

LOVE NOT FEAR: LEARNING ABOUT LIFE FROM NORMAN BY MYRNA MEDINA, CDBS FAMILY SPECIALIST

Dilated cardiomyopathy—what a scary thing, especially if this is a diagnosis and your son is the one receiving it, or at least it was for me. When the cardiologist approached me and said that my son Norman’s heart was failing due to dilated cardiomyopathy (or DCM), everything in my mind went blank. The only thing I remember hearing was that “his heart is very weak and could stop any minute.” I remember hearing words like could resuscitate, life support, medication, and heart transplant. Norman’s father and I were devastated to hear these words. It was terrifying to think that our precious child was slipping away from us. For so many years these words lived in our minds. We thought of nothing more than to enjoy Norman as much as we could, day-by-day, and to make him as comfortable and happy as possible.

Norman is the younger of our two children. By the time he was two years old, Norman had been diagnosed with deaf-blindness and low muscle tone. Throughout his life, Norman has been given several diagnoses: Leber’s congenital amaurosis, mitochondrial disorder, Usher syndrome and finally Norrie syndrome, all not life threatening. But none of these diagnoses affected us as hard as when he was four years old and was diagnosed with DCM, which *is* life-threatening.

Our family of four—me, my husband Juan, our daughter Dolores, and Norman—enjoys activities like family gatherings and traveling. It was during our last family vacation before this diagnosis that Norman started to show some unusual symptoms like eyelid puffiness and swollen feet. At first, we thought he was just tired from the trip and that he needed to rest. The next day we took Norman to see an eye doctor for the eye puffiness and he was prescribed an antibiotic ointment. Later the same day Norman started to complain of discomfort, and we knew these symptoms were very unusual for him. My husband and I rushed Norman to the emergency room, where they said that he needed to be admitted to the hospital.

Norman was admitted to the hospital for a condition that was, at that time, unknown to us. We were scared and felt very uncertain. All we knew was that his eyes and feet were puffy. The cardiologist came and went, ran one test after another including ultrasounds and x-rays, and finally after hours of investigation a team of doctors broke the news to us: Norman was suffering from heart failure due to DCM. Everything happened so suddenly that it was hard for us to digest it all. It didn’t occur to us at the time to ask for more information about this particular heart condition so all we knew was what they had already told us. A week after Norman was released from the hospital, he was assigned a cardiologist to follow his progress. A strong and trusting relationship eventually developed between our family and this doctor, along with the development of open communication about Norman’s progress.

When all of this happened, our family routines were thrown out of balance. We realized we had to make big changes to the way we did things. Our family outings were postponed indefinitely. We stayed close to home so we could reach the cardiologist in the event of an emergency. I became obsessed with Norman’s heart condition—always on alert, and fearful that something bad was about to happen. I remember constantly touching Norman’s feet to see if they were swollen, and checking his eyelids to see if they were puffy. Norman’s heart condition became our family’s number one priority, or at least it was mine. One day I realized that I had unwittingly transmitted these fears to our daughter, who was seven years old at the time, because the things we liked to do as a family were long gone. Every time we talked about planning

something, the memory of all the words said by Norman's doctors came to our minds and held us back. For years I lived with the information Norman's cardiologist had explained to us, along with the personal research I did when he was first diagnosed. Every time he was due for a follow up appointment and we were told that he was stable and not getting worse, this was good enough news for me.

One day Norman's cardiologist approached my husband and I with the news of his imminent retirement. It was devastating to think that Norman's doctor for over nine years, a cardiologist to whom my entire family trusted, the person to whom we as parents trusted with our son's health, was saying goodbye. Later on, we felt much uncertainty about the new doctor. All kinds of questions seeped into our minds: Male or female? Would we like this new doctor? Would it be easy to bond with him or her? We didn't know what to expect—a fear of the unknown. Also, I knew I had to bring this new doctor up-to-date on Norman's background. For nine years it was easy; Norman had a doctor who knew almost everything about him, and didn't have any major questions for us after the first year when Norman was diagnosed with DCM. I felt that I knew all I needed to know about Norman's heart condition.

When we finally met Norman's new cardiologist, I gave him a full report on Norman's health history. During my report, I discovered that I had questions that had never before been brought up or answered, information that I had previously just taken for granted. The new cardiologist helped by clarifying these things and gave me a whole new way to look at Norman and his diagnosis. I found out that all of our fears and anxieties were baseless!

All this time I had been thinking that our life as a family should revolve around Norman's comfort, that we should always have our guard up and be on alert. I didn't realize that, as the years went by, our family had been unfairly deprived of all the things we enjoy doing together. Speaking with the new cardiologist, who had a fresh and different point of view, he shared with me that life should be enjoyed to the maximum, should be lived around people that you love, and that it's okay to be just be a mother and a wife. Only then did I finally allow myself to understand that living in fear limited my ability to enjoy life to the fullest extent. I really wish I had known earlier that DCM did not mean the end of the world for Norman, and that we could've spent more time enjoying our life with Norman and as a family.