

Reflections

The Real Strength

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Introduction

The birth of every child brings with it the utmost joy, ultimate delight, and an eternal dream. A dream bore by every parent to witness their offspring evolve into vibrant, victorious, and virtuous human beings. The voyage to reach this desired fate is encompassed by bitter-sweet struggles and relentless responsibilities. And these efforts are magnified when raising a child with special needs.

No one would truly understand the meaning of this struggle as much as Nosheen, a headstrong mother of a 16-year-old valiant boy, named Bilal.

Just like every mother, Nosheen began knitting and stitching baby clothes and socks when she discovered she was expecting her firstborn, four years after her marriage. This new-to-be mother was eager to experience his first cry, his first tooth, his first crawl, and his first word. She promised herself to guard him all his life, just as she guarded him in the womb. With every yarn loop interlinked by the knitting pin, she designed hope and happiness.

Despite being cautious of her health, Nosheen was diagnosed with Gestational Diabetes early in her pregnancy. She was started on Insulin injections. Constant blood sugar checks and repeated needle pricks seemed far less stressful as compared to the persistent fear and anxiety about the wellbeing of her baby. She did all in her power to keep the blood sugar under control to prevent it from harming the baby.

It was during her eighth month of pregnancy that her world came crumbling down. What was supposed to be a routine ultrasound scan turned out to be the worst news of her life. She was informed that her baby had “water in his head” and a “lump at the spine”, which she later learned is termed Hydrocephalus and Myelomeningocele respectively. She was told that the children with this condition do not live for long. She lived in a small village of Sindh then. She decided to get a second opinion, for which she traveled to Hyderabad. Unfortunately, the consultants gave the same conclusion there as well. She was benumbed and frozen by this piercing news. She had never heard those terms before. She had



never felt so broken before either. She spent the rest of her pregnancy in pain. Not the physical form of pain, but the pain of being helpless. She did not have the strength to bear this agony, but she did not have a choice either.

Ever since that day, she was flooded by a cascade of advice and suggestions. Most of which were directed towards the termination of her pregnancy. This resilient lady paid no heed to such opinions. She was adamant to bring forth this child into the world.

On the 17th of July 2005, she gave birth to a baby boy. As she held this delicate little life in her arms for the first time, she was taken over by a feeling of being strong. It was not only a little boy who was born that day but

also a courageous mother who was determined to provide him with shelter and protection. She was meant to raise this baby in her womb and now in her arms. And he was chosen to be her son. She named him Bilal.

His birth was welcomed by a line of check-ups, examinations, and tests. Nosheen did not get the chance to truly celebrate her son's birth. She ran from one city to another and from one doctor to another, carrying her son in her arms and hope in her heart.

Soon came the day when she had to kiss her sweet, big-eyed boy in the operation theatre as they prepared him for the general anesthesia for his first surgery by a neurosurgeon for the placement of a Ventriculoperitoneal (VP) shunt to help drain the extra fluid from the brain. This was followed by another surgery on his spine. Each procedure lasted for hours, which felt like an eternity to this mother who waited and prayed right at the door of the waiting room. With every turn of the door knob, she anticipated hearing the good news of the operation being successful. Everything about that room was uncomfortable and unsettling. The chairs, the ticking of the clock, the silence.

Much to her relief, both the lengthy procedures went well, but she was informed that her son would remain paralyzed from the waist down. This was unfortunate and distressing news that completely altered her life. For a mother to know that she won't be able to see her child take his first step was agonizing and heart-rending. But this iron-willed lady was determined to be Bilal's strength.

From then onwards, Bilal suffered several health problems. He was found to have multiple stones in the only kidney he had as the other was congenitally absent. As a result, he had repeated infections and excruciating pain. His VP shunt got blocked on an occasion that required another procedure. His life swung back and forth between infections, pain, hospitals, and surgeries. He was met with so many health adversities that medicines and injections did not scare him anymore. By this time, Nosheen was caught in an inescapable financial and emotional whirl, but she soldiered on.

Days turned to months, and months turned to years. Bilal grew up to be an intelligent, brave and high-spirited 4-year-old boy. Although he could not take his first step, he learned to drag his lower body around with the help of his arms. His growing age chaperoned growing curiosity. He would often ask why he could not walk like other children. Not finding the right words, Nosheen always comforted him by saying Allah made him unique and very special.

He was keen to learn and go to school like his younger sister. Nosheen contacted the local schools in her village, which led to utter shock and disappointment. He was

denied admission based on his inability to walk. She was anguished when some people remarked that children with disabilities do not need to study. She then planned to leave her village behind and move to Hyderabad, so her son could pursue education just as he desired. This was a big step, but her aim was bigger.

She carried this young hopeful lad in her arms to a school in the city for an interview. The teachers were in awe of this boy's intelligence and he was swiftly enrolled. He was picked up and dropped by a van. The driver was kind enough to assist him and to reserve the front seat for his comfort. Unlike other kids of his age, he woke up excitedly every day, eager to learn something new from the teachers. He stayed in the class at lunch breaks, as other kids went out to the playground. His sister always stayed back in the class to give him company. They ate together. The first few years at school were calm and peaceful for him. He was an obedient student who was adored by all. This bright child topped every test and exam despite missing several academic days due to his frequent bouts of illness and hospital admissions.

When he reached class 4, he started getting bullied by other children at school. They would throw away his pencils and notebooks far from his desk, knowing he won't be able to pick them up. He was frustrated and helpless. He longed to have the ability to walk away from them. He would return home every day with inconsolable cries, owing to constant bullying. He refused to go back to school. If being special meant being tyrannized by the bullies, he did not want to be special anymore. Nosheen could not bear to see her son in such a sorrowful state. With the help of the headmistress, Bilal was permitted to sit in the same class as his sister, so she could assist him when needed. And he started studying again. Throughout the years, they went through several twists, turns, peaks, and valleys, but they bounced back from each adversity.

Bilal is now a 16-year-old heroic boy who currently studies in the ninth grade and wishes to become a bio-engineer when he grows up. He continues to fascinate people with his talent and intellect, while his mother continues to stay by his side, just like she once promised.

With each passing day, Bilal has begun to acknowledge and accept all that he is capable of, rather than focusing on his disabilities. That has helped his emotional growth process. He has gathered that the real strength of a person lies in his heart and his soul, and that is what makes him push ahead and step forward. In that sense, he is the strongest boy there is.