

Learning to Live With Autism: Lessons Learned and Advice for Newly Diagnosed Families

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1. Cherish the good times. Preserve positive memories.

How can I preserve some of my children's memories here at home? If you are like me, you find it



hard to throw anything away. When you do find the nerve to throw away their "works of art" you hide them in the bottom of the trash can so they won't see what you've done. My kids are growing fast and I can't imagine losing those memories.

A simple way that I've found to preserve these memories is to scan them into my computer, reduce them in size and print 4 to a page, like photographs. Then cut them out and put them in a photo album or scrapbook for safekeeping. You can now have hard-cover, bound picture books printed for around \$20 through places like Wal-Mart and Shutterfly.com. Not only do these make great gifts, it's a great way of saving some of their most treasured art without keeping boxes full of paper in the attic. There will always be those things that you can't seem to part with - like the first letter your child ever writes to you or his drawing of the family. No digital image could ever replace some of these memories.

We all like to look back from time to time and take a walk down memory lane. It's good for the soul. Take some time out to reflect on the positive impact that Autism has had on your life. Remember that it's not all negative and gloomy. Autism has brought unity into our family. It has brought passion and friendships that we'll treasure for a lifetime. Despite the daily struggles we face with safety issues, sibling issues, education struggles and insurance failing to pay for needed therapies, there is definitely a bright light that is always shining. There are moments worth treasuring in our everyday lives. When you start feeling down or that everything seems hopeless, pull out your scrapbook and take a walk through the past. It can do wonders.

2. Seek advice and input from other parents who have "been there" and as you learn, share your experiences with others.

There are many ways to seek advice and input from other parents and professionals based on past experiences. The more you tap into existing groups, the more comfortable you'll feel about asking questions. Listservs, support groups and workshops are just a few of the helpful ways to weed out the "quacks" and the treatments which are all hype. YahooGroups! is a website with thousands of

listservs on any topic you can think of. Some local groups publish a list of higher-quality websites, listservs and support groups; word of mouth is usually your best bet when it comes to finding support.

Offer yourself to others as an avenue of support. One of the most rewarding feelings comes from sharing what you've learned with other parents so they do not have to go through the same setbacks that you have. This is a good way to maintain a sense of accomplishment in your personal life, even when things may not be going so well with your own child's progress. In other words, it helps to even out the bumps along the road you'll experience as a parent.

3. Do not isolate yourself.

It is often said by parents of children with Autism that their old friends kind of fade away the more their child's behaviors and communication deficits come to the surface. Try not to take this personally. It is nothing that you have done. It is simply their inexperience and lack of understanding related to Autism. Try to educate them without being forceful or putting them off. If they take the time to get to know your child they are sure to love them. If they choose not to, that's ok. True friends will accept your family despite the changes. You will also find new friends within the Autism community. While it is always hard to replace any type of loss, it is easy to find others who will understand and will fill the gaps created by your personal losses.

4. Go shopping for doctors and therapists.

Don't choose to see a doctor just because they're local to you. Sometimes, paying that increased co-pay through your insurance - - or even 100% out-of-pocket - - is well worth it. Mileage for medical appointments and out-of-pocket expenses for medical treatment are sometimes tax deductible. You can always recoup those extra expenses on your taxes. Some chapters of The Arc of the United States (<http://www.thearc.org/>) publish yearly tax guides that detail these deductions. Some local groups even offer small "grants" toward things that traditional insurances do not cover (i.e. biomedical, therapy items). The Autism Society of America (<http://www.autism-society.org>) has information on their website regarding various types of treatments and therapies, along with a great resource called "Autism Source", which is an online resource referral database.

5. Research options for education.

You don't always have to take what is handed to you. Your input is vital in the process of determining what services are suitable for your child. Do your homework and find out what your child needs in order to receive a "Free and Appropriate Education (FAPE)", which is what they are entitled to by Federal law. Don't be afraid to ask questions at Individualized Educational Planning (IEP) team meetings about your child's progress, goals and objectives, placement, or anything else that requires clarification in your mind.

Attend *all* meetings related to your child, workshops offered by your state's Parent Training and Information Center and other state/local groups, and conferences on topics that will further your knowledge.

Ask for all documentation, including evaluations and test results, from the school. Graph your child's progress (see Wrightslaw's books) - - this will give you a great timeline/visual of whether or not your child is gaining knowledge as time goes by and may provide the ammunition you need to justify requests for added or increased services (including frequency, scope, and duration).

Two of the greatest tools that I've come across in my "career" as a parent with children receiving special education services are 1) Wrightslaw publications and websites (<http://www.wrightslaw.com>, *From Emotions to Advocacy*, and *Special Education Law*) and 2) a book called *The Goal Mine* (<http://www.ieps.net>), which contains thousands of goals broken down by category. Since the law changes periodically, it is important to keep learning as much and as often as you can.

6. Always keep safety in mind.

Safety is usually the #1 priority of any parent and this is no exception for parents of children with a developmental disability. We may be some of the most vigilant parents in existence – by sheer necessity. The constant stress of caring for a wandering child can wear on any parent or caregiver.

There are many things that you can do to promote safety within your own home, your local school, or the community. As with any young child, children with Autism tend to explore every nook and cranny of the home. They may rattle through drawers and cabinets, rifle through closets, or dump contents from bottles and containers that they find in the kitchen, basement, garage or bathroom. Nothing is safe from the curious child.

Traditional plastic cabinet locks or door knob covers may work for a while but this all depends on your child's ability to control his impulsivity or on his desire to continue, despite the barriers that you set up for him. You may consider using screw locks with hook-and-eye clasps or key locks to keep hazardous materials out of reach.

Many children with Autism have the tendency to wander or run away. Since they are usually "silent" in their intent, they usually slip out unnoticed. This is extremely dangerous. You can never be too careful. A tall fence around the backyard and constant supervision may prevent your child from wandering. GPS (Global Positioning System) watches are a more high-tech option, which allows the owner to track the individual wearing the watch via the Internet (usually requires purchase of watch and subscription to tracking service). These devices have proven useful in many cases nationwide, as more and more people are "found" using this advanced technology, making these watches worth their weight in gold to those families.

You may have to resort to door and window alarms if the problems become increasingly dangerous. Some children wander from their beds late at night while others wander day in and day out. There are many types of door and window alarms ranging from cheap plastic ones to whole-house security systems which must be installed by a security company.

Leaving a child in the care of an older sibling may be the only opportunity that a parent can take a shower, in some extreme cases. By doing so, the parent is taking a great risk. It is important to realize that children can become distracted even when they've been entrusted with a loving sibling. Video games and television shows can be a major distraction that can take their focus off of the sibling left in their care. The responsibility may be too great for a child to handle. If the situation is stressful for you, the adult, it is most likely many times more stressful for another child. Keep this in mind when placing responsibility upon a child.

A key point to remember is that you must never impede safety by trying to prevent an accident. Windows must be kept clear and never boarded or blocked. There must be an escape route in case of fire at all times. It is a very hard balance to achieve.

When visiting the home of a family member or friend, be extra vigilant in scoping out potential hazards and escape routes for the potentially wandering child. Pools are a big draw for children that cannot be overlooked. Be aware of lakes or water holes nearby. Always keep your child within eye sight as an extra measure of safety. Don't be ashamed to discuss these issues with your host.

It is always easier to have a good time and to relax when you know that your child is safe and that everyone has their safety in mind. In trying to keep your child safe, diligence is key. Seek support - - don't try to do it alone - - and whatever you do, don't lose hope.

7. Planning for the future (and for emergencies).

We can truly never know what the future will hold for our families, which is why it is even more important to make "future plans" and "emergency plans" for your family. We can't just assume that our loved ones will know what to do - - and even more so, we can't just assume that our child's siblings will be able to drop everything and take on the care and support of a grown sibling with a disability. One very important item that you can't afford to be without is a "Letter of Intent", which is a lengthy, personal document about your child or loved one's needs, likes, dislikes, insurance information, health status, and just about anything that someone would need to know about your child if something were to happen to you without warning. It is important to update this document periodically to ensure that it is up-to-date.

The Arc of the United States (<http://www.thearc.org/>) is a good place to seek documents of this nature and referrals to Future Planning and Special Needs Trust Advisors in your area. Wrightslaw maintains

and informational page on Future Planning at <http://www.wrightslaw.com/info/future.plan.index.htm> which provides information and resources in more detail. The Red Cross website (<http://www.redcross.org/>) contains a lot of important information on emergency preparedness, including specific information on disabilities (http://www.redcross.org/services/disaster/0,1082,0_603_00.html).

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