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Remember
to Breathe..



Again

By Mary Romaniec

Five years ago I felt as though I was on the verge of death; perhaps about to leave my husband a widow and my children without a mother. Even if death bypassed me, I was certainly headed toward a lifetime of serious, debilitating illness with no end in sight. The cause: chronic anxiety-riddled stress.

We all hear stories of people who drop dead of heart attacks brought on by grief, stress and poor health choices. Life today is complex, difficult. How did I get to this point, where my body and mind were literally hanging on by threads so thin that at any moment they could snap and the life force would leave me? I'm a mom of a child with autism and it was all on my shoulders to help him. That's how.

Most other parents of children on the spectrum reading my story will probably readily identify with my experience. We shoulder huge amounts of grief and stress like warriors; we battle autism on many fronts, with little thought of ourselves. However, we may be legions of ticking time bombs as we let our own lives spin out of control in the quest to help our children.

It happens so easily and consistently. In the midst of the fog of diag-

nosis parents are faced with so many choices coupled with the expressed and unexpressed pressure of "a small window of opportunity" in which to make the right decisions. The unknowingness about autism and what to do to help our child burns a hole in our hearts and sets our mind reeling. As if the stress and grief of those early days and months are not enough, we have to deal with uneducated onlookers, loss of friendships and a change in family relationships as many close to us question our every decision. All this on top of our own sense of dread for our child's health and future.

Today, books abound about effective strategies for living with and educating children with autism spectrum disorders (ASD). But little is written to help parents cope with their child's disorder from a personal perspective. How do we redefine our roles as a parent and caregiver, while holding on to our own health and sanity in the process? Chat groups and online blogs discuss the sky high divorce rate in autism, the growing number of single parents raising these kids, the families buckling under the emotional and financial toll autism brings. Sadly in our singular focus to raise awareness for autism, we have neglected to also raise awareness for the toll

autism takes on the health of the primary caregiver. This is a toll with a long term impact yet to be seen and recognized as a health crisis of a different sort. And certainly the medical community is not prepared for the stress-related health issues that will come with the long term care of children with autism. . .multiplied by the thousands of parental caregivers.

The parents of children with ASD *are* statistics of a different sort. How many of them develop stress-related heart disease or autoimmune disorders? How many become dependent on medication (legal or illegal) or alcohol to cope with the anxiety? How many gain weight, lose weight, develop mental health disorders or perhaps even life-threatening illnesses? This is absolutely one aspect of autism not openly discussed, not commonly written about and certainly not a presentation topic at autism conferences. As the effects are now being seen more regularly, this is a topic we can no longer overlook.

My Story

When my son was diagnosed with autism, and even beforehand, my adrenaline levels were already skyrocketing into the danger zone as we began to deal with his many issues. Somewhere within me arose a battle cry: NOT MY SON! It was a drive like no other, a quest to do all I could for my son and his recovery. The paucity of information from the medical community and even the

Stress Busters



Seek support from like-minded friends and family members (avoid nay-sayers).

Educate yourself about your child and how autism affects him/her. Each child is different. Not knowing what to do is a major stressor in parents. Learn.

Start or continue an exercise regime; recent research suggests just 10 minutes a day makes a difference.

Eat healthfully (remember to drink plenty of water too).

Get a decent night's sleep. This can be especially challenging with a child who does not sleep through the night. If needed, get outside help with the child's sleep issues.

Find healthy personal ways to relax (yoga, meditation, music, counseling, etc.).

Take vitamins and supplements. Stress depletes the body of essential nutrients, rendering you fragile physically and emotionally.

Take a break. It is OKAY to say "no" to others' requests or ask for help. Sometimes 15 minutes of alone time is all that's needed. Seek out respite care, enlist the help of willing relatives or neighbors. If you never ask, you'll never receive.

Pray. Prayer helped me perhaps the most when I was literally at the end of my rope. When I had nothing left to give I prayed for the ability to endure. When it was unclear how to help my son I asked for guidance. Allowing a "higher being" to take over has a powerful effect on our own well-being and gives us a sense of renewal.

Slow down the pace of your life. Give up the idea of having to do and be "everything to everyone." Breathe.

tragic misinformation left me seriously confused and deeply disillusioned. Yet, my crusade to seek out answers was unstoppable; it would eventually drive my mind and body to levels of sustained endurance that made Superwoman pale in comparison.

I began long hours late at night – once my day was "done" - on the computer searching for any tidbit that might help my son. I'd grab a few hours of sleep, then wake to another long day of taking my children to preschool and therapy appointments. Of course, my 2800 square foot home had to be immaculate for all the therapists in the house. Eating healthy applied to my kids; for me, I was good to go on the easiest thing I could put in my mouth. Exercise consisted of pushing a vacuum or running up and down the stairs with another load of laundry.

The angst I felt about my son's future was overwhelming. I would not give in to the idea that he would not fully recover. I researched biomedical and

educational options. We tried whatever seemed appropriate for him. The refrigerator had 25 bottles of supplements that I had to "creatively" get into my son every day. The bath had Epsom salts to remove toxins; the food was gluten/casein free and we were ever mindful of cross contamination. My typical daughter needed attention and my husband would choose 10 p.m. to have our budget discussions. My own needs – even those as basic as sleep - fell far down on my daily to-do list. At 7 a.m. duty called and I shifted into high gear for yet another day.

In a sense I was possessed with the fight against my child's autism, taken over by the sense that if I didn't do absolutely everything I thought could help then my son would not recover - *and it would be totally my fault.* If my son had a good day I could relax for a moment, but a bad day meant I had failed somewhere, and the overpowering angst arose like a demon all over again.

The price paid for this all-consuming tunnel-vision was my health. It started with a shortness of breath that came and went. Then I noticed I would be lying in bed, my heart racing wildly. I caught every cold and flu that came around and had nine sinus infections in a year. The final wakeup call happened when I called my husband home with the sense something was not right. I ended up passing out in the ER because I couldn't breathe. The doctors came in later and announced I had developed a stress-induced heart condition. I was so absorbed in my child's needs I had forgotten to even breathe right, which was shutting off the oxygen flow to my brain. The constant adrenaline rush weakened my immune system; the chronic fatigue didn't give my body any chance to heal itself. I needed to get a handle on my health or suffer long term consequences.

It wasn't as though I hadn't been warned - *I just didn't listen.* A long time friend had developed severe

autoimmune disorders herself by similarly ignoring her body's warning signs. She told me I was heading for trouble, but I neglected to heed her advice. Now the clock was striking and time was running out for me this time.

It took nearly a year to regain health and feel comfortable in my body again...struggling physically, mentally and emotionally as I learned to change the way I was living. The physician initially prescribed medications that left me with a tremendous sense of helplessness, not to mention the side effects. In the end, a combination of alternative therapies that included acupuncture and regular massages, coupled with easy walks and "girl therapy" discussions with close friends slowly brought me back to health. I started eating better and cut back on caffeine and alcohol. The 10 pm budget discussions had to stop, as did my late-night internet activities. My house was still tidy just not as clean as I liked. I worked hard to let go of my attitude that I should be a perfect housekeeper, perfect neighbor, a perfect friend or even a perfect wife. Although I still sought to be a perfect mother.

My son continued to make steady progress but I could not totally let go of the gigantic sense of angst and responsibility I felt toward him and his sister. But, by shifting my focus away from "what I should be doing" it actually freed me to experience more of the every day mom moments like going to the park and the library with my kids. It allowed "normal" to enter our lives again.

The best advice I received on this healing journey came from the acupuncturist who told me a story about a man who had been in a Chinese concentration camp for over a decade. He said the man noticed that those who survived the camp did everything, but they did it S-L-O-W-E-R. He told me to do the same. Do it, just do it slower.

Don't be in a rush to get everything done at once. The mantra I adopted then, and repeat to this day, is "go slow" and "breathe."

At times I wonder if my son's recovery from autism came about because of that single-minded determination and focus that eventually landed me in the hospital. Or would my son have recovered anyway and my health would not have suffered the consequences? Both my son and I regained health, yet there is not a day that goes by that either is taken for granted. My body tells me much quicker now when I'm heading for trouble, and now I am more apt to listen. I rejoice in my son's accomplishments and my own ability to carry on as a wife and a mother of a family that needs me.

As the autism numbers rise at alarming levels, it is time we acknowledge the impending crisis that has the potential to reach the same magnitude as the autism epidemic itself: the physical health and emotional well-being of the caregivers involved. Awareness of the problem and open discussion is the first step. Yet, like so much involved with ASD, the answers are not easy and the issues are complex. They involve not only the individual and family,

but the role that education, therapy and services play in helping families cope with what can be a devastating, life-distorting disorder. A shift in attitudes and perceptions as well as services and programs is needed. More definitive help needs to be available for children with ASD and their families. In the meantime, as parents we need to learn what we can and cannot control. Letting go does not mean giving in to a sense of despair. It means freeing ourselves up for the possibilities that are within our reach at this moment.

Our children rely on us to love, care and provide for them. Taking care of ourselves is definitely one thing we CAN control. From a parent who only has her experience to offer as advice I say PLEASE start today taking better care of yourself. The very true cliché applies: *if you cannot do it for yourself, then do it for your family.* Final words: Slow down, and remember to breathe. ■

Mary Romaniec is the mother of three children including a nine-year-old son recovered from autism. She has written articles about her son's journey through autism and mentored many families along the way. Email her at mromaniec@aol.com.

Take it to Heart!

Think this will never happen to you?
You're heading for health-related problems when:

- You feel isolated from family and friends
- You sleep too little or too much
- You eat sporadically or all of the time with little thought
- You catch colds and flus with regularity
- You develop stress-related conditions like heart palpitations, skin eruptions, allergies, etc.
- You develop digestion problems
- You develop an autoimmune disorder or one you have flares up
- You reach for alcohol or medication (legal and illegal) to cope
- Your frustration level is high and your tolerance level is low
- You lose your sense of joy