

## Five Things To Do For a Family Dealing With Autism

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Your nephew, grandchild or work colleague's son received a diagnosis of autism and now you feel uncomfortable talking with the family about it? Or maybe your neighbour's daughter is autistic and you aren't sure what exactly you could do to help.

Believe it or not, it's fairly common for family and close friends to pull away. Whether because of discomfort or simply not knowing what to say or do, many parents caring for a child with autism feel isolated from people they once thought cared. Ironically, friends and family explain they are acting on their best intentions to "give the family space" and to "not impose" because the parents seem so busy.

You're probably right that they're completely consumed by the world of autism, but they still want to know that you're there. Forget the formalities. Reach out, communicate, and support them. An email, a voice message, or a text to say "I'm here and sending you love," even if unanswered, can be supportive in and of itself, more than you might ever imagine.

Keep in mind that on the other side of your voice message or text, these parents face incredible demands within a society that isn't designed for special needs. They weather inconsolable tantrums; they fight school system inflexibility, and act as interpreters to decipher their autistic child's language delay. It's extremely hard to find babysitters who can manage the different autistic behaviors. Toddler-parent-drop-in centers are often too loud for their sensory disordered children. Along with routine parent duties like changing diapers and

cleaning up the daily breakfast tornado that hits the kitchen, many parents of children with autism also have to cope with sleep disorders, bed wetting into the teen years, and cooking special diet meals. This becomes their life. On top of earning a living, they coordinate intensive therapies that can run up to seven days a week. They pay for many of these therapies out-of-pocket which adds financial strain. It's exhausting.

But you can make a positive difference. Understanding more about their situation is a good first step. Don't be shy to ask the parents directly to explain more about the diagnosis and what kinds of challenges and triumphs they are dealing with. It's better to ask than to assume or to ignore. Online resources abound and I also recommend my recent book *Challenging the Myths of Autism* (Harper Collins) specifically because it provides research that cuts through negative stereotypes to offer a practical and hopeful reframing of this misunderstood disorder.

Over the past two decades I've had the honour to educate and train hundreds of parents of children diagnosed with autism. I think of them as all-star parents. There are hundreds of thousands who care for children with special needs around the world and at least a few in your very own neighborhood; each family has different resources, varying levels of support, and some are in desperate situations.

Here are some concrete actions that neighbours, friends, and family can confidently take to give these parents a boost of support.

# 5 Ways to Help and Be Supportive

## 1. LISTEN

Much of their time with other adults is spent explaining about autism and their child. There is almost never time to chat about the latest movies, fashion, and other frivolous news. More importantly, with so much focus on their child, there is often no space for them to talk about what's going on for themselves. Spend time just listening, without an agenda, without giving advice, and without feeling sorry for them. Create space for them to let their thoughts and feelings out and to chat about whatever they need to express.

## 2. LET THEM SLEEP

Years and years of broken sleep because of their child's bed wetting, sleep disorders, and hyper-activity can have a serious negative effect on physical and emotional health. Offer to babysit for an hour or two at a time so they can just nap. Turn the TV down, close the bedroom door, and anything else you can do to create an environment for the parents to have a restful sleep.

## 3. DON'T JUDGE

Have you ever thought to yourself that a parent you know should stop giving her child certain foods or that she should not let her child cry for so long? Like any parent, the moms and dads of children with autism are trying to do their best with a very challenging situation that they themselves are still learning about. They are doing their best to allocate limited resources. Everyone has an opinion looking from the outside in. These parents have almost always done endless hours of research and consulted professionals. Better to bite your tongue and give them the benefit of the doubt.

## 4. BE A "TYPICAL" FRIEND

Over the years I have heard from so many moms that as soon as their child received a diagnosis many of their friends disappeared. Friends who used to call several times a week just to check in and to invite them for a movie or to a party stop calling. Friends assume these parents are overwhelmed, emotional, and don't want to be bothered. Even long-time friends can feel uncomfortable not knowing what to do or say about a child with autism. Instead of retreating, continue being that old familiar friend. A glass of wine with a friend and regular check-in phone calls can be just the right trick to balance the intensity of raising an autistic child. It's nice for a parent to know you are there to help when times get rough. But don't wait for rough times. Simply be a regular presence of friendship in their lives. If they need more or want less, trust that they'll tell you.

## 5. BE A CHEERLEADER FOR EVEN SMALL STEPS

Cheerleaders encourage their team throughout the game and cheer even louder when the team scores points. Put your advice for an autistic child's parents aside and instead pick a project they are working on for their child and become the world's most enthusiastic cheerleader. It is reinforcing to be acknowledged for accomplishing a goal, but for many parents of children with autism the steps toward goals are mini and slow. Take the time to let them know that you notice their parenting efforts and the positive development you see in their child. In other words, be a cheerleader of the process not just the end goal. Call them or write a note and share a specific example of what they should feel good about. Maybe you notice their son is talking a little more or you notice their daughter is more attentive and listens better. Whatever the accomplishment, it can be reason to celebrate!

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