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Lessons Learned From the Front Lines

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I have the unusual, gratifying, and yes, at times paradoxical role of both professional working in the autism field as well as parent of a child on the spectrum. This gives me some unique insights into the subject of autism and coping with stress. First, let's define stress.

Our friends at Wikipedia.org tell us that stress is: A term in psychology and biology, first coined in the biological context in the 1930s, which has in more recent decades become a commonplace term of popular parlance. It refers to the consequence of the failure of an organism – human or animal – to respond appropriately to emotional or physical threats, whether actual or imagined.

Symptoms of Stress

Stress symptoms commonly include a state of alarm and adrenaline production, short-term resistance as a coping mechanism, and exhaustion, as well as irritability, muscular tension, inability to concentrate and a variety of physiological reactions such as headache and elevated heart rate.

Alarm is the first stage. When the threat or stressor is identified or realized, the body's stress response is a state of alarm. During this stage adrenaline will be produced in order to bring about the fight-or-flight response. There is also some activation of the HPA axis, producing cortisol.

Resistance is the second stage. If the stressor persists, it becomes necessary to attempt some means of coping with the stress. Although the body begins to try to adapt to the strains or demands of the environment, the body cannot keep this up indefinitely, so its resources are gradually depleted.

Exhaustion is the third and final stage. At this point, all of the body's resources are eventually depleted and the body is unable to maintain normal function. The initial autonomic nervous system symptoms may reappear (sweating, raised heart rate etc.). If stage three is extended, long term damage may result as the capacity of glands, especially the adrenal gland, and the immune system is exhausted and function is impaired resulting in decompensation.

The result can manifest itself in obvious illnesses such as ulcers, depression, and diabetes trouble with the digestive system or even cardiovascular problems, along with other mental illnesses ([wikipedia.org/wiki/Stress_\(biology\)](http://wikipedia.org/wiki/Stress_(biology))).

Let's first tackle the *alarm* stage. This stage may be repeated during different phases of your child's development but I would say at the time of diagnosis you will feel this most acutely. There is a sense of alarm at the unknown of the fu-



ture for your child and your family. You may find yourself on hyper-speed trying to get as much information as possible. There are many life altering discussions suddenly foisted upon you and the feeling that no matter how early you may have received this diagnosis...it may not have been early enough. You are constantly feeling behind the eight ball in terms of making those therapeutic, medical and educational decisions. Much of this is done without the support of other families who have gone through this before.

In this next phase called *resistance*, you may find yourself second guessing what you have put in place. Those necessary coping mechanisms will be your saving grace. I can guarantee the stressor will persist as there is currently no cure for autism and our resilience will be called into action over and over again.

Lastly *exhaustion*: In the Wikipedia model this stage sounds dire. I think we should work on the second stage and define those essential coping strategies so the last stage of exhaustion can be kept at bay. Yes, there will be times when all of the complexities we must maneuver through will get the better of us. Yes, there will be times when we feel overwhelmed by the scope of the diagnosis, but with strategies in place for ourselves and our family, we can navigate successfully through an undoubtedly complex field of life challenges an autism diagnosis presents to us.

Oftentimes the real burden of this diagnosis falls to the Mom caregiver. I mean no disrespect to the Dads out there who I am calling on to be present in every aspect of your new normal called autism. The reality, however, is that much of the research into, and ultimate program or therapeutic and medical decision making, will fall on the shoulders of our Mom caregivers. You may find yourself feeling like the warrior superpower Mom one day and the guilt ridden martyr Mom the next. When things are going well and you ob-

serve progress you are the warrior superpower Mom. When things seem derailed and you are not seeing progress or, worse, there is a new behavior and a loss of skill, you are the martyr Mom. What did I do? What didn't I do? What didn't I do enough? Did I make the right decisions and choices? Is there something new out there I should try? If I try something new, will it help or harm? Whom do I trust to help me make these difficult decisions?

Peer Support

First and foremost find a network of supportive peers you can bounce ideas off of and commiserate with when those difficult days become overwhelming. I have found that as time goes on you may discover that your peer group will change. These relationships in your life are so vital that your friends who do not have an affected child may not be the ones you can rely on for your support. Even those peers who have a child with autism may change. If for instance your child is on a different educational trajectory, or you or your peer are at odds in your therapeutic approaches, you may find yourself needing peers who follow in the same circles both educationally and therapeutically. Having friends who are truly walking in your shoes is so important. An example of my own experience happened early on upon the path of autism. My son had a particularly brutal day filled with numerous bouts of tantrum activity filled with self-hitting and head banging. He was three and one half year old at the time. I had just gotten him down to sleep, by rocking him cradled in my arms with a blanket wrapped tightly around his flailing body to keep his arms contained.

I was scratched, bruised and exhausted. I received an urgent call from a dear friend. She was distraught and needed to talk about her day. Though I was tired, I called her to find out what was going on. She related the story of

how distressed, to the point of tears, she was that her daughter had not made the cheerleading squad and what an emotional and social tragedy this was for the poor child. How was she ever going to cope with the fallout?

Though I was thoughtful in my response I could not put myself into her shoes, and she most assuredly could not put herself into mine. I found that it was vital to my self-preservation to surround myself with empathic sounding boards for the many difficult times ahead. Do not think for one moment, however, that I am the bearer of doom and gloom. I am endlessly practical. I will not sugar coat the family impact this diagnosis will have. The impact is great and lifelong. But also know, along with the difficult times there are potentially countless times of great elation at the hard won progress against insurmountable odds. I needed that encouragement and shared delight when my son made those incremental achievements which were to us herculean strides forward. It is all about the perspective. Sharing the joy is as important as sharing the pain. There is great joy and love and beauty in autism. Sometimes the price to be extracted between those times of beauty and joy may be high. Never doubt, however, that there is always great love.

Family Awareness

Make everyone in your family aware of what you are going through. Do not be apologetic at family get-togethers. Ensure that you are accommodated and welcome. You will be welcome if you are open and concrete in what they can expect from your visits and encounters. The term autism is derived from the Greek term 'autos', meaning aloneness. There are so many times when the isolation of autism will surround you. Do not isolate yourself from those who can truly support you: your family. But to make this experience a positive one, you must educate them on how they can be a support to you. You may need to limit the time of your visits. You may need to prepare your family for the often counter-intuitive behaviors which are often present with autism. You must get them on board to your chosen therapeutic and educational treatment methodologies so everyone is on the same page when there are encounters together.

Educate Yourself

Educate yourself as much as you can. Learn the law and let that be a guide to receiving the recourses which are your child's and your family's right to receive. Again, do not be apologetic for seeking services. You need them. Your child needs them and they are your right under the law. We are ultimately consumers of the services we use. Those services may

be health related, therapeutic or educational. Be an educated consumer!

Organization is Essential

Another vital strategy in the planning of autism is organization. With the amount of evaluations and testing for school programs alone you may very well find yourself overwhelmed by the onslaught of paper from evaluations and reports. There are needs assessments and speech evaluations, plus Occupational Therapy reports and Psychological testing of many sorts and description. There are medical evaluations and study team reports. The list is endless. Create an organized filing system. I would encourage you to have a filing cabinet with an entire drawer devoted to autism. If you do not have a filing cabinet, I would at minimum have two expandable legal files. I want you to make sure you have at least two copies of all evaluations and reports organized in an easy to access place. You may want to organize these folders sequentially by year.

Start each year with the IEP, or Individualized Education Plan. Your child will have one if he or she is receiving special education services through the school system. Most of our children with

a diagnosis of autism spectrum disorders (ASD) will be found eligible for special education services and have an IEP. A child over three years of age who is found to be eligible for this service will have a plan. I am amazed at how many families do not read and review this document. The IEP is often the most important document about your child in your possession and one which you have the most influence over. If you have not done so, take it out and read it cover to cover. You must understand everything that is written inside. If you do not, you must ask for an explanation! The school's obligation to you and your child is to educate your child. No more, no less. How that will be done is delineated in that document. Progress is monitored and reported. If you do not know what the school is expected to teach your child or how that will be accomplished, how will you ever know if they are meeting their obligations?

The more organized you are, the more effective you will be in advocating for your child. There may be a lot of chaos in your world as you traverse through this path. The more organized you are the easier your life will be. If you are an unorganized individual this may be challenging, but I implore you to give this a try. This can bleed over into other aspects of

your life. Having an organized home and an agreed upon schedule for your child's daytime and evening routine can reduce the chaos and stress at the end of the day. Believe me when I tell you, implementing these types of strategies into your life can have a positive impact on everyone. There are so many times you will feel powerless over this, yet if you are organized and structured in your environment you can carve out at least a small area of control into your life.

Remember to Take Care of Yourself

The other important piece of the coping with stress puzzle is **self care**. It is very easy and even compelling for us to put ourselves last. With all there is to do and to learn and to know that is understandable. I cannot overstate the obvious. If you are not taking optimal care of yourself you cannot be optimally effective in caring for your child. Do not put off your well doctor visits. When was your last visit to the Gynecologist? Are you up to date with your mammogram? At the end of a very stressful day do you go for the box of chocolates and a glass of wine or a brisk walk around the block to clear your head? Both, I think may be effective. The key here is balance. Are

you using healthy food to fuel your system? Are you using unhealthy food to help you cope?

Making healthy choices for ourselves is so important to how we feel and cope with the stress of raising a child with autism, in all its manifold incarnations.

Being proactive in the creation and implementation of strategies will put the power and control back into your life, when so much of what is autism may seem so out of your control. Autism may be the new normal, but how we cope with the stress will be the difference in how we perceive what can be a wondrous journey of discovery about our children and ourselves.

As a final note, my son is now seventeen and entering his senior year in high school. We are currently searching for the four year university that will meet his needs and his goals. He is interested in a communications major. There is assuredly some irony in that.

Take good care with my best wishes for you and your child's success.

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