

Autism Spectrum Disorder (ASD)

This leaflet has been produced with and for parents and carers

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in 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 had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhuft.nhs.uk/patientinformation

An advice pack for parents and carers



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You have been given this leaflet because your child has been diagnosed with autistic spectrum disorder, or ASD. The leaflet gives an overview of ASD, how to look after yourself and siblings of your child with ASD, as well as listing further information and support groups in East Kent.

This booklet will use the term ASD. However, you may also see it referred to as ASC, or autistic spectrum condition. These are 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. All of these have now been replaced with the diagnosis of ASD. Although these labels are out of date, some people and information sources may still use them.

What is ASD?

Autism Spectrum Disorder is described by the National Autistic Society as

“A lifelong developmental disability that affects how people perceive the world and interact with others.”

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

Challenges typical of people with ASD are social interaction difficulties, communication difficulties, and differences in behaviour and imagination.

- **Social interaction**

This is about joining in with people, 'reading' people, understanding and expressing emotions. Problems experienced by those with ASD may include:

- avoiding or limited eye-contact, or staring
- standing too close to people
- wanting to spend a lot of time alone
- wanting affection on their own terms
- not readily understanding social rules - they may seem 'odd' or socially inappropriate
- ignoring or appearing insensitive to other people's needs, thoughts, and feelings
- difficulties making and keeping friends
- getting on better with adults or younger children rather than children of the same age; and
- finding 'having a chat' difficult, perhaps ignoring what is said to them, talking 'at' people, tending to interrupt or to needing prompting to know when to speak.

- **Communication**

This is about using spoken language and body language to communicate with people for a range of reasons. For example to request something, to point things out, to explain, to share a joke. Some children (those most severely affected by ASD) may never learn to communicate. Most will, and some may develop good language skills, but challenges may remain. These may include:

- using words and phrases repetitively
- speaking without always understanding
- copying what others say
- speaking voice sounding different to others, perhaps high-pitched or too quiet
- differences to others in facial expressions and gestures, and
- difficulties understanding what these mean in others; and
- forgetting what is said to them.

- **Behaviour and Flexible Thinking**

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

- moving their bodies in unusual ways such as stretching their fingers, flapping their arms or spinning round
- preferring to play alone or wanting to tell others what to do in 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 for example in IT, engineering, science and the law
- finding it difficult to see situations from others' points of view; and
- difficulties coping with change.

What causes ASD?

Nobody knows the exact cause 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 - which 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 hundred genes, rather than just a few.

There seem to be other factors that can be associated with ASD. More research is needed, but possible factors include low birth weight, difficulties in pregnancy and labour, blood and oxygen flow in the womb. Parenting is not one of these factors.

My child's individual report

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

- The **first section** will be an overview of your child's developmental history and include evidence from your child's life. This will include many different aspects of your child's life such as school, sleep, 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' (ADOS-2). The report will highlight in detail your child's strengths and areas of weakness, as observed in clinic.

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

What happens next with the report is up to you. With your consent, it can be shared with other professionals (such as 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. However, people with the diagnosis can be happy, proud, and successful. However, difficulties with development, learning, behaviour, emotional wellbeing, communication, and social life can be experienced.

Specialised treatments and approaches are always being developed. These can have a positive impact on a 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. Teachers are often experienced in working with children on the autism spectrum and know how to access further support and training. This is often via the Specialist Teaching and Learning Service. To help them do this, you may be asked to give consent for them to talk about your child at a Local Inclusion Forum Team (LIFT) meeting.

- **Behavioural therapies**

These may help a family cope with any behavioural issues associated with ASD. They may also be helpful to teach your child social skills.

- **Medicine**

For some children medication can be an option to help improve specific symptoms, for example obsessive or agitated behaviour.

How can I support myself and my child?

The experience of having a child diagnosed with ASD is different for everyone. Some people feel upset, some surprised, others feel relieved that their child's difficulties have been identified, and others can feel frustrated and helpless. Whatever your reaction is, it is perfectly natural and nothing to be ashamed of. 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 difficulties have been identified. Identifying their difficulties early will help your child and allows you to be equipped for the years ahead.

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

Look for a support network. Please refer to the sources of local support provided on a sheet with this leaflet. Family and friends can provide invaluable help.

You will be offered the opportunity to attend an ASD information day following your child's diagnosis. These run twice a year in Canterbury. Currently during the pandemic, the presentations are available online: www.ekhufft.nhs.uk/patients-and-visitors/services/child-health/community-child-health/children-with-autism-spectrum-disorder-asd/

Parent programmes lasting around six weeks are also generally offered to families. For those with pre-school children, this is usually the EarlyBird Programme. Cygnet is available for parents with school-aged children. These programmes are coordinated by different services in different areas

How can I support my other children?

You may feel that your child with ASD takes a lot of your time and attention. Siblings might feel this way too. When possible:

- make time for siblings
- do some activities with them separately
- allow siblings to have time to themselves, for example a sleepover at a friend's home or their own TV time
- allow siblings to bring their own friends home and enjoy themselves without interruption
- listen to their worries, concerns, and the things that are important to them; and
- listen to their ideas; older children in particular 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 cannot.

Siblings' Group

In order to provide support for siblings of children with ASD, we run small groups at various times throughout the year across East Kent in Canterbury, Ashford, Dover, and Folkestone.

The siblings' group is for children aged 7 and above. There are four group sessions which take place across four weeks. It is run by two or more staff members. It aims to increase children's understanding of ASD, gives them the chance to express their feelings, and to meet other children who share experiences.

If you would like more information, or feel that your child would benefit from joining the siblings' group, contact Psychological Services via the number on the top of your report.

There are other services which support young people who can be taking on additional caring roles at home. You may want to find out what is available locally. Talking to the Carers' Trust and IMAGO (a local social action charity) would be a good place 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 can have a good eye for detail. They may be good at learning and recalling factual information. Many people with ASD have successful careers in science, engineering, technology, and working with animals.

People with ASD may have similar traits and similar skills to each other. However, they are just as individual as other people without ASD. Each person with ASD has their own likes and dislikes, their own strengths and weaknesses, and 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.” - SL 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 outweigh 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 people with ASD are talented and successful. Here are just a handful of people who have (or in the case of historical figures, are believed to have had) ASD.

- Albert Einstein and Issac Newton, influential scientists (proposed by Ioan James, Royal Society of Medicine, 2003)
- Susan Boyle, singer (as quoted in the Guardian, 2013)
- Daryl Hannah, film actress (as quoted in the Guardian, 2015)
- James Durbin, American Idol contestant (as quoted in Autism Speaks, 2013)
- Ladyhawke, singer (as quoted in the Independent, 2008)
- Danny Beath, award-winning landscape and wildlife photographer (as quoted in Shropshire Star, 2013)
- Jessica-Jane Applegate, swimmer (as quoted in Great Yarmouth Mercury, 2010)
- Derek Paravicini, blind British musician (as quoted on BBC, 2011)



EarlyBird course

“Whilst there is no cure for autism, and no magic wand, EarlyBird is the closest thing you could wish for.”

Parent who has attended the EarlyBird course

EarlyBird is a programme of group and individual learning opportunities, spread over three months, with supporting book information. It is run by local professionals, with experience and understanding of ASD, who have been trained to deliver the programme by the National Autistic Society.

The programme is for families of a pre-school child with a diagnosis of ASD. It aims to empower parents/carers, to support them in the period between diagnosis and starting school, and to establish good habits during the early years of their child’s development.

You may have been given information about how to access a local EarlyBird programme at your diagnostic appointment. You can ask about it further when you meet the Clinical Nurse Specialist.

The Cygnet Programme

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

In the Cygnet course, families are usually grouped with others who have similarly aged children, so that the sessions can be tailored to their age. The programme includes up to seven weekly two and a half hour sessions.

The course is designed to help parents’ and carers’ understanding of how their children see the world and what causes their behaviour. It gives practical advice and strategies, which can be used to help support your child and manage behaviour. The course covers sensory issues, communication, understanding behaviour, 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. Make language simpler 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 really want to.
- Notice what they are interested in and join them in that interest.
- Encourage joining in and taking 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 cannot go into detail here, but these ideas are all covered in the EarlyBird and Cygnet courses. You can also talk and think about them with other parents at various support groups. Please come along!

How can I use visual resources to help my child?

Sometimes children with ASD become overloaded with too much spoken information. One way of helping children with ASD to navigate their social world is to write a visual timetable, social story, or comic strip conversation. These include visual images to help understanding.

- **Visual timetables**

These are timetables or lists which 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 refer to the visual timetable, so that they know what to expect.

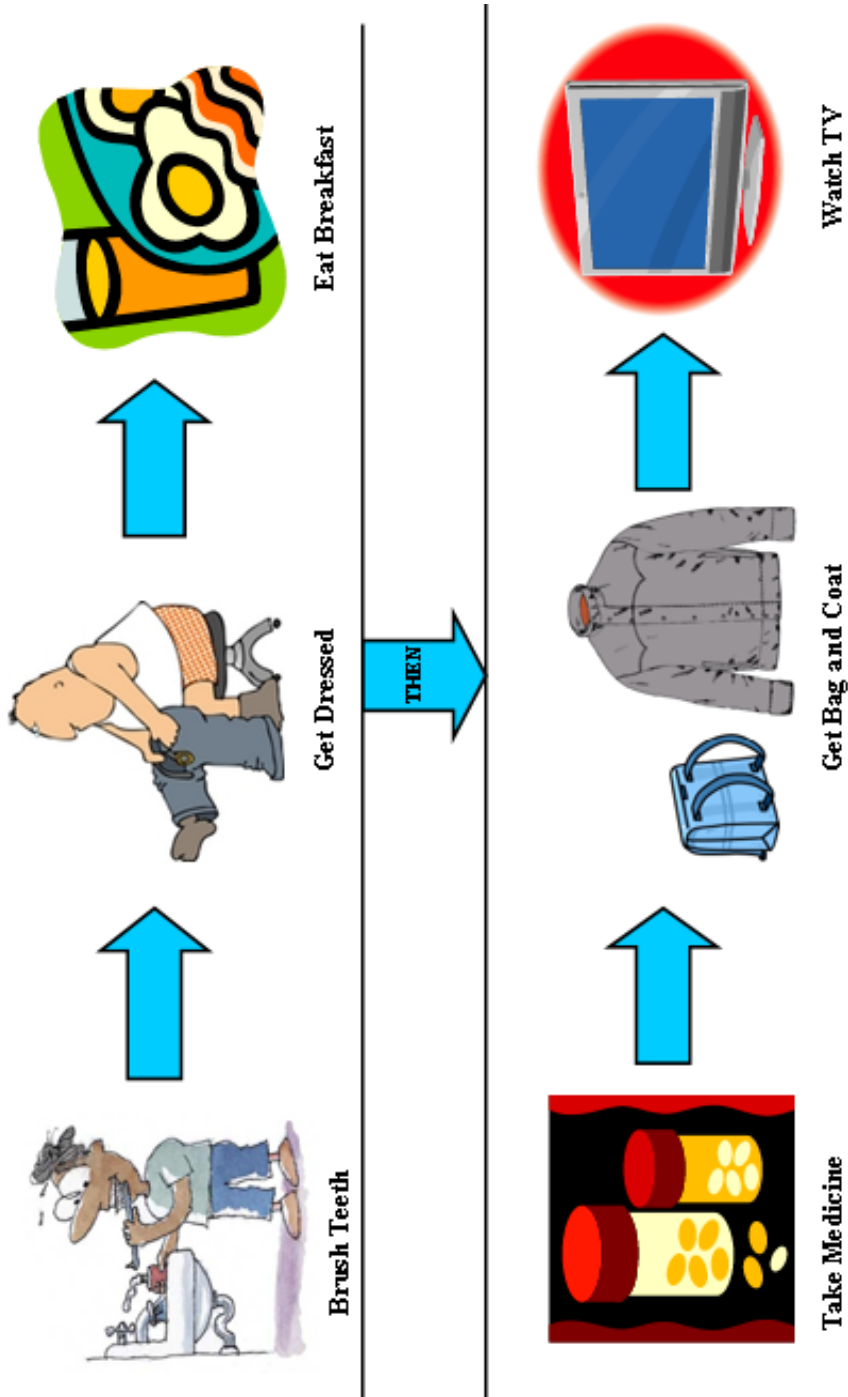
They can be used both for routines (such as their morning routine or school day), or for events which your child may be unfamiliar with, such as a special day or trip out. An example of a visual timetable is on the next page.

A simple visual timetable might include showing a single picture of what is happening next or a now/next board.

A countdown to the number of 'sleeps' to an event could be a visual support, to manage waiting which can be tricky for some children with ASD.

Learning to refer to school timetables and to use calendars supports and helps children as they grow up.

Jim's Morning Routine!



- **Social stories**

Social Stories are stories written for a particular child by a parent/ carer or a professional who knows the child well. The story will be specific to an individual child and looks at a difficult situation that they are either currently experiencing or need to prepare for (for example encouraging them to use the toilet correctly or what will happen as they go through puberty). Rather than being a list of things for the child to do or not to do, the Social Story communicates a message in an engaging manner using an appropriate level of visual support.

It is important that the story is based around the child (using 'I' in the first person). This makes it clear that the story is about them and not someone else.

The story uses two different types of sentences:

- **Descriptive sentences** which are factual and correct (for example Christmas Day is the 25th December or everybody gets ill sometimes).
- **Coaching sentences** are a response (or responses) for behaviour in a particular situation. It is always positive and allows for mistakes. 'Try' is used rather than 'Must', to allow for mistakes. For example 'I will try to cover my mouth when I cough' or 'I might like to play outside during lunchtime'.

The story can then be read in a calm place, to prepare them for the situation.

For more information and examples, visit www.carolgraysocialstories.com/social-stories or siobhantimmins.uk

- **Comic strip conversations**

Comic strip conversations can help to increase social understanding for those whose ASD is higher functioning. They are a visual conversation that uses symbols, stick figure drawings, and colour.

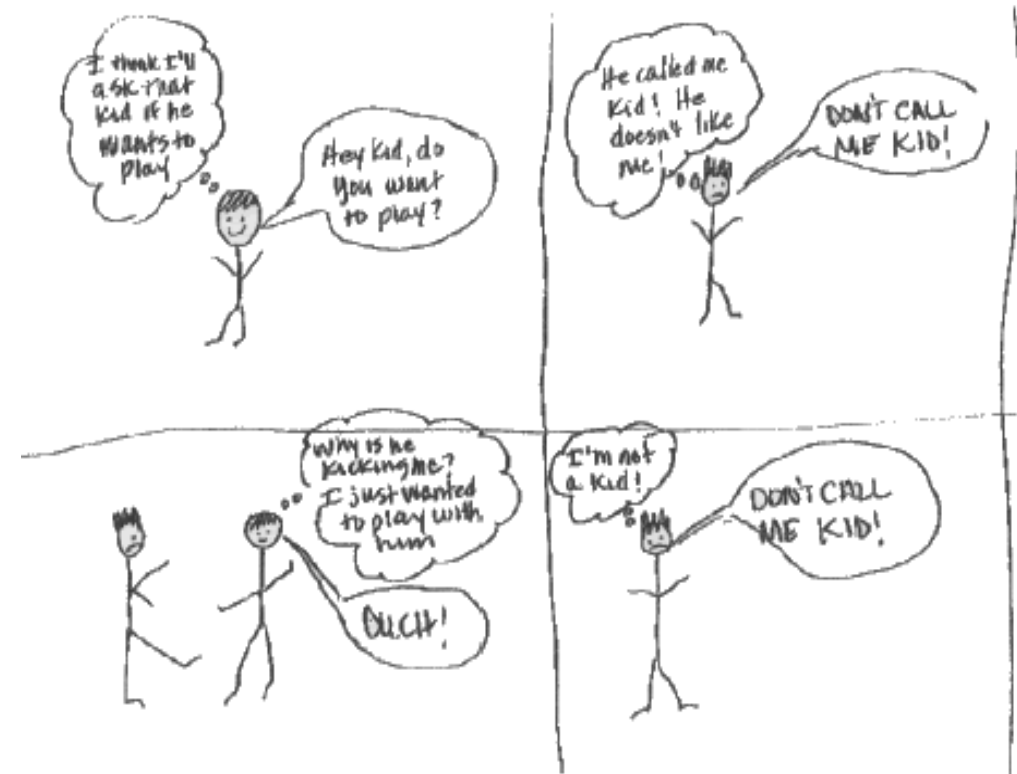
By presenting this visually, some more 'abstract' aspects of conversation (for example, the feelings and motivations of others) are made more 'concrete' and easier to understand.

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

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

More information can be found on the following web site
www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/social-stories-and-comic-strip-conversations

Comic Strip Conversation: Example



Tom called me kid because he didn't know my name, but wanted to play with me. The next time Tom or someone calls me "kid," I'll tell them my name and that I don't like to be called "kid." I'll apologize to Tom and tell him my name is A.S. I will also tell him I don't like being called "kid," and please don't call me that again.

National support and information

- **National Autistic Society (NAS)**

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.

Helpline: 0808 80 04 104

Web: www.autism.org.uk/

- **Independent Parental Special Education Advice (IPSEA)**

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

Web: www.ipsea.org.uk

What support and information groups are in East Kent?

You should have been given an information sheet about the services available in your area, along with this booklet. By making contact with these services or groups, you will be able to meet up or speak to 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
- A 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
- The Cradle of Thought: by Peter Hobson
- 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 (1): by Alis Rowe (available online: thegirlwiththecurlyhair.co.uk/)

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

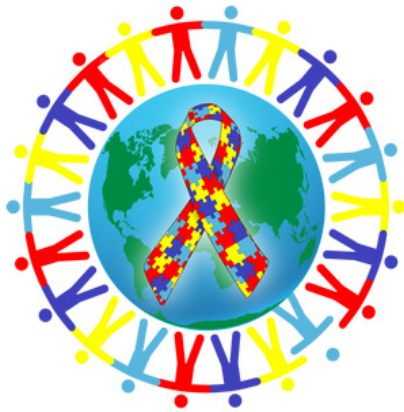
For siblings

- Everybody Is Different (Fiona Bleach)
- I'm a teenager get me out of here (Carolyn Brock)

These are just a few of the books available. For more books on specific areas relating to ASD, browse the internet or visit the NAS website for more publications and articles.

Online resources

- **The Curly Hair Project, Alis Rowe**
Web: thegirlwiththecurlyhair.co.uk/
- **National Autistic Society: Too Much Information**
Web: 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 have been made additional appointments for further support or you will have been discharged. The clinical nurse specialist will have discussed this with you and made sure you were happy with the decision.

We usually hold an information day for parents/carers of children with ASD twice a year. You will receive an invite to this by post. During the pandemic, the presentations from this day are available online: www.ekhuft.nhs.uk/patients-and-visitors/services/child-health/community-child-health/children-with-autism-spectrum-disorder-asd/

You will have been given information on how to access a longer parent programme (EarlyBird or Cygnet).

ASD is a lifelong condition and sometimes you may want additional 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 or, for older children with mental health difficulties alongside their diagnosis, it may be the Child and Young People's Mental Health Service, or another service.

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

Notes

Please use this space to write down any information you may want to take away with you from your appointment, such as phone numbers, details of courses, and names of books. You might want to use it to jot down questions in preparation for your appointment with the clinical nurse specialist.

We hope this leaflet helps your understanding of your child's diagnosis. We know that 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.