



Autism Spectrum Disorder (ASD)

An advice pack for parents and carers

You have been given this leaflet because your child has been diagnosed with autism spectrum disorder (ASD). The leaflet gives:

- an overview of ASD
- how to look after yourself and siblings of your child with ASD, and
- further information and support in East Kent.

This booklet will use the term ASD. However, you may also see it referred to as ASC, or autism spectrum condition or autism. These are all the same.

Before 2013, ASD did not exist as a diagnosis. Instead other diagnoses were made, such as childhood autism, atypical autism, and Asperger syndrome. These have now been replaced with the diagnosis 'ASD'. Although these labels are out-of-date, some people and information sources may still use them. You may also have heard the terms 'neurodiverse' or 'neurodivergent'. These terms are also used to refer to autistic people and people with ADHD (attention deficit hyperactivity disorder) or learning differences.

What is ASD?

The National Autistic Society describes autism as:

“a lifelong developmental disability which affects how people communicate and interact with the world.”

ASD is a spectrum condition. Some people with ASD may need a significant amount of support through their lives. Whereas others will build independent, successful lives and careers.

Challenges for people with ASD are generally around:

- social interaction
- communication
- being able to think and behave flexibly, as well

- as differences in the way they experience the world through their senses.

Social Interaction

This is about joining in with people, 'reading' people, understanding and expressing emotions. Autistic people show differences in these areas, which may include the following.

- Differences in eye contact.
- Standing too close to people.
- Preferring time alone.
- Not readily understanding social rules. This may mean they seem rude or unkind at times when they do not mean to be.
- Difficulties making and keeping friends.
- Getting on better with adults and older or younger children, rather than those the same age.
- Different ways of 'having a chat'. They may like to talk rather than listening and sharing conversation. They may interrupt or talk over others, or prefer not to talk very much at all.

Communication

Communication is using spoken and body language to communicate with people for all different of reasons. For example to ask for something, to point things out, to explain, or to share a joke. Some children most severely affected by ASD may not develop communication. Most will, and some may develop good language skills, but challenges may remain. These challenges may include the following.

- Using words and phrases repetitively.
- Speaking without always understanding.
- Copying what others say.
- Having a speaking voice that sounds different to others, for example high-pitched or too quiet.
- Differences to others in facial expressions and gestures. Difficulties understanding what others mean when using them.
- Forgetting what is said to them.

Behaviour and flexible thinking

Children who have ASD may show some repetitive and unusual behaviours. These may include the following.

- Moving their bodies in unusual ways, such as stretching their fingers, flapping their arms, or spinning.
- Preferring to play alone or wanting to tell others what to do during play.
- Not being very interested in a range of imaginative play.
- Tending to inspect and arrange toys and possessions, rather than playing with them, for example lining them up.

- Developing intense interests, which in older children and adolescents may continue into adulthood. These may lead to careers in IT, engineering, science, and the law.
- Finding it difficult to see situations from others' points of view.
- Difficulties coping with change.

Sensory differences

Children with ASD can experience the world through their senses differently. They may be over sensitive, under sensitive, or have a mixed picture and one which can vary daily. They may avoid or seek out sensory experiences. This can affect all senses: sight, hearing, smell, taste, touch, balance, a sense of your body position, a sense of your insides, and how they are feeling. These sensory differences can include the following.

- Covering ears to block out sound
- Making loud sounds
- Looking intensely and closely at items
- Bumping into objects
- Walking on tip-toes
- Avoiding certain foods
- Licking or eating non-food items
- Sniffing items
- Not noticing when they have injuries
- Not tolerating dirty hands
- Squeezing into small spaces
- Preferring not to hug
- Wanting certain textures or colours of clothes

What causes ASD?

Nobody knows the exact causes of ASD. Evidence suggests that genetic factors are involved, affecting the development of the brain. However, it is certain that parenting does not cause ASD.

Although it is possible that children with ASD are born into families with no history of ASD, it does often run in families. Research findings suggest that identical twins (who share the same genes), have up to 90% overlap of ASD. This means that up to 90% of the time if one twin has ASD, the other will have it as well, suggesting a strong genetic influence. It is possible that ASD is caused by the combination of several hundreds of genes, rather than just a few.

There seem to be other factors that can be linked with ASD. More research is needed, but possible factors include:

- low birth weight, and
- difficulties in pregnancy and labour such as blood and oxygen flow in the womb.

My child's individual report

After your child's diagnosis, a report will be produced which is split into two sections.

- **The first section** is an overview of your child's developmental history. It will include many different aspects of your child's life, such as school, sleep, diet and physical attributes.
- **The second section** will focus on the assessment carried out with your child. This will usually be the Autism Diagnostic Observation Schedule second edition (ADOS-2). The report will highlight in detail your child's strengths and challenges as seen in the clinic.

The conclusion will be clearly stated. Recommendations may be made. What happens next for you and your child with the Child Health team will be included.

What happens next is up to you. With your consent, the report can be shared with other professionals, including schools and therapists. This may help people understand your child better. It may lead to additional support. You are welcome to share it with any person or service you wish.

What might help my child?

There is no cure for ASD, but people with the diagnosis can be happy, proud, and successful. Differences in development, learning, behaviour, emotional well-being, communication and social life can cause challenges, but with the right support these can be overcome or reduced.

Specialised approaches and therapies are always being developed. These can have a positive impact on your child's development.

- **Education**

Some children with ASD have special education. For example they may go to a special school or a specialist unit in a mainstream school. However, most children with ASD are part of an ordinary class in a local school. Teaching staff are often experienced in working with children on the autism spectrum. They will know how to access further support and training. Speak to your child's school or nursery to learn more about the support that might be available.

- **Behavioural therapies**

Behavioural therapies may help your family cope with any behavioural issues linked with ASD. This can include challenging behaviour, and feeding or sleep difficulties.

- **Medicine**

For some children medication can help improve their symptoms, including sleep difficulties, or soiling or wetting issues.

How can I support myself and my child?

Having a child diagnosed with ASD is different for everyone.

- Some people feel upset.
- Some are surprised.
- Others feel relieved that their child's difficulties have been identified.
- Others can feel frustrated.

Whatever your reaction is, it is normal to feel this way after diagnosis. It may be helpful to remember that your child is the same now as they were before their diagnosis. All that has changed is that their strengths and difficulties have been identified. This early identification will help your child and allow you to be equipped for the years ahead.

It is important to look after yourself. Take time from your day to focus on you and your needs as a parent or carer. This could be as simple as going for a short walk or reading a book.

Look for a support network. Family and friends can provide invaluable support.

Following your child's diagnosis, you will be offered the chance to attend an autism information session. These run twice a year in East Kent. They include information on sleep, behaviour, anxiety, feeding, and sensory processing. After your child's diagnosis we will contact you by email to invite you to a session.

Parent / carer programmes are also offered across some areas.

- For those with **pre-school children**, this may be the EarlyBird Programme.
- For those with **school-aged children**, this may be the Cygnet Programme.

These programmes are coordinated by different services in different areas. More information and resources are available from the Kent Adult Education web site (<https://www.kentadulthoodeducation.co.uk/course-areas/family-courses/parenting/>).

How can I support my other children?

You might feel that your child with ASD takes a lot of your time and attention. Siblings might feel this way too. When possible, try include them as much as possible.

- Make time for brothers and sisters.
- Do some activities with siblings separately.
- Allow siblings to have time to themselves, such as their own TV time or sleepovers.
- Allow siblings to bring their friends home sometimes and enjoy themselves without interruption.
- Listen to their worries, 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 brother or sister with ASD, they may be able to ask them to do things that parents or carers can't.

Siblings' sessions

Our psychology students on placement provide support for siblings of children with ASD. Siblings are offered up to four sessions of virtual input. These sessions are at various times throughout the year across East Kent.

These siblings' sessions are for children aged 8+ years old, and they have three aims.

- Increase children's understanding of ASD.
- Help them express their feelings.
- Build resilience and coping strategies.

For more information, contact Psychological Services on the number on the top of your child's diagnostic report.

There are other services which support young people who might be taking on more caring roles at home. You may want to find out what is available to you in your local area. Talking to the Carers' Trust and IMAGO (a local social action charity), would be good places to start.

Strengths

People with ASD can have many strengths.

- They may have long attention spans and work with things many people would not find interesting.
- They may have an eye for detail.
- They may be good at learning and recalling factual information.
- Many people with ASD have successful careers in a wide range of areas such as science, engineering, technology, and working with animals.

People with ASD may have similar traits and skills to each other. However, they are just as individual as other people without ASD. Each person with ASD has their own likes, dislikes, strengths and weaknesses. They have their own character and personality.

"I see people with ASD as a bright thread in the rich tapestry of life." - Tony Attwood, ASD expert

"What would happen if the autism gene was eliminated from the gene pool? You would have a bunch of people standing around in a cave, chatting and socializing and not getting anything done." - Temple Grandin, autism activist

"Autism, is part of my child, it's not everything he is. My child is so much more than a diagnosis." - S.L. Coelho, author

"I'm not damaged, I don't need fixing. I'm just different. Embrace different" - Tina J. Richardson, social networker with ASD

"The positives out weigh the negatives." - Tina J. Richardson, social networker with ASD

"Autism - a different way of thinking." - Tina J. Richardson, social networker with ASD

“If you’ve met one person with autism, you’ve met one person with autism” - Stephen Shore, ASD expert with ASD

Many talented and successful people are neurodiverse. Here are some of the people who have ASD, or in the case of historical figures, are believed to have had ASD.

- Albert Einstein and Isaac Newton (influential scientists) (Proposed by Ioan James, Royal Society of Medicine, 2003)
- Chris Packham (naturalist)
- Greta Thunberg (climate activist)
- Tallulah Willis (actor)
- Sia (musician)
- Christine McGuinness (celebrity)
- Melanie Sykes (TV presenter)
- Elon Musk (tech entrepreneur)
- Daryl Hannah (actor, as quoted in the Guardian, 2015)
- Jessica-Jane Applegate (swimmer, as quoted in Great Yarmouth Mercury, 2010)
- Derek Paravicini (British musician, as quoted on BBC, 2011)

The Cygnet Programme

Cygnet is a course designed for the parents and carers of children with an ASD diagnosis who are of school age (5 to 18 years).

Families are usually grouped with others who have children of a similar age, so the sessions are tailored to their age group. The programme includes up to seven weekly two and a half hour sessions.

The course helps parents and carers understand:

- how their children see the world, and
- what causes their behaviour.

The course gives practical advice and strategies, which can be used to help support your child and manage behaviour.

The course covers sensory issues, communication, and understanding and supporting behaviour. It is also a good way to meet other parents, who may have very similar experiences to yourself.

How can I help my child?

Below are some useful ideas parents can use to help support children with ASD.

- Try to make information visual.

- Keep language straightforward. Simplify language and limit what you say, especially when your child is upset or stressed.
- Make use of routines to increase predictability.
- Help your child manage their sensory experiences.
- Notice how your child expresses their feelings.
- Work out what helps them stay calm.
- Work out what helps them want to try new experiences, that they might not want to.
- Notice what interests them, and join them in that interest.
- Encourage them to join in and take turns.
- Try to have fun and share that fun, by looking and smiling at each other.
- Support their friendships.
- Support their interests and try to broaden them.
- Look after yourself.

We can't go into detail here. These ideas are usually covered in the parenting courses listed above. You can talk and think about them with other parents at the support groups.

How can I use visual resources to help my child?

One way of helping children with ASD to navigate their social world is to write a:

- visual timetable
- Social Story, or
- comic strip conversation.

Sometimes children with ASD become overloaded with too much spoken information. Visual images can help them understand better.

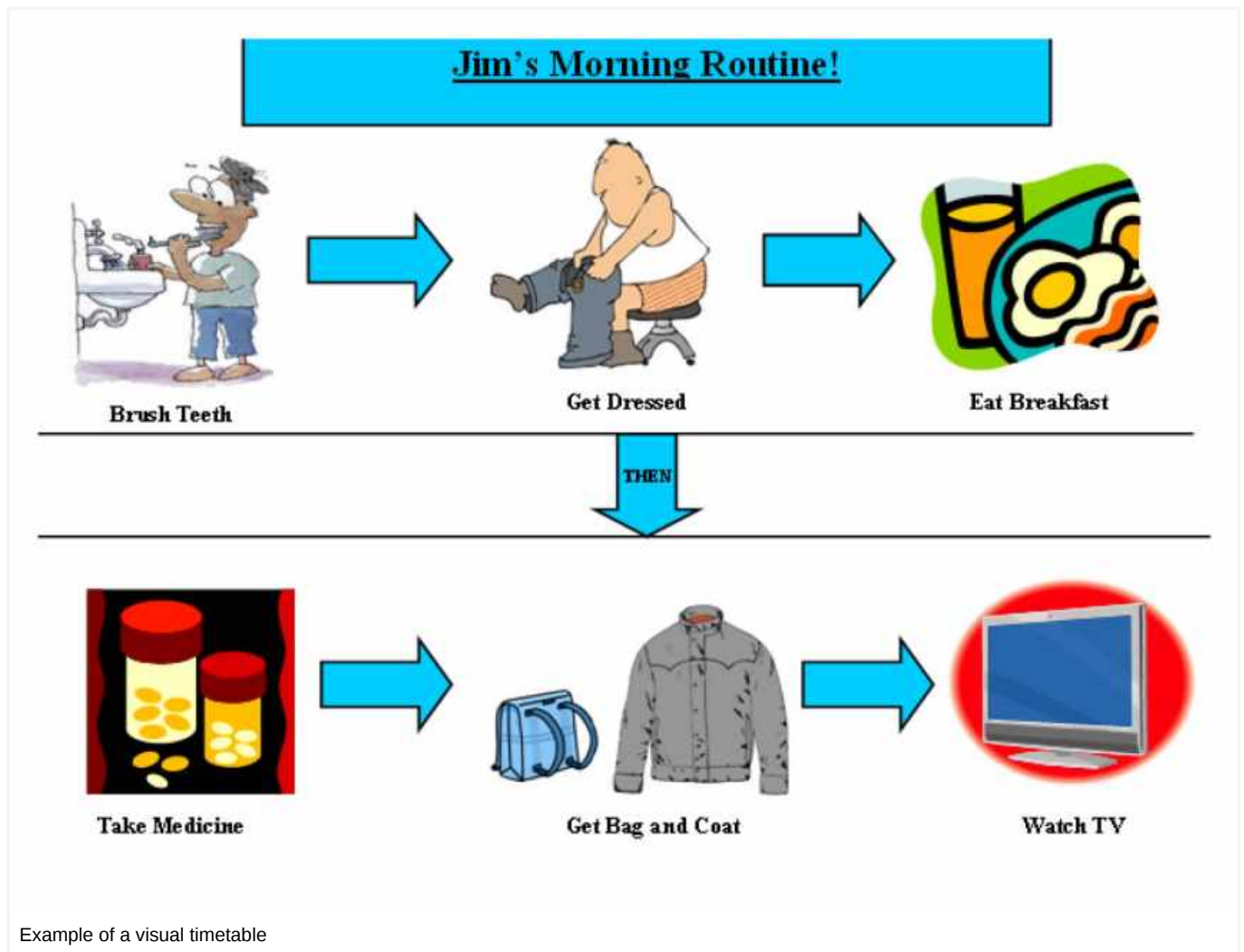
Visual timetables

Visual timetables or lists can have symbols and pictures alongside words. This can reduce confusion. Pictures can help children with ASD to make sense of a situation.

Children can regularly check the visual timetable, so that they know what to expect.

They can be used for usual routines, such as:

- morning routine
- the school day, or
- for events which your child may be unfamiliar with, such as a special day or trip out.



A simple visual timetable might include the following.

- Showing a single picture of what's happening next. Or a now / next board.
- A countdown to the number of 'sleeps' before an event. This could be a visual support to manage waiting, which can be tricky for some children with ASD.
- Learning to check to school timetables.
- Using calendars to be supportive and helpful as your child grows up.

Social Stories

Social Stories are stories written for a particular child. A parent, carer, or professional who knows the child well writes the story. The story will be specific to a child. It will address a difficult situation that they are either currently experiencing, or one that they need to prepare for. This could include encouraging them to use the toilet, or what will happen as they go through puberty.

A Social Story is not a list of things for your child to do or not to do. A Social Story communicates a message in an engaging manner, using the right level of visual support.

It is important to base the story around your child (using, 'I' in the first person). This makes it clear that the story is about them.

The story uses different types of sentences.

- **Descriptive sentences** are factual and accurate. For example Christmas day is 25th December or everybody gets ill sometimes.
- **Coaching sentences** are a response to behaviour in a particular situation. The sentence is always positive and allows for mistakes. Use 'try' rather than 'must', to allow for mistakes. For example:
 - "I will try to cover my mouth when I cough"
 - "I might like to play outside during lunchtime".

You can then read the story in a calm place to prepare your child for the situation.

More information and examples are available on the Siobhan Timmins web site. (<https://siobhantimmins.uk/social-stories/>)

Comic Strip Conversations

Comic Strip Conversations can help to increase social understanding for some children with ASD. Comic Strip Conversations are visual conversations. They use symbols, stick figure drawings, and colour. By presenting this visually, some more 'abstract' aspects of conversation (for example, the feelings and motivations of others) are made more 'concrete' and easier to understand.

When writing a comic strip conversation, it is worth considering the following.

- Where is your child / young person?
- Who else is there?
- What is your child doing?
- What happened?
- What did your child think?
- What did others do, say, and think?

More information are available on the National Autistic Society web site. (<https://www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/social-stories-and-comic-strip-conversations>)

National support and information

- **National Autistic Society (NAS)** (<https://www.autism.org.uk/>)

The NAS is the leading UK charity for autistic people and their families. They provide a range of services including information and support for people with ASD. They also campaign for a better world for autistic people.

- **Independent Parental Special Education Advice (IPSEA)** (<https://www.ipsea.org.uk/>)

IPSEA is a national charity that provides free and expert advice to parents of children with special educational needs.

What support and information groups are in East Kent?

You may have been given an information sheet about the services available in your area, along with this booklet. By using these services or groups, you will be able to speak to both parents, carers, and professionals who have experience of ASD. They will be able to discuss any concerns with you and provide support.

Are there any books I can read?

For parents

- Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence: by Luke Jackson
- The Curious Incident of the Dog in the Night-Time: by Mark Haddon
- It's Raining Cats and Dogs: by Michael Barton
- Ten Things Every Child with Autism Wishes You Knew: by Ellen Notbohn
- Thinking in Pictures: by Temple Grandin

For children

- All Cats have Asperger Syndrome: by Kathy Hoopmann
- The Superhero Brain: by Christel Land
- The Girl With The Curly Hair, Asperger's Syndrome (<https://thegirlwiththecurlyhair.co.uk/>): by Alis Rowe

Books about managing emotions

- When My Worries Get Too Big: by Kari Dunn Buron
- Exploring Feelings – CBT to Manage Anxiety / Anger: by Tony Attwood
- The Incredible Five Point Scale: by Kari Dunn Buron
- The Incredible Years: by Carolyn Webster-Stratton

For siblings

- Everybody Is Different (Fiona Bleach)
- I'm a Teenager Get Me Out Of Here (Carolyn Brock)

These are a few of the books available. For more information on specific areas of ASD, browse the internet or visit the NAS website.

Online resources

- The Curly Hair Project (<https://thegirlwiththecurlyhair.co.uk/>)
- National Autistic Society: Too Much Information campaign (<https://www.autism.org.uk/what-we-do/campaign/public-understanding/too-much-information>)

What next?

You are now either at the end of, or nearing the end of your child's ASD diagnostic process.

Today you will either:

- make another appointment for further support, or
- your child will be discharged.

The clinical nurse specialist will have discussed this with you, and made sure you were happy with the decision.

We usually hold information sessions for parents and carers of children with ASD twice a year. You will receive an invite to this by email.

You will have been given information on how to access a parent programme or support group.

Being neurodiverse / having ASD is a lifelong condition. Sometimes you may want more support for your child. To do this, contact your GP who will be able to refer you to the most appropriate service. This may be Child Health. Older children with mental health difficulties alongside their diagnosis, may be referred to the Child and Young People's Mental Health Service, or another service.

As children approach their teenage years, we suggest that you review information about ASD. All children change at this point, and those with ASD are no different. Adolescence may bring many different challenges, but will also be a very rewarding stage of your child's growing up.

We hope this leaflet helps your understanding of your child's diagnosis. A diagnosis of ASD can be challenging, but with the right information and guidance, the journey can be made easier. Each child is unique and individual and an ASD diagnosis does not change this.

This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekh-tr.pals@nhs.net).

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

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