



Faces of Hope



Ann Castle's daughter, Caitlin, has been a source of help and hope as Ann has struggled with CFS. On a spring day last year she got a message from Caitlin that she'll always remember.

I woke up from a nap one afternoon in early June of last year and noticed that my daughter had left me a telephone message. "Hi, Mom," she said with that shot of enthusiasm that colored her voice when she was excited and happy. "I just left Union Station where I saw ["The Faces of Chronic Fatigue Syndrome" photo exhibit]. It had good information, brochures and a website for people to contact if they wanted to know more. And Mom . . . I read about one woman who had CFS for 15 years, and she recovered. So we have to keep our hopes up. I'll call you soon. Hope you're feeling well. Love you!"

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My 21-year-old daughter, Caitlin, had visited the CFS exhibit while it was at Union Station in Washington, D.C., where she was a college student. Cait was constantly on the go—involved in many things, looking toward the future and trying to figure out what it is she wants to do for a career. Yet seeing this exhibit was important to her.

Caitlin was no stranger to suffering, having been introduced at a young age to the pain of a family affected by a devastating chronic illness. She had witnessed the changes to a mother who had always been active and involved. I had been a partner and clinical social worker in a large psychotherapy practice, walked three miles a day and loved to work in my garden. I read voraciously. An only child, Cait thrived in the love that her father and I gave her, growing strong and curious and, in many ways, fearless . . . until a disease named CFS came to stay.

She witnessed the slow, dramatic decline of my health. It toppled like dominoes beginning with a severe viral infection, fever, rash, a complex thyroid disorder, hysterectomy for a rare type of endometriosis, post-operative infections that lingered for months, tingling and buzzing sensa-

tions and weakness in my limbs, mysterious staph infections, balance problems which caused me to fall and drop things, spinal disc injuries, a three-year fungal sinus infection almost impossible to eradicate, yeast overgrowth and irritable bowel symptoms. I also developed trigeminal neuralgia with horrific shooting pain in my jaw. I gained 30 pounds, but I ate next to nothing.

Blood tests eventually revealed certain abnormalities, and MRIs of my brain showed enlarged ventricles of "uncertain significance." By then I was having trouble remembering the names of patients I had been treating for many months. I knew it was serious when I had to ask my secretary for my own phone number and address. I knew it was the end of my career when, try as I might, I had to leave an appointment early because I could no longer fight the need to close my eyes and sleep.

Then at night I couldn't sleep, at least not the wee hour of the morning which eventually rendered me even more exhausted. Fatigue permeated every cell in my body. I often slept for 20 hours a day, seven days a week. I could no longer read or even watch TV. I didn't possess the strength to follow a plot or keep my eyes open. Pain began to creep into each and every muscle and joint. It was as if every tendon in my body was twisted tight like rubber bands and then studded with razor blades. And that was joined by headaches, sore throats and lymphedema which had become regular 'guest symptoms.'

Caitlin suffered right along with me, even though I tried to protect her. I vowed that her life would be as normal as possible, and she was busy. Along with studying and volunteering she had a lot of friends, was class president and had a part-time job.

However, because her father traveled much of the time, Cait was often my caregiver; left to take me to doctor's appointments, pick up prescriptions and shop. She would often come and hold my hand as I got tender point injections. It was she who was there to rub my back and arms and help me into a warm bath when the pain kept me awake with its relentless hold. Though she hid it well most of the time, my daughter worried and grew weary under the weight of this illness that affected us both in so many ways.

I went to her high school graduation in a wheelchair. I was so mentally confused and immersed in such a thick blanket of brain fog that my eyes could not find her during the ceremony even when she gave the class speech. I remember being overwhelmed by the lights that stung my eyes, the sickening fumes of clashing perfumes and the visual and auditory overload of color and sound. I had to go home and sleep immediately afterward. It was a month before I recovered from that outing enough to get out of bed.

On one visit home from college Cait cried when she saw me. That day I had tried so very hard to muster the energy to shower, blow dry my hair

and get dressed in "real clothes." It took me five hours, but I did it. Cait confessed that she hadn't seen me up and dressed for so long that she had forgotten what I used to look like. She cried because of what I had lost and for what had been stolen from her.

I feel great tenderness, love and compassion for this young daughter of mine, who had spent a beautiful spring day in D.C. making a pilgrimage to the CFS exhibit at Union Station, gathering pamphlets, talking to and educating her friends about the disease. On the message that day I heard that great spark of hope which has been such a gift to me: "Mom, if someone can recover after 15 years, then you can too! I just know that you are going to walk into my college graduation without a cane, and you'll stay awake for my party. I believe in you, Mom."

From these two faces of CFS—mine and Cait's—there's gratitude for

the people who've worked so very hard and lobbied tirelessly for research and treatment. Cait will soon complete her senior year of college and apply to graduate school. I will continue to work to get well; doing the things that I've learned can help me live a life within a different framework. For all that was taken, however, much has also been given—perhaps largest among these, the feeling of hope. Hope that I *can* walk unaided into her graduation, hope that I *will* recover. Those of us who make up the many faces of CFS—from patients, to children, spouses and friends—understand that we must not lose hope and that we must never give up. Ever. ■

CFIDS Association member Ann Castle, MSW, ACSW lives in Dover, Delaware. She was owner/partner of a psychotherapy center from 1996 until 2003. She's looking forward to Caitlin's graduation this month.

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"I believe in you, Mom."

TELL YOUR STORY OF SURVIVAL!

The "Living with CFS" department shares first-person stories of challenge and survival. What's your source of inspiration? What coping strategies have you learned? Send your 500-900 word story to chronicle@cfids.org. Though we can't print every story, we always value hearing from you.