging days ahead.

Since Nancy's tumors returned quickly and did not respond to the standard BCG treatment, the doctors at UNM in Albuquerque strongly recommended that the best course of action was to remove her ovaries, 13 lymph nodes, and perform urostomy surgery to remove her bladder. When the doctor explained that she would have to wear a bag to collect her urine for the rest of her life, she was stunned. What kind of life could she lead? Could she teach again or play the sports that were so important to her? Overwhelmed and scared, Nancy didn't have much time to dwell on the reality of her situation-- her surgery was scheduled for December 9, 2016, just a few days away. She told her students that because she was going to have surgery they would be taking their finals a week early.

Nancy's sons were a tremendous help to her before and after her operation and encouraged her as she endured rough days. For that, she was incredibly grateful. It was the words of Marilu Henner, however, that came back to her as she began to face her new life and reminded her of an important truth. She recalls telling herself, "Ultimately, you are the one going through this, and you are the one who has to face it and be responsible for your attitude and recovery."

Through her reading, Nancy discovered the Bladder Cancer Advocacy Network a trusted resource that also provided great hope. As she learned of the inspiring stories of other women in the fitness industry, she was pleased to see that many were able to return to active lifestyles. With that encouragement and her spirits lifted, she began to believe she would be okay. She



Nancy Mike displaying her medal from the W65 bronze division in volleyball at the 2019 Senior Games in Albuquerque, NM.

would be able to play volleyball again and even get back to the work she loved.

The first few weeks after the operation were tough, painful, and full of uncertainty as she battled a leaky pouch with few available resources. She learned later that she was the very first patient of her new WOC nurse, so they were both learning together. Nancy said it was actually a representative at Meridian Medical Supply who became her greatest ally, calming her when she was "panic-stricken" and sending her samples of different products until they found one that worked. She will be forever indebted to that rep for her patience, kindness and encouraging spirit.

Once Nancy found the right pouching system, things started to look up and she began to set small goals like, 'If I can just go three hours without leaking, that will be a victory.' That three hours stretched to five hours, and three days turned into five days. Slowly, she began to recover, feel better and grow stronger and more optimistic. She upped her goals from laps around the hospital floor to short walks in the neighborhood and dreamed of returning to running one day.

Nancy decided she needed a bigger goal, so set her sights on entering a five-mile race in Moab, Utah. As she began preparing for her "new normal," she wondered how she would manage running that long with a bag.

"It took me a long time to finish as I was trying to figure everything out as I went along. In some ways, it felt all new to me and then I realized it was just me putting one foot in front of the other like I had done hundreds of times before. I was ecstatic at what I had accomplished physically," she recalls, "but more important was what it did for my mental well-being. Once I crossed the finish line and spent time reflecting on the difficult months I had just been through, I knew I could do anything I set my mind to!"

These days, Nancy is active in her ostomy group

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where she gets to encourage other new ostomates, and still enjoys running and playing volleyball in the Senior games. She's played on two Senior women's volleyball teams and won a gold medal in the bronze division in W65s and a bronze medal in the gold division in W70s. She has learned to keep an extra pouch and tape in her gym bag just in case—but has yet to have any problems with leakage. Nancy returned to teaching six weeks after surgery at the same community college and enjoys encouraging her students in their business careers.

Although Nancy accomplished her goal of being able to return to a high level of physical activity, what she is most appreciative of is how her ostomy has changed her and gifted her with a more compassionate heart. "It's humbling," Nancy says. "I used to be a bit hard on people and now have a whole new level of empathy for what others might be going through...and for that...I am very grateful."

Nancy has been in remission for more than three years and has this advice for anyone facing ostomy surgery: "It isn't easy at first, but if ostomy surgery is necessary, you can still have a great life. Don't be afraid to jump in and go for the gold!" 🐾

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than any equipment you have on your body. You might be focused on your pouch, but men just don't focus on that...so try to let that go."

"And lastly," Julie concludes, "People pick up on whatever attitude you have about yourself, so make sure it's a positive one. You don't have to lower your standards for the partner you are looking for. I dated many desirable men before I met my husband. We've been happily married for 30 years. The ostomy has not interfered with our relationship or any type of sexual activity we choose to do."

Robin mentioned that she feels her ostomy has been a blessing in disguise, enabling her to attract men who were interested in a meaningful relationship. "My husband and I have been together now for 12 years. You can still find the right man, have a satisfying sex life, and have a family."

Heather adds, "Intimacy is not just about sex. In fact, some of my most intimate moments with my husband were during the time before my surgery when I was so sick. Sex, really, is just icing on the cake. And if someone truly loves you, having an ostomy doesn't matter. That's the bottom line." 🐾



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