

12. Give yourself time to figure out what your child *really* enjoys.

Surrender to that joy whenever possible. Your child is a child, after all. Don't let people frame your child's enthusiasms in pathological terms like "special interest" or "obsession", while other people simply have hobbies. If your child likes something, and they're not hurting anyone, let them like liking it. It will give them pleasure, help ease stress and make them an expert!

13. Give yourself time to plan for your child's *future* at different stages.

As your child grows their needs will change and develop and this will include them becoming an adult. Whilst they will need extra help at times they will also need support to become independent and to do things for themselves wherever possible. As they grow help them to learn what they are capable of. This might be something as small as dressing for themselves or as big as running their own company. It will be different for every child. Remember you will not always be around to do everything for them.

If you would like further support and advice please contact us via SHaRON (Support, Hope and Resources Online) our secure online support network with a CAMHS Autism Assessment Team subnet (named Jupiter) for parents and carers of young people with an autism diagnosis or who are waiting for an autism assessment. SHaRON is moderated on a regular basis by the Autism Assessment Team clinicians, voluntary agencies such as Autism Berkshire and Parenting Special Children, other autism services such as ASSIST and specialist autism advisors from across Berkshire. Most importantly other parents and carers are also there to share their own experience, advice and questions. To simply send an email to sharon.jupiter@berkshire.nhs.uk with your name, your child's name, an your contact details and email address all included in the email.

Thanks to **Shannon des Roches Rosa** for permission to abridge her blog post and to Ruth Moyse for her support in providing this leaflet. Full text here:

<http://www.thinkingautismguide.com/2017/03/after-autism-diagnosis-13-necessary.html>

After an Autism Diagnosis

13 Next Steps for Parents: Give Yourself Time

1. Give yourself time to *adjust*.

Some parents feel relieved when their child is diagnosed with autism, whilst others feel scared. A big reason why parents sometimes feel frightened is because the media is so often full of negative stories about autism. However, your child is the same person today, after diagnosis, as she/he was before. Most problems you come across will be due to a lack of understanding about autism from other people and society in general, and not *because* of autism. Give yourself time to be thoughtful, and let the diagnosis help guide you and your approach to parenting in the right direction.

2. Give the *people around you* time to adjust, and keep them in the loop.

Like you, your friends and family may know nothing about autism to begin with, and might not know what to say. You can help them by saying things like, "It's okay to ask us questions, but we might not know the answers yet," and "Please keep inviting us over; we'll say no if it doesn't work". Share information on autism with them, perhaps by email or by giving them a leaflet from the National Autistic Society, so you have less to explain when you see them. Get them along to workshops organised by local charities such as Parenting Special Children and Autism Berkshire.

3. Give yourself time to *process information critically*.

There is a lot of wrong and sometimes dangerous information about autism on the internet, especially from people trying to sell 'cures' (there's no such thing – autism is a neurological condition, not a disease). Be careful. But there's also lots of useful information, too. And the more you learn, the more your perspective and understanding of autism and parenting will develop.

4. Give yourself time to learn which organizations work for you.

Not every person or organisation will fit for you. Give yourself time to explore support from different organisations and books and don't give up if one thing doesn't give the help you had hoped for. It can be very helpful to read books and blogs by autistic people, as they can explain the condition (and the effect on them of support vs 'treatments') from their perspective.

5. Give yourself time to figure out what autism means for *your* child.

Autistic people's brains work in similar ways, but they are all different, just as your brain is different to mine. Learning to recognize and understand how your child thinks, and why your child behaves the way he does, may take time as well as trial and error. Sensory experiences, and perception of pain, can be very different to what you might expect. Your child may not be able to filter out lights, sounds, or touch—to the point where just walking into a supermarket can cause a meltdown because it is so painful for them to be there. Many autistic people also experience high levels of anxiety, and may learn to self-soothe through stimming. Try to understand *why* your child may be behaving differently than their peers.

6. Give yourself time to work out what *communication* looks like for your child.

Everyone communicates, but speaking can be hard for autistic people. If your child can speak a lot she may not be able to communicate all her thoughts and intentions. Be very careful about this, as these seemingly fluent talkers can often have their communication needs underestimated.. And if your child doesn't speak or doesn't speak much: be careful to presume competence, to treat them as though they can understand everything you say. Your child is a person with thoughts and feelings, and expressing them differently doesn't make her any less of a person. Find out how *your* child prefers to communicate, whether that's speaking, using a symbol-to-speech device, or typing, or something else. There is no wrong way.

7. Give yourself time to work out which supports, schools, therapies, and environments will help your child *succeed* and *be happy*.

What helps? What doesn't help? What support can be put in place for them at school and which is the right school? Do you know how to write educational goals that will best serve your child's needs? This is where you rely on those

trustworthy resources, as much as you can, and use free local services such as Reading IASS www.readingiass.org (add other Berkshire IASS services).

8. Give yourself space to be *flexible about needs*, and *pick your battles*.

You may need to adjust your life and expectations to those of a child who doesn't sleep much, whose limited diet means bringing their food along whenever you don't eat at home, and/or whose sensory needs mean they can't stand to be in certain environments. Remind yourself that your child isn't doing any of these things by choice, and isn't trying to be 'naughty'. Watch your child to find out what he needs; and just because it's different, doesn't make it wrong.

9. Give yourself time to find autistic *role models* for your child.

If your child doesn't know any other autistic children or young people like themselves, they may feel alone and isolated (or even broken, or defective). Don't let that happen if you can do anything about it. There are good role models in blogs by autistic people, and in books about autistic people. There are talks you can go to, and films and YouTube videos to watch. And, of course, meeting up with other autistic children at places like Camp Mohawk and Articulate.

10. Give yourself time to think about *shared traits*.

Do you recognise any traits? Many parents and siblings get diagnosed as autistic themselves after another family member's diagnosis makes them more aware of what autism can mean. This is especially important for female siblings and family members, as autism in girls often looks different to autism in boys, and is often overlooked due to gender bias in diagnostic criteria.

11. Give your child space to *grow and change*.

Autistic development can be different to non-autistic development. Your child may learn things at different ages to other children – later, or earlier. Remember that she is an individual, and teach her the skills she needs as she develops, not according to her age. Remember too that your child today, at the age of 2 or 5 or 11 or 14, is not the young person they will become by the time they are 18 or 21 or 25. Take one day at a time.

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