

## Being a parent on the autism spectrum

Parents who are on the autism spectrum deal with the same challenges as other parents, and they can also face some particular challenges related to being on the autism spectrum. At the same time, it is important to remember that being on the autism spectrum can be accompanied by unique strengths that can be drawn upon when parenting, particularly if the family also has a child on the autism spectrum.

Just like any other adults, people on the autism spectrum can be exemplary parents. An acceptance and appreciation of their autism and access to appropriate support for themselves and their families can help them to effectively manage the unique challenges they face.

*"I'm a parent much like any other. I'm trying to parent my kids to the best of my ability. Ability and energy are a constant struggle. I put as much as I can into taking care of my children first, followed by taking care of myself, and then finally taking care of everything else. My children's care and safety are the most important things to me."<sup>1</sup>*

*"How many NT (neuro-typical) parents would dedicate themselves to doing everything 'right' as an autistic parent usually does? We tend to take parenting very seriously. There are way worse things to have than an autistic parent! Please, don't stereotype, make assumptions, or by default blame the autism for any failing an autistic parent might have (they are still individuals with their own personalities and upbringings)."<sup>2</sup>*

### What do we know about being a parent on the autism spectrum?

Very little formal research has been published in academic journals about the experiences and needs of families with a parent on the autism spectrum. There is, however, a considerable amount of valuable online information in webpages and blogs. These are mostly anecdotal or biographical accounts written by parents on the autism spectrum or adult children of parents on the autism spectrum. A small number of professionals, such as Tony Attwood, have also written on the subject.<sup>3,4</sup>

These personal accounts shed some light about parenting on the autism spectrum.

## **1. Parents on the autism spectrum often deal with challenges that are related to their autism.**

### *The need for social skills and networks*

- Parents on the autism spectrum may not have extensive social networks, and may not be comfortable dealing with the array of social communication that is often part of everyday parenting. Tasks such as arranging playdates, meeting other parents and their children at playgroups, communicating with teachers, attending events at school, and taking children to medical appointments can be daunting and sometimes overwhelming.
- As parents, we often need to be advocates for our children - at school, with other family members, in social situations, and with health professionals. Many of these situations where parents are expected to advocate for their children can be intimidating or difficult to navigate for someone on the autism spectrum. Many autistic parents also have children on the autism spectrum, who need strong parent advocates.
- Some parents on the autism spectrum worry that their own social difficulties may mean that they are not well-placed to help their own children to learn to socialise: *“It’s been hard to teach the kids things we ourselves are no good at”*; *“When you don’t understand social rules to begin with, this can be a daunting proposition”*.

### *Sensory needs*

- Being a parent often means living with the noise, smell, mess and chaos of children and family life. For people on the autism spectrum with particular sensory needs, this can sometimes be overwhelming, and lead to sensory overload. Parents on the autism spectrum report that they often need to manage situations where their own needs compete with those of others in the family. Finding time and space of one’s own, away from sensory stimulation and intrusions can be a challenge for any parent, but may be a necessity for a parent on the autism spectrum.

### *Routine and flexibility*

- The ability to be flexible and adapt to quickly changing situations can be essential to managing family life. For some parents on the autism spectrum, without good coping techniques, disruptions to their routine may prompt sudden and intense emotional reactions and lead to meltdowns.

### *Mental health*

- Postpartum depression is a serious issue for all new parents. Many parents on the autism spectrum may already be dealing with mental health issues, such as anxiety or depression, and this may be exacerbated at this time. An additional factor for these parents on the autism spectrum is that they may feel that asking for help with parenting is an admission that their autism means they are not able to cope with parenting.

- Parents on the autism spectrum, notably mothers, report feeling alienation, guilt, depression, loneliness or inadequacy when comparing themselves with other parents. This may be partly because parents on the autism spectrum can tend to take parenting very seriously. This is exacerbated by the stigma surrounding autism, causing them to worry that other people will think that they are incompetent or emotionally lacking because of their autism. *“I know now that there is, and was, nothing wrong with me, but a lot of lingering thoughts make me feel faulty when I act in autistic ways”.*

**2. Having a diagnosis - knowing that one is on the autism spectrum, and understanding and accepting one’s autism – helps.**

- For people on the autism spectrum who have not received a diagnosis until sometime after becoming a parent, caring for a child can be confusing and frustrating. In addition, not being aware of one’s own autism can be a confounding factor in the experience of postpartum depression.
- Knowing what ‘being on the spectrum’ means in terms of sensory sensitivities, emotional regulation, communication styles and managing stress, can help to deal with the challenges faced as a parent on the autism spectrum. It can also enable access to appropriate support and services to help the parent and their family.

**3. People on the autism spectrum may have notable strengths to draw on to be an effective parent.**

- An affinity for systems means that many parents on the autism spectrum develop highly organised family routines. These routines can benefit their children and also provide certainty and stability for the parent on the autism spectrum.
- Many people on the autism spectrum have deep focus and strong researching skills. These skills can help them to learn about parenting, and can enable them to focus on the needs and development of their children.
- Many people on the autism spectrum are highly observant, and have the ability to be deeply tuned in to their surroundings and potential problems – this is a vital skill for all parents caring for one or more children.
- As a person who has experienced being on the autism spectrum, a parent on the autism spectrum can understand and empathise with their children when they don’t conform to conventions or a rule that they don’t understand, or are subjected to social pressures.
- Parents on the autism spectrum can provide a positive role model for any of their own children who are on the autism spectrum. The child can observe the parent being comfortable, accepting and understanding of their autism, and learn various coping mechanisms and self-advocacy techniques from the parent.
- It has been suggested that when both parent and child are on the autism spectrum, this may actually improve their ability to understand and relate to each other.<sup>5</sup> Parents on the autism spectrum may have experienced the same differences and challenges that their child faces.

However, there is a great diversity across the autism spectrum, so a parent on the autism spectrum may have very different traits, preferences and coping styles to those of their child.

## Getting the support you need

Different types of support work for different people – here are the most common supports that parents on the autism spectrum find work for them.

### ***Talk and network with other parents on the autism spectrum.***

Being a parent on the autism spectrum is a unique experience, so having other to parents on the autism spectrum to turn to can provide you with validation of the issues you're facing, valuable empathy and practical support.

### ***Find a parenting mentor.***

This may be a relative, friend, club or church members who you respect as parent, who can act as parenting role models and provide a listening ear, and advice based on experience.

*Seek professional help* with family communication, including parent-child and partner communication. Consider individual or family therapy to help you identify problems and come up with solutions. Therapy isn't about "curing" autism, it's about finding effective ways to manage the challenges of living on the autism spectrum.

### ***Find an advocate to assist in communication with schools, doctors and other professionals***

*Try a parenting class or course.* The class can teach skills in a variety of areas, and can describe the "unwritten rules".

*Look for disability services.* You may be able to get help with cooking, cleaning, advocacy and respite care.

### ***Find time to personally recharge.***

***Build structure and routine*** into family and personal daily life.

As much as you can, ***be open about your autism***, and your needs.

## Resources

The following blogs and webpages provide valuable and very interest first-hand accounts from people who are parents on the autism spectrum. In these blogs, they share their experiences as a parent, and how they have dealt with the challenges of being a parent on the autism spectrum.

<http://autismwomensnetwork.org/motherhood-autistic-parenting/>

<http://www.parents.com/health/special-needs-now/4-moms-share-what-its-like-to-be-an-autistic-parent/>

<https://musingsofanaspie.com/aspergers-and-motherhood/>

<http://autismwomensnetwork.org/autistic-motherhood-honoring-our-personal-choices/>

<http://autismwomensnetwork.org/motherhood-autistic-parenting-and-supports-that-make-a-difference/>

<http://www.jamiepacton.com/?p=666>

<http://www.jamiepacton.com/?p=670>

<http://www.jamiepacton.com/?p=674>

## References

1. Jamie Pacton. *Thoughts from an Autistic Parent Part 2: Melody Latimer*. Available at <http://www.jamiepacton.com/?m=201602>. Also at <http://www.parents.com/health/special-needs-now/4-moms-share-what-its-like-to-be-an-autistic-parent/>
2. Kim, C. 2014. *Motherhood: Autistic Parenting*. Available at <http://autismwomensnetwork.org/motherhood-autistic-parenting/>
3. Attwood, T. 2006. Long-term relationships (Chapter 11) *in The Complete Guide to Asperger's Syndrome*, London/Philadelphia: Jessica Kingsley Publishers
4. Holliday, Willey L. 2001. *Asperger Syndrome in the Family: Redefining Normal*, London/Philadelphia: Jessica Kingsley Publishers.
5. Aston, M. 2005. Growing up in an Asperger family, *Counselling Children and Young People*, Summer, pp. 6–9.