

Autism at a Glance

A Guide for Parents and Carers

Young people with Autistic Spectrum Conditions (ASC) have complex needs and each individual is unique. However, there are some key points that all parents may find useful. There is lots of literature available on ASCs - this handout is to serve as a quick reference guide of the key points, mainly surrounding communication and managing behaviour.

Remember you are the expert on your child, this is just to serve as guidance and may support you with living with your child with ASC.

There are a few suggestions and tips within this guide. Try one or two things at a time - do not try to change everything all at once. Refer back to this guide as you need it. Some suggestions will work and others may not but do give them a try.

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COMMUNICATION

In order to have a diagnosis of ASC the individual must have 'impairment' in communication. Therefore it is important to consider how we are communicating with children. Often people can be misled into thinking that those individuals who are very verbal have good communication skills. However, these individuals will often have difficulty with comprehension, expressing their thoughts and feelings and understanding others language (including body language).

Be specific - say exactly what you would like them to do

Example:

Try to avoid saying: "*Sit nicely at the dinner table*"

Try to say: "*Stay sitting on your chair, use your knife and fork, don't shout*" etc

Avoid asking open-ended questions

Give choices if possible or ask questions with a definite answer ('yes' or 'no')

Example:

Try to avoid asking: "*What would you like for dinner?*"

Try to ask: "*Would you like pizza or burgers for dinner?*"

Avoid using sentences that can be misinterpreted.

Individuals with ASC will often take things literally.... If you tell them to "*pull their socks up*" ...they will probably bend down and pull their socks up. If you say "*I need you to try and work harder at school*" ...they may try and work harder at school. We often use non-literal language without realising e.g. "*were going shopping in the car*". If the individual with ASC seems confused think carefully about what you have said and what it might mean to them.

Try not to keep rephrasing sentences or questions.

If necessary repeat the question in the same way as it may take an individual with ASC longer to process the information or to give you an answer. If they still indicate that they do not understand then you may need to rephrase it in a simpler sentence or using verbal cues.

Positive Phrasing

When speaking to your child try to phrase things in a positive context. Tell them what they **should** be doing rather than what they should not be doing. By doing this you are taking the negativity out of the situation and telling them exactly what you expect.

Example:

Try to avoid saying: "Don't shout!"

Try to say: "We need to talk quietly"; "can you show me how quietly you can talk"; or "Can you use your indoor voice?"

Try to reduce the amount of language used if the YP is becoming stressed or anxious.

Often their ability to process language is impaired at this time and you will just cause them to become more distressed. Try to use simple, directive sentences. Again do not try to rephrase things in this situation and do not try to argue or reason. It is best to wait until they are calm.

Example:

Try to avoid saying: *"Tell me what's wrong? Why are you doing this? Maybe you need you to calm down, because you are getting really loud and your scaring your brother. I think you need to calm down and go to your room. Then once you have calmed down you can come out here and then I will talk to you and then you can tell me why you are doing this... Etc, etc"*

Try to say: *"Go to your room to calm down – then I will come and talk to you"* or even simpler if needed. Repeat this sentence.

Call their name first

When giving instructions or directions, ensure that you have their attention before giving the instruction. Call their name first and ensure they are listening and then give the instruction.

Keep it Simple

Where necessary keep language and sentences simple. Obviously it is important not to appear patronising to the child and to encourage their language. However, it is also important that you are understood. Try to keep instructions and directions as simple as possible and break them down if needed.

Body Language

Try to ensure that your body language matches the message you are trying to relay. Individuals with ASC find interpreting body language and facial expressions difficult at the best of times, but if you are not matching the two up this may lead to further confusion. By ensuring that our body language and words are conveying the same message it will support them to develop these skills.

Example:

If your child has done something well ensure that you are smiling when you praise them. If you are speaking to the child about inappropriate behaviour, try to avoid laughing (even if it is quite amusing)!

Encouraging Communication

Some children may not have developed language at all. It may be helpful to use a small number of single words regularly when they are doing activities they enjoy, e.g. "jump" when they are on the trampoline or "Thomas" when

they reach for their favourite toy. It may be useful to use phrases such as “ready steady go” before doing something fun. After some time you may be able to just say “ready steady...” and find that the child will say “go!”

BEHAVIOUR

Young people with ASCs will often display various forms of challenging behaviour. This is often caused by anxiety or an inability to be able to communicate their needs. Where possible include them in plans and strategies. They are more likely to work if they are involved in the implementation.

A large percentage (not all) of children with ASC will reach '**crisis point**' at some point. You may have your own phrase for this time e.g. rage, melt down, tantrum, outburst. They all refer to that point where your child has 'lost control'. You will have no doubt learnt through experience that once your child has reached 'crisis point' there is no reasoning with them or calming them until the anger or distress has passed. Some individuals describe going blank during these times and not being able to remember what has happened. It is best to support individuals to avoid reaching this point of distress.

Prevention rather than reaction is the key to managing behaviour.

We can look at this behaviour in 4 different stages:

Triggers

In this stage you can support them to cope with or avoid the triggers.

Build-up

This is the stage where the aggression begins to build. The individual signs will be different for each child but they may show behaviours such as, picking at their clothes, pulling a certain facial expression, pacing, or tapping objects. At this stage you need to support the child to calm and avoid getting more distressed. This period can be very short and quick for some children.

Crisis Point

There is nothing you can do at this point but give them space and time to calm. You should avoid verbal interaction but ensure that the child and others around them are safe.

Recovery

What the child needs to do in this stage is again unique to the child. Some individuals will sleep, others will become quite withdrawn and some may carry on as if nothing has occurred. This stage should be managed carefully to avoid the individual re-entering the Crisis Point stage.

It may be helpful to do an activity where you identify your child's behaviour at each stage and what are the most beneficial actions to take at these stages. It is useful to complete this with other family members and your child if appropriate. It will help to raise awareness and encourage you to think about the different stages. It may also be helpful to share this with other professionals supporting your child. Once again remember that you are the expert on your child and that professionals will benefit from hearing your opinions and knowledge of your child.

Included are some strategies that may help at the first three stages.

TRIGGERS

Identify triggers

As parents you will know your child best and you will be aware of what triggers episodes of challenging behaviour. If you are not sure what these triggers are it may be worth keeping a note of what has occurred before each episode, to see if there is any pattern. Common triggers include:

- Loud noises (and other sensory over-stimulation)
- Anxiety (for various reasons)
- Not having their requests met
- Things not going exactly as they had planned them to
- Not being able to communicate their needs or understand what they are being told

The triggers for your child will be unique to them. You should discuss these with other professionals involved with your child so everyone has an awareness of these. Once you have identified the trigger you then need to plan how to approach these situations

Preparation

It is always important to be as prepared as possible when supporting a child with ASC. If you know that an event or an activity is likely to cause them to become distressed try to prepare them as much as possible. This could be done in a variety of different ways including:

- Giving them photos of a new situation
- Giving as much warning as possible (unless this is going to cause more distress – you know your child the best)
- Introducing new ideas slowly – ‘drip feeding’ them information
- Talking them through an event, giving them as much detail as possible... what it will look like, what it will smell like, who will be there, how it will feel
- Use visual prompts if appropriate
- Tell them what is expected of them....using positive language
- Gradually get them used to a situation e.g. if they do not like change, start to introduce small changes at a time when they are calm and secure. It can be helpful to introduce a phrase such as “change is good” whilst they are enjoying a positive change. You can then introduce the same phrase to calm them during unexpected changes.
- It is best to try to get the child used to a situation especially if it something that they will continue to encounter throughout life. However, if it is something that can continue to be avoided or it is not possible to do this, try to avoid the situation (e.g. if lifts make them anxious... take the stairs!!)

Structure/Routines

Children with ASC respond better in environments that are controlled, predictable and calm. By creating a calm atmosphere in the home you are supporting your child to feel reassured. Understandably, home environments are not always calm and structured and there can be an element of chaos at times. However, it is important that wherever possible you introduce a routine and structure, this is particularly important at times such as bedtimes, dinner

time and in the morning (getting ready for school). If possible it may be beneficial to depict these routines visually.

BUILD-UP

Calming techniques

You will know what calms your child. If you can implement these at the first signs of them starting to get agitated this will help. Some examples are:

- Doing a certain activity, e.g. listening to music, walking, drawing etc
- Counting
- Going to a certain area e.g. their bedroom, the garden, or a low stimulation area such as a table with a blanket over it
- Singing
- Playing with a certain object/toy

You will know your child and what activities and items help to calm them. It is important that you give them access to these in times when they may be more stressed or anxious.

Redirection

This is an effective tool if used correctly and at the right time. You will know when the best time to use this with your child is. When your child is starting to get distressed and showing signs of agitation try to redirect them to another activity. This obviously works best if it is an activity they enjoy. It may simply be talking about a subject that they enjoy and feel comfortable talking about. For example, if a child is interested in cars try: *“Wow, look at that car!”* or *“I saw an amazing car yesterday....”*

CRISIS POINT

Ignore/Praise

As with any child if they appear to be displaying inappropriate behaviour to get attention or a certain reaction from someone then it may be appropriate to ignore the behaviour. However, you will first need to determine why they are displaying the behaviour if it is because they are anxious or trying to communicate then it will not be appropriate to ignore them. If you decide that the behaviour needs to be ignored you should:

- Withdraw all verbal interaction
- Observe them for their safety
- Intervene physically but not verbally if they are displaying dangerous behaviour (e.g. taking a toy off them if they are about to throw it at someone but do not talk to them)
- Remove yourself from the room (if appropriate and safe)
- Praise them as soon as they start to display appropriate behaviour
- Ensure that you are giving them attention for all positive behaviours (even if this is just sitting still if that is what you would like them to do).

Be in control

It is important that your child sees that you are in control of the situation at all times. Even if you do not feel in control it is beneficial to keep an air of control. This will help to reduce your child's anxiety and may reduce or lessen the impact of outbursts and challenging behaviour. It may be helpful to think beforehand what action you will take if your child was to have an 'outburst' and try to think one-step ahead of them. It may also be helpful during the

outburst to take a step back take, take a deep breath and decide what you are going to do.

OTHER STRATEGIES

Visual Aids

Visual aids are extremely beneficial with children with ASC and can help to reduce their anxiety and support their communication. The home environment is not as predictable as a school environment and with all the other pressures at home it is more difficult to implement structured visual tools. There may also be the issue of access to symbols and photos etc. However, if you use your imagination you will find ways to use visual prompts at home. Be creative and think outside the box. Don't be afraid to try new things to see if they work, you know your child the best. There are lots of tools out there to support so be prepared to research things or talk to other parents and professionals to get ideas. Some examples of approaches are:

- Use everyday objects from around the house to signify what activity will be happening next e.g. a sponge at bath time, cereal bowl for breakfast
- Cut pictures out of catalogues or magazines
- Take photos of places or your child doing activities.
- Draw pictures
- Use pictures to show that if they have to do an activity they do not enjoy a positive one will follow e.g. 'shopping' then 'park'
- If your child is able to read simply write down the order that you will be doing things e.g. if you are taking a trip to town write down the order that you will be doing things in and allow them to carry this around. It may be that they are not willing to change this ... so plan carefully!
- Using visual aids as a reminder of what is expected of them e.g. create place mats with dinner time reminders on them; having a sign reminding them to wash their hands near the toilet
- You can use photos of a child at different stages of completing a task to help them to learn to do it independently

Timers

People with ASC often have difficulty understanding the concept of time and may find it difficult to wait or to understand when things are happening. They may also take things very literally for example if you say "I'll just be a second" they will be expecting you to just be a second!! These tips may help:

- Try to give them something concrete (and preferably visual) to measure time against. You could use a stop watch, egg-timer, clock or by asking them to wait until the end of a television program or until they have counted to a 100!! By giving them something definite and measurable you will reduce ambiguity and anxiety and give yourself a bit of time and breathing space
- Try to stick to the times that you give. This will help the child to trust that you are going to do things when you say you are going to do them and again help to reduce their anxiety
- Over time try to increase the amount of time that you are asking them to wait for. Ask them to wait for 1 minute (or 5 seconds if needed) once they have grasped this increase the time to 2 minutes and so on
- Ensure you are using clear language to convey this

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- Give them something to do in this time (even if it is just watching the egg-timer for 3 minutes)!! So that they know what it is expected of them or what they need to do

General Information

Living with a child with an ASC can be both rewarding and challenging for a variety of reasons. Some of the suggestions below are just some general advice that could ease the challenges.

Recognise and share strengths and positive attributes

It can sometimes be easy to overlook the strengths and positive attributes of a child with an ASC. People will often focus on their difficulties. It is important to shift this perspective. Whilst, we need to support children in overcoming their difficulties we also need to help to celebrate their strengths, achievements and positive traits. As a parent you are one of the key people in achieving this. You will be able to recognise your child's qualities and share these with others.

It is important to note that individuals with ASC usually have lots of strengths and can contribute greatly to the worlds of those around them. Children with autism are often honest, meticulous, logical, observant, able to excel in a specialist subject, have a good sense of humour, and can be affectionate at times. It is also important to recognise your child's individual personality as well and that they are unique, and have a great deal to offer.

What is Autism and what is just behaviour?

When managing behaviour in a child with ASC it is important to distinguish between what is behaviour due to their diagnosis and what behaviour could be considered as them being 'wilful', 'defiant' 'rude etc. This is a concern that a number of parents present.

It is important that your child learns that they do not get what they want by displaying aggressive and violent behaviour. While exceptions need to be made to allow for their differing needs, the child with ASC also needs to learn boundaries and consequences to support them as they grow older.

You know your child best. If you feel that they are displaying negative behaviour as a way of communicating it is important that you look at other ways of helping them to communicate. If you feel that it is because they are anxious and genuinely distressed it is important to help them to look at other ways of managing or reducing this anxiety.

However, if you feel that their behaviour is in order to get their own way or is a learnt behaviour it is important that you do not give in and stick your ground. Your child needs to learn boundaries and consequences as any other child. It is also important that they do not learn to use aggression to control situations as this will continue with them into later life.

Support can be gained from professionals or various support groups surrounding certain behaviours. It is important that you do tackle these behaviours. Whilst, it may seem like hard work in the short-term (and it potentially will be) it is important to see this through as it will be extremely beneficial in the long-term. Behaviours that are deemed as relatively acceptable when they are younger will not be viewed as such when they are older and will be more difficult to address at this stage.

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Sensory Issues

The majority of individuals on the autistic spectrum have sensory issues. This can be being under-sensitive or over-sensitive to different senses. This varies between individuals but common sensory impairments relate to hearing and touch (including touching others and different materials). However, all the senses can be affected

It is important to consider how these may affect your child, their ability to cope in different environments and their behaviour. You may need to avoid situations that are difficult for your child where possible (if it will be practical to continue to avoid this situation throughout their life) or support your child in being able to adapt and cope in these situations (especially if they will continue to encounter this situation as they get older).

Examples:

- Encourage them to wear earphones or listen to calming music in environments that are noisy
- They can wear sunglasses if lights are too bright
- Wearing clothes that are comfortable to them (speak to schools if this is an issue)

These are just examples and there will be other issues and coping strategies that you will discover with your child. It is worth speaking to your child about these issues and asking them what would help. You may observe certain behaviour in your child that you can relate to sensory difficulties.

Support groups

It may be helpful for you to seek support from support groups in your area. They can offer a chance to talk to other families and parents of children with ASC, offer practical support, have specialist speakers in and provide books and resources. See below for contact details for groups in your area.

Siblings

Living with a sibling with ASC can have a major impact on a child. It is important to consider the effect this may have and ensure that siblings are giving individual time and attention away from the child with ASC. It can be difficult to explain to siblings why their brother or sister is 'different' but it may be beneficial to talk about how everyone is different. It is also important to focus on the positives and strengths of each child.

Useful tools

There are some known strategies that can be effective when supporting children with ASC. Some well known strategies include: Social stories, Social articles, Comic strip conversations, Power Cards, and Visual Timetables. If you need some more information on these there are several books you can buy or contact professionals for more information.

Useful Contacts

Angels Support Group

A support group run by parents for parents and carers of children with a diagnosis of ADHD or an autistic spectrum disorder, or who are being assessed for the above.

The group offers support and advice to bring parents and carers together to share experiences and reduce isolation. They have a qualified group facilitator and professional guest speakers are also invited to help with new strategies for coping. Angels provide a service to North Herts and Stevenage residents.

Website: www.angelssupportgroup.org.uk

E-Mail: info@angelssupportgroup.org.uk

Contact Numbers: **07815 458355** (Leise Cooper - Enquiries)
07718 755167 (Jane Wareing - Enquiries)

ADDvance

ADD-Vance is a support group run by parents and carers of children with ASC and ADHD that operates in St.Albans and Herford areas. They aim to support parents/carers of children with ADHD, ASC and related conditions, as well as supporting adults and siblings. ADD-vance also work with families, teachers and other professionals to run workshops and training sessions to gain wider acceptance and understanding.

ADD-vance run a helpline to talk through issues and provide information and specialist behavioural coaching for families and individuals. They also hold monthly meetings in St Albans and Hertford. ADDvance provide a coaching service to families; refer to the website for more details.

Website: www.add-vance.org

E-Mail: herts@add-vance.org

Contact Number: **01727 833963**

National Autistic Society (NAS)

This Society aims to promote a better understanding amongst professionals and the general public of the difficulties that people with autism and their families face. It offers information, advice and support to people with autism, their families and carers.

Website: www.autism.org.uk

E-mail: autismhelpline@nas.org.uk, nas@nas.org.uk

Autism Helpline: **0845 070 4004**

Hertfordshire Autistic Resource Centre (HARC)

This is the Hertfordshire branch of the National Autistic Society (NAS). They provide information and support to individuals and their families and campaign for better local services for those affected by Autism Spectrum Condition.

HARC supports people of all ages, across the full autism spectrum.

HARC runs support group meetings on a variety of topics of interest; refer to the website for further details.

Website: www.harc-online.org.uk

E-mail: support@harc-online.org.uk

Contact Number: **07836 667 394**

Hertfordshire Additional Needs Database (HAND)

This is a database of children or young people (0-19) with an additional need or disability. If you choose to join you will receive a card. This can be a way of getting assistance and understanding for their child in many different situations. Some establishments will offer discounts to individuals with HAND cards. By joining you will also get a subscription to the HAND news letter that provides lots of information on new and changing services, play schemes, holiday schemes and welfare benefits.

Any child can join that is aged 0-19 with has an additional need or disability which have a substantial impact upon their everyday life. Registration is optional. If you are interested in registering you can register on-line (see details below). If registering online isn't for you, look out for the paper membership form at GP practices, schools, health centres and clinics.

Website: www.hertsdirect.org/hand

E-mail: hand@hertscc.gov.uk

Contact Number: **01992 556984**

Parent Partnership

Parent Partnership offers advice and support to parents of children with Special Educational Needs. They offer the following support:

- To help parents, schools and other professionals listen to each other, work closely together to meet the child's educational needs
- Offer local confidential helplines to discuss your child's needs
- Give impartial information and guidance on special educational needs to parents, carers and professionals.
- Try to help if there is a disagreement with the school or local authority about the way a child's needs are being met.
- Do their best to find other relevant statutory and voluntary services if you need further support.

Helpline: **01992 555847** (8.30am to 5pm Mon-Thurs, 8.30 to 4.30pm Fri)

E-mail: parent.partnership@hertscc.gov.uk

Specialist Advisory Service

This is a service provided by Children, Schools and Families and consists of a specialist Autistic Spectrum Disorder service. The team consists of Advisory Teachers and Early Years Autism Specialist. They offer advice to educational settings on how to support children with ASD. A referral to the service is made through the Child Development Centre if they are in an Early Years Setting and by the school if they are of school age. Parents cannot directly make a referral to the service but there is a helpline available for parents to contact during school time if they need advice and support. Children will need a written diagnosis to access the service.

The Helpline cannot handle large volumes of calls and so it may be more appropriate to use some of the other services above. If you are having difficulties with your child's school it is advised that you speak to parent partnership.

Helpline: **01707 320697**