

Children and young people on the autism spectrum

Advice and support pack

Who is this pack for?

This pack is intended as an introduction if your child has recently been diagnosed as autistic. Friends, family and anyone working alongside an autistic child will also find this guide useful.

This guide provides a general overview of autism and explains some characteristics autistic people have.

It also provides some strategies that you can implement at home to help you and your child. This information should be used alongside information from the National Autistic Society website and any healthcare professionals involved.

The content for this support pack is based on “The NICE Guideline on the Management and Support of Children and Young People on the Autism Spectrum.” This guideline uses the experiences of parents who have an autistic child to inform their recommendations.

Parent Carers Together

This advice and support pack has been created by professionals working in the Child Development Centre (CDC).

As it was designed to help families better understand their autistic children, we felt it was important to collaborate with 'actually autistic' adults and young people. We achieved this by consulting with Parent Carers Together, the official parent and carer forum for Bournemouth, Christchurch and Poole, to gain access to autistic voices and to ensure the pack includes the important information local SEND families will need to know during the early stages of their child's diagnosis.

Additionally, many forum members' children have been assessed by the CDC, making their experiences and advice valuable.

We have proudly incorporated their contributions into the final version of this pack.

Language

There are lots of different terms and preferences surrounding autism language. We sought local opinion when creating this document and found that much of the autistic community prefer the term 'autistic person'. After carefully listening to their thoughts and opinions, we decided to maintain this language throughout the advice pack.

You may hear other terms such as 'person with autism', 'person with autism spectrum condition' or 'person with autism spectrum disorder'. Ultimately autism is an individual diagnosis and it is important to ask autistic people their language preference. There is more information about autism language at the end of this advice pack.

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What is autism?

Autism is a lifelong neurodevelopmental condition that brings both strengths and challenges to autistic people. Autism impacts the way individuals experience and interact with the world. The clinical diagnostic criteria summarises autism as difficulties with social interaction and communication. However, it doesn't discuss how autistic people face the additional challenge of non-autistic people often not understanding how they think and feel.



The Spectrum

When people talk about autism they might say 'on the spectrum'.

Autism is considered a spectrum because every autistic person is different.

People used to think of the autistic spectrum as being 'more' or 'less' autistic.



Now, we think of the autistic spectrum as being much more varied. Each individual has different strengths, differences and needs in lots of different areas. More like a circular spectrum than a line.

An autistic child's capacity fluctuates (changes). This is the reason they can do something one day, but not the next.

Their ability to do something depends on a lot of different factors including:

- how stressed they are (their emotional state)
- how tired they are
- how noisy their environment is
- if they're hungry or thirsty
- if they are in any discomfort (their sensory state)

Children do well if they can. It is important to accept that some days they can and other days they don't have the capacity.

The way we view autism is very important. It can have a huge impact on the way we behave towards and support autistic people. We can talk about autism as a difference not deficit.

www.youtube.com/watch?v=h-bc1CJlhbM&t=12s

We can think of these differences as being like two different operating systems. For example, iPhone and Android, or Xbox and PlayStation. These phones or games consoles both do the same job, but they operate and process things differently. One is not any better than the other.

<https://autismunderstood.co.uk/what-actually-is-autism/introduction-to-neurodiversity>

It is not yet clear what causes autism. There is evidence of a genetic link, which means it can affect people in the same family. Autism is not caused by:

- bad parenting
- vaccines, such as the MMR
- diet
- an infection

Autistic girls

Autism in girls may look different to autism in boys. Autism was previously regarded as a male condition, with girls often being misdiagnosed or underdiagnosed. Girls are often better at masking their autism and their interests may be more similar to other girls, therefore their autism may go unnoticed for longer. They also may be more involved in social play and have a better imagination.

Please see the below short film about what autism is:

www.youtube.com/watch?v=RbwRrVw-CRo

Autistic Girls Network:

<https://autisticgirlsnetwork.org>

Camouflaging

Camouflaging (also known as masking) is a term used to describe when autistic people consciously or subconsciously hide or mask their autistic traits to 'fit in' among non-autistic people. It can be incredibly draining to maintain this and extensive camouflaging is linked to lower mood and wellbeing.

Sometimes autistic people may:

- refrain from talking about their special interests, this can be upsetting for them
- make eye contact even though it feels uncomfortable
- suppress repetitive behaviour/movements even though it helps to calm them down or they enjoy it
- push through intense sensory discomfort to hide sensory challenges
- say they're ok when they're not, to avoid attention and blend in
- act like other people to fit in and avoid being spotlighted
- people please - doing things to make others happy even if they don't want to
- disguise the reasons for their behaviour by taking on a role like the class clown, the loner who doesn't care what anyone thinks, etc.

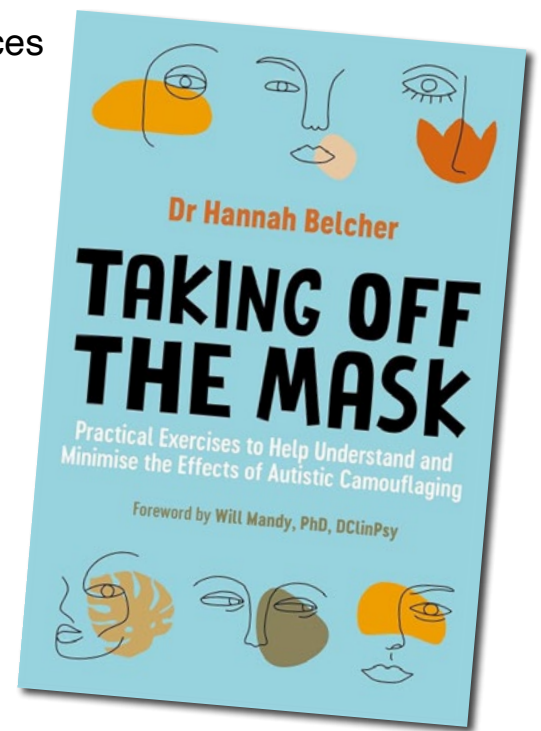
Signs of maskers:

- Often quiet (but not always!)
- Perfectionist tendencies
- Reluctant to ask for or access support because they don't want to appear different
- Seem fine at school and then have meltdowns or shutdowns at home
- Rehearses conversations and use rehearsed answers

How to help your child who is masking:

- At home - build in downtime each day where they don't have to mask. Maybe include sensory activities or space to focus on their special interests.
- Plan out your child's week based on how much energy they have and how much energy each activity will use up. They are then less likely to burn out.
- Work with school to find regular opportunities during the day for your child to unmask.
- Remind yourself that regular meltdowns or shutdowns after school are a sign your child feels safe enough to drop the mask at home.
- Learn more about autism and support your child to understand their diagnosis in a personal and positive way.

- Support your child to figure out their own preferences and advocate for themselves, rather than just following others.



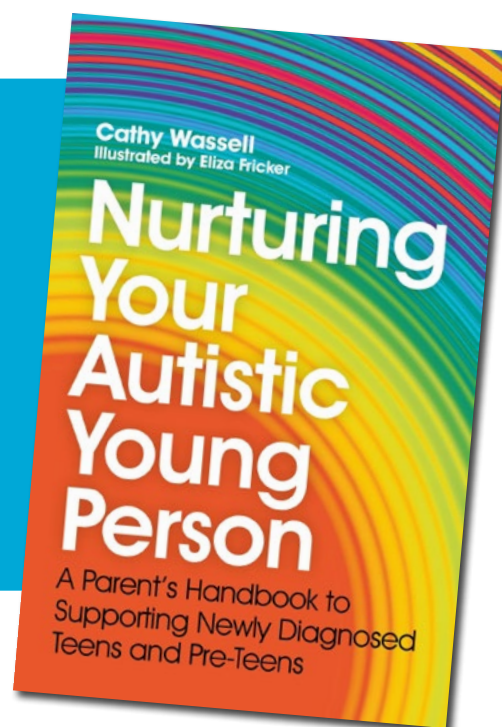
The dangers of camouflaging

- Some autistic people are so good at camouflaging they aren't diagnosed until later in life. This is becoming increasingly common with girls.
- Camouflaging is incredibly draining and exhausting. People who camouflage can lose sight of their sense of self through pretending to be someone they are not.
- Camouflaging throughout the school day can lead to breakdowns at home.
- Evidence suggests there is an increased risk of depression, anxiety and suicidal thoughts in people who frequently camouflage.

Autism in adolescents

Teenage years can be a difficult time for both the adolescent and their parents. Teenage years can be particularly challenging for autistic people.

To support parents with older children who are at the identification stage. Walking them through the basics in an accessible manner, addressing key challenges, including co-occurring conditions, puberty, and safeguarding, as well as looking to the future. Advising on schooling options and beyond. This is a guide with a focus on difference - not deficit.



Late diagnosis

- While many autistic children are diagnosed in early childhood, some are diagnosed later in life.
- It might not be until they're at primary school or secondary school (or even adulthood) that the question of autism comes up.
- During the adolescent years, social and behavioural differences can become more obvious.
- The diagnosis itself **won't change your child, or the way that you think or feel about your child**. It might help you and your child understand your child's strengths, challenges, needs and differences.
- A diagnosis describes your child's strengths and abilities. It can help to tailor support for your child and help with getting services and funding for things such as extra help in school.

Autism and empathy

The myth

One of the most well-known stereotypes about autistic people is that they lack empathy. There is the belief that autistic people are unable to feel emotions the same way that neurotypical people do. They can therefore be perceived as cold and unemotional.

The reality

The reality is that this is an extremely unhelpful and inaccurate perception. Autistic people can feel emotions just as strongly as non-autistic people. They may even experience emotions too strongly and become overwhelmed and unsure of how to react. It may be that their genuine, empathic responses are misunderstood by others (see the double empathy problem).

The double empathy problem

This theory suggests that people with very different experiences of the world (autistic people and people who are neurotypical) find it relatively difficult to empathise with and understand each other. This is due to their different ways of thinking and how they experience the world.

Mental health and autism

Research is increasingly suggesting that autistic people are more likely to experience mental health problems (see the table below). Potential reasons for this are outlined at the bottom of this page.

	Autism Population	General Population
Anxiety Disorders	20%	7.2%
Depressive Disorders	11%	4.7%
Sleep-wake Disorders	13%	3.7%
Obsessive-Compulsive and Related Disorders	9%	0.7%
Hallucinations	6%	3.8%
Bipolar and Related Disorders	5%	0.71%
Schizophrenia and Psychotic Disorders	4%	0.46%

Why might autistic people experience mental health problems?

- Difficult interactions with non-autistic people
- The exhausting impact of masking their autistic traits
- Negative social interactions and lack of social support
- Difficulty regulating emotions
- Sensory sensitivities
- Challenges with daily living skills can cause further stress
- Neurodivergence (thinking differently to non-autistic people) presents its challenges and strengths. These strengths may not be recognised or valued by others.

<https://camhsdorset.org/about-camhs/mental-health-support-teams>

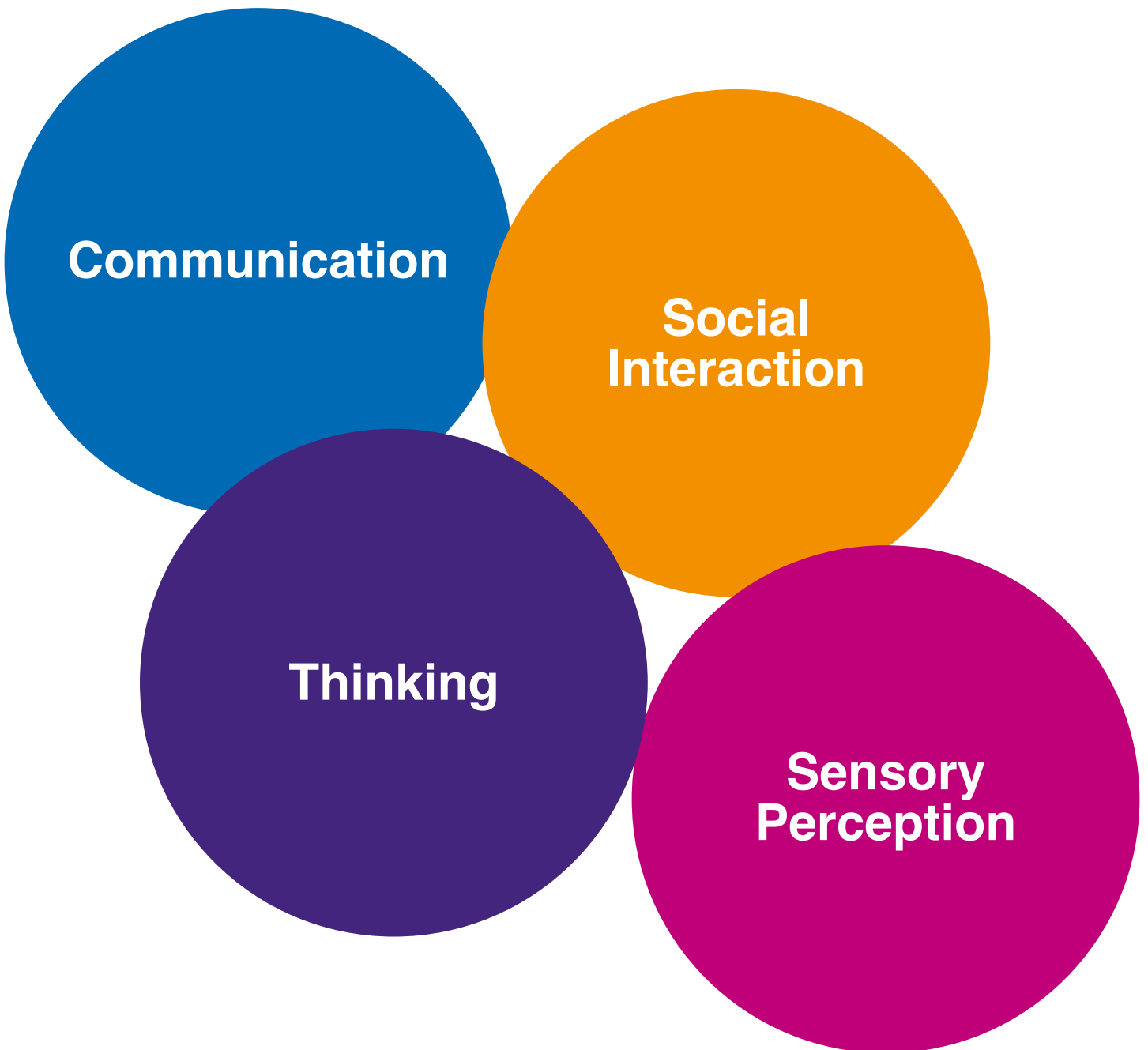
Neurodiversity and celebrities

It's also crucial to emphasise and celebrate the countless success stories of autistic and neurodiverse individuals. As you can see below, there are many talented celebrities who are neurodiverse.



Characteristics

Every autistic person has different strengths and challenges. However, there are some similar characteristics frequently found in autistic people. Your child may experience differences in: communication, social interaction, thinking and sensory perception. An autistic person's ability to adapt to their environment changes from situation to situation depending on many internal and external factors.



Communication

Processing and understanding everyday communication can be challenging for autistic people. Some autistic people may never speak, but communicate using other methods such as: pictures, sign language, or by using an iPad. Some autistic people may have good language skills, but they have challenges understanding things such as facial expressions, tone of voice, body language and sarcasm.

Below is a table showing what you might notice in some autistic people, and explaining why they might behave in this way.

What might I see?	Why might I see this?
Communicating without speaking (nonverbally)	Some autistic people never speak, but communicate using other methods
Taking a long time to respond to questions	Some autistic people experience processing delays and need more time to respond
It might look like they are not listening	Eye contact can be difficult, giving the impression that they aren't listening
Repeating phrases from films or other people (echolalia)	These are often attempts to initiate communication

Echolalia

People with echolalia repeat noises and phrases that they hear. In many cases, echolalia is an attempt to communicate, learn language, or practise language.

Below are some tips you can use to use when communicating with your child. This can help them to understand and make communication easier and less stressful for them.



Keep verbal communication short, clear and concise

It's okay if your child doesn't look at you, know that they may still be listening even if it doesn't look like it



Use visual information to support verbal information

Check their understanding



Allow for extra time for them to process information

Use what interests them to build their trust and engage them in conversation



Make sure you have their attention by using their name before speaking to them

Encourage choice making. Show two visual items and encourage your child to pick what they want



Social Interaction

Autistic people can find social interaction exhausting and confusing. They may not want or need much face-to-face social interaction and can be overwhelmed by large groups. They may find it more difficult to make friends, often due to their difficulty understanding unwritten social rules and cues.

These unwritten rules can be unpredictable and confusing for autistic people. Some autistic people may prefer to have **routines** so they know what is going to happen. This predictability is reassuring for them.

Some autistic people may engage in **repetitive behaviour** and movements such as rocking or hand flapping (also known as **stimming**), often this helps them to calm down when they are stressed or anxious. Some autistic people simply do it because they like how it feels and it is enjoyable.

Preventing them from engaging in repetitive behaviour can cause stress and anxiety. If you do try to prevent this, it is likely they will develop a new coping strategy anyway, so avoid doing this where you can.

What Might I See?	Why Might I see this?
Not socialising as much as other children	Autistic people can find social interaction exhausting and frightening
Keeping to themselves	They can feel overwhelmed by large groups
Not being able to make friends as easily	They have difficulty understanding unwritten social rules and cues
Distressed behaviours (tantrums, self-injury, aggression)	They are confused, frightened, drained or extremely anxious. They may be trying to control their environment to feel safe

Below are some tips you can use to help your child's social interaction. This can help them to understand and make social interaction easier and less stressful for them, as well as help you to be more accepting of their challenges.

Be explicit about unwritten social rules



Be open minded to people's differences



Be accepting of them,
they may appear rude or blunt,
but that isn't their intention



Change of routine is sometimes
unavoidable, however where possible
give as much notice and preparation as you can



Support your child to attend social events.
However, if it is causing unnecessary anxiety,
let them know they can opt out

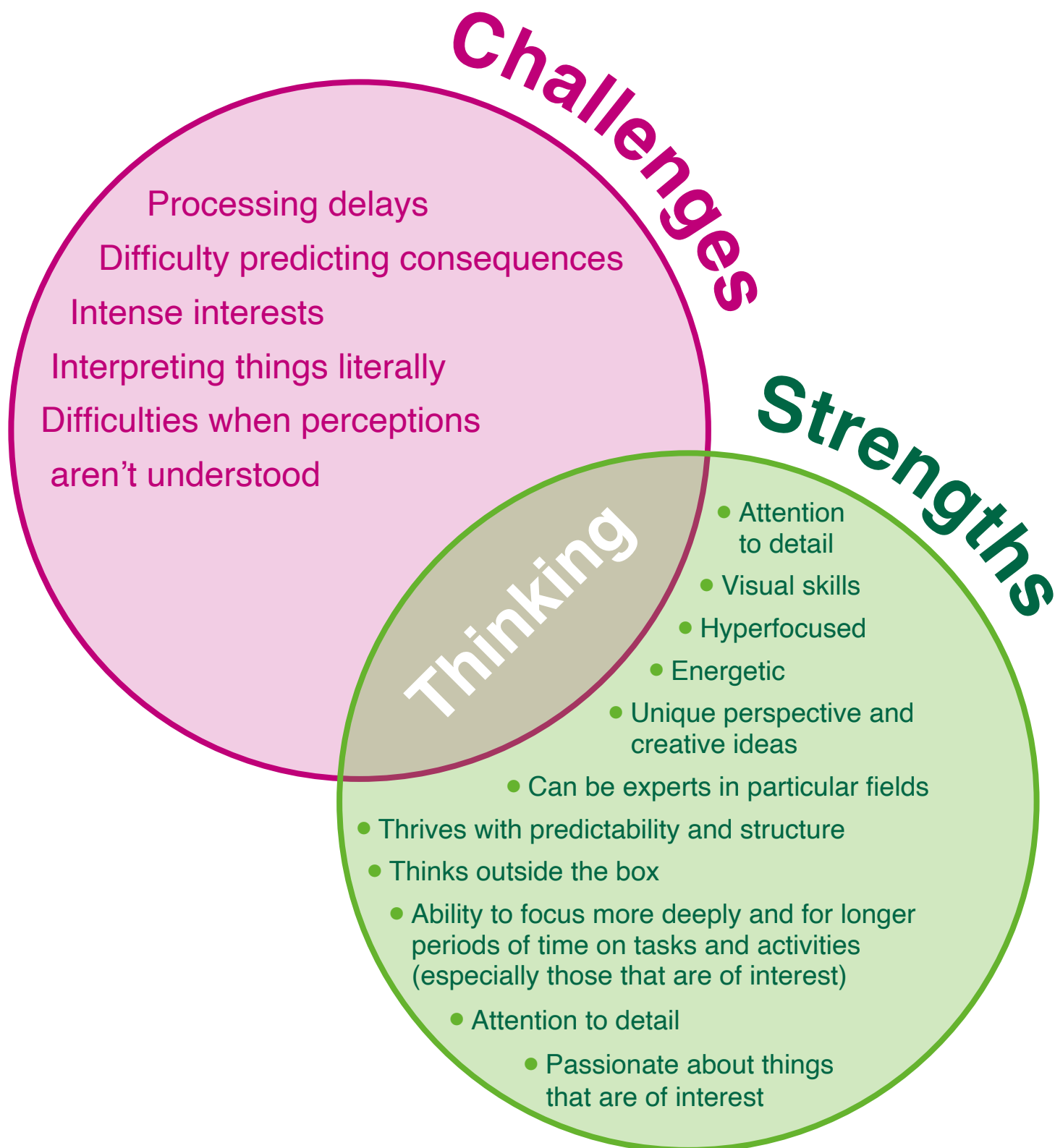


Provide plenty of information
about an event beforehand



Thinking

Autistic people see the world differently to people who are neurotypical. Below you can see that whilst this can be challenging for them, it also means they think in unique and often creative ways.

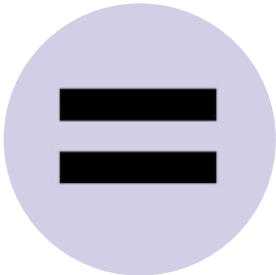


Below are some tips you can use to help your child. These can help you to understand your child and it can help provide them with structure. This can help to reduce their anxiety.



Create structure using visual timetables/schedules

Wait at least 10 seconds before repeating a question, they may just be taking time to process



If you do repeat a question or statement, make sure it is exactly the same

Incorporate their special interests into tasks



Allow them to spend time on their special interests

When Interests Become Harmful

For more information on whether their special interest is becoming harmful use the link below:

www.autism.org.uk/advice-and-guidance/topics/behaviour/obsessions/all-audiences

Sensory Perception

Autistic people may experience sensory challenges. There are two types of sensory perception: **hypersensitivity** (or over-sensitivity) and **hyposensitivity** (or under-sensitivity). The table below provides some examples of both, for each of the eight senses.

Sense	Hyposensitive	Hypersensitive
Sight	Poor depth perception and problems with throwing and catching. May seem clumsy.	Unable to tolerate certain types of lighting such as fluorescent lights.
Sound	Not noticing certain sounds, enjoying crowds and noisy places. Making loud vocal sounds.	Find it hard to focus on what someone is saying because they get distracted by other noises . Can find loud noises bothersome and even painful.
Smell	Failing to notice strong smells or seeking out smells through sniffing food or everyday objects.	Aversion to certain strong smells (such as perfume).
Taste	Enjoy strong tastes, smothering food in hot sauce/ketchup. May like putting things in mouth, including inedible things.	Having a limited diet. Not being able to tolerate certain foods, only eating bland food or foods with certain tastes and textures.
Touch	Might seek out pressure. Holding others tightly, behaviour such as self injury, chewing.	Not being able to 'tune out' the feeling of clothes. Can't tolerate people touching them (e.g. hugs).

Sense	Hyposensitive	Hypersensitive
Vestibular	Poor balance, clumsy, need to be on the move all the time - rocking, bouncing, and spinning. May not appear to get dizzy.	Appear fearful of movement, resists certain positions i.e. does not like feet off the ground. May avoids swings and other playground equipment.
Proprioception	Clumsy, accident prone, bumps into and spill things, use too much or too little force, loves rough and tumble play, chews or bites on objects.	Currently, there is no evidence that a child can be hypersensitive .
Interoception	Failing to notice when they are hungry or thirsty or when they are full. Does not notice they need the toilet until the last minute when feeling is intense.	Become hot too easily. Feel emotions/pain very intensely. Frequent trips to toilet as slightest urge to urinate causes a feeling of discomfort or emergency.

For further information on sensory processing:

www.youtube.com/watch?v=Rsw-cBs74q0

<https://www.autism.org.uk/advice-and-guidance/topics/sensory-differences/sensory-differences/all-audiences>

More information on diet

For more information on diet, including strategies you can try, please log on to: www.uhd.nhs.uk - then click on the following links:

Your visit, patient leaflets - find your leaflet here,

Children's Therapy - scroll down to **sensory** and click on **oral, olfactory and gustatory systems**

You can also find information about **picky eating sensory issues** and **food fun** here:

www.uhd.nhs.uk/visit/patient-information-leaflets/childrens-therapy

Sensory invalidation

Sensory invalidation describes when an autistic person's sensory challenges aren't taken seriously. It can lead to confusion, emotional outbursts, anxiety and camouflaging. It is important to respect autistic children's sensory differences and validate their feelings and experiences even when you don't understand it. Below are examples of sensory invalidation.



Sensory validation

Make sure you acknowledge your child's sensory challenges and make appropriate adaptations where possible. Below is an example of sensory validation.



Sensory perception

Below are some tips you can use to help meet your child's sensory needs, this can make their day to day experience less stressful and more enjoyable.



Create sensory activities that provide joy and either stimulate or calm and regulation your child

Offer a quiet and safe space to relieve sensory overload



Try practical solutions such as wearing ear plugs or headphones, or providing an oral chewy toy

Try to accommodate the person if they request sensory adjustments (e.g. turning loud music down)



Alternatively you can try using relaxing music as this can be calming for some autistic people

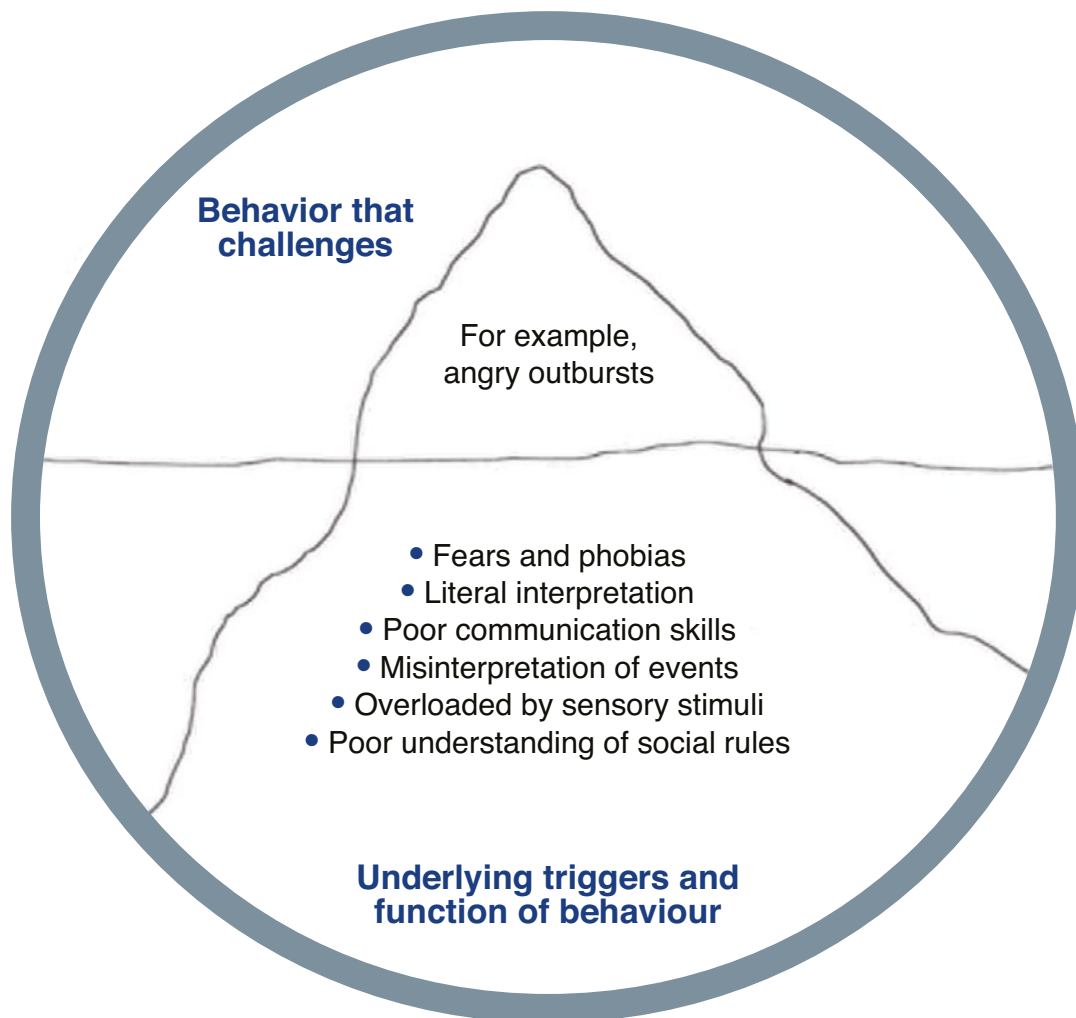
Check basic sensory needs such as whether your child is hungry, thirsty or tired



Accommodate personal preferences for sensory needs (e.g. clothing)

Distressed Behaviours

Some autistic people might display behaviours that can put themselves and others at risk. This is often known as behaviour that challenges. As autistic people experience the world differently to others, it can be more challenging for them to communicate their frustrations. The iceberg metaphor below illustrates how all behaviours have triggers and functions, however this can sometimes be difficult to spot. It is important to try and see the challenges from your child's perspective and in the context of the difficulties they experience every day.



See the Challenging Behaviour Foundation for further advice and resources:

www.challengingbehaviour.org.uk

How can I help my child?

Autism isn't a condition that needs to be cured. However there are strategies you can implement at home that can have a positive impact on your child's development. The National Autistic Society describes the importance of visual support for autistic people. They can be used in most situations and are adaptable and portable.

Visual supports can help to:

- provide structure and routine
- encourage independence
- build confidence
- improve understanding
- avoid frustration and anxiety
- provide opportunities to interact with others

Visual supports can make communication physical and consistent, rather than fleeting and inconsistent like spoken words can be. This brochure will briefly describe: **social stories, contingency maps, visual timetables** and **first/then boards**.

Social stories

Social stories present information in a literal and concrete way. This is beneficial for autistic individuals who sometimes have challenges understanding unwritten social cues and expectations. Social stories can help prepare individuals for new or challenging experiences. Social stories explain what they can expect in a new situation, let them know what options and accommodations are available, and help them feel less worried. They can help individuals understand what comes next in a series of activities and help with planning and organising. Knowing what to expect can help reduce anxiety in unfamiliar situations. Social stories can build understanding and reduce uncertainty

The National Autistic Society website explains that social stories can be used to:

- Develop **self-care skills** (for example how to clean teeth, wash hands, or get dressed), **social skills** (for example sharing, asking for help, saying thank you) and **academic abilities**
- Help someone to understand how others might behave or respond in a particular situation
- Help a person to cope with changes to routine and unexpected or distressing events (e.g absence of teacher, moving house)
- Provide positive feedback to a person about an area of strength or achievement in order to develop self-esteem

Social stories can be helpful for all ages and can be presented differently according to the individual's age, needs, and interests. For example, it could be a social story YouTube video, or a story with pictures and text, or it could be a series of bullet points.

Here is an example of a social story about fire drills at school

- School buildings are safe places.
- There will be a fire drill at school tomorrow at 10am (specific details)
- This is a practice, so everyone knows what to do in case of a real fire (reason given)
- The alarm is loud, but I will have my headphones on ready (sensory accommodation)
- All teachers and students will go outside calmly, quickly, and safely. Each class has a special safe area outside where they stand. This is where my teacher will take the register to make sure everyone is out of the building (what I can expect, who will be involved, location)

- My teacher will stay with me and my class. She will remind us that there is not really a fire (who will look after me, addressing worry)
- We will wait outside for a few minutes until my teacher is told we can go back to class. If I have worries, I can try to tell my teacher, she will try to help me. I can squeeze my squishy ball. (duration, person to help me, coping strategy)
- Each time there is a fire drill, every class leaves the school building the same way. They go to the same special safe area outside of the building. (what I can expect, location)
- Fire drills help teachers and students practice leaving the building calmly, quickly, and safely. (reason given)

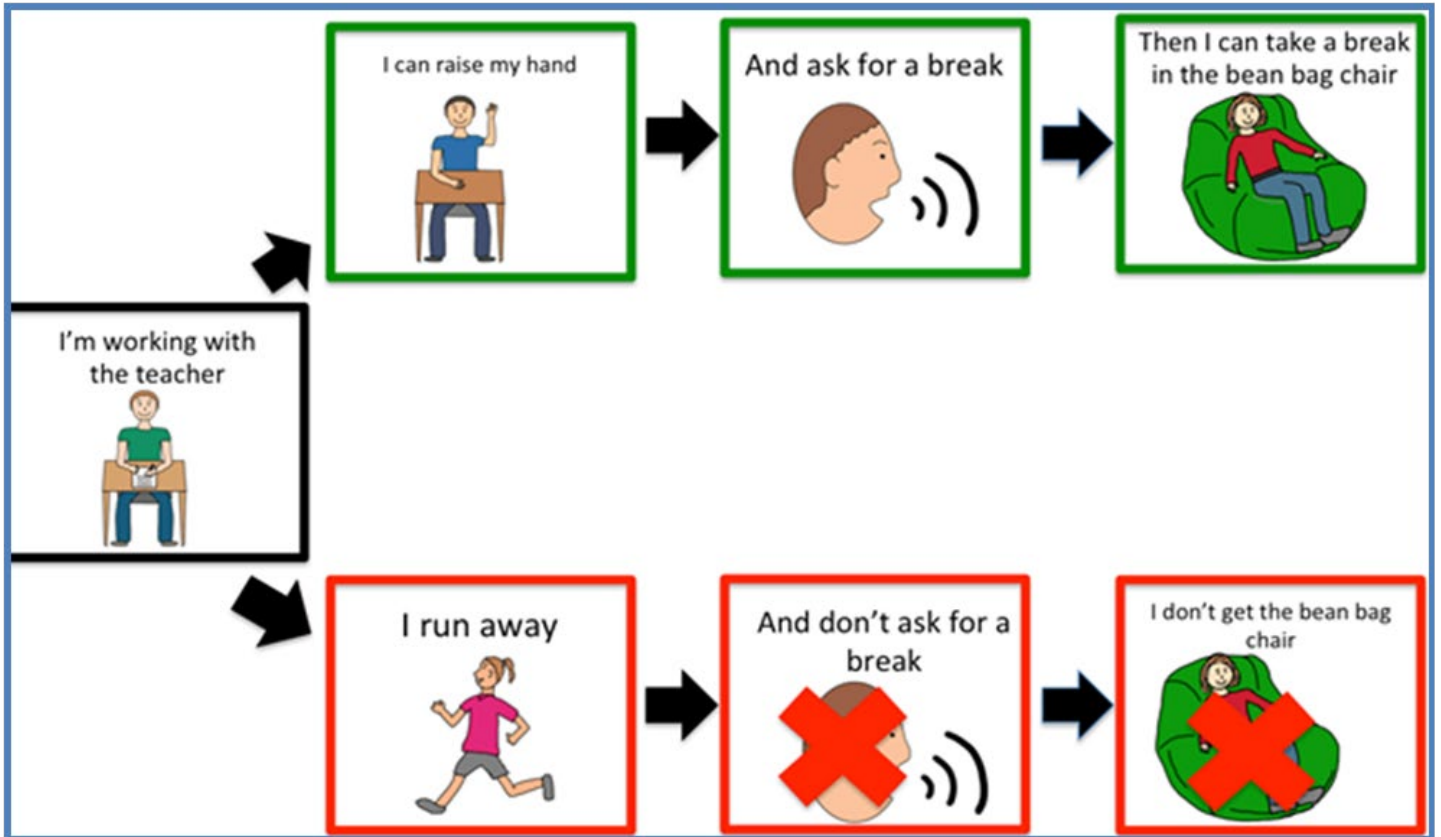
Here are some examples where using a Social Story can be helpful:

- It's ok to make mistakes
- If the answer is "no"
- Please 'hurry up'
- Telling my teacher about a problem
- Staying calm with difficult schoolwork
- How to take a shower
- Personal hygiene
- (See The New Social Story Book by Carol Gray)

The National Autistic Society website has more information on social stories. They also provide information on **Comic Strip Conversations**, which are simple visual representations of conversations.

Contingency maps

Contingency maps are a method for helping an individual to understand the consequences of their behaviour. They are particularly useful for teaching individuals alternatives to the unhelpful behaviour they may typically use.



Make sure you go through the map with your child. Explain why and when you will use the map and answer any questions they may have. You may want to only have the right (the green) consequence visible. Some autistic people can get overly focused on the inappropriate way to handle the situation (the red). Others may feel overwhelmed by the amount of visual information.

It is important to note that each autistic individual is different and you should use visual support that works best for your child. The techniques described in this advice pack may not be appropriate for every child.

Visual timetables

Visual timetables are a really helpful way to provide routines for your child in a visual and accessible format. Below is an example of a morning schedule from the 'do2learn' website.



If your child is struggling with a particular aspect, you can break it down even further:

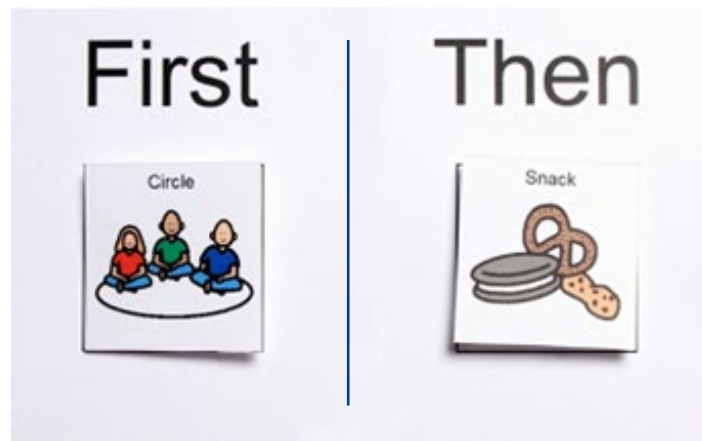


How can I make them myself?

See the 'Websites and Resources' section for websites you can use to make your own visual supports or find existing resources.

First/then boards

First-then (also known as now-next) sequences present what we need to do now (first) and what we will do next (then). These boards are used for individuals who need a greater level of breakdown, so that they can focus on one task at a time without being overwhelmed.



First/then boards are also useful in teaching your child the concept of 'first' and 'then'.

A whiteboard is a useful tool for first/then boards as you can draw what is coming up next.

The National Autistic Society provides more information on different types of visual support you can use and how you can implement them in your own home.

The website below has a free blank first/then template:

<http://autismcircuit.net/tool/first-then-card>

Transitions

Autistic children and young people can find transitions very challenging. The types of transitions that are particularly difficult are outlined below, along with how to help make transitions easier for autistic people.

Challenges with transition

It can sometimes be difficult for autistic people to switch their attention between different tasks and transition between activities. This is true even for activities that are particularly enjoyable for the autistic person.

There can also be challenges with transition between schools. For instance between primary and secondary, or secondary to college or university.

Transitioning between locations can also be challenging for autistic people. For example getting into and out of a vehicle to move between destinations.

How to Help with Transitions

Provide plenty of warning before a transition is about to occur. Use visual information to support verbal information (e.g. First/Then Board).

You can use social stories to explain the transition and help them feel more confident.

Be encouraging and positive when your child successfully transitions between tasks.

Using a visual timer can help the autistic child 'see' how much time they have before they transition to the next activity.

Visual timetables also help with transitions as they increase predictability. Your child can view an upcoming activity and have a better understanding of the sequence of activities that will occur.

Siblings

The impact having an autistic child can have on siblings is often on parents' minds. While it can be challenging for siblings, it can also be rewarding too. Often, children are more accepting, compassionate and tolerant when they have an autistic sibling. However, they might feel sad, anxious or confused about their sibling's unfamiliar and 'unusual' behaviour. Try to help them understand their sibling. By talking about autism with them, it ensures they have accurate information.

YoungSibs is a website which provides information specifically for siblings. Below is some information from their website about what it's like to have an autistic sibling.

What is it like for siblings if their brother or sister is autistic?

Siblings often have a really good relationship with their autistic brothers or sisters. However, they may sometimes feel that everything has to revolve around their brother or sisters' needs.

It may be hard to go on days out or to do things that other families do. Even though siblings understand that their brother or sister needs lots of attention, they can feel left out or jealous of the extra time their parents spend with them. They may feel that they have to look after their brother or sister all the time.

The logo for YoungSibs, with 'young' in a purple sans-serif font and 'Sibs' in a grey sans-serif font.

The following link from the National Autistic Society website has resources on talking to your non-autistic child about autism.

[Family relationships - a guide for siblings of autistic people \(autism.org.uk\)](https://www.autism.org.uk/family-relationships)

Telling your child they are autistic

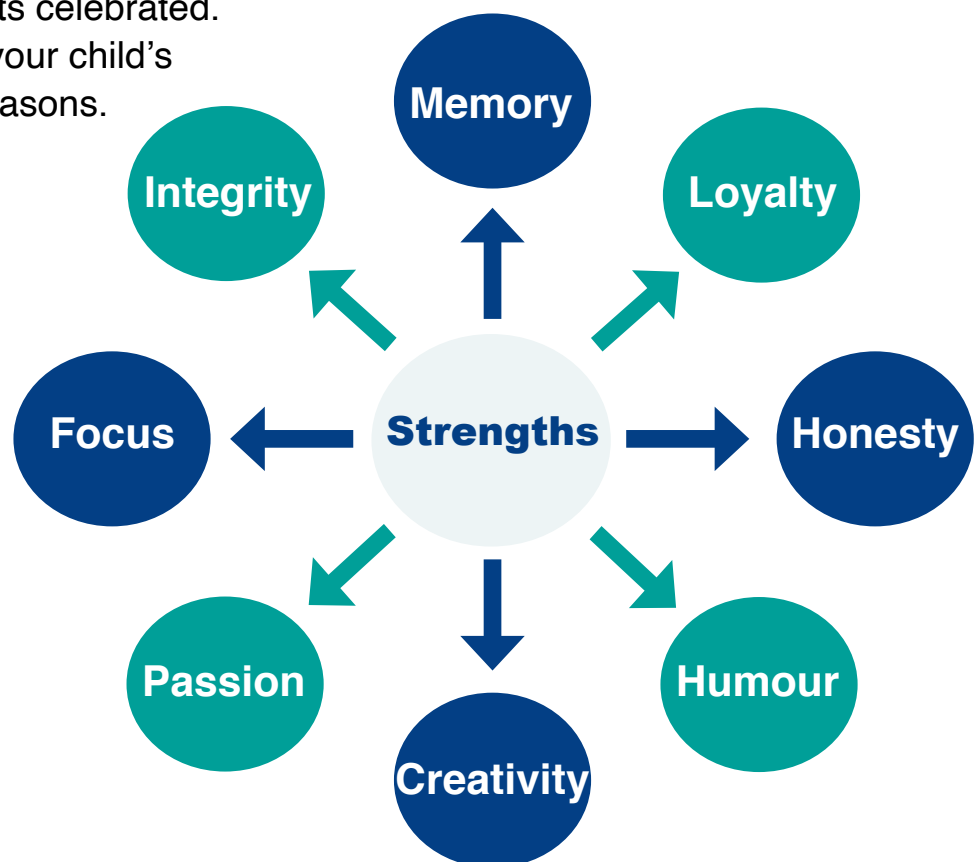
This can be a daunting task for parents, and ultimately the decision is up to you how and when to tell your child. The National Autistic Society website advises that you should choose a time when you're both in a calm mood and in a place where you both feel comfortable. They provide lots of advice on telling your child about autism.

Strengths

Autistic people have strengths which should be recognised and celebrated. They should be seen as individuals with their own character and personality and their successes and achievements celebrated.

It is important to recognise your child's strengths for a number of reasons.

- So they aren't defined by their autism
- So you and others see them as a person with their own character and personality
- To help celebrate their successes and achievements



“If I could snap my fingers and be nonautistic, I would not. Autism is part of what I am.”

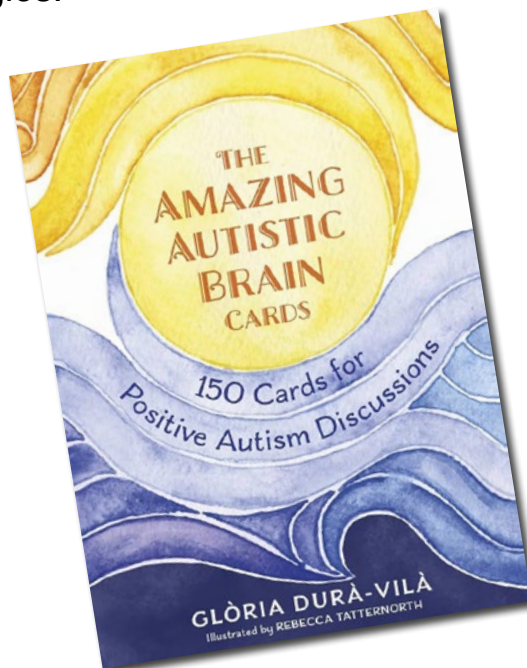
Dr. Temple Grandin

“If you've met one individual with autism, you've met one individual with autism.”

Stephen Shore

www.bristolautismsupport.org/all-about-your-autism-diagnosis

Autistic children often already know they are different and are aware of their challenges. Telling them they are autistic and what this means for them in a positive way will help them understand themselves better. Help your child gain an understanding of what autism means for them, their differences, talents and challenges, and coping strategies.



The cards can be used to start a conversation about autism and personalise autism for your child.

Explaining autism to relatives and friends

It can be hard for relatives and friends to understand autism as they may have no experience of it. It's important to remember that parents have a lot longer to get their heads around their autistic child than other people in their lives. Parents may believe there is something different about their child from a very early age and may learn about autism before their child receives a diagnosis.

The link below includes some tips on explaining autism to grandparents (or other people who help look after your child) but bear in mind that it may be quite a lot for them to take on all at once.

www.bristolautismsupport.org/grandparents-dont-believe-child-autistic

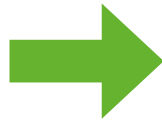
Self-care

Having an autistic child can present challenges for parents. It is important to take time for yourself. You should also remember that having a break from caring for your child is not an admission of failure, or saying that you don't care. Without any breaks, you risk becoming unwell or exhausted. Make sure you still make time for things you enjoy doing. If you notice your own mental health deteriorating seek support from you GP.

The National Autistic Society website has a **Parent to Parent Service**, where you can talk about your experiences with people who have been in a similar situation. It is a UK wide confidential emotional support service, provided over the phone by trained volunteers, who are all parents who have a child with autism. They also have an **online community** where you can ask for advice from people who understand your situation.

Self-Care Myths

Self-care is an indulgence



Self-care contributes to personal growth. Self-indulgence is often spontaneous and doesn't have long term benefits

Self-care is selfish



When you make time for yourself, rest and exercise you will be able to do more for yourself and those around you

Self-care is a one-time experience



Looking after yourself is an on-going practice

Self-care is time consuming

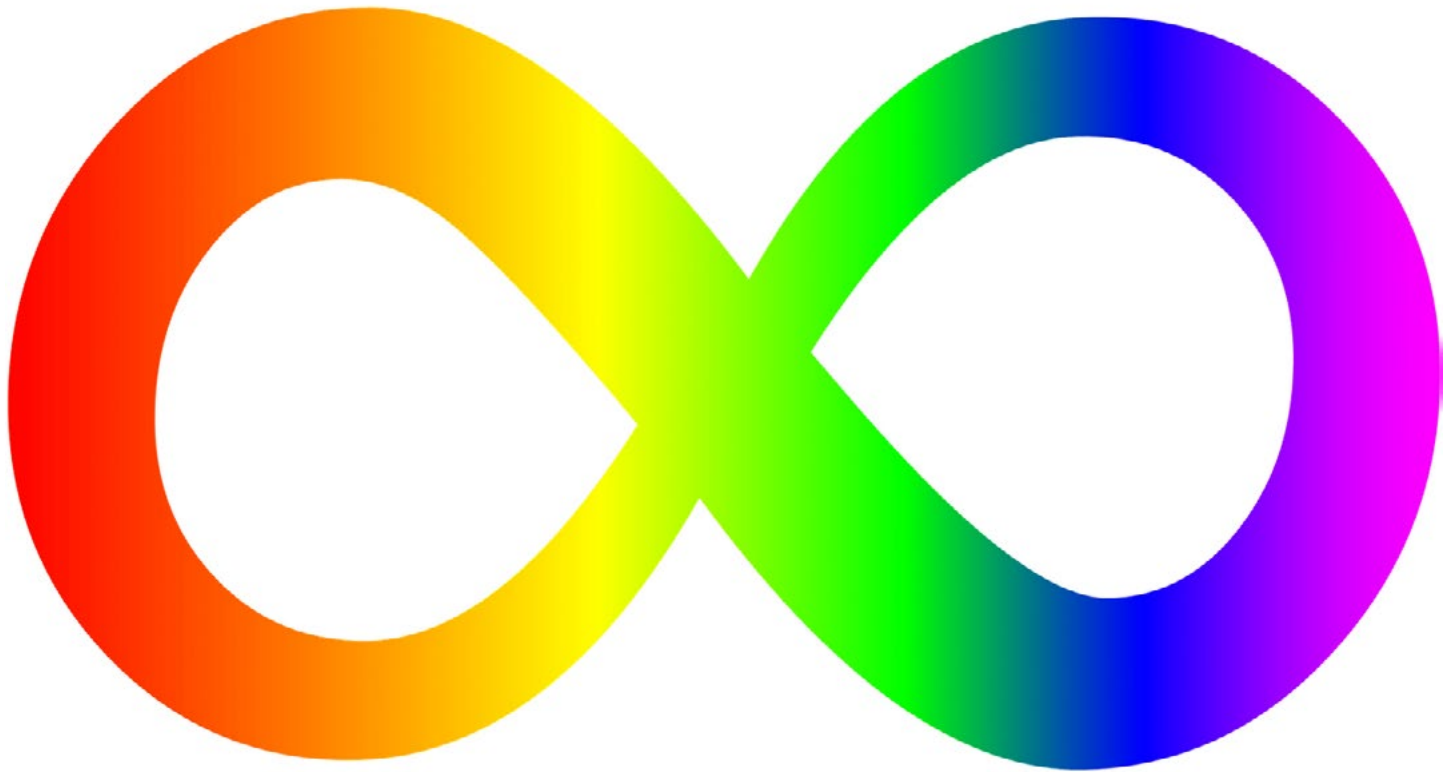


Self-care doesn't need to take up a huge chunk of your day

Autism language

Preferred language varies from person to person. Make sure you listen to what they prefer, and if you're not sure just ask. Give your child freedom to find their own preferences and discover what works for them.

The rainbow-colored **infinity symbol** represents the diversity of the **autism** spectrum as well as the greater neurodiversity movement.



Identity-First:

Autism is an inherent part of an individual's identity.

Person-First:

"Person-first language," puts emphasis on them as a person, rather than being defined by their autism.

Other language you might hear

- Autism Spectrum Disorder (ASD)
- Autism Spectrum Condition (ASC)
- Asperger's Syndrome
- Asperger's
- Aspie

Website and resources

Useful Websites

The National Autistic Society: www.autism.org.uk

Autism Unlimited: www.autism-unlimited.org

Ambitious About Autism:

www.ambitiousaboutautism.org.uk

Autism Education Trust: www.autismeducationtrust.org.uk

NHS Website: www.nhs.uk/conditions/autism

Autism Understood <https://autismunderstood.co.uk>

Autistic Girls Network <https://autisticgirlsnetwork.org>

NHS Dorset Neurodiversity Hub provides information to support neurodivergent people in Dorset, with a particular focus on autism and ADHD.

<https://nhsdorset.nhs.uk/neurodiversity>

Children's Therapy Services - Poole Hospital Child Development Centre on Facebook

Parent Support

EarlyBird and Early Bird Plus: www.autism.org.uk/what-we-do/support-in-the-community/family-support

SEND Violent and Challenging Behaviour:

<https://yvonnenewbold.com/resources-on-send-vcb/violent-challenging-behaviour-the-basics>

Parenting support courses:

www.dorsetcouncil.gov.uk/children-families/get-help-for-your-family/parenting-support-courses.aspx

The Umbrella Group is a parent led support group for parents/ carers of children and young people with ASD. For details please contact Debbie at: debbiewestbourne@gmail.com or Clare Lockyer **07450 210911**

<https://m.facebook.com/groups/312179982770667?ref=share>

Venue - The Pool room at Portfield School, Parley Lane, Hurn, Christchurch BH23 6BP

On - Usually the 4th Saturday of the month but occasionally changes due to school holidays and speakers' availability.

Time - 10am-12.30pm approximately. Please note our meetings often over-run to give parents chance to chat to each other but parents can leave at their own convenience.

Cost - £1 donation for refreshments and administration.

HOPE programme for parents of autistic children - free self-management course. For information email:

contact@h4c.org.uk or visit www.h4c.org.uk

Families in mind - understanding parental wellbeing:

www.edasuk.org/training/free-courses/families-in-mind

SCOPE offer 'Navigate' which is a programme of up to six sessions with a personal advisor who provides online emotional support for parents and carers who are finding out about their child's additional needs. The personal adviser will help you to talk about your feelings and concern and can help you with: organising your thoughts and feelings, practical advice and suggestions, coping strategies and insights, taking positive actions and helping you with emotional wellbeing.

www.scope.org.uk/family-services/navigate

Courses/training

Autism Unlimited offer two e-learning courses which take 60 - 90 minutes to complete and are a great way to learn at your own pace. 'Understanding Autism' and 'What is Neurodiversity?' are interactive and informative e-learning courses which have been co-produced by the charity's autistic community. Ideal for parents, carers, and extended family members, these courses will increase and enhance your understanding of autism and neurodiversity, highlight sensory differences and help you to gain appreciation for the uniqueness of neurodiversity.

View our latest courses here

<https://www.autism-unlimited.org/courses>

Autism Unlimited shares resources and provides information. If you would like some help from them, please complete the form on their website www.autism-unlimited.org/support/help

ADAPT After Diagnosis of Autism Parent Support Training course for parents

www.recoverycollegeonline.co.uk/mental-health/autistic-spectrum-disorder-asd/parents

Understanding and Supporting Autism a free 3-week course to parents/carers which covers: what is the autistic spectrum, the strengths and talents often associated with autism, myths and facts, support strategies. For further details please see the link below:

www.skillsandlearningace.com/courses/course/family-learning-understanding-and-supporting-autism

Family Activities

Diverse Abilities: offers play schemes, youth club, sessions for siblings, help, support, advice, information, and friendships.

<https://diverseabilities.org.uk/coping-with-chaos>

Young Sibs: www.youngsibs.org.uk

Dorset Youth: <https://dorsetyouth.com/send-for-parents>

Magdalen Farm: <https://magdalenfarm.org.uk>

Education

SENDiass:

www.sendiass4bcp.org

www.dorsetsendiass.co.uk

Dorset Local Offer:

www.dorsetcouncil.gov.uk/children-families/sen-and-disability-local-offer/dorsets-local-offer.aspx

BCP Local Offer:

<https://fid.bcpcouncil.gov.uk/send-local-offer>

IPSEA A unique range of services has been developed to ensure that families understand children and young people's legal rights and entitlements to special education provision. Please see their website for more details.

www.ipsea.org.uk

Mental Health Support Teams are working with a small number of schools across Dorset to tackle the challenges children and young people experience, by helping them to feel more resilient, arming them with techniques to look after themselves and strategies to help them cope better with life's ups and downs.

Please see their website for more information, YouTube videos and webinars.

<https://camhsdorset.org/about-camhs/mental-health-support-teams>

Not Fine in School: Family Support for School Attendance Difficulties

A Facebook group for parents/carers of children who experience barriers and difficulties attending school.

They aim to facilitate and share peer support, to empower parents to advocate for their children by sharing or signposting to relevant information and advice.

Support Direct From School

School Nurse:

www.dorsethealthcare.nhs.uk/school-nursing

Support for Young People

Autism and Me. Chat and chill autism film for young people recently diagnosed www.youtube.com/watch?v=D2ljyxUpI58

Bristol Autism Support website has an autism diagnosis guide for young people: www.bristolautismsupport.org/all-about-your-autism-diagnosis

Stop. Breathe. Think. Online counselling for young people without the wait <https://www.stopbreathethink.org.uk/>

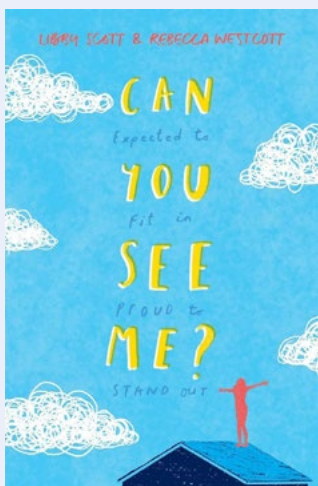
Dorset Discovery Project combines the expertise of NHS Healthcare Professionals, the lived experience of Peer Specialists and the voice of Young People to create spaces to explore and share what mental health, recovery, and wellbeing means by looking at what matters to you. See website for discovery videos and podcasts.

Dorset Discovery Project has a Facebook group helping young people and their families to explore mental health / wellbeing in non-clinical settings.

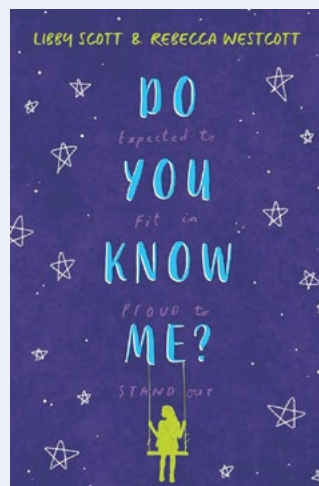
www.dorsethealthcare.nhs.uk/patients-and-visitors/our-services-hospitals/mental-health/discovery-project

A series of four books By **Libby Scott** and **Rebecca Westcott** to change the way people think of autism.

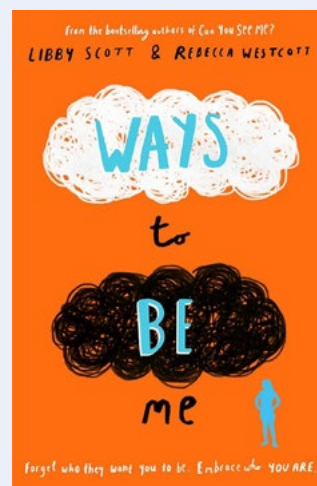
A story of an 11 year old autistic girl starting secondary school



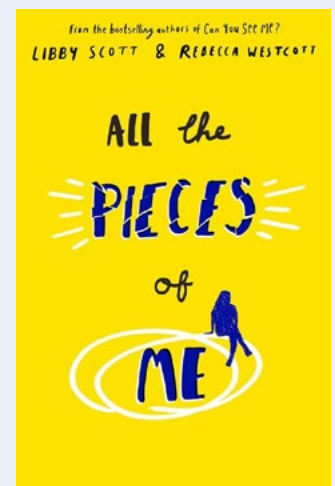
Can you see me?



Do you know me?



Ways to be me



All the pieces of me

www.youtube.com/watch?v=dqbebgO3ang

A Kind of Spark - BBC iPlayer Children's drama about an autistic girl Addie.

Videos

YouTube Videos for young people created by the clinical psychology team at Royal Derby Hospital focusing on understanding ASD, understanding emotions and thoughts and strategies to manage emotions and thoughts when they become overwhelming.

Chapter 1 - Understanding ASD

www.youtube.com/watch?v=y0z44Nxx8o4

Chapter 2 - Understanding emotions

www.youtube.com/watch?v=mzKI6JN8hXo

Chapter 3 - Why do we have emotions?

www.youtube.com/watch?v=gdBBfEbV7p8

Chapter 4 - Why do emotions feel overwhelming sometimes?

www.youtube.com/watch?v=0ub_j-tfocg

Chapter 5 - Understanding thoughts

www.youtube.com/watch?v=IDHhXnE9SIs

Chapter 6 - How do our emotions and thoughts affect our bodies and behaviours?

www.youtube.com/watch?v=7-gAz_NCogQ

Chapter 7 - Strategies to manage thoughts and feelings

www.youtube.com/watch?v=1oviaXKMXsE

Chapter 8 - When to use strategies

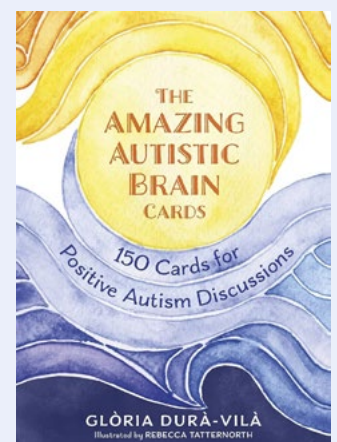
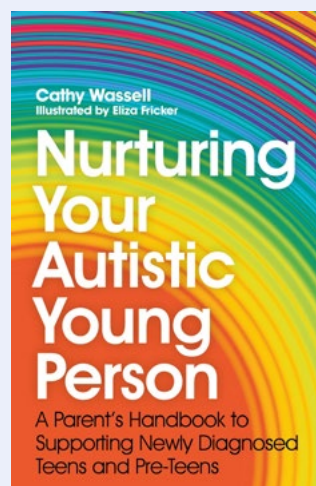
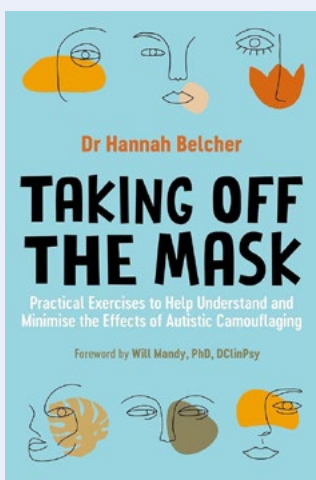
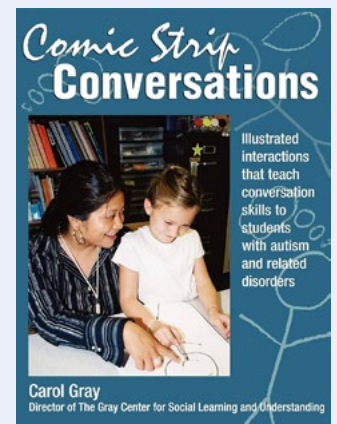
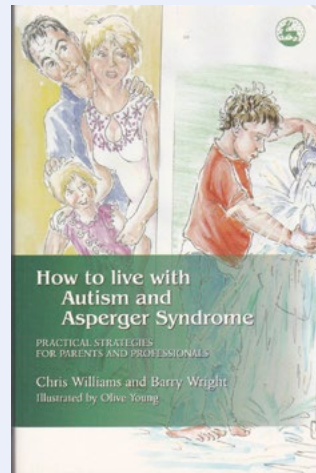
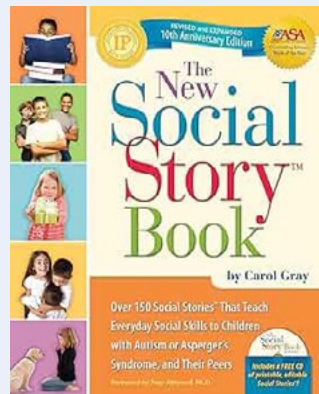
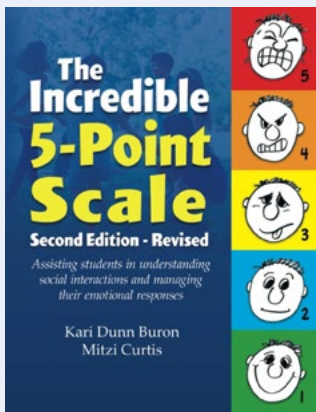
www.youtube.com/watch?v=uAQD0EBsjO8

Curly Hair Project's YouTube page is great for all things ASC:

www.youtube.com/@thegirlwiththecurlyhair4412/videos

If you would like any of the links emailed to you, please email [**cdc.ndp.support@uhd.nhs.uk**](mailto:cdc.ndp.support@uhd.nhs.uk) and include your child or young person's name and date of birth.

Books



Youth Groups and Activities

RELATE: www.relate.org.uk/relationship-help/help-children-and-young-people/children-and-young-peoples-counselling

Diverse Abilities Youth Club: <https://diverseabilities.org.uk/awesome-nights>

The Remix: <https://activateperformingarts.org.uk/project/the-remix-and-premix>

For more youth groups and activities visit:

<https://fid.bcpccouncil.gov.uk/family-information-directory/directory>

<https://familyinformationdirectory.dorsetcouncil.gov.uk/kb5/dorset/fsd/home.page>

Creating Visual Supports

Widget Online: <https://widgitonline.com>

Easy on the i:

www.learningdisabilityservice-leeds.nhs.uk/easy-on-the-i

Do2Learn: <https://do2learn.com>

Makaton: www.makaton.org

For more visual resources:

www.twinkl.co.uk/resources/parents

Being a Carer

Support for carers

www.dorsetcouncil.gov.uk/w/support-for-carers

www.bcpccouncil.gov.uk/ASC-and-health/Carers/Carers.aspx

CRISP (Carers Information Service):

[If you look after someone, we're here for you. \(crispweb.org\)](http://www.crispweb.org)

Parent carer forums

The following parent carer forums were set up to represent the voices of parents/carers of children and young people (0-25 years) with SEND. By working together, their aim is to improve services for, and make sure the services meet the needs of, children and young people with SEND in Dorset. Please see their websites for further details.

Parent Carers Together - BCP:

www.parentcarerstogether.org.uk

Dorset Parent Carer Council:

www.dorsetparentcarercouncil.co.uk

Other Useful Links and Tips

Keep an eye out for autism friendly cinema/theatre experiences. You can check your local cinema's to see if they offer this.

Dorset Max Card

discount card for eligible children and young people

www.dorsetcouncil.gov.uk/-/dorset-max-card

Accessing Sunflower Lanyards (for hidden disabilities): <https://hiddendisabilitiesstore.com>

Being safe online: www.getsafeonline.org

Self-injurious behaviour:

www.autism.org.uk/advice-and-guidance/topics/behaviour/self-injurious-behaviour/all-audiences

Please see the Children's Therapy section on our website for more information leaflets on a range of topics:

www.uhd.nhs.uk/visit/patient-information-leaflets/childrens-therapy

The Family Fund can provide grants for families to help with the purchase of essential items such as a washing machine, sensory or play equipment, technology for your child, or a much-needed family break. For more information about eligibility please see:

www.familyfund.org.uk

To read this leaflet in a different language, please visit our website: www.uhd.nhs.uk/visit/patient-information-leaflets and use the language and accessibility function available along the top of the site.

To ask for this leaflet in larger print, please contact the patient experience team on **0300 019 8499** or email patientexperienceteam@uhd.nhs.uk.

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