



By Caryn Sullivan

**AUTISM AND HOPE
MORE RESEARCH, MORE UNDERSTANDING, THE PROMISE OF LESS
ISOLATION**

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I can't pinpoint the person who first spoke the word "autism." I do recall with great certainty that I could not repeat the word for months after I first heard it. I didn't really know what it meant; I just knew that it was not good.

I now know that it is something bigger than I could ever have imagined; that it wrought changes in my life that I would never have anticipated, pushing me to limits I didn't know I had; that it is an extremely isolating disorder; and that it is a black hole that seems endless.

I wrote these words last August, after an exceptionally difficult summer. They were the beginning of a lengthy essay in which I poured out 15 years of grief I had carried around like a boulder on my shoulders. Any day now, that essay will be published in an anthology of works by women whose lives have paralleled mine.

I find myself writing personal things about my family -- things they likely prefer not to read about in the newspaper. And I am conflicted. Because when this newspaper ran a piece I wrote about the drowning deaths of two autistic children, my e-mail box filled with messages from mothers, grandmothers and even aunts whose world was also rocked by an autism diagnosis.

I found I was part of a sisterhood, and that filled me with a sense of solidarity -- and sadness. I learned we shared that sense of isolation I wrote about last August and that they, too, had lived in fear and desperation for years. There was a painful theme in the e-mails: No one understands what it means to have a family member with autism. And they were grateful that I had put their stories on paper. But there was so much more to say.

So here I am again. I am only one in maybe 10,000 mothers in Minnesota who struggle with these issues. I am no expert. I can only tell my story. And, forgive me, family, but I feel I must so that others may no longer suffer in silence.

For years, from the moment he wakes up to the moment he crashes, my son's needs, actions and whereabouts are always on my mind -- almost like having a busy toddler who never grew up. When he was younger, our life was a roller coaster ride that was driven by his moods, his activity level and his chronic sleeplessness. Each day was unpredictable.

I have spent years addressing his medical needs, hoping that I would find a magic bullet that would cure him and restore our lives to normalcy. I have taken him to more than 40

health professionals, for he has developmental delays and chronic, complicated and confusing medical issues. We have seen neurologists, psychologists, psychiatrists, pediatricians, gastroenterologists, urologists, cardiologists, orthopedists, speech therapists, occupational therapists, vision therapists and more.

I have filled out dozens of medical forms, each time reliving the heartache as I recounted his development and regression, reported his symptoms, and related the treatments we've tried, embraced and discarded. I've had to bite my tongue to keep from screaming, "Can't someone develop a universal medical history form?"

I did not appreciate that his autism was not like other medical conditions that could be cured. This point became painfully clear when his sister contracted a rare blood disease that was cured by a bone marrow transplant (for which my son was the donor). Diagnosis to discharge took roughly three horrific years. She was cured because they understood the disease.

But I have not lost hope for him. In the past year, my son's health and behavior both have improved dramatically. We don't know whether it is the result of the medicine, nutrients, diet, therapy or maturation, but he is more stable and high functioning than ever. He does more with less supervision; he is fighting for his independence, as a teenager should. His stomach is more settled, and with the right meds he sleeps through the night.

My paradigm is changing. I am focusing more on his positive attributes -- his sweet nature and great sense of humor -- and less on his challenges. I am trying to move beyond the pain over things that likely matter more to me than to him -- having friends, for instance. Perhaps I am in the acceptance stage of my grief. I think that's a good thing because my heart is so much lighter now.

For the members of the sisterhood (and the even more silent brotherhood) -- in fact, for all who share my concerns about the enormous ramifications of this disorder -- I believe there is reason to be hopeful, even in the face of enormous heartache and challenges. As more children are being diagnosed with autism spectrum disorders, public awareness is increasing, so there is more acceptance and less social isolation. There are vastly more resources available to families now than when we first learned the "A" word -- Internet support groups, books, workshops and more. Considerable research is under way worldwide.

Doctors at the University of Minnesota are planning a much-needed clinic that will focus on diagnosis, treatment and research. I suspect it will be more a step in the right direction than the silver bullet I've sought. Sadly, that clinic will not be available as fast as we would like, because we needed it yesterday. But the prospect of having it in our community fills me with optimism for others. So, for those whose lives have been consumed by this disorder, do not despair. Hope is on the horizon.

Caryn Sullivan, a retired attorney, lives in Mendota Heights with her husband and two children. Her essay, "Dancing with Despair," is featured in "Special Gifts: Women Writers on the Heartache, the Happiness and the Hope of Raising a Special Needs Child" (Wyatt-Mackenzie).

