

Relationship Rehab Show

Episode #30: Thriving Through Tragedy

When six-month old Tyson, son of Cameron and Brandi Coon was hospitalized with a very high fever and neurological symptoms, they were terrified, of course, but had no idea how their lives were about to change. Over the next few days it was determined that Tyson had bacterial meningitis. Shortly after he was diagnosed with irreversible brain damage, cerebral palsy and epilepsy from the strokes he experienced from bacterial meningitis.

At first Brandi and Cameron, in shock, worked with the doctors, learned all about acute medical methodology and terminology and roughly 5 weeks into Tyson's hospitalization a care conference was held with Tyson's 15 to 20 medical specialists to coordinate care. During this conference with all of the doctors present, Brandi began to speak up on Tyson's behalf. One of those conversations included, "Could we give him a probiotic to help his digestion recover from all the antibiotics?" The doctors were hesitant. She asked, "Would probiotics harm him?" No...so the team added probiotics.

In the next few weeks Cameron and Brandi brought their son home. They were given a daunting list of instructions for his care. As his care became their new normal, they worked with his doctors on an outpatient basis to slowly reduce the doses of some of the medications.

Brandi reports, "I found and developed my advocacy voice. No one knew Tyson's range of behaviors and responses better than me. No one spent as much time with him as my husband and I did. One of us had to be a full-time caregiver. For about two years, I worked full time while Cameron went to school online, and was Tyson's full time caregiver. He was just as involved as I was working with Tyson's doctors and therapists. We make a great team." Over the next few years, they lived in three different states, searching for the best care for Tyson and the best support for themselves.

At the time he became ill, they were in their early twenties but wise enough to know they would need help if they were going to manage the stress individually and on their marriage. They saw counselors as individuals and as a couple. In spite of how difficult it was to arrange for Tyson's care, they made it a priority to go on short trips together once or twice a year. These times away helped them hang on to their love for each other and strengthen the bonds between them even while so much of their energy was consumed with making ends meet and caring for Tyson.

They even decided to have a second child. Trevan was born when Tyson was 4 years old. The relationship that has developed between the two brothers is deeply moving.

Meanwhile, Brandi developed a network of friends who shared the experience of having a special needs child. She started a Facebook group where they could go for mutual support and advocacy. She researched and then worked with the State Medicaid Department and Elected Officials to extend programs that were helping parents of special needs children beyond some Covid-19 policy flexibilities. Most parents have to quit their jobs when their child becomes disabled. Prior to the Covid-19 Pandemic, there was a caregiver shortage. Once the pandemic hit it reduced the number of caregivers even further. Prior to 2020 parents of minor disabled children, in Arizona, were excluded from being paid caregivers for their own children despite providing this care on a daily basis. Brandi and her friend, Lauryn Van Rooy co-wrote a petition and proposal that would allow parents of special needs children, who had to quit their jobs prior to or during the pandemic, to be paid as their child's caregiver. Through their advocacy efforts, additional funds were approved by the Arizona State

Legislature to allow a bridge program to continue this caregiver flexibility beyond the Covid-19 Public Health Emergency. Now Brandi, Lauryn and thousands of parents are lobbying to have the bill extended indefinitely. There are many parent lead groups in other states now collaborating with Brandi and her team as they work to create Paid Parent Provider programs in their own respective states.

Due to Tyson's diagnosis of TBI, CP and Epilepsy, he is expected to have a shortened life span. Due to changes in his health, Brandi and Cameron have elected to begin Palliative Care. Through this specialty Tyson and his parents will be able to consult with a doctor experienced with quality-of-life decisions, be provided social services support and make the decision with his team to start Hospice care when that time comes. Tyson has taught his parents and extended family to live in, and love every day and moment.

Recent themes of this show have included, how to stop being a victim, how to heal yourself from trauma with Inner Child work, how to create a life that has meaning and purpose, and how to create and sustain a healthy, lasting marriage. My own passion for helping relationships thrive was borne from the pain of my parents' marriage and the suffering Jim and I experienced in our marriage. So often pain, when met with courage, and the seasoning of time, is the launch pad to a challenging but awesome journey of amazing personal growth and a passion to help others. My deepest gratitude to Brandi for her willingness to be so transparent about the journey that began with their child's tragic illness, but has developed this powerful voice on behalf of special needs children and their parents.

Are you the victim of a difficult or tragic circumstance? What small step can you take today that will give you a sense of your own power to improve that circumstance? A call to find professional help? Do a Google search to explore your options? A choice to use one of the new communication skills you've learned from this program? Even the decision to bring order to one messy drawer or closet will act as a potent metaphor for bringing a clarity to your confusion and positive change into your life.

You have my support and best wishes,

A handwritten signature in cursive script that reads "Nancy Landrum".

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