

Exploring the Resilience and Love Cultivated through Raising a Child with Severe Cerebral Palsy: Evidence from Eritrea

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I am writing to share the heartbreaking journey of my eldest son, Mishael, who was born on June 20, 2015 in Eritrea. Mishael was a source of joy and hope for our family, but his life took a challenging turn when he was diagnosed with severe cerebral palsy three months after his birth. As an Orthodox priest and my wife as a nurse, we were familiar with the trials of illness and suffering, but nothing prepared us for the pain we would endure watching our beloved son battle this debilitating condition. From the very beginning, Mishael's life was marked by struggle and pricking sensations. We sought out every intervention strategy available, hoping and praying for a miracle that would ease his suffering and improve his quality of life. Countless trips to hospitals, consultations with specialists, and long nights of worry and tears followed, but despite our best efforts, the outcome remained the same – our son continued to suffer, his condition worsening with each passing day. As a Priest, I found myself grappling with questions of faith and divine purpose. Why would a child as innocent and pure in heart as Mishael be subjected to such profound suffering? How could I reconcile the teachings of my faith with the cruel reality of my son's debilitating condition? In moments of despair, I found myself turning to my faith for solace, seeking answers that would bring some measure of peace to my troubled heart.

My wife, a nurse dedicated to caring for others, faced her own struggles as she watched Mishael endure pain and discomfort that no child should ever have to experience. She worked tirelessly to ensure that he received the best possible care, advocating for him at every turn and never giving up hope that a breakthrough would come. But as the months turned into years, and Mishael's health condition showed no signs of improvement, her tenacity began to waver, and the weight of her grief became almost too much to bear. Through it all, our family remained united in our love for Mishael, finding strength in each other as we navigated the uncertain waters of his illness. We clung to moments of joy and laughter, however fleeting, cherishing the small victories and milestones that marked his journey. And though the road was long and fraught with heartache, we never wavered in our commitment to doing everything in our power to ease his suffering and bring him comfort and peace. Parallel to that, the challenges we faced as a family caring for Mishael were multifaceted as stated below.

Emotionally, we grappled with the pain of watching our lovely son endure constant physical discomfort and struggle with even the most basic activities. My wife, a nurse by profession, found it particularly challenging to separate her professional responsibilities from her maternal instincts, often feeling overwhelmed by the enormity of caring for a child with such complex needs.

Financially, we struggled to cover the mounting costs of Mishael's medical care and therapies. In a country like Eritrea with limited resources for children with disabilities, accessing adequate healthcare and support services has been constant battle. From my side, my position as a religious figure in the community made me to perceive Mishael's condition as a divine punishment and/or vengeance from preternatural forces.

Spiritually, our faith was tested as we wrestled with the question of why our prayers had apparently gone unheard. As a priest, I found myself questioning my beliefs and struggling to reconcile my deep faith with the harsh reality of Mishael's deteriorating health condition. The use of holy water, a common practice in our community, did not yield the miraculous healing we had hoped for, leaving us feeling lost and disillusioned. Nonetheless, saying so is not to underestimate and dishonor the role of holy water and miraculous healing.

Today, therefore, as I reflect on the painful memories we carry with us – the sleepless nights spent tending to Mishael's needs, the endless rounds of appointments and treatments, the moments of helplessness and despair – I am reminded of the depth of love and resilience that sustained us through the darkest times. Mishael is no longer with us, and his spirit is now free from the confines of his earthly body, but his memory lives on in our hearts, a constant reminder of the fragility and preciousness of life. Importantly, despite the overwhelming sense of despair and uncertainty that clouded our lives, we found moments of solace in the love and bond we shared with my wife and our extended family. Through our collective grief and struggles, we found strength in our unity and resilience as a family. We clung to the hope that, despite our failed attempts at healing Mishael, our unwavering love and support would continue to guide us through whatever trials lay ahead. Of note, as we navigated the turbulent waters of our journey, we learned valuable lessons about resilience, acceptance, and the power of unconditional love in the face of adversity. We discovered that healing is not always about finding a cure or fixing what is broken, but about embracing the journey with courage and grace, trusting that our unwavering love for one another would light the path forward, no matter how uncertain it may be.

To this end, I share our story not for sympathy or pity, but as a testament to the strength and courage that we found in the face of unimaginable adversity. Mishael's life may have been short, but its impact on our family has been immeasurable, shaping us in ways we never could have anticipated. And though the pain of his loss remains ever-present, we take comfort in the knowledge that he is finally at peace, and his suffering at an end. Time and again, I would like to highlight that life is a journey filled with unexpected challenges and hurdles that may seem insurmountable at times. In turn, it is easy to get lost in the darkness of adversity and feel like there is no way out. "Nevertheless" amidst the shadows, there is always a flicker of light, a glimmer of hope that reminds us that behind every challenge lies a great opportunity. Indeed, the departure of our eldest son due to cerebral palsy brought immense pain and sorrow, but it also brought the blessing of two lovely daughters and an adorable son. This reminds us that even in our darkest moments, there is something beautiful waiting to unfold. As such, it's important to remember that challenges are not meant to break us but to mold us into stronger, more resilient individuals. They provide us with the opportunity to grow, to learn, and to discover our inner strength. Every setback is a setup for a comeback, and every closed door leads to a new opportunity waiting to be embraced. Therefore, as we navigate through life's twists and turns, remember that behind every challenge, there is a silver lining waiting to be discovered. Ipso facto, embrace the difficulties, for they are the stepping stones that will lead you to greater heights. Trust in the journey, have faith in yourself, and believe that the best is yet to come by God's grace. Thus, I ask that readers hold their loved ones close, cherish every moment together, and never take for granted the gift of health and happiness. For life is a precious and fragile thing, a gift to be treasured and celebrated, regardless of the challenges we may face along the way.

In closing, let this gentle reminder be a beacon of hope in times of darkness, a reminder that every challenge you face is an opportunity in disguise. Embrace the present, stay resilient, and keep moving forward with courage and grace. The future holds endless possibilities, and with every challenge overcome, you grow stronger and more prepared for the beautiful opportunities that lie ahead.