

INTRODUCTION



As with all young brides, when I was married, I walked down the aisle oblivious to the challenges that lay ahead of me. I looked toward the altar to the man waiting for me with a love that would never die. It was when we started having children that the long journey of darkness began. In spite of the reality that four of my children lived with, and died of cystic fibrosis (CF), the fact that they lived the fullest possible lives is my greatest source of contentment now.

Sean died before his second birthday and so was not capable of processing the impact this disease would have on the course of his short life. I'm not sure just how old Cheryl, Chrissy, and Jimmy were when they understood that they would not live long lives, but I believe that, with the way I raised them, they were more interested in living each day than they were in fearing not being alive tomorrow. They lived as regular lives as I could give them. I strived to keep up their treatments while not taking them away from their playtime and friends, celebrating every possible occasion, surrounded by family, in the knowledge that another chance to do so might not come.

I have often been asked why I continued to have children when I knew that my firstborn had cystic fibrosis. I was raised in the love and joy of a large family. It is important to me for people to understand that my philosophy of hope extended even to this. I wanted a large family myself and I risked having more children because the genetic odds were slim that I would have more than one child born with cystic fibrosis. After the birth of each child, I was

reassured that it was unlikely another of my babies would be diagnosed with cystic fibrosis, and I realized that I had the strength and stamina to accept whatever God handed to me. Babies were always a big part of my life and I knew that without children, my life would never feel complete. I have no regrets over my decision to have five children; in fact, I might have had more.

My hope in writing *A Mother's Memoir – Living While Dying* and sharing my experience is that the reader might acquire some knowledge which could help them through their own challenges. I want to give people insight into life with cystic fibrosis while at the same time providing hope and faith to anyone in a similar situation. There is light at the end of every tunnel. I also hope that by reading about the way I raised my children, and celebrated life in light of chronic illness, they might be inspired to treat their children as if there may not be a tomorrow, and by doing so, create more fulfilling lives for everyone.

Among the many supports I have drawn upon, I have learned that my spirituality and belief in the importance of family, as exhibited by the strong women who were such exemplary role models in my life, have ensured my survival and enabled me to be in this happy place today.

Over the years, two questions have regularly been asked of me. The first is why did you and your husband continue to have children, knowing there was risk of them being born with cystic fibrosis? The second question is how have you been able to manage, mentally and physically, to cope with the many challenges that this dreadful disease brought into your lives over the years? This book is a response to both questions.