

Alicia Maciel

Cystic Fibrosis



My name is Alicia Maciel. My husband Peter and I have two sons. Our second-born, Marc Anthony, is 19 years old, and has cystic fibrosis (CF).

When one becomes a parent, one simultaneously enters the role of caregiver. Babies require round-the-clock care that usually decreases as they grow older. However, for parents of children with a chronic illness such as CF, the role of caregiver takes on a whole new meaning.

From birth, Marc Anthony exhibited breathing and digestive problems that were misdiagnosed by his doctors, leading us down a frustrating path of hit-or-miss diagnoses until he was finally accurately diagnosed with CF at the age of six.

Initially, I thought dealing with my son’s medical needs was something I could simply add to my standing to-do list. However, as I immersed myself in the caregiver role, it was sobering to discover the extraordinary demands it placed on my time and physical and emotional energy. Soon it became impossible to downplay the strenuous implications of dealing with what felt like a constant juggling act: endless medical appointments, insurance bills, prescriptions, medical equipment, and daily treatments. Yes, let’s pause here to collect ourselves after going through that list. I decided to go on a quest to find caregiver support and thankfully, discovered that I was not alone.





Over time, my approach to caregiving has morphed from checking tasks off a to-do list to adapting to a new way of being. At a certain point, effective caregiving is no longer about doing more, it's about caring more for what you're already giving. This begins with remembering to care for myself and to nurture my resilience; that precious resource that enables me to care for others. I'm better at loosening the grip on the way I think things should be. This enables me to stay open to receiving and learning from what life brings so that I can continue to evolve along with my son's needs.



The CF community includes a robust ecosystem of caregivers consisting of dedicated doctors, nurses, specialists, researchers, pharmaceutical companies, and CF patients and their families. For the past 10 years, my husband and I have been involved with the annual Cystic Fibrosis Research Institute's (CFRI) National CF Education Conference.

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I have chosen to embrace my role as a caregiver by aligning opportunities within the caregiver ecosystem with the things that I’m skilled at and enjoy doing. The more involved I become in the ecosystem, the more nourished and equipped I feel to support myself, my family, and others on a similar journey. Caregivers give care through sharing their time, skills, and energy. As individuals, our capacity is limited, and one can only give so much. Therefore, I focus on expanding my impact in caring for others by working with organizations that value the patient and family perspective. I currently serve as a member of the CFRI Diversity Committee and the CFRI Embrace Mothers Retreat Planning Committee. Simply mentioning the Embrace Mothers Retreat brings a smile to my face. This event has shown me that amidst the adversity of a caregiver’s journey, it is possible to experience joy and fulfillment from building loving, connected relationships with others who can relate.

I’ve also led the creation of a Parent Advisory Council at the CF Care Center at Children’s Hospital of Orange County (CHOC). And have served as a CHOC Parent Partner on the national Cystic Fibrosis Learning Network.

Looking back at 2008 when Marc Anthony was diagnosed with CF, I could have never predicted how my journey as a caregiver would evolve. Over the last five years I've transitioned my professional skills and expertise to serve others as a resilience coach and a mindfulness meditation teacher through my practice called BeingWell.life. Each day I feel more content and fulfilled than ever as I look forward to learning from and supporting others, as I feel blessed by all that I've received. I'm inspired by the possibilities that lie ahead. ●

Cystic Fibrosis

Cystic Fibrosis occurs when a person inherits a mutated (abnormal) copy of the CFTR (cystic fibrosis transmembrane conductance regulator gene) from each parent. It is an autosomal recessive disease meaning only people with two CFTR mutations have the disease. While there is no cure, life expectancy has steadily improved in the United States. Some other facts about Cystic Fibrosis are:

- There are now more adults than children with CF in the United States.
- Newborn screening for CF done on blood samples can identify most children before one month of age, which allows for early treatment and disease monitoring.
- CF individuals have abnormally thick mucus, which blocks the airways (obstruction) and leads to repeated infections and damaging inflammation in the lungs. Treatments are directed at trying to prevent and treat these problems.

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