Seven Things I Wish Someone Had Told Me When My Daughter Was First Diagnosed with Autism

by Bobbi Sheahan and Kathy DeOrnellas

1. You’re not alone. No, really, really not alone. About one in 110 of us are on the autism spectrum. Throughout the world, autism affects all races, social classes, religions, and income levels. You are going to meet some amazing people who are walking this road right with you. You may even find that you or your spouse are on the spectrum, but that’s a whole ‘nother subject.

2. You’re worrying about the wrong stuff. The behaviours that embarrass you in public probably aren’t the ones you need to really be concerned about. The quirky and repetitive behaviour, lack of eye contact, communication challenges, lining up the toys, social immaturity, the fixation on favourite topics or objects – those may be the things that others notice, but my daughter’s sensory challenges (that means she didn’t feel pain – or didn’t seem to – in situations where others would have been screaming) and her lack of understanding of danger were the things that were real dangers. The fact that my child spins and repeats herself may freak some people out, but it’s not in the same category as running away or hurting herself or someone else.

3. Nobody else is an expert on YOUR child. Dr DeOrnellas, my co-author and one of the most helpful people on our family’s road to some understanding of autism, will tell you herself: she may know more than you do (heck, more than just about anybody does) about autism, but you know more about your child than she or any other professional ever will. Trust yourself, and arm yourself with all of the wisdom and support you can. When you find a professional or a friend who is really helpful, you will never take them for granted. When you are interacting with a school, a counsellor, or anyone else, it’s good to start expecting that they really want to help and that they will deal with you in good faith. (You can always get mad out, but it’s not in the same category as running away or hurting herself or someone else.

4. Do not take garbage from anybody. You may find some people who are overly anxious to judge your family, or your mother-in-law may think that autism is a figment of your imagination. This is their problem; don’t let them make it yours. I don’t care if you have the most helpful relatives in the world; if the cost of their help is that they drive you crazy, their help ain’t helpful. The same logic also applies to the intrusive stranger in the grocery store who thinks that she is being helpful.

5. You will find angels in the most unexpected places. We found that we had only the nicest people left in our lives because, well, a lot of the rest just fled. And maybe the stranger in the grocery store will surprise you with her kindness too.

6. You are parenting a child, not a diagnosis. It may feel that way right now, but you won’t always feel that way. The first couple of years after a diagnosis can take you from shock to mobilisation to the realisation that your life has become one long car drive from one therapy to another. Over time, you really will figure out what works for your child and your family. And if it doesn’t lend to the peace of your family and the well-being of your child, it doesn’t matter who says that a particular therapy is The Answer to Autism. I applaud parents who are fearless about trying things that might help their child. When something works, there are a lot of us cheering for you, whether that particular approach helped our child or not.

7. If you’ve seen one child with autism, you’ve seen one child with autism. Nobody can tell you what your child will be capable of tomorrow or next year. Keep a journal and listen to kind people who haven’t seen your kid in a while so that you don’t lose perspective on how far he’s come. And, for that matter, how far you’ve come. You will be impressed.

And One More Thing: And, finally, please, please, take care of yourself. Do not underestimate the basics like sleep, a good support system, sleep, and a good cry. And more sleep. Children can make you tired anyway. Autism can definitely make you tired. You and your child are living with a challenge that will test you to the end of your patience. Our children are watching us, even if they can’t tell us with words, and they need us.

Join Sue and Bobbi (author of this article and book) on Sue Larkey’s LiveChat on Tuesday 12 June 2012 at 8.00pm. See www.suelarkey.com for more details.

New Resources for Understanding ASD

What I Wish I’d Known about Raising a Child With Autism
By Bobbi Sheahan & Kathy DeOrnellas

A mother and a psychologist offer heartfelt guidance for the first five years. From the moment you realise your kid is different, to the self-righteous mums on the playgroup, to holding your marriage together in the realm of routines. They candidly tackle ASD issues such as picky eating, bedtime battles, potty training, speech delays, discipline, early intervention, sibling rivalry and much more.
CODE B56 $25 (incl P & H)

Autism Every Day: By Alyson Beytien

Stemming from a wealth of both professional and personal experience, this guidebook combines real-life stories of challenges and successes with practical ideas for handling autism, every day. Autism consultant and mother of three sons on the spectrum, Alyson Beytien outlines over 150 tried-and-true techniques for home, school, and community.
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