

Your Child or Young Person has been newly diagnosed with autism

Autism spectrum disorder is the medical name for autism and is often shortened to ASD

Things that you might find helpful:

Give yourself time

People react to a diagnosis of autism in different ways.

For some, it's a relief to find out why they or their child think, feel and act the way they do. For others, it can be a shock.

Try to give yourself time to come to terms with the diagnosis.

Remember:

- help and support is available
- even if things are hard now, they can get better
- you or your child are still the same person as before
- autism is not an illness or disease with treatments or a "cure"
- autistic people, like all people, have things they're good at as well as things they need help with



Find help and support services

You might feel alone when you or your child are first diagnosed, but there are places you can get support

You can get help from:

- local support groups
- national charities
- your school, college or workplace
- your local council
- your GP or the autism team who diagnosed you



[Find out about the support you can get if you're autistic](#)

Listen to other people's stories

Some people find it helpful to find out about other people's stories of autism.

[The charity healthtalk.org has stories from autistic people and parents of autistic children](#)

You could also search online for autism blogs, videos or books.

IMPORTANT

Remember, autism is different for everyone. What happened to other people might not be the same for you or your child.

Find out more about autism

It might help you and your family to find out more about autism.

There can be quite a lot to take in. You do not have to read everything.

You can get trusted information from:

- the NHS – for information about [what autism is](#) and advice on [autism and everyday life](#)
- [National Autistic Society](#) – for autistic children and adults, parents and carers
- <https://www.specialneedsjungle.com/>



[Find out about the local support available to you. Below are just some of the organisations that you may find helpful](#)

Barnardo's Cygnets parenting support programme is a 6-week training course for parents whose children are aged 4 to 18 years with a diagnosis of autism spectrum disorder or social communication difficulties. Those without a formal diagnosis are able to attend. [Barnardo's Cygnets](#) | [Hillingdon Directory](#)

Hillingdon SEND Local Offer: Our local offer provides information for children and young people with special educational needs and disabilities (SEND) and their parents/carers. It allows families to see what they can expect from a range of local agencies and how to access them. [Hillingdon Council](#)

Hillingdon Council SEND Advisory Service is here for all general enquiries, support and advice. They're able to help or signpost for all things SEND. Email: saskeywork@hillingsdon.gov.uk

Hillingdon Autistic Care and Support (HACS) <http://www.hacs.org.uk>

The Centre for ADHD and Autism Support <http://adhdandautism.org/contactus>

If your child has behavioural feeding issues, please visit to the link for further advice and information. <http://www.weightconcern.org.uk/tinytastes>

You may be eligible to apply for Disability Living Allowance, further information can be found on <https://www.gov.uk/disability-living-allowance-children> (please see the information on the Local Offer if you would like support in completing the application).

There are also tips and advice on completing the application on the National Autistic Society (NAS) website <http://www.autism.org.uk/about/benefits-care/benefits/children/parents-carerstips.aspx>

Where there are concerns with managing behaviour within the home, you can access parenting courses to support how you manage challenging behaviour (eg. Brilliant Parents). Their contact details are: Meave Darroux, Manager - enquiries@brilliantparents.org / Phone number: 02033569705

For concerns regarding speech, language and communication, occupational therapy or physiotherapy. Contact Children's Integrated Therapy Service (CITS). [Hillingdon Talks, Moves, Plays: Children's Integrated Therapy Service \(CITS\) \(cnwl.nhs.uk\)](https://www.hillingdon.gov.uk/cnwl/nhs.uk)

For concerns regarding access to education contact SENDIASS (Special Educational Needs and Disability Independent Advice and Support Service - **Email:** sendiass@hillingdon.gov.uk **Phone:** 01895 277001

What is autism? Autistic people may act in a different way to other people

Some Autism Traits



Autistic people may:

- find it hard to communicate and interact with other people
- find it hard to understand how other people think or feel
- find things like bright lights or loud noises overwhelming, stressful or uncomfortable
- get anxious or upset about unfamiliar situations and social events
- take longer to understand information
- do or think the same things over and over

Autism is not an illness

Being autistic does not mean you have an illness or disease. It means your brain works in a different way from other people.

It's something you're born with. Signs of autism might be noticed when you're very young, or not until you're older.

If you're autistic, you're autistic your whole life.

Autism is not a medical condition with treatments or a "cure". But some people need support to help them with certain things.

Autistic people can live a full life

Being autistic does not have to stop you having a good life.

Like everyone, autistic people have things they're good at as well as things they struggle with.

Being autistic does not mean you can never make friends, have relationships or get a job. But you might need extra help with these things.

Autism is different for everyone

Autism is a spectrum. This means everybody with autism is different.

Some autistic people need little or no support. Others may need help from a parent or carer every day.

It's not clear what causes autism

Nobody knows what causes autism, or if it has a cause.

It can affect people in the same family. Evidence suggests that autism may be genetic. Scientists continue to try to identify which genes might be implicated in autism.

Autism is not caused by:

- bad parenting
- vaccines, such as the MMR vaccine
- diet
- an infection you can spread to other people

Autistic people can have any level of intelligence

Some autistic people have average or above average intelligence.

Some autistic people have a learning disability. This means they may find it hard to look after themselves and need help with daily life.



Autistic people may have other conditions

Autistic people often have other conditions, such as:

- attention deficit hyperactivity disorder (ADHD)
- developmental Co-ordination Disorder (DCD)
- dyslexia
- anxiety
- depression
- epilepsy



Your Child's Education

Having autism will not necessarily mean that your child will require additional help at school. As your child is developing, the nursery or school will be able to assess if extra support is needed for your child to learn and thrive in the classroom.

All Hillingdon schools have Ordinary Available Provision Guidance, which is a type of handbook that lays out what a school should provide for all children without the need for extra funding.

There is a lot of local support in the community for your child – this includes:

Early Support Funding (the school can apply for additional funding without an EHCP to support your child).

Speech and Language Therapy

Occupational Therapy

Physiotherapy

Local support groups and play groups



If your child is still struggling at school due to their sensory needs and neurodiversity, they may need an Education, Health Care Plan (EHCP). Your clinic, school, nursery, care workers should be able to support you with requesting an EHC needs assessment. This is only for children who will require a higher level of educational support in order to sustain school attainment and attendance.

AND FINALLY!



Please see some additional resources below that you may find interesting and supportive

Communication Tips - Visual Cues and Social Stories:

- Visual cues are useful to help your child understand what is happening around them and to understand what to expect. Visual strategies should include the use of pictures, diagrams and demonstration of tasks, as well as visual timetabling to help your child to know what to expect and reduce any anxiety. These can be used both at home and at school. Free resources can be found on the 'twinkl' website: - www.twinkl.co.uk/resource/t-c-6631-ks2-visual-timetable
- **Talkabout: A Social Communication Skills Package'**, By Alex Kelly. This resource perfectly aims to improve your child's awareness of self and others, including physical appearance, likes, dislikes and problem-solving.
 - ✚ - Allowing children to assess their own communication skills
 - ✚ - Taking your child through eight levels of body language
 - ✚ - 'Talkabout the way we talk' improving paralinguistic skills
 - ✚ - Taking your child through the processes needed to improve conversational and listening skills
 - ✚ - Developing awareness and use of assertiveness skills.
- **Blacksheep Press:** 'Talking About Conversations, social skills'
<http://www.blacksheepress.co.uk/product/talking-about-conversations/n>

The aim of this programme is to help teach children the skills required to be a good conversational partner. Children need to integrate these skills into a range of situations that require a sophisticated interplay of behavioural responses. These include:

-  Identifying the appropriate moment to start a conversation
 -  Selecting appropriate topics for conversation
 -  Asking to join in
 -  Offering assistance
 -  Requesting help.
- **Social Stories’ and ‘Comic Strip Conversations’**; highly structured programmes that use stories to explain social situations to children and provided visual thought processes.

Try Social Stories, like ‘The New Social Story Book’ by Carol Gray as this contains a CD of printable social stories. Social Stories are used to lay out all the unwritten rules and conventions of situations which often help young people with their behaviour and lower their anxiety. (Tools for ‘social stories’ are widely available on the internet e.g. <http://www.thegraycentre.org/social-stories/what-are-social-stories>).

There is also a book ‘Successful Social Stories’ for Children (Growing Up with Social Stories) by Siobhan Timmins, which may be of interest. The ‘Look Inside’ feature on the ‘Amazon’ listing of this book allows you to see not only a list of contents but also some of the stories.

Understanding Emotions and Emotional Regulation:

Children may require support to enable them to express their own emotions and to understand the emotions of others. These skills are important in developing and maintaining social relationships and fostering their good mental health. The following resources may be helpful for them to explore with support from parents and school:

- When My worries get too big by Kari Dunn Buron
- Extension of Black Sheep Press ‘Emotions’ pack, ‘Socially speaking’ and ‘Social use of language programme’ ‘Talkabout’ • The incredible 5 point scale <https://www.5pointscale.com/>
- Zones of regulation chart. Zones of regulation chart to reference how your child is feeling in different situations, accompanied by relevant coping strategies e.g. “I’m in the yellow zone (feeling anxious), I can listen to music, talk to my mum”. Please see more information on <https://www.zonesofregulation.com/learn-more-about-the-zones.html>

Studies have shown that the key to empowering a child with autism are:

-  Accept your child’s autistic features.
-  Do not suppress their natural ways of being including their interests.
-  Ensure that they are not socially isolated as this can lead to co-occurring mental health difficulties.

- ✚ However, get the balance right, do not force them to socialise, particularly in groups.
- ✚ Adjust the educational environment. Rigid discipline systems and expecting people with ASD to fit in with neuro-typical children may be unrealistic and lead to low self-esteem.

TED Talks

Each child with neurodiversity will present with a unique profile of strengths and difficulties. There are now a number of inspiring people with ASD who advocate for recognition of neurodiversity. There are also some very interesting TED talks by young people about their experience of ASD below that you may find interesting:

<https://www.youtube.com/watch?v=Qvvrme5WlWA>

https://www.ted.com/talks/rosie_king_how_autism_freed_me_to_be_myself

https://www.ted.com/talks/alix_generous_how_i_learned_to_communicate_my_inner_life_with_asperger_s

Online Training

Online training about ASC: There is a very helpful and comprehensive online resource about ASC, which can be accessed free of charge and might be of interest to 's family:

<https://www.open.edu/openlearn/science-maths-technology/understanding-autism/content-section-overview?active-tab=description-tab>

Girls with autism

As there is a higher number of boys with ASD, there seems to be more information related to boys. However, this is changing and there has been a great increase of both recognition and understanding of ASD in girls. There are now a number of inspiring, strong female figures with ASD who advocate for the needs of girls and women with ASD such as Sarah Hendrickx or Robin Steward

- ✚ There are also some very interesting TED talks by young women about their experience of ASD:

<https://www.youtube.com/watch?v=Qvvrme5WlWA>

https://www.ted.com/talks/rosie_king_how_autism_freed_me_to_be_myself

https://www.ted.com/talks/alix_generous_how_i_learned_to_communicate_my_inner_life_with_asperger_s

- ✚ There is a series of books by Libby Scott called 'Can you see me', 'Do you know me' and 'Ways to be me'. They are diary entries written by 11-year-old girl with autism, based on her own experience. Many young girls with ASD have reported that they really enjoyed reading these books.

- ✚ For young girls, 'The Girl with Curly Hair' is a lovely series of books on a series of topics, such as exploring ASD, emotions, anxiety, and other relevant topics, which allow exploration and can be individualised.

<https://thegirlwiththecurlyhair.co.uk/product/aspergers-syndrome-in-8-11-year-olds/>
<https://thegirlwiththecurlyhair.co.uk/product/aspergers-syndrome-and-anxiety/>

Celebrating Neuro-Diversity

There are many helpful articles and resources. The following link can be a helpful starting point for them and the family to explore various approaches to celebrating neurodiversity, as it pulls a wide range of resources together:

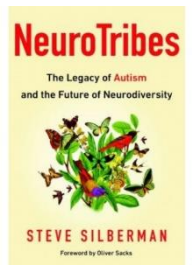
<https://heller.brandeis.edu/diversity/learning/nd-challenge.html>

In addition, there is a link to a brief video explaining the concept of neurodiversity:

<https://www.youtube.com/watch?v=aWxmEv7fOFY>

Children with ASD have many areas of wonderful strengths and whilst we are often focused on working on the areas of difficulty, focusing on areas of strength and developing these can bring about many positive shifts. Autism Spectrum is now understood to be a part of the normal neurodiversity we see in the general population. If you are interested in learning more about neurodiversity and the strength-based approach, we would recommend the following books:

- ✚ The Power of Neurodiversity: Unleashing the Advantages of Your Differently Wired Brain by Thomas Armstrong
- ✚ Neurotribes: The legacy of Autism and how to think smarter about people who think differently by Steve Silberman.
- ✚ There is also a podcast about a strength-based approach, which may be of interest to parents: <https://www.acamh.org/podcasts/autism-parents-guide-empower-your-autistic-child/>



Friendships and Social Skills

Children benefit from continuing support in developing their understanding of emotions as well as their social skills. As they start to encounter more complex social interactions in secondary school, they might benefit from opportunities to discuss ways of balancing neuro-divergent and neuro-typical ways of communication. The following resources might be helpful in discussing ways to address certain social situations. However, it is important to ensure that this is fully led by your child and that they do not feel under any pressure to 'copy' rules of social interaction in the neuro-typical population. They should feel free to express themselves in their own way. If they are interested in understanding social interaction better, the following may be helpful:

- 🌈 Socially Curious and Curiously Social by Michelle Garcia. This book has sections on various topics such as 'feeling shy' and 'talking out an argument', 'dating' and 'social media'.

However, it is important to ensure that we all work towards creating neurodiversity friendly and inclusive environments, where we ensure young people with neurodiversity are respected and understood with their unique contributions.



Explaining the ASD diagnosis to your child:

It is important that children are supported to learn more about their neurodiversity. There is a very helpful information sheet with resources on the National Autistic Society website. We recommend the following books which will help your child to develop a sense of their own individual strengths and challenges:

- 🌈 My Autism Book by Gloria Dura-Villa and Tamar Levi
- 🌈 Series of books: "Do you know me", "Can you see me?" and "Ways to be me" Rebecca Westcott and Libby Scott
- 🌈 See also: Talking about Dx: <https://lucysanctuary.com/inspirational-people-with-autism>



Coping With Change

It is well recognised that significant change and transitions can be a particularly challenging time for many young people on the Autism Spectrum. Children need support with significant changes in their life.

The transition to a new school is stressful for many young people but it can be particularly challenging for young people with ASD and some other neurodevelopmental disorders. It is important to plan and prepare for this transition. Your child's schools will need to work closely together to share their understanding of their needs, areas of difficulties and to identify with you what support will be helpful.

The information on autism spectrum disorder and the Autism Spectrum Disorder and the Transition into Secondary School: A Handbook for Implementing Strategies in the Mainstream School Setting Paperback – 21 Jan. 2016 by Josselyn Hellriegel and Will Mandy Marianna Murin (Author)

*We hope you find this information helpful.
Please reach out for any help or support if needed.*

Sources of information – NHS.Net; National Autistic Society