

After your child's diagnosis

An <u>autism diagnosis</u> can be difficult to come to terms with. You may be coping with a condition you know very little about, and trying to find new ways for everyone to live together and feel supported. Many parents aren't given any guidance on what to do next. Moving on from a diagnosis can seem daunting, but we're here to help.

Our <u>Autism Helpline</u> offers confidential information, advice and support. We can also point you towards local sources of <u>help and support</u>.

Here we talk about the effect of diagnosis on your family, support for your <u>autistic child</u>, for their <u>brothers and sisters</u>, and for <u>yourself</u>. We also talk about <u>telling your child</u> about their diagnosis.

Support for your child

Your child is the same person they have always been. Now that you know they are on the autism spectrum, you can begin to better understand their needs, arrange the right support and help them to maximise their potential.

This is important for autistic children, who can benefit from appropriate, sometimes intensive, support from an early age. It's also important for families, who may benefit from services such as short breaks.

A diagnosis can help your child to get autism-specific support, but this doesn't happen automatically.

At school

Help at school is based on need, in addition to the diagnosis. You can speak to the school about how your child might be able to <u>get extra help</u> before or after a diagnosis.

Social care

Local authorities have a duty to provide services for children in need. Your child does not have to be diagnosed to be considered in need.

You should contact your local social services (in England and Wales), social work department (in Scotland) or Health and Social Care Trust (in Northern Ireland) to ask for an assessment of your child's needs.

You can also ask for an assessment of your <u>needs as a carer</u>. You might be able to access a variety of support such as short breaks.

We have some model letters that you can use to ask for an assessment.

The person who diagnosed your child might have told you that they would contact these services for you. But it can take some time for them to do this. You may wish to contact your education and social services department yourself anyway. They will contact the diagnostician for information if they feel it is needed.

Financial help

Your family may be eligible for <u>benefits</u> such as <u>Disability Living Allowance</u> and <u>Carers Allowance</u>.

At home

The diagnosis itself, and the profile of needs if the diagnostician gave this, may help you to better understand your child and their needs.

EarlyBird post-diagnostic support programmes for parents and carers can help you to understand autism, build your confidence to encourage interaction and communication, and understand behaviour. Find out more about <u>EarlyBird</u> and whether you have a <u>local EarlyBird team</u>.

We run one-day family support seminars on topics such as understanding behaviour, sensory needs, and supporting siblings.

You can also find guidance on our website about <u>behaviour</u>, <u>communication</u>, <u>health</u>, <u>holidays and days out</u>, and other aspects of <u>home</u> and <u>daily life</u>.

Support for siblings

Siblings might feel that your autistic child takes a lot of your time and attention. When possible:

- help siblings to better understand their brother or sister and their needs
- make time for siblings

- do some activities separately
- allow siblings to have time to themselves, eg a sleepover at a friend's home
- allow siblings to bring their own friends home sometimes and enjoy themselves without interruption
- listen to their worries and concerns and the things that are important to them
- listen to their ideas older children may have good ideas about how best to manage certain situations. If they have a good relationship with their autistic brother or sister, they may be able to ask them to do things that you can't.

Find more information for <u>brothers and sisters</u> and how to <u>tell siblings</u> about the diagnosis.

Looking after yourself

It will take time to learn how to help your child and family cope with day-to-day life. You have the right to feel annoyed or frustrated. It's hard to remain positive when things don't go as planned and it is natural to feel upset.

Try to get some time on your own to relax, even if it is just to walk the dog or do the washing up, and try not to feel guilty about doing this. Everyone deserves some time out to recharge the batteries.

You can also ask for an assessment of your <u>needs as a carer</u>, so that you can access support such as short breaks.

It may help to talk about your experiences with people who have been in a similar situation, such as through our Parent to Parent Service, our online community, or one of our branches.

Telling your child about their diagnosis

When should I tell my child?

This is your decision. Some parents tell their children about their diagnosis when they're quite young (primary school age), as their son or daughter becomes aware of their differences and starts to ask questions. Other parents wait until their child is slightly older, as they feel they will understand the diagnosis better. You may want to ask your child's school or specialist psychologist to support you with your decision and approach.

How should I tell my child?

There isn't one 'right' way to tell your child about their diagnosis. However, here are some points to consider.

Who is the best person in the family to help bring up the subject? If your child is comfortable with a grandparent or aunt, it might be a good idea to get them involved, too.

Choose a moment when you're both in a calm mood and in a familiar place where you both feel comfortable. Autistic children can find it difficult to process new information, especially if they're feeling anxious, stressed or are in an unfamiliar environment.

Try to make sure you won't be interrupted. Your child may need time to think about what you're saying or to ask questions.

One of the ways some parents start a conversation about autism is to talk first about differences. For example, you could write a list of family members' strengths and weaknesses, then talk about what your child is good at and what they find difficult. You could point out that there is a name to this particular pattern of strengths and weaknesses.

Your child may have met other autistic people. You could explain that although autistic have some things in common, they are all different.

The following might be helpful:

- Autism: talking about a diagnosis by Rachel Pike
- I have autism. What's that? (for 4-9 year olds) by Kate Doherty, Paddy McNally and Eileen Sherrard
- I am special (for children, teens and adults) by Peter Vermeulen
- What is autism? (Easy read)

How might my child react?

Your child may be pleased that they now have a better understanding of themselves.

Some children will become concerned that there is something seriously wrong with them which will affect their health. You may need to emphasise that autism is not a disease and no one can die from it. Although autism cannot be 'cured' there are ways of helping to overcome some of the difficulties you child

experiences. For example, your child might have a support worker at school who helps them with tasks they find difficult. You could also point out that your child is good at some things at school which other children need help with.

Be there if your child wants to talk or ask questions. Some children may not want to ask questions face to face. Having a question box, diary or email system can make it easier for some children to ask personal questions. It also gives them more time to process your answer or think of other questions.

What if my child wants to meet other autistic children?

Some children find it helpful to meet other autistic children and to learn that they are not alone. Our <u>Autism Services Directory</u> lists social groups, afterschool clubs and support groups around the UK.

How should I tell my other children?

If you have other children you may want to talk to them separately about your child's diagnosis. You will probably explain things differently depending on their ages. The following books might help your children to understand:

- My family is different (for 4-9 year olds) by Carolyn Brock
- Everybody is different: a book for young people who have brothers or sisters with autism (for 8-13 year olds) by Fiona Bleach
- I'm a teenager... get me out of here! by Carolyn Brock

What if my child wants to tell their friends at school?

We have written a <u>lesson guide</u> which teachers can use with their class to help pupils to understand autism. You can also download an <u>autism awareness pack</u> for teachers. You could also talk to teachers about the <u>Circle of friends</u> approach to supporting the inclusion of children with disabilities in mainstream schools.

More from our charity

- Helpline and advice services
- Family support services
- Our online community, a place to share your thoughts and experiences
- Our <u>Autism Services Directory</u> for local parent groups and <u>NAS branches</u>
- After diagnosis, our short guide to support and benefits you may be entitled to, sources of local support, and how we can help you.

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Autism Helpline

Tel: 0808 800 4104

(open 10am-4pm, Monday-Thursday, 9am-3pm on Fridays)

Online: Visit www.autism.org.uk/enquiry.

The <u>Autism Helpline</u> provides impartial, confidential information, advice and support for autistic people and their families.

Taken from: https://www.autism.org.uk/about/diagnosis/children/recently-diagnosed.aspx