Supporting Your Neurodiverse Child

Written for parents, by parents

family voice peterborough
together improving services

Cambridgeshire & Peterborough
Integrated Care System

NHS

PETERBOROUGH
CITY COUNCIL

Contents

Introduction

When you first realise that your child experiences the world in a different way it can feel overwhelming, but once you begin to understand their way of thinking it can be rewarding and you can learn so much from your child.

We are a group of parents, at various stages on this same journey. We were desperate for guidance and didn't know where to look to find what we needed. A few years on, our knowledge has grown. We now know there is a lot of information available, but it can be hard to find the bits that are factually correct and relevant to your own situation.

We have provided an overview of what we have found to be the most relevant information from sources such as the NHS website, national charities and IPSEA but we aren't trying to recreate textbooks that are already available.

There are links included that you could follow to find out more on specific topics. We have also recommended some books, videos and blogs, which are all resources that we have used ourselves. We are extremely grateful to the parent carer groups and Forums in Essex that first created this resource, using funding from health. Without them sharing the core document, funded by our local health services, we simply wouldn't have been able to provide this to you in Peterborough.

We don't intend for you to read this whole pack in one go, but dip in and out when each section becomes relevant to your family's situation.

Just as every child is unique, every family's experience will be different, but we hope there will be some information here that will help you.

Some of the information in this booklet reflects the national picture and may not be available locally

Books and websites can provide very useful guidance but we believe it is equally important to find your own 'tribe' of other SEND parents, who will understand how you are feeling and provide emotional, as well as practical, support.

Family Voice aims to empower parent carers and we hope this booklet does just that.

Good luck on your journey, from the team at Family Voice

family voice
peterborough
together improving services

family voice
peterborough
together improving services

Cambridgeshire & Peterborough
Integrated Care System

www.familyvoice.org

Please give us your feedback!

We wouldn't have been able to produce this booklet without the funding we've had from Cambridgeshire and Peterborough Integrated Care Partnership. They, and we, need to know what you think about the booklet, how useful it is and what else you might want to support you and your child. The survey takes just a few minutes and we would be grateful for your time to complete it.

Use the QR Code to access the survey

Or use this link to the survey
https://forms.gle/TPCM8Nazaqrbu4CV8

Section 1

What is Neurodiversity?

What is Neurodiversity?

‘Neurodiversity’ is an umbrella term which is used to describe people who have brains and thinking styles which work in a slightly different way to ‘neurotypical’ people.

It includes a wide range of differences, such as autism, ADHD, dyspraxia (Developmental Coordination Disorder), OCD,Tourette’s Syndrome and literacy and numeracy difficulties.

We believe that being neurodiverse provides our children with strengths that should be nurtured, and challenges that should be effectively supported. Because no two children are the same, all neurodiverse children will experience the world differently and it is important to think about how approaching things in a different way may minimise challenges and benefit your child in a neurotypical world.

> **“If you are always trying to be normal, you will never know how amazing you can be.” Maya Angelou**

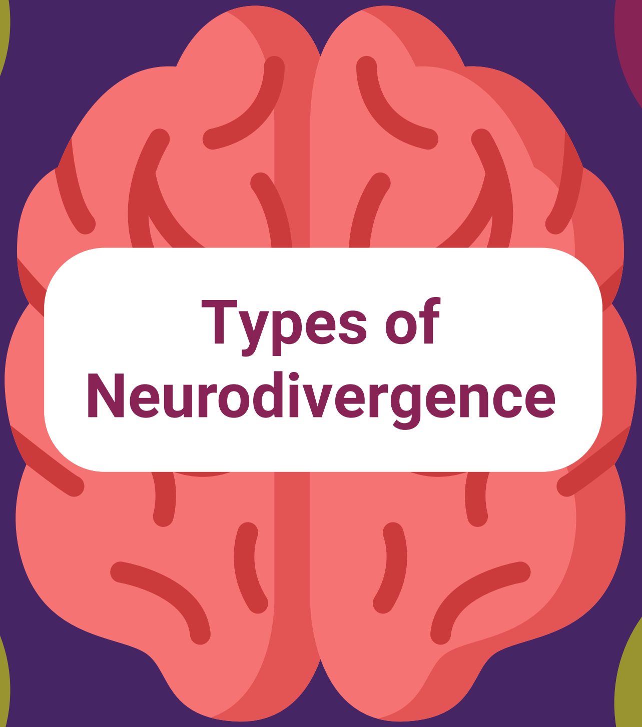
A Note on Terminology

The terminology used to describe neurodiversity is changing, driven largely by the research and writings of neurodiverse adults. As a parent of a neurodiverse child, discussions over the use of language are probably way down on your list of concerns, but as your experience and knowledge grows you may see how some of the words used to describe your child have subtly negative connotations. Within this pack we have chosen to use identity first language (autistic child) rather than person first (child with autism) as the majority of autistic adults prefer this.

We also understand that grammatically, it is correct to say that a person is neurodivergent, however, we received feedback from some families and service providers that this isn’t a term with which they can easily identify. In light of that feedback and the fact that the NHS and some other services still use the term, we have used ‘neurodiverse’ as the best- understood description at this time, recognising that terminology will continue to change.

If you are speaking to neurodiverse/neurodivergent individuals, be led by the terminology that they prefer – if in doubt, just ask them.

To understand more about the impact of the words used to describe disabilities please read this excellent blog article by Ann Memmott Ann’s Autism Blog: Appropriate Descriptions around Autistic People **(https://annsautism.blogspot.com/2021/07/appropriate-descriptions-around.html)**



Types of Neurodivergence

- **Dyslexia and Dyscalculia**
- **Dyspraxia**
- **Autism**
- **ADHD -** Attention Deficit Hyperactivity Disorder
- **Tourette's Syndrome**
- **Hyperlexia**
- **Bi-Polar**
- **GDD -** Global Developmental Delay
- **OCD -** Obsessive Compulsive Disorder
- **FASD -** Foetal Alcohol Syndrome Disorder

Please note, this is not an exhaustive list.

What is Autism?

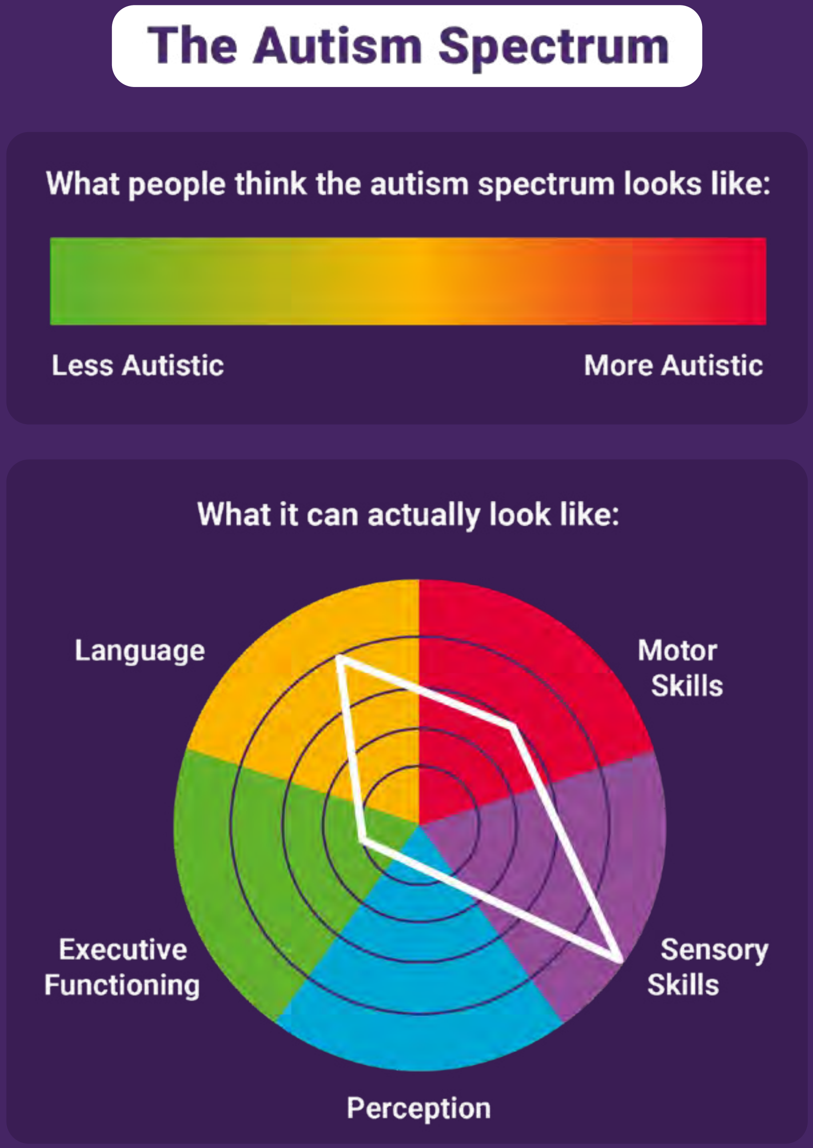
Autism is a lifelong Neurodevelopmental difference that affects how people communicate and interact with others.

Most autistic people see, hear and experience the world differently from neurotypical people, but like neurotypical people, every autistic person is unique and complex.

Historically, there was a common misconception that the autistic spectrum is a straight line between low and high functioning, but as understanding has increased, it is clear that everyone is completely different and has different strengths and weaknesses - you might hear this referred to as a ‘spiky profile’ and it is a great way to explain the differences of ability that are associated with neurodiverse conditions. For example, one autistic person may be highly creative, but struggle to organise themselves. Another may excel at maths, but find it hard to join in two-way conversations.

> **“Sometimes I am very proud of who I am because I can prove people wrong who think I can’t do things, but the other side is annoying because people can label me as just being ‘autistic’ and I am much more than that.”**

This graphic shows that when a person is on the autism spectrum they may demonstrate great strengths in some areas but be lacking in skills in another.



Autistic people will typically have challenges in some of the following areas:

1. Social Interaction

They may:

- Find it difficult to initiate and maintain friendships and relationships
- Prefer to have daily routines
- Demonstrate repetitive behaviours
- Like to strictly follow rules
- Have a strong sense of justice
- Speak in a way that is overly direct
- Prefer to interact with objects or animals to people
- Have difficulty reading facial expressions and body language cues correctly and use facial expressions themselves that can be misinterpreted
- Find it hard to understand and express their feelings
- Like to feel in control, and may have difficulty taking turns

> **"I often felt like I was my child's interpreter."**

For further information about communication difficulties please see section on **Speech and Language**

2. Communication

They may:

- Need more time to process information
- Sometimes find it painful to make eye contact and therefore avoid doing it - or sometimes stare too much!
- Have a language delay or be non-verbal or selectively mute
- Appear very articulate but actually lack understanding
- Use repetitive language
- Mimic phrases they hear or tones of voice/ accents (this is called Echolalia)
- Take things literally – so may have difficulty understanding sarcasm or expressions like 'It's raining cats and dogs'
- Find it difficult to maintain focus, or engage in a conversation which does not spark their interest
- Will give their honest opinion, not realising that the other person was fishing for a compliment!

3. Sensory Processing Differences

Autistic children experience the world differently to neurotypical people and this can be across all of their senses. As Sensory Processing is a challenge for so many neurodiverse children, a specialist Occupational Therapist has provided a thorough overview of the difficulties, and suggested some hints and tips, and this information can be found in the **Sensory Needs Section**.

Sensory things that may be difficult

I can be overly sensitive to loud noises

New clothes can be itchy

I find it really hard to focus or concentrate

I find some foods scary

I get muddled and confused in keeping up with conversations

I am not keen on someone touching me to get my attention

I find being tickled or cuddled uncomfortable

I don't like the smell of cooking

I chew on everything

Hand dryers scare me

I hate fire alarms

I hate having my hair brushed or washed

4. Processing information

Autistic people often have a good eye for detail, although this may be at the expense of looking at the bigger picture and they may need more time to build up connections and associations. Psychologists call this having Central Coherence differences. There may be other differences related to their ASD, such as:

- They may benefit from support in learning sequences (in an early years child, that might be the steps involved in getting dressed/undressed or cleaning their teeth).
- They may benefit from multi-step instructions being broken down into smaller steps (both of these points may be due to what psychologists call Executive Function differences). The picture opposite shows the Executive Functioning tasks that neurodiverse people may find challenging. There are many interventions that can be put in place to help with this. We discuss some of these on **pages 64** and **85**.
- Neurotypical people may find it hard to work out how an autistic person sees the world. In the same way it can sometimes be difficult for an autistic person to imagine something from the point of view of someone else. Psychologists call these Theory of Mind differences and you may also see it referred to as the Double Empathy Problem. You can read more about it here: **Milton's 'double empathy problem': A summary for non-academics | Reframing Autism (https://reframingautism.org.au/miltons-double-empathy-problem-a-summary-for-non-academics/)**

Executive Functioning

01

Impulse Control

Think before acting

02

Emotional Control

Keep feelings in check

03

Flexible Thinking

Adjust behaviour to unexpected changes

04

Working Memory

Keep key information in mind while using it

05

Self-Monitoring

Self-awareness to how one is doing in the moment

06

Planning and prioritising

To set and meet goals

07

Task Initiation

Take action to get started on tasks

08

Organisation

Keep track of things physically and mentally

5. Special Interests

Your child may have an interest in one subject to the exclusion of everything else.

Many autistic people find their interests hugely enjoyable, therapeutic and rewarding. This intense focus (hyper-focus) can be very useful, as it can be used to help solve problems or find new ways of looking at things, but they can be so absorbed in something that interests them that they forget to undertake self-care, such as remembering to eat or drink!

The special interest may be something like an interest in trains, dinosaurs, LOL dolls, make-up tutorials, or Minecraft; it may be a person, a pet or a cuddly toy, or it might be something more unusual like vacuum cleaners! Sometimes the interest can be in sorting items by colour or lining them up, rather than in role play activity. They may consider that anything which doesn't include their special interest is a waste of time and to some other people this may appear rude.

You may find that your child loves to talk about their special interest at length. If they do, try to remember how happy it is making them to share their interest with you (even if you don't find the subject interesting) and that they are likely to only "info dump" on people they feel safe with.

✓ **Top tip** – If you, or your child's school, can find ways to work their current special interest into their education it will help your child to focus and learn.

Greta Thunberg's special interest is protecting the environment.

Autistic Masking

It can be difficult to obtain a diagnosis of autism when a child appears sociable, but if you know them well enough you can see how much energy they are having to put into performing to appear “normal”. This is called ‘Masking’.

Some autistic people can socialise incredibly well, but this can be exhausting as it is often learnt behaviour rather than intuitive. Pretending to be something you are not can take up a lot of emotional and physical energy.

How this might affect your child?

Some autistic children learn to mask without even realising they are doing it. They are noticed for autistic behaviours (**stimming**, talking about their special interests, not maintaining eye contact etc.) and naturally try to suppress them to stop the criticism. Some autistic children and young people worry about being ostracised by their peer group, so learn to mimic how others might behave.

The problem is that the longer the child masks their natural autistic self, the more stressed they become. It is one of the reasons why teachers may not see a problem with some autistic children in school, but when that child gets home the stress from being the model student all day long becomes too much to bear and they end up mentally exhausted and overwhelmed; perhaps exploding with rage, tears, or withdrawing completely. It is even more likely to occur if they don’t have a diagnosis, which helps them to understand why they may behave in a certain way, or why they may have specific needs that differ from their peers.

Masking may also make diagnosis more difficult as schools will be asked for their observations, and if a child is masking at school, the school may say that they see no signs of neurodiversity, even though a parent provides a long list of things that they are concerned about. We have provided links to information about masking, which you may wish to share with your school to help explain that this is a common problem.

Further information

- **www.reframingautism.org.au/self-reported-camouflaging-behaviours-used-by-autistic-adults-a-summary-for-non-academics**
- Autistic Masking resources from Kieran Rose, The Autistic Advocate **www.theautisticadvocate.com/autistic-masking**

What masking may look like

Copying gestures

Learning scripts

Ignoring sensory needs

Hiding stims

Excessive self-monitoring behaviour

Trying to disguise or contain meltdowns

Worrying or overthinking previous conversations to understand what you did wrong

Trying to behave ‘normally’

Girls and Autism

The way that boys and girls are assessed for autism is the same, however, the areas in which they face challenges can be different. Please note that these are generalisations and that some girls will present with typically “male” autistic traits and some boys will present with the “female” traits and it is often the case that parents of these boys will also struggle to secure a diagnosis.

> **“It took 3 years for my daughter to be diagnosed and were initially told she didn’t have autism because she had an imagination! My son’s diagnosis took around a year. We were fortunate to have the support of their primary school who put many interventions in place while we were going through the long diagnostic processes. We were relieved when they were both diagnosed as it meant there were reasons behind their behaviours and proper structures and interventions could be put in place to limit their anxiety.”**

For girls who have complex needs, autistic traits may be clear, but for many in a mainstream environment, the way that autism presents may differ significantly to the male presentation.

Historically, more boys than girls were diagnosed with autism, as the diagnostic criteria was biased towards boys. That is starting to change as understanding improves about the differences.

Girls are more likely to:

- Have special interests in the same way that many boys do, but are often in more culturally acceptable areas, for example, Harry Potter, Our Generation dolls, boy bands, make-up tutorials on YouTube etc.
- Seem better able to manage social relationships when they are young, but difficulties often occur in later primary years as they approach adolescence.
- Be more likely to become withdrawn than behave aggressively.
- Mask their differences. Many boys do this too, but it is a very common feature for girls.
- Have a group of friends who support them and guide them through difficult social situations. However, these relationships can change as girls grow up and interests change, and they may find it very difficult to lose not only friends but also their support network.

Further information

- Free mini guide - **Girls and Autism: Flying under the radar | Nasen (nasen.org.uk/resources/girls-and-autism-flying-under-radar)**
- **Book - Women and Girls with Autism Spectrum Disorder – Sarah Hendrickx - Girls and Women and Autism: What's the difference?**
- **Sarah Hendrickx - YouTube (https://www.youtube.com/watch?v=yKzWbDPisNk**
- **You tube presentation by Tony Attwood: Autism in females (https://www.youtube.com/watch?v=wfOHnt4PMFo**

> **"If people just understood all our differences a little more, especially about girls, because a lot of girls mask like me and then this makes things very hard for us"**

Demand Avoidance Behaviour (sometimes referred to as Pathological Demand Avoidance - PDA)

Demand Avoidance Behaviour is a characteristic whereby the child or young person avoids the demands of everyday activities due to fear, anxiety, reaction to sensory or communication difficulties etc. If these demands feel overwhelming there will be a desire for the person to try to control situations/environments.
It goes beyond simply not wanting to do something and can cause extreme anxiety and resistance. As a parent, it can be very challenging to support a child who is struggling to cope with the demands of everyday life, but it is important to understand that they are not deliberately being defiant, they are having difficulty adjusting and are trying to take control of their environment.

Not all professionals agree with the diagnosis of PDA or that it is something that should be diagnosed separately from ASD. This is why we are using the phrase Demand Avoidance Behaviour.

There are strategies that can help reduce pressures from demands and potential conflict and the most important thing is to show understanding. With the right support in place, the ability to cope and self-confidence will grow, which can help people better cope with day-to-day life.

Parent experiences of Demand Avoidance Behaviour

Parenting a child with this profile may need a different parenting approach and challenges can be different for every child. We asked families for their experiences and tips on what has helped them:

- 'Demands aren't bad per se but too many can cause problems and can result in a meltdown'

- ‘Try to have a joint decision-making process so that when a demand is made, your child may not respond as dramatically’.
- ‘Agree the non-negotiable rules and boundaries. If you can give clear reasons for these boundaries and agree them together then this can help. ‘
- ‘When a rule cannot be compromised, it can be helpful to remove the personal aspect and explain why it is needed. We use sentences like. ‘Sorry it is health and safety rules, that’s just how it is. I can’t do much about that‘
- ‘ We always have an exit strategy and so does the school. We support my child to know how to appropriately remove themselves from an anxiety provoking situation. Together with school and at home, we understand my child may need to avoid a stressful situation, but you need to agree an appropriate way to do this together. For instance, you might agree a quiet zone to which a young person can retreat. You can also provide reassurance that if something can’t be done today it can be tried again another time.’

Rewards can be challenging

- ‘My son does not like praise and rewards as it can be trigger point, particularly personal praise can be overwhelming, as it feels like an expectation and we handle it very sensitively.’
- ‘In fact, rewards can create a demand in themselves, as there is pressure to do well to get the reward. Surprise rewards work a lot better for us.’
- ‘We find that saying something like “you’ve put a lot of effort into that and I know you were a bit worried about it, why don’t you have a break/do something of the you are interested in now’ can be helpful.’

Sanctions and consequences

- ‘My child has difficulties with sanctions or consequences. This often leads to escalations as she feels out of control when the sanction is being given to them. When she calms down, we find it useful to talk through ways to avoid these situations arising in future. We will ask for her views on what she thinks she could have done differently, or what she would feel is a fair outcome.’

Read the experiences of adults with PDA:

- Kirsty Forbes is a highly qualified PDA support specialist and blogger. **Kristy Forbes - Autism & Neurodiversity Support Specialist (www.kristyforbes.com.au)**
- **Sally Cat PDA (www.sallycatpda.co.uk)**

Further information

- Understanding PDA (The priory): **(www.priorychildrensservices.co.uk/news-blogs/understanding-pathological-demand-avoidance-pda)**
- **www.pdasociety.org.uk/resources/understanding-pathological-demand-avoidance-syndrome-in-children-a-guide-for-parents-teachers-and-other-professionals-jkp-essentials/**
- **www.pdaparenting.com/2019/01/16/me-and-my-pda-a-guide-to-pathological-demand-avoidance-for-young-people/**

The Positives of Autism

Autism can be challenging, but many autistic adults can have successful relationships and families of their own and have discovered that combining their autistic ability to hyper-focus and their special interest has led to a fulfilling career.

There are numerous ways in which autistic individuals have contributed to both scientific and cultural advancements within society. These are just a few:

- Greta Thunberg
- Thomas Edison
- Elon Musk
- Albert Einstein
- Sir Isac Newton
- Thomas Jefferson
- Mark Twain
- Wolfgang Mozart
- Vincent Van Gogh
- Chris Packham
- Alan Turing
- Anthony Hopkins
- Darryl Hannah
- Satoshi Tajiri – Creator of Nintendo's Pokémon
- Eminem

> **“The best thing about being autistic is being myself, in a unique way.”**

Autistic Bloggers/Writers

A good way to find out more about autism is to follow the blogs of autistic adults.

- Emily@21andsensory who is an amazing autistic graphic designer, blogger and podcaster **www.instagram.com/21andsensory/**
- Dean Beadle - **deanbeadle.wordpress.com/**
- Pete Wharmby - **www.patreon.com/pwharmbyautism**
- Ann Memmott - **http://annsautism.blogspot.com/2019/01/autism-some-vital-research-links.html**
- Chris Bonnello – writer of the Underdogs children's novels, based on the adventures of a group of neurodiverse children. Blog Autistic Not Weird - Insights from an Autistic Teacher and Speaker **https://autisticnotweird.com/**

Further reading

- **The Reason I Jump: The Inner Voice of a Thirteen-Year-Old Boy with Autism** - by Naoki Higashida – provides an insight into the mind of a non-verbal autistic child. The film adaptation of this book was released in cinemas in June 2021.
- The National Autistic Society website - What is autism **www.autism.org.uk/advice-and-guidance/what-is-autism**
- Tony Attwood lecture of the characteristics of Aspergers - Could It Be Aspergers? - **www.youtube.com/watch?v=LuZFThlOiJI**
- Autism Education Trust **www.autismeducationtrust.org.uk**

What is Attention Deficit Hyperactivity Disorder / Attention Deficit Disorder (ADHD/ADD)?

People with ADHD have difficulty regulating their attention because of poor neurotransmitter activity (the way chemicals are released and transferred within the brain) and differences in the structure of the brain. ADD is similar, but without the hyperactivity.

> **"My brain doesn't sit still, ever!"**

ADHD usually presents in three different ways, hyperactivity (which means the need to move around more), impulsivity and inattention. Children with ADHD may be labelled as disruptive, for behaviour which they cannot control.

These are the main features of ADHD but there are many more that have a significant impact on a child's organisational skills and emotional well-being.

ADHD can present differently in females - we've included a book recommendation below that describes the differences and dispels some myths.

ADHD can occur with other neurodevelopmental conditions such as ASD, specific learning disorders, tics/Tourette's syndrome.

Signs of Inattention

- Makes careless mistakes in work, due to lack of attention to detail
- Often loses or misplaces things
- Avoids activities that require a lot of concentration
- Has difficulty organising themselves, tasks and activities
- Does not seem to listen, even when spoken to directly
- Cannot follow complex, multi-step instructions (especially verbal)
- Easily distracted

Signs of Hyperactivity

- Fidgets with anything to hand, taps feet, rocks on chair, wriggles in seat
- Gets up from the desk/table during lessons/mealtimes for no apparent reason
- Talks excessively and often at a louder volume than others
- Runs or climbs in situations where it is not appropriate
- Has trouble engaging in leisure activities quietly
- Always seems to be ‘on the go’
- Long term rewards, or delayed punishment do not work as disciplinary tools

Signs of Impulsivity

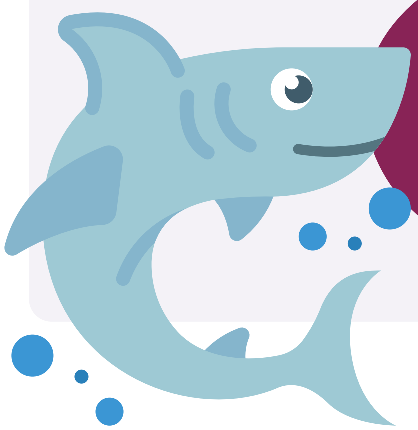
- Blurts out answers before the question has been read out in full
- Unable to consider long term consequences of actions
- Interrupts or speaks over other people
- Seems totally unaware of danger
- Accident prone
- Emotional outbursts
- Answers back – speaks before thinking

Hints and tips

School

There are many strategies that can help. Ensuring the correct provision is in place at the child's educational setting will help them to thrive. Consider asking them to:

- ✓ Introduce brain/sensory breaks
- ✓ Think about desk placement - seat a child where they are less easily distracted, but near their friends so they don't feel that they are being punished
- ✓ Break down the work into small manageable steps. Use a whiteboard as a checklist to list these and allow the child to tick them off as achieved
- ✓ Use a timer to help manage tasks and activities
- ✓ Use visuals to help organisation.



"I just can't stop moving. I'm like a shark!"

Hints and tips

Home

- ✓ Don't mistake distraction for defiance. If you ask your child to put on their shoes, but instead you find them playing with a pet, it is likely that they were distracted from completing the task, rather than deliberately not doing as they were told.
- ✓ Use timers/apps and visual timetables.
- ✓ When undertaking a task help your child to visualise what the end result will look like. Children with ADHD often struggle to plan how to do something, because they don't know what they are aiming for. Working backwards from the end result can help them to start the task, as they can then see the path they need to take.
- ✓ For **some** children it can be helpful to treat their ADHD with medication. https://www.nice.org.uk/guidance/ng87/chapter/recommendations

"Now that I have medication, my brain seems clearer and I can concentrate better."

Writers/Bloggers with ADHD

- Rene Brooks - **Black Girl Lost Keys | Putting the Ayy in ADHD (https://blackgirllostkeys.com/)**
- Joshua Grenville-Wood (co-author of **The Umbrella Gang** comics and a professional golfer) **ADHD Foundation Comic Preview (www.adhdfoundation.org.uk/wp-content/uploads/2019/10/Hi-RES-ADHD-Foundation-Umbrella-Gang-comic.pdf)**
- **Dyskinesia: Love, Lunacy, and Life on the Spectrum: Life with ADD, Asperger's, autism, and a dog. (https://dyskinesia.wordpress.com/)**

Further information

- ADDitude - Inside the ADHD Brain: ADD Symptom Tests, Treatment, Support (**additudemag.com**)
- **Book: Smart but Scattered: The Revolutionary "Executive Skills" Approach to Helping Kids Reach Their Potential** by Richard Guare and Peg Dawson
- **Book: Women With ADHD: A Life-Changing Guide to Overcome the Hidden Struggles of Living with ADHD** by Roberta Sanders

Did you know... Justin Timberlake, Emma Watson, Lewis Hamilton, Mark Ruffalo, Simone Biles, Dav Pilkey – author of the Captain Underpants and Dogman children's books and Will.i.am have ADHD?

What are Specific Learning Difficulties, like dyslexia?

Specific Learning Difficulties (SpLD) including Dyslexia, Dyscalculia and Dysgraphia: Literacy and Numeracy difficulties

A Specific Learning Difficulty is a neurodevelopmental condition which can occur across a range of intellectual abilities. Identifying Specific Learning Difficulties is not always easy - it can be complex. It is vitally important to understand children's learning differences. Literacy and numeracy difficulties are best thought of as being on a continuum, with dyslexia, dyscalculia and dysgraphia falling at one of the spectrum. Its common for people who are neurodiverse to have co-occurring conditions (more than one at the same time), for example children with ADHD or dyscalculia may also be dyslexic.

With the right help and support the majority of children do learn to read, write and do maths. It is important to understand why a child is struggling: in common with other neurodiverse children, dyslexic children may have problems with aspects of executive function such as working memory, organisation or time management. It is important to understand a child's strengths and how a child thinks. This needs a good assessment to ensure that the right approach is used. Playing to our strengths can help overcome the things we don't naturally find as easy. It will also help the child understand why they may not be able to do what their peers do and stop them from thinking they are stupid! The Educational Psychology Team can help schools with free assessment tools.

There is also a free screening checklists for neurodiversity on the British Dyslexia Association website: **https://www.bdadyslexia.org.uk/dyslexia/how-is-dyslexia-diagnosed/dyslexia-checklists**

If a specific learning difficulty is not identified and supported, the young person may be embarrassed and try to mask their difficulties, or exhibit distressed behaviour and may not meet their true potential. As a result, there is an increased risk of low self-esteem, poorer overall mental health, unemployment/under-employment and dropping out of school.

Different terms are used to describe the conditions:

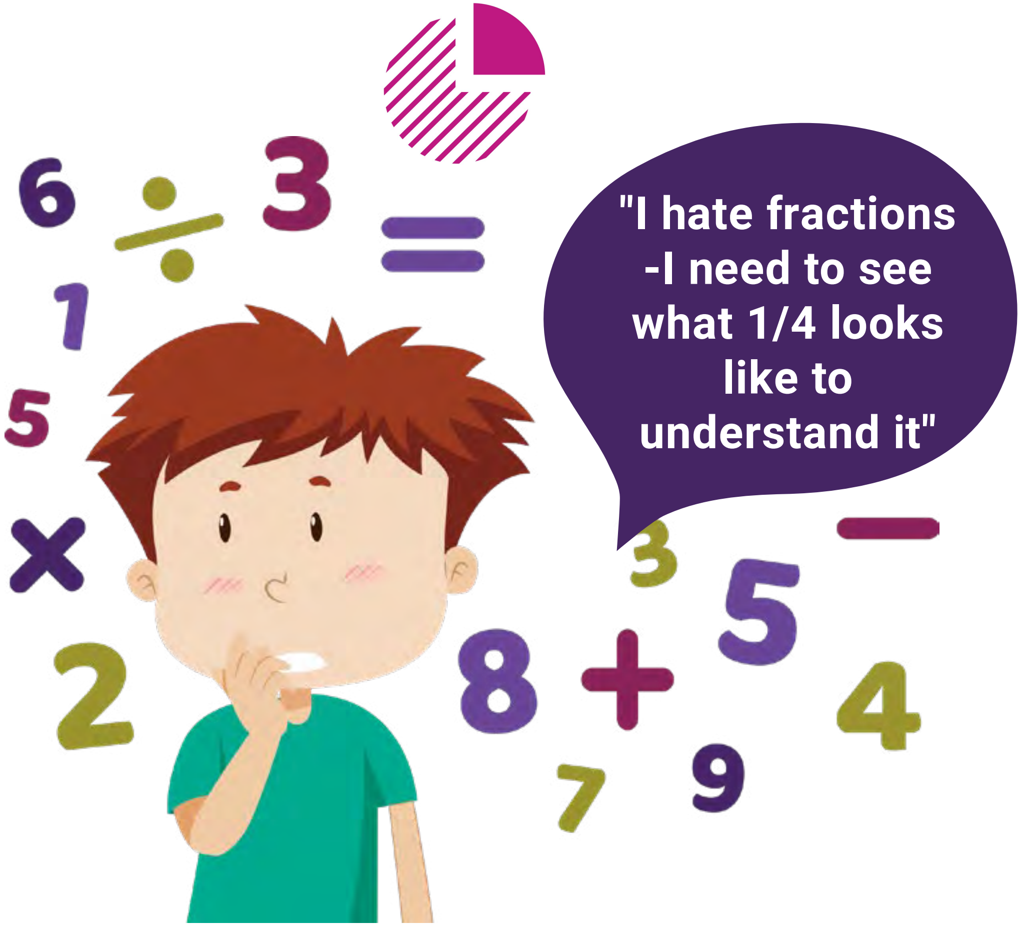
Dyslexia is a term for children who may have difficulty with reading, writing and spelling. As a result, these tasks may be slow, effortful, and not fluent processes for the child. Sometimes this shows later as the demands in school / college for reading and writing increase. It can also show in getting ideas down on paper for essays and exams.

Problems may begin even before learning to read, for example having difficulties with phonics and having trouble breaking down spoken words into syllables and recognising words that rhyme. Younger children may not be able to recognise and write letters as well as their peers. People with dyslexia have difficulty with accuracy and fluency in reading and with spelling. Children may find it difficult to complete the same amount of work as their peers. They may find it hard to read written instructions and so give verbal or written answers that seem inappropriate.

Children and adolescents with dyslexia often try to avoid activities involving reading. They may find it easier to understand pictures, video, or audio rather than written words.

Dysgraphia is a term used by some people for writing difficulties including difficulties with handwriting and fine motor skills - for example holding a pencil with sufficient control, forming letters and shapes, or spacing of words when writing.

Dyscalculia is a term used by some people to describe difficulties with learning number related concepts or using the symbols and functions to perform maths calculations. Problems can include difficulties with number sense, telling the time, memorising number patterns, calculations and maths reasoning. Whilst 25% of the population may have maths difficulties, only around 6% may have dyscalculia.



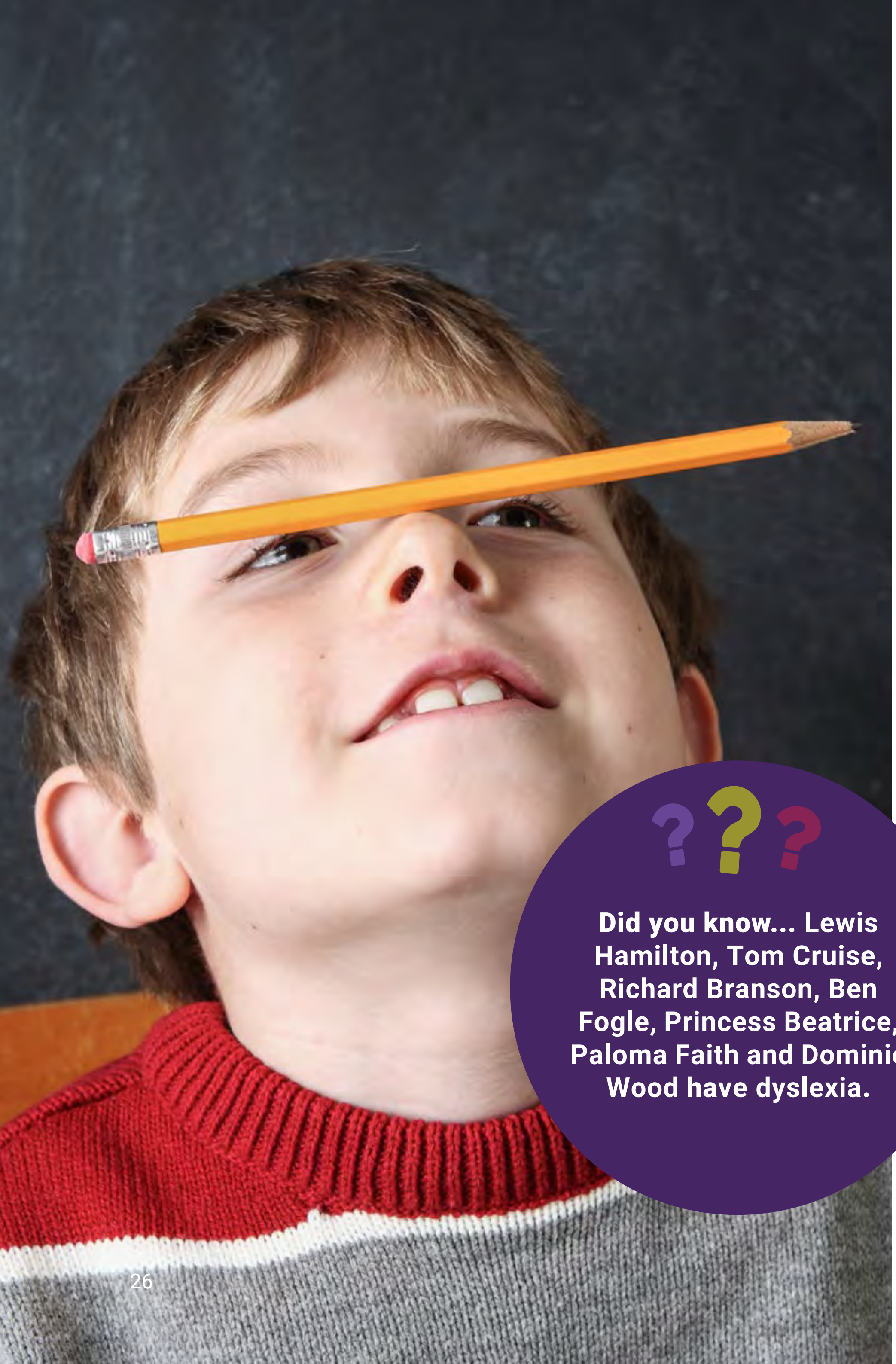
Within the UK, most neurodiverse conditions have agreed medical diagnostic criteria (e.g., ASD, ADHD, Dyspraxia, Tourette's); Dyslexia, Dysgraphia and Dyscalculia are educational diagnoses which means that these terms are not used by some organisations, but they are types of neurodiversity. A thorough assessment as part of the assess, plan , do, review cycle , is very important to ensure that a child's needs are fully met through future teaching and the support the child gets, without needing a diagnosis!

Assessments need to include recognising and celebrating a child's strengths as well as their difficulties to maintain their self-esteem and achieve their potential.

Peterborough City Council want all children to get the help that they need, based on their literacy and maths needs, regardless of whether or not they have particular patterns of difficulties or whether the parents have paid for a particular assessment. You should not need a diagnosis of dyslexia or dyscalculia to access this support.

However, it should be recognised that children and families may want a diagnosis. Currently these are only available by paying for a private assessment. Formal assessments may also form part of an Education Health Care assessment. **https://www.bdadyslexia.org.uk/services/assessments**

The NHS provides a link to the British Dyslexia Association www.nhs.uk/conditions/dyslexia



Did you know... Lewis Hamilton, Tom Cruise, Richard Branson, Ben Fogle, Princess Beatrice, Paloma Faith and Dominic Wood have dyslexia.

> **“A laptop helps me get down what I want to write.”**

> **“I love colour, I need visual resources. I don’t want to be made to feel stupid though.”**

Help at school

If you have concerns, talk to your child’s school about how they identify and meet literacy and maths needs. There are various assessments that schools can use to analyse a pupil’s literacy and maths difficulties in detail. The results should be used to decide if extra help is required to make progress, and if so, what type of help.

These strategies should be used as early as possible, to help any child or young person with literacy or maths difficulties.

Training and resources are available from the Local Authoritiy to help schools and support your child and may include access to a literacy programme.

What you can do to help your child

The approach for supporting literacy and learning difficulties in Peterborough schools is support based on need, without the requirement for a diagnosis. Peterborough expects schools to make this 'ordinarily available' to every child that needs it - will call this Ordinarily Available Provision' (OAP). It may be helpful for you to understand what is available so that you are empowered to discuss the help you child needs with teachers and the SENCo.

Peterborough

Learn Together (where you will find the 'Ordinarily Available Provision' resources)
Peterborough has a website, Learn Together, that provides lots of practical advice and support about helping children with their reading, writing and maths. Whilst this is written for professionals, it can be useful for parent carers. Specific Learning Difficulties are under the cognition and learning section. www.cambslearntogether.co.uk/

Dyslexia Guidance in Peterborough

https://fis.peterborough.gov.uk/kb5/peterborough/directory/service.page?id=tbydD9SGck4

Further information

- Cambugs 1, 2 and 3 (evidence-based app developed by Educational Psychologists, parents and Cambridge University): a fun way to teach children letter sounds, phonics and key words. You can watch a YouTube video on Cambugs letter sounds here (**https://www.youtube.com/watch?v=zbltMVnEhWw**), and a video about Cambugs phonics here (**https://www.youtube.com/watch?v=gLae3lJPXYY**).
- **British Dyslexia Society - What is dyslexia?** - British Dyslexia Association (**www.bdadyslexia.org.uk/dyslexia/about-dyslexia/what-is-dyslexia**)
- Jobs for Dyslexics UK - Exceptional Individuals - **exceptionalindividuals.com/jobs-for-dyslexics/**
- What is Dyscalculia? - The British Dyslexia Association -**(www.bdadyslexia.org.uk/dyscalculia)**
- Dysgraphia - Psychology Today United Kingdom - **www.psychologytoday.com/gb/conditions/dysgraphia**

What is Dyspraxia?

Dyspraxia (sometimes known as developmental co-ordination disorder (DCD)), affects physical co-ordination for both fine and gross motor skills.

This can make it hard to participate in everyday activities such as:

- Writing
- Self-care - getting dressed and toileting, tying shoelaces etc.
- Riding a bike, learning to drive and many elements of sport and play, and a child may appear clumsy.

Oral motor skills may be affected too which can affect eating, drinking and speech.

Not only is physical co-ordination affected, thought processes can be disorganised too and this can increase anxiety.

> **“Giving me time to think can help.”**

✓ Hints and tips

- ✓ Talk to your school - strategies such as using a gym trail, wobble cushions, sensory breaks, using a laptop and pencil grips may help.
- ✓ Scooter boards and balance boards can help to teach a child to feel and understand their body movements and help spatial awareness.
- ✓ Sometimes just encouraging your child to slow down and think about what they are doing can help with their organisational skills.
- ✓ Chunky cutlery is easier to grip and control.
- ✓ Help strengthen hand dexterity by engaging in activities with play dough, rolling, cutting, slicing, picking up with a fork etc.

“Once my school understood I had dyspraxia, there were lots of things they could do to help me, like using a laptop in class.”

Did you know...
Daniel Radcliffe, actress/ model Cara Delevingne, singer Florence Welch (Florence & the Machine), photographer David Bailey and scientist/ presenter Maggie Aderin-Pocock are Dyspraxic.

Further information

- Peterborough local offer
- https://fis.peterborough.gov.uk/kb5/peterborough/directory/site.page?id=ktJhI0HVMoc
- www.dyspraxiafoundation.org.uk

What is Tourette's Syndrome?

Tourette's Syndrome (TS) is when somebody makes movements and noises that they can't control. These noises and movements are called tics.

Tics are usually fast and happen again and again. Tics are preceeded by an internal sensation called a 'premonitory urge' that is typically reported as uncomfortable feeling (like an itch) that they need to get rid of, which is why they perform the tic (i.e. to relieve the uncomfortable sensation).

TS is a genetic condition, with onset typically at around 5 years of age but an increase in tics is often seen around the time of puberty. It is characterised by the presence of multiple motor tics and one or more vocal tic that are present for over a year. Some people only have motor tics and others only have vocal tics, these are referred to as Persistent (or Chronic) tic disorders. For people with tics that present for less than one year, this is referred to as Transient tic disorder.

A diagnosis of TS does not reference severity so some people may have just a few tics which do not interfere with daily life, whereas for others, tics can be more frequent and complex so it can have more of a significant impact.

Contrary to popular opinion, **only about 5-10% of people with TS have vocal tics which involve swear words** and these can be managed using therapies in the same way as other vocal tics.

Tics will naturally 'wax and wane', with periods where people will have more or less tics, with no apparent pattern to this increase/decrease in tic frequency. However, tics are also related to emotional expression and may be more evident at times of high emotion, anxiety, stress or tiredness – so there may be good days and bad days. Tics can be made worse when stressed, nervous, excited or anxious, so young people may find that they tic more than usual in these situations, such as standing up in front of people to give a talk, getting in from school, at Christmas or when going on holiday.

Some people can learn to control or suppress the tics, for example, in a social situation. For some people this may happen automatically and they may not realise they are controlling their tics, whilst for others it can be effortful and may be exhausting. In the majority of cases, the tics will improve and may go away completely by late adolescence/early adulthood. This is thought to reflect changes in the brain and ongoing development of inhibition networks.

TS is often associated with other neurodiverse conditions (co-morbidities) such as ADHD, anxiety, especially social anxiety, Obsessive Compulsive Disorder (OCD) and specific learning difficulties. It is often most helpful to support children and young people with tics in managing co-morbidities, as this can have a positive impact on the tics.

Getting a diagnosis for TS

The first step is to visit your GP who will ask about the tics, how often they occur and what kind of things your child does. They will then refer to a specialist who will ask you and your child lots of questions and base their decision on meeting your child. There are no medical tests like blood tests or scans to work out if you have TS.

Learning about tics and identifying how best to support your child will be the first treatment approach and behavioural therapies may be recommended.

There are two evidence-based therapies for tics, which are Habit Reversal Therapy and Exposure and Response Prevention.

Both therapies help your child to recognise premonitory urges and learn how to react differently to the signals, for example, if the brain sends a signal to the hand to punch the leg, then learning to recognise that signal and instead of punching the leg your child can learn how to resist the urge and just make a fist with the hand and clench the arm instead. This can be helpful if your child has tics that are interfering with daily life, causing harm to themself, or that may be socially embarrassing (e.g. shouting out).

For some children, medication may be suggested to manage TS and your doctor will discuss with you and your child if they think this may be helpful. You should talk to your doctor about all the options available for treating TS.

Did you know... musician Billie Eilish and Youtuber Caspar Lee have Tourette's

Hints and tips

- ✓ Be understanding – tics are involuntary and can't be controlled.
- ✓ Be sensitive that the person with tics may feel self-conscious or embarrassed.
- ✓ Practice mindfulness and breathing exercises to help to relax.
- ✓ Physical activity and intense concentration can help to lessen tics - encourage those activities.

Further information

- www.nhs.uk/conditions/tourettes-syndrome
- www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/tourette-syndrome
- www.tourettes-action.org.uk
- www.tourettes-action.org.uk/storage/downloads/1487860486_TS--the-simple-truth---A-guide-to-TS-for-children-and-young-people.pdf

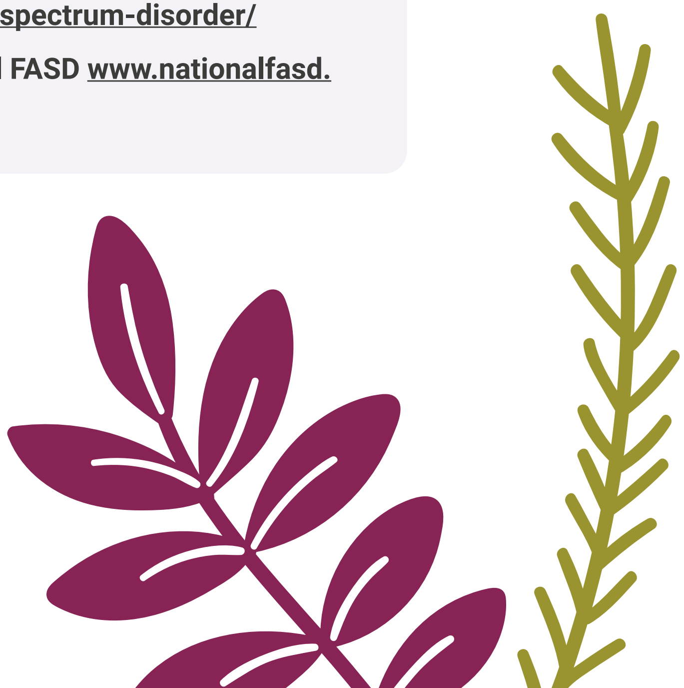
What is Foetal Alcohol Spectrum Disorder (FASD)

Little is known about the effects of alcohol in pregnancy, but research and awareness are increasing, which are helping to provide early support for children and help for affected parents in a non-judgemental way. We have a local group that can offer support to families: www.facebook.com/groups/1320037864718272

Further information

- **www.nhs.uk/conditions/foetal-alcohol-spectrum-disorder/**
- **National FASD www.nationalfasd.org.uk**

> **“What’s interesting is that my child has so many diagnoses, yet a consultant thought that was preferable to giving the diagnosis of FASD. They experience difficulties in many areas and have deteriorated throughout their school life. I wonder whether it would have been worth having the more accurate label so that others could understand all the problems together? Currently, we feel like we’re being pushed around many services where everyone focuses on only one aspect, then when they don’t fit those criteria exactly, we’re moved on. I just want someone to see my child as I do - a complete, lovely person!”**



What is Obsessive Compulsive Disorder (OCD)?

OCD can be a debilitating condition and is often misunderstood; so much so that many people hide it for many years. The good news is that OCD is a treatable condition, with both therapy or medication available that can help with management and recovery. Children and adults with OCD experience intensely negative, repetitive, and intrusive thoughts, combined with a chronic feeling of doubt or danger (obsessions).

Common OCD themes include fear of germs, harm, symmetry, sexual thoughts, violence and thoughts of harm to self and others. These thoughts are known as ‘ego dystonic’ as they are completely against the suffers values and feel ‘wrong’ to them.To suppress the thought or lessen the anxiety, they will often repeat an action, again and again (compulsions).

1 Obsessive thoughts

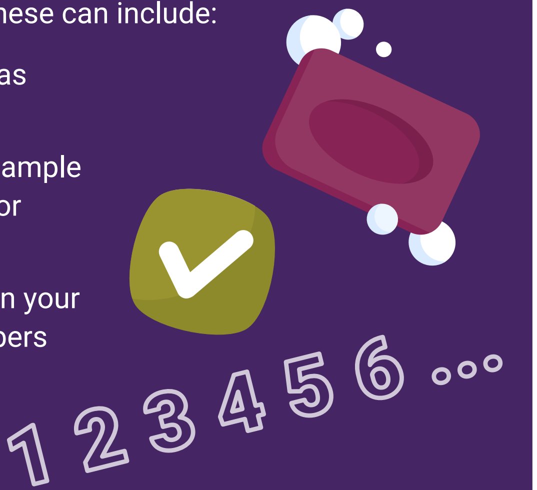
These are thoughts, ideas and intrusions which occur repeatedly. These thoughts are likely to be unwelcome and frightening and they can make people feel scared, anxious, and out of control.

There are two aspects to OCD

2 Compulsive actions

These are activities which are repeated to try and take control over a situation to reduce the anxiety caused by obsessive thoughts. These can include:

- Physical actions such as washing hands
- Checking things, for example that doors are locked, or plugs switched off
- Repeating sequences in your mind – words, or numbers
- Constantly asking for reassurance



The main treatment is cognitive behavioral therapy (CBT). If this does not help, medication may be offered or a combination of both.

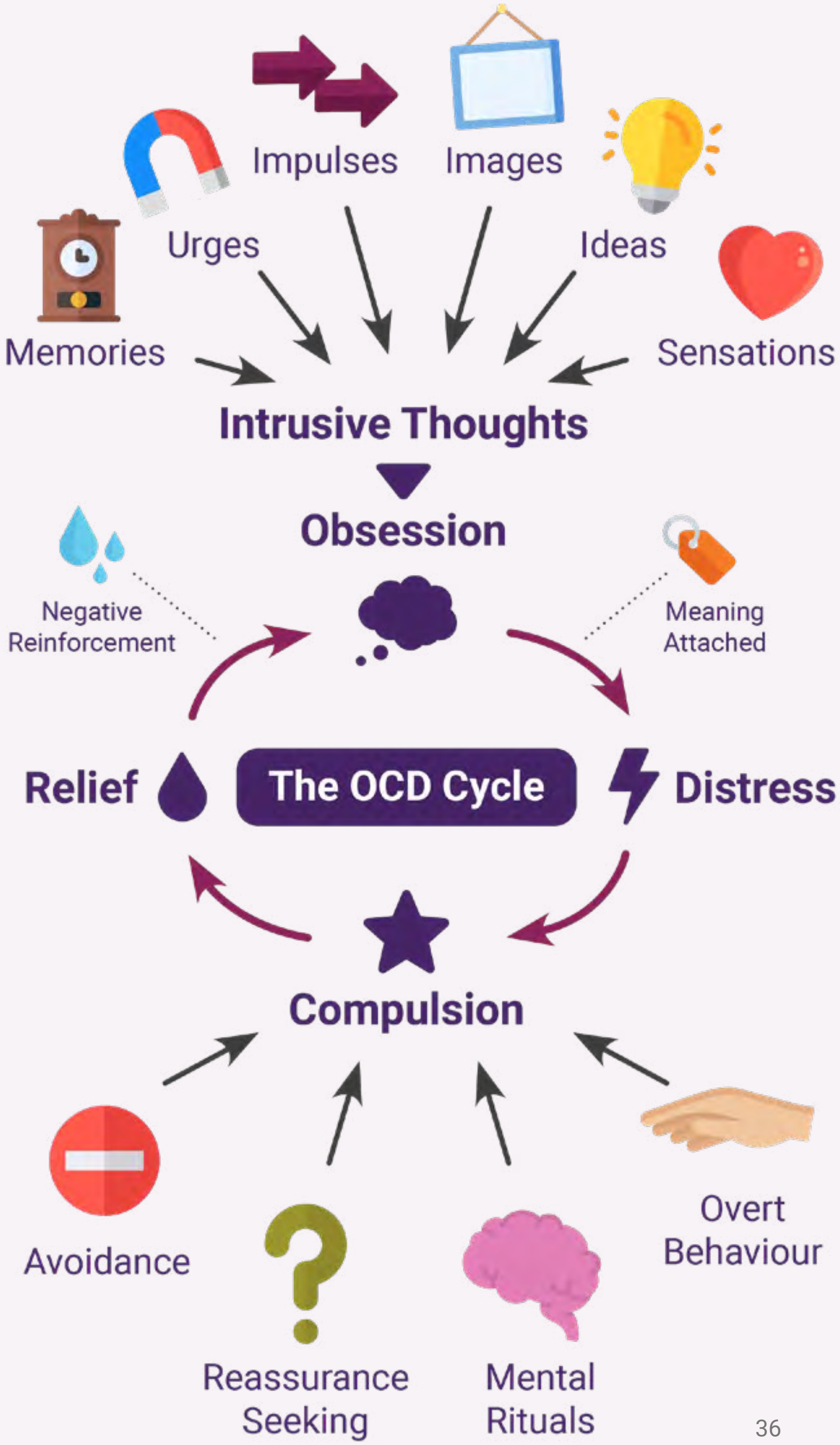
One of the greatest challenges if you have OCD, is to debunk the widely held belief that OCD is a mild or even “quirky” problem that is nothing more than hand washing. People might use the phrase “a bit OCD” without understanding what it really means.

There are also positives! People with OCD can have incredible attention to detail, and many are creative. By understanding the way they deal with their own difficulties, people with OCD often can be understanding of others who are dealing with things that they can’t control.

Further information

- **www.nice.org.uk/guidance/CG31/chapter/1-Guidance#steps-35-treatment-options-for-people-with-ocd-or-bddP**
- **www.youngminds.org.uk**
- **www.mind.org.uk**
- **www.nhs.uk/mental-health/**
- **www.ocdaction.org.uk**

Did you know... Leonardo Di Caprio, Charlize Theron and David Beckham have OCD?



Co-Occurring Conditions (Comorbidities)

‘Co-morbid’ is a scary word but it just means other conditions that are likely to exist along with the main diagnosis, or biggest area of need. These can be other neurodiverse conditions: for example, people with ADHD may also be dyslexic or have dysgraphia. People can also have medical conditions alongside neurodiverse conditions.

This list is not exhaustive, but some examples are:

- **Learning disabilities and learning difficulties** – which affect the way that a person learns new things, and they may have difficulty understanding complex information, or coping independently.
- **Hypermobility** - very flexible joints which may cause you pain. **www.hypermobility.org**
- **Ehlers-Danlos syndromes (EDS)** are a group of rare inherited conditions that affect connective tissue. Connective tissue provides support in skin, tendons, ligaments, blood vessels, internal organs and bones. **www.ehlers-danlos.com/eds-types**
- **Scoliosis** - curvature of the spine which may result in back pain. **www.sauk.org.uk**
- **Irritable Bowel Syndrome (IBS)** - chronic tummy pain, cramps and diarrhoea. **www.nhs.uk/conditions/irritable-bowel-syndrome-ibs/further-help-and-support/**
- **Epilepsy** - a neurological disorder which can cause seizures or unusual sensations. **https://epilepsysociety.org.uk/**
- **Fragile X** – a genetic condition with traits including learning disabilities and some pronounced physical features. Some autistic children will be tested for Fragile X. **www.fragilex.org.uk/**
- **Prosopagnosia (Face blindness)** – people with this have great difficulty recognising faces that they have seen before, even many times, especially if they are not in their usual context i.e. you see a teacher at the shops. **www.faceblind.org**
- **Auditory Processing Disorder (APD)** – Anyone with this problem does not actually have an issue with their actual hearing, but rather the brain’s ability to process and interpret the signals it is receiving from the ear. This can result in a delay in processing what someone is saying to you, difficulties in differentiating between similar sounding words and being unable to filter out background noise. **www.additudemag.com/what-is-auditory-processing-disorder**

Section 2

Early Intervention and Diagnosis Process

Pre-diagnosis - first steps

If you have any concerns about your child or young person then trust your instincts. You know them better than anyone else and are their greatest advocate.

You may have a sense that some of your child's reactions seem to be extreme or excessive, or don't follow similar development patterns of other children their age. Sometimes you might have support from those around you, but for some it can feel that staff at school/ pre-school, family members and friends may see things differently and dismiss your concerns or seem to be judgmental. If this happens, talk to another professional such as your GP, health visitor or a trusted member of staff from school/pre-school.

Not all families will want to seek a diagnosis and that is ok, it is an individual family choice.

Sometimes it can be that you are not the first to notice differences. Some parents will naturally make adjustments to their own communication and interaction with their child to compensate, without realising, especially if there is no sibling for comparison. If your child's difficulties are pointed out by other family members or staff at pre-school/school in the first instance it is not your fault for not seeing it.

For younger children, sometimes the first difference you or others become aware of is their delayed communication. You may be referred to Speech and Language Services.

> **"Originally, I didn't want to label my child as autistic because I was worried about what people would think. Now my child has been diagnosed, I am so glad that we did because it has really helped me to understand him."**

> **"I felt no one understood my child. I didnt understand why my child was getting upset."**

Recognising that you need help

When you realise that your child needs support, the first step is usually to speak to your GP, health visitor, teacher or special needs co-ordinator (Senco) at school. It can also help to increase your own understanding by reading books, looking at information available online (but make sure that it is a reputable site as there is lots of misinformation online), or talking to other parents in a similar situation. Family Voice Peterborough offers free information sessions and parent to parent support . If you don't know anyone, there are many support groups across Peterborough– check out the Council's 'Local Offer' which provides information for families of children with special educational needs and disabilities. You can also search on social media for terms like 'SEND', 'Autism', 'ADHD' etc. It can be a great relief to find other people dealing with the same emotions and challenges. It's important to note that you don't need a diagnosis to access help.

Further information

- **Family Voice: www.familyvoice.org**
- **Peterborough Early Help Information: https://www.peterborough.gov.uk/healthcare/early-help**

> **"This doesn't mean your child is broken, just that their brain works differently. Give your child the tools to operate in a neurotypical world on their terms, without dimming who they are."**

> **"Some days I wondered whether I was imagining her difficulties but when I started to keep a note of things that happened on difficult days a pattern started to emerge and it helped me understand the things that triggered her behaviour."**

Keeping a record

It will help the medical professionals to understand your child if you keep a chronological record of behaviours that you find unusual or concerning, including dates and places. Also include any comments made by professionals, other family members, child-minders, former or present teachers, or friends as this helps to validate your concerns. These examples may include distressed behaviour, anxiety, sensory difficulties, unusual speech patterns, interactions with other children, or executive functioning issues.

> **"Try to detect when your child reacts poorly to certain smells, sounds or other sensory stimuli. Sometimes they don't even realise what has triggered them. Sometimes it feels weird for them to say when a sensory thing is bothering them due to the public need to mask and not "act autistic"."**

Many neurodiverse children can have good days and bad days – it is helpful to understand the factors that lead to distressed behaviour and to have those examples to hand when you are talking to professionals.

GPs and health visitors do not have the expertise to diagnose neurodiverse conditions but most do have a lot of experience of them and can refer your child to a paediatrician or other clinician who is qualified to undertake an assessment. They can also provide details of other services that may help. You can ask them to include your observations when they make the referral, which will give the professional making the assessment an opportunity to read the information before your appointment.

As part of the health visitor contacts, you and your child will be invited to attend an Under 1 Year and a 2-3 Year Review. These reviews provide an opportunity for practitioners to assess the strengths and needs of your child and your family and to plan further care. During each review the practitioner will explain their role and what the review will entail and go through the Ages and Stages Parental Questionnaire with you and discuss any concerns you may have regarding your child's development. Following on from that, practitioners can provide further support, signpost to groups and other agencies and make referrals to other professionals such as a paediatrician if needed.

If the difficulties aren't immediately obvious, (which often they are not!), sometimes the GP or Health visitor may ask you to undertake further observations or may ask you to return to them in six months if you still have concerns.

Your GP may also refer you to a parenting course. This does not mean that you are a bad parent, it is simply to share different parenting techniques which may help your neurodiverse child.

Parent top tip

✓ Buy a big folder and start keeping a copy of everything, literally everything, to build a complete picture of your child. My son bit a child at school, and the teacher spoke to me on the school gate, at the time I was upset and couldn't really focus on what they were saying so I asked them to confirm in writing and this was actually really useful information when I spoke to my GP about my son's difficulties.

What if my GP does not refer my child?

If your child is not referred for a further assessment, ask for the reason why. If you don't agree with their decision, you can ask for a second opinion. Meanwhile, continue to add to your log of evidence.

"A friend recommended that I read Tony Attwood's book about Asperger's and I couldn't put it down. It was as though he was writing all about my son – everything started to make sense."

Overview of the diagnostic process and what to expect

The process, and amount of time that you need to wait to see a paediatrician, or diagnosing clinician varies depending where you live in the UK.

The NHS guidance from the National Institute for Health and Care Excellence is currently being reviewed. You can view updates online at: **www.nice.org.uk/Guidance/CG128**.

The current recommended timescale from referral to appointment is 18 weeks although these timescales are often exceeded.

You can request an alternative provider to carry out the assessment (especially if you find an alternative with a shorter waiting list) and these rights are outlined in the nhs patient choice leaflet (**www.nhs.uk/NHSEngland/patient-choice/Documents/patient-choice-leaflet.pdf**) with more detailed information available here **www.gov.uk/government/publications/the-nhs-choice-framework/the-nhs-choice-framework-what-choices-are-available-to-me-in-the-nhs.** We suggest that you check with other families and your local support group to hear their recommendations.

What can I do whilst I am waiting?

Just because you are waiting for an assessment and your child does not have a diagnosis, it does not mean that you need to wait to access support. Many services, charities and support groups will be happy to help without a formal diagnosis. A diagnosis is not required to access support for your child at school or pre-school so you should talk to them to ask what they can do to help.

Look through the information in this guide to find information that may help you now and look for accessible talks and webinars that are available from local practitioners.

I’ve got an appointment, what can I expect to happen?

The diagnosing clinician may be a paediatrician, psychiatrist and speech and language therapist. Specialist nurses and occupational therapists may also provide input. Usually, the appointment is with one professional but sometimes there may be more than one person in attendance and this can be called a Multi-Disciplinary Team Meeting (MDT)

They may have received your observations with the referral but will also ask you to tell them about your concerns, so it useful to keep your own copy that you can refer to.

They may talk to your child and try to engage them in conversation or get them to participate in some simple games or activities to observe their responses. They will also consider reports and observations from school or other education settings.

✓ Top tips

- ✓ Make sure you bring your list of the signs you see (chronological diary).
- ✓ Bring a pen and paper with you so you can take notes.
- ✓ Consider bringing your partner/a friend/family member – there’s a lot to take in at these meetings so it helps to have an extra set of ears and some moral support.
- ✓ Take a drink and snack for your child as well as a favourite toy for whilst they are waiting.

Various diagnostic tools are used, depending on the specific condition, where you live and which specialist you see. The most commonly used are:

Autism Diagnosis

Autism Diagnostic Observation Schedule (ADOS)

The majority of NHS and private providers undertake initial assessments and then use an ADOS which is an observational tool used to assess children for ASD. It includes a variety of activities such as puzzles, books, role play, which may differ depending upon the age of the child. Most children enjoy these activities and don’t find the assessment stressful.

- The ADOS assessment will be considered alongside a developmental history and general observations and is not a stand-alone tool. **www.nice.org.uk/guidance/cg128**
- The assessment usually takes 60-90 minutes. Parents of younger children are usually invited to stay for the duration of the assessment. Parents may be asked to leave the room for some of the assessment if the clinician feels this is appropriate.
- After the assessment, there will be an MDT meeting where other information is considered before a decision is made. A report is then produced which is usually shared with parents/carers at a follow-up appointment within 8 weeks of the assessment.
- In some cases a "play based assessment " is used when ADOS is not suitable.

Brief Observation of Symptoms of Autism (BOSA)

The BOSA diagnostic assessment for autism was introduced in some areas when ADOS assessments could not be undertaken because of Covid-19. The assessments have been well received by families and clinicians, so are likely to continue.

Other diagnostic tools and evidence, in addition to BOSA are used in order to get the relevant information and compare with a standardised diagnostic criterion.

Overview of the BOSA assessment

- There are opportunities for a parent to engage in social interactions and activities with their child through games and conversation, creating an environment in which symptoms of autism can be observed by the clinician.
- To ensure that the assessment runs smoothly, the clinician will provide clear instructions in advance so parents can be well prepared. They will also be able to support parents with what to do during the assessment if needed.
- In most cases, there will be a screen in the room which will be blank so that the child is not aware they are being watched. Sometimes the observation could be from the next room with an observation window or in the room with observers wearing PPE and being socially distanced.
- The observation is planned to last 12 to 14 minutes – but often takes longer.
- The parent and child then leave the room and the professionals all discuss what has been observed. They also look at the history and any information from school, parents and other professionals. Then the parent is called in and a diagnosis is given if appropriate. Parents can ask for their child to be told but it is up to the parent if they want this to happen.
- The team involved in observing the BOSA are all ADOS trained and have experience in the ADOS assessment process.
- BOSA has been well received by families - children are calmer as their parents are there with them and it feels like they are just playing some games and chatting. Parents feel more involved and can better understand what is happening.

In the event that the BOSA observation did not provide evidence of the presence of autism, additional evidence should be sought through alternative methods (e.g. Autism Diagnostic Interview-Revised parent report) before it is concluded that it doesn't exist.

Developmental, Dimensional and Diagnostic Interview (3Di)

The clinician undertakes a 3Di interview to assess a person for autism; asking parents/carers multiple choice questions, although comments can be added. It covers areas such as:

- Family history and background
- Behaviour
- Eating habits
- Sleeping habits
- Communication
- Social interaction

The ADI-R (Autism Diagnostic Interview - Revised)

The clinician undertaking this assessment interviews the parent or carer who is familiar with the developmental history and current behaviour of the person being assessed.

The questions focus on behaviour in 3 areas:

1. **social interaction;**
2. **communication and language; and**
3. **restricted and repetitive, stereotyped interests and behaviours.**

It can be used with adults and children from the age of two.

As well as being used to give a formal diagnosis, the findings can be helpful to suggest appropriate support.

Other tools for autism diagnosis are available such as the DISCO assessment for autism - DISCO (**www.autism.org.uk/what-we-do/diagnosticservices/disco**), The use of a particular assessment tool often depends on which diagnostic tool the clinician is trained in - all are equally valid.

> **'The interview was very thorough and took over 2 hours. I was asked about my son's behaviour as a baby and toddler – he was 13 when the assessment took place so it was a lot to remember! We found it useful to look at old photos and videos, and to talk to family and friends before the interview to discuss any unusual behaviours.'**

ADHD Diagnosis

Diagnosing ADHD in children depends on a set of strict criteria. To be diagnosed with ADHD, your child must have 6 or more symptoms of inattentiveness, or 6 or more symptoms of hyperactivity and impulsiveness.

To be diagnosed with ADHD, your child must have:

- been displaying symptoms continuously for a minimum of 6 months
- shown symptoms of ADHD before the age of 12
- Display symptoms in at least 2 different settings – for example, at home and at school
- symptoms that make their lives considerably more difficult on a social or educational level

The specialist can make an accurate diagnosis after a detailed assessment. The assessment may include:

- a physical examination, which can help rule out other possible causes for the symptoms;
- a Qb test
- a series of interviews with you or your child and the completion of a Conners Questionnaire (for ages 6 and over);
- reports from other significant people, such as teachers. Your child's school will usually be sent a Conners Questionnaire to fill in too.

What is a QbTest?

A Qb Test is a computer-based test which measures attention, ability to concentrate, impulsivity and motor activity, to assess for ADHD.

The test results are analysed straight away and presented in a report that compares the young person's results with a group of people of the same age and gender who do not have ADHD.

The Qb test is not a stand-alone test and does not replace clinical judgement but will be used alongside other assessment tools detailed above.

The test:

1. Provides unbiased information
2. Standardises decisions
3. Reduces appointment times and delays in the diagnostic process
4. Can monitor how your child responds to treatment.
5. Is improving confidence in diagnosing or excluding ADHD.

The test is performed on a computer and takes 15 or 20 minutes. The test equipment consists of an infra-red camera, a head band with a reflective marker and a response button. During the test a number of symbols are shown on the computer screen and the task is to push the button when a certain symbol appears on the screen. The test is easy to perform and your child will receive instructions during the appointment.

Further information

- What is the Conners rating scale for ADHD? (**www.healthline.com/health/adhd/conners-scale#Short-and-Long-Versions**).
- For more information about the Qb test visit **www.qbtech.com**

Dyspraxia (Developmental Coordination Disorder)

The diagnosis of DCD is usually made by a paediatrician and/or occupational therapist.

Standardised assessments such as Motor Assessment Battery for Children (M-ABC) and the Beery Buktenica Development Test of Visual-Motor Integretion (Beery VMI) ABC Assessment are usually used to ascertain whether a child has DCD. It involves:

- gross motor skills tests – which measure the ability to use large muscles to walk, jump, catch/throw a ball and balance;
- fine motor skills – which measure the ability to use small muscles for accurate co-ordinated movements, such as drawing, writing and placing small pegs in holes;
- In older children they may also test to see if the child can produce significantly more work using a laptop than when writing.

Your child's performance in the assessment is scored and compared with the normal range of scores for a child of their age. The assessment may also involve discussions of family health history and any particular difficulties the child is experiencing in day-to-day life.

Once the diagnosis is confirmed, the paediatrician/OT involved will produce a report detailing the particular issues affecting your child and will suggest tools and exercises to help your child improve their fine/gross motor skills.

What next?

What to do if your child does not receive a diagnosis

You might be relieved to hear that the specialist does not consider your child's differences significant enough that a formal diagnosis is required. As with all spectrum conditions, many children with some neurodiverse traits can manage their differences very well. However, if you were concerned enough to make a referral, you may still have questions.

> **"We were referred to the paediatrician by my son's infant school. Looking back, we didn't really know anything about autism, other than Rainman and the other stereotypical idea of autism (which we now realise is hugely inaccurate). We didn't believe our son was autistic, he made eye contact with us, we communicated well with each other and didn't think his behaviour was particularly odd. We should have researched it, but just totally rejected the idea and carried on parenting. A couple of years later my friend was getting her daughter assessed for autism and I read a few articles she had shared about it. There were lots of traits mentioned that I didn't even realise were signs of autism and the more I read, the more I realised that my son is autistic and so am I."**

As a first step, you might find the information in this support pack will give you enough knowledge to be able to help your child and suggest things that will help at school/pre-school. You can also discuss with your Health Visitor, School Nurse, School Senco or Therapist. A lack of diagnosis should not mean that your child's needs, whatever they may be, are not supported by their school or setting.

Sometimes difficulties can become more evident as children get older, especially for children with what used to be called Asperger's or High Functioning Autism* who learn to mask their differences. In these cases, continue to keep evidence and if you believe it is needed, return to your GP to ask for a re-referral for a second opinion and this may be outside of the geographical area. Or call **Contact - for families with disabled children (www.contact.org.uk)** who may be able to give you advice about your options, including private assessments.

You can access Information on the family voice website, we also offer signposting :
www.familyvoice.org

---

* Asperger's and high/low functioning labels are no longer used, and where appropriate, a diagnosis of Autism Spectrum Condition (ASC) will be given. However, it can be useful to access resources using these terms, although the terminology has now been superceded.

Your child has received a diagnosis. What you can do now.

How do **YOU** feel?
However you feel is ok.

The route to getting a diagnosis can be emotional. Other parents have described their feelings:

“Shocked, even though it was expected.”

“Relief that I was being listened too and very emotional.”

“After the diagnosis I got told what I already knew but it felt good to have it written in black and white.”

“I started to accept it and take it as a blessing instead.”

“Relieved, sad, guilty and I felt it was my fault.”

“We received our diagnosis yesterday. It didn’t take long to confirm what I already knew that this gorgeous amazing little boy is autistic. We can get all the help and support he deserves now.”

It can be helpful to recognise that even though you might have expected a diagnosis to be given, you may be feeling shocked and need some time to process the diagnosis. Remember that your child is the same person that they have always been, and take time to speak to other families who will understand how you are feeling.

Moving on from a diagnosis can seem daunting, but there is support available. Once a diagnosis is confirmed, you can begin to better understand what is going to help and get the right support to help your child maximise their potential - but in the same way that every person diagnosed is unique, the best way to help and support them will also vary from person-to-person.

> **“I found it really helpful to join a local support group and talk to other parents who have gone through the same experiences.”**

Local support groups online or groups that may run drop-in sessions or coffee mornings are a vital support network for families.
Some groups and charities also offer activities for your child and opportunities to meet other children who are neurodiverse. Family Voice offer coffee mornings and some activities for the whole family and we can signpost you to other sources of support:
http://www.familyvoice.org

Telling your child about the diagnosis

There is no definitive right or wrong way or time to tell your child. Different things work for different children depending on their emotional maturity, social awareness and ability to process what you are telling them. They may not be ready, or able to understand or they may struggle to accept it. If they are not ready, leave it until they are.

When you do speak to them about their diagnosis, it's really important to remind your child of all their good and positive traits, to reinforce that you love them, and that you would not want them to change or be any different. Sometimes it can help to tell them about the many positive role models and famous people who share their diagnosis.

How do you feel about your diagnosis?

"It has two sides, sometimes I am very proud of who I am because I can prove people wrong who think I can't do things because I have a disability, but the other side is annoying because people can label me as just being 'autistic' and I am much more than that."

"I have now come to terms with it because more people have listened to me and I now feel confident to talk about it too and help others understand."

"I like being myself, in a unique way."

Top tips

- ✓ Stay positive and don't let it come across that you are worried or concerned. This range of differences is just a natural variation in the human mind.
- ✓ Emphasise to your child that no two people who are neurodiverse are the same so how they experience something is unique and personal to them.
- ✓ Your child may have lots of questions, feel relieved or find it difficult to process. Be supportive but allow breathing space and time for your child to process this information.
- ✓ Share other neurodiverse successful role models - who may be famous or people you know.
- ✓ The SNAP charity has developed a really useful guide to introducing a diagnosis which includes a range of useful resources (**www.snapcharity.org/wp-content/uploads/2021/06/Talking-About-a-Diagnosis.pdf**)

As your child grows and develops, you will discover the amazing unique individual that they are and can be.

“My son was at the final appointment where he was diagnosed so the doctor explained it to him which helped a lot. We explained it very simply, that all our brains are wired up with lots of blue wires and that because he was extra special, he had a couple of red wires that made him feel, think and act differently, but that made him unique. We also encouraged him to share a book with his class called Let Me Tell You About My Autism. The first bit was for him to read to the class and the second part is for the adults. He took it into his school and the teacher took about a week reading it with the class. It helped him take control of his autism, which empowered him.”

Further information

It can be helpful to have information or books to support your conversations – we like:

- **Talking to children about Autism | Reframing Autism (www.reframingautism.org.au/talking-to-children-about-autism)**
- **All Cats Are on the Autism Spectrum - Kathy Hoopmann**
- **When should I tell my child they’re autistic, and how do I tell them? - Autistic Not Weird (https://autisticnotweird.com/when-should-i-tell-2020)**
- **Share the Umbrella Gang Comics with your child about children with ADHD - (www.adhdfoundation.org.uk)**
- **Helping autistic children & adults make sense of the social world - Siobhan Timmins (www.siobhantimmins.uk)**
- **This is a list of books with neurodiverse characters - it may help to share these with your child. Children’s Books with Neurodiverse Characters for Kids, Parents, Teachers and Therapists (www.littlebookroom.com.au/neurodiversity)**
- **There are more helpful books listed in the Useful Information Section at the end of this pack.**

Section 3

Education and School

Does my child need additional help at school or pre-school?

All children are entitled to a fulfilling education, but neurodiverse learners may need extra support to be happy and meet their full potential at school.

In this section, we have included information about the help that is available to you, suggestions of interventions and reasonable adjustments and tips on how to effectively communicate with the school.

You know your child and you are their best advocate. If you notice that your child has significant difficulties with some of these things, it may be an indication that they need help:

- Making friends
- Sitting still in class
- Maintaining focus
- Not eating at lunchtime
- Being upset when they go into school
- Being upset when they come out of school and they have a meltdown or withdraw when they get home

- Showing anxiety when you leave them
- Not wanting to go to school
- Getting into trouble at school for their behaviour
- Finding it hard to learn
- Finding it hard to follow instructions
- Finding it hard to move from one activity to the next
- Having difficulty controlling their emotions
- Being overwhelmed by smells or loud noises at school
- Not making progress academically
- Child cannot say what is wrong or worrying them
- Not being able to go to the toilet

Or perhaps the school has identified that your child needs support.

What you need to do to get help for your child differs depending on their age.

Support in Early Years

Most early years settings are able to support children with special educational needs and/or disabilities (SEND) without additional funding.

If you are concerned, please speak to your pre-school setting, health visitor or GP, who will work with you to access help. If a health professional believes that a child has or probably has special educational needs or a disability then they have various duties, including telling the local authority (education services). Their duty is set out in **Section 23 of the Children and Families Act 2014 (www.legislation.gov.uk/ukpga/2014/6/section/23)**.

You can find out more about "Early Years SEN Specialist and Portage Service" and "early identification/intervention" following the link below

https://fis.peterborough.gov.uk/kb5/peterborough/directory/family.page?familychannel=8-1

Hints and tips for pre-schoolers – Ideas for things that may help at nursery or pre-school

- ✓ Coming in either slightly before or after the other children to so that they can come in at a quieter time and have a more settled start to the day.
- ✓ Being allowed to have a comforter (something they like to carry from home) - some settings may discourage this but it can help to reassure your child.
- ✓ A clock or digital timers can help to visually reinforce all transitions.
- ✓ Not having to follow a strict healthy eating policy – for example being able to drink juice rather than water. For children with a limited diet, it is more important that they are able to eat and drink regularly.
- ✓ A flexible approach to session times to meet the child's needs, for example, shorter session times that can be gradually increased as the child settles.
- ✓ Group sessions such as musical communication, attention autism and social skills games.
- ✓ Visual tools such as PECS (**https://pecs-unitedkingdom.com/pecs**), Makaton (**www.makaton.org**), timetables, photos.
- ✓ Sensory toys, weighted blankets, wobble cushions.
- ✓ Sensory breaks and a quiet place to go to if feeling overwhelmed.

Further information

You can find more information about SEND help for under 5’s here:

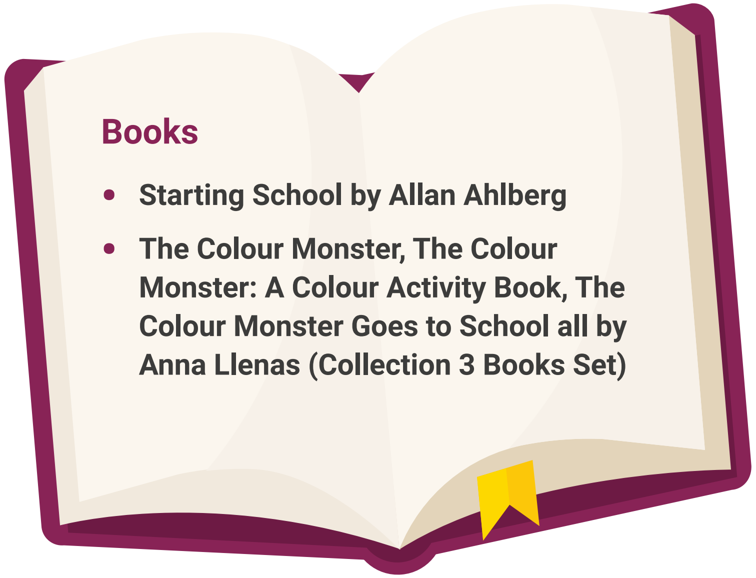
- **Peterborough Early Help**
  https://www.peterborough.gov.uk/healthcare/early-help
- **Child and Family Centres**
  https://fis.peterborough.gov.uk/kb5/peterborough/directory/results.page?familychannel=1_11

> **“Do not feel your child has to go to preschool or nursery just because everyone else’s child does. Trust your instinct!”**

Educational Support from 4-16 years

Moving from Preschool to school

Starting school can be daunting for our children as well as for us as parents. The more planning you can do in advance of the change, the smoother the transition should be.



Books

- Starting School by Allan Ahlberg
- The Colour Monster, The Colour Monster: A Colour Activity Book, The Colour Monster Goes to School all by Anna Llenas (Collection 3 Books Set)

> **“Before my daughter started school, we laid out her uniform and practised changing into it. We also did the walk to school over the summer holidays, and this helped a lot too.”**

Support for children and young people of school age

Every neurodiverse child is unique and will have different educational and sensory needs. Some children may require a specialist setting, however, with appropriate support, the majority should be able to thrive in a mainstream environment, and this is outlined in the **Special Educational Needs and Disability code of practice: 0 to 25 years (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf)**.

Top tips

- ✓ Visit the school as many times as possible before your child starts. Many schools have summer fairs or open days, and these can be good ways to familiarise yourself with the school, in addition to any formal visits.
- ✓ Take photos of any key people who will be with your child in school, for example, teacher, teaching assistant, dinner ladies/men, headteacher, lollipop person.
- ✓ Use visual supports to reinforce what to expect during the school day – for example pictures of the cloakroom, toilets, lunch area, playground and where they will sit in class.
- ✓ Perhaps ask the school for a timetable before the September and look at this with your child during the summer holidays.
- ✓ Use social stories. These are short descriptions of a particular activity, event, or situation so that your child will know what to expect in their school day.
- ✓ If your child uses visual supports such as PECS (Picture Exchange Communication system) then it is important that this is available at school.
- ✓ Practise morning routines in advance and get things ready the night before.
- ✓ Use a calendar during the summer to encourage your child to count down to the start day.

Choosing a school

Tips for choosing a setting

It is a good idea to meet the Senco at any schools you are considering, to understand their approach to SEND and their ability to meet your child's needs. You may want to ask about:

- The school SEND policy – the Senco should be able to give you a copy. The school anti-bullying policy, behaviour/discipline and exclusion policies may also be useful.
- What SEND training the staff have received – particularly in the area of specialism that is needed for your child.
- How the school organises its special needs provision - are children withdrawn from class for extra lessons in small groups? How does the school use its support staff? Are there non-teaching staff working in classrooms to support children's learning?
- How many children are in each class?
- Their policy on 1:1 learning support assistants for children. Do they have a dedicated person for each child with an EHCP or do they utilise the class Teaching Assistant?
- How is the day structured? Are there structured breaktime / lunchtime activities for children?
- How is technology used to help learning?

> **"I asked if my son would be able to have a laptop to support his diagnosed dyspraxia and they said no, so we decided this wasn't the right school for him."**

- Whether there is a safe space/quiet area that your child could go to if they needed some time out?
- Schools are becoming increasingly skilled at meeting the needs of SEND children. Ask whether the school has experience of working with children with difficulties similar to your child's, and whether it was successful.
- How they would support your child transitioning to the school.
- How does communication take place between school and parents?
- Ask what support your child will receive.

“The school had a policy that all children must have school dinners. My child is a very picky eater and I asked if he could bring a packed lunch as a reasonable adjustment. The school said no - he either has school dinners or has to go home for lunch. I realised this would not be the best school for him and crossed that school off my list.”

The government guidance to schools is set out within the **Special Educational Needs and Disability Code of Practice (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf)** which states that each school or setting must:

- use their best endeavours to make sure that a child with SEND gets the support they need;
- ensure that children and young people with SEND engage in the activities of the school in an inclusive way, alongside pupils who do not have SEND. They should not be excluded from an activity or school trip because of their SEND;
- inform parents when they are making special educational provision for a child.

It is also helpful to read the school’s/setting’s policy for supporting children with SEND. This should be available on their website under the policy section, or you can request a copy from the school.

Useful Links

- www.goodschoolsguide.co.uk
- www.gov.uk/school-performance-tables
- https://reports.ofsted.gov.uk

What can I do if I think my child needs additional support?

Building and maintaining good relationships with schools

It is important to build a positive relationship with staff at your child’s setting so you can work together to get the best possible outcomes for your child.

To help achieve this:

- Introduce yourself to the staff working with your child.
- Recognise when school does things well.
- Encourage open and honest communication.
- If there are issues, try to identify solutions for things that could help.

1

Stage 1: Contact class teacher/key worker

- Contact your child’s class teacher to discuss your concerns and to understand whether issues are also being seen at school. It may be that school have also noticed that your child is having difficulties and you can discuss with them ideas and interventions that could help.
- If you and the school are not seeing the same difficulties, consider a review period where you both monitor any particular problems that your child is having.

“It was useful to keep a home / school communication book which showed the things that my child found hard in school.”

“I couldn’t read what was on the board”

“I had no one to play with”

“I didn’t eat much lunch today”

Interventions that could help your child:

- Having a clock or a timer on the table to help focus on starting a task, manage timekeeping, and estimate how long tasks will take.
- Extra time for tests and exams.
- Sensory fidget toys.
- Access to a quiet room.
- Visual timetable.
- Toilet card.
- Sensory breaks.
- Being given an option to not go to assembly (many children with sensory difficulties find this hard)
- Sitting on a wobble cushion.
- Pencil/pen grips.
- Use of a laptop in class and in exams.
- Being able to wear ear defenders at playtime or noisy times of the day.
- Breaking down tasks into small steps.
- Tasks written as well as verbal instructions.
- The teacher letting the student know in advance when they are going to ask them a question in class - or having an arrangement where they won't be asked at all if this is something that they find particularly difficult.
- Having a card to put on their desk or hold up if they are struggling, rather than having to verbally tell the teacher in front of the whole class.

Interventions for students who struggle with task initiation

Teach task initiation skills explicitly

Use a countdown timer

Incorporate areas of student interest

Provide directions orally and visually

Practice the "rocket ship countdown"

Reduce most challenging work

Train peer mentors to provide support

Use brain breaks between tasks

Make it a race to get started on work

Take turns writing to get started

Develop a work contract with rewards

Give more student choice

2

Stage 2: Speak to the Senco (Special Educational Needs co-ordinator)

If progress is not being made as expected, you can speak to your school Senco (Special Educational Needs co-ordinator). Sencos are qualified teachers who have usually had extra training in how to support children with additional needs and may be part of the senior leadership team.

The Senco may suggest that you approach your GP, Health Visitor, Paediatrician or social care, for their advice or they may signpost you to information on the Local Offer for your area. They can make referrals via Early Help, Brighter Futures or Family Solutions as appropriate.

> **“The best thing though is that she’s on a dedicated SEND pathway through GCSEs. It’s a slight reduction in subject slots, but it allows for dedicated support lessons for both emotional and educational support.”**

They may also decide that your child needs help in one or more of the following areas:

- **Speech and language**
- **Developing social skills**
- **Phonics, reading, writing**
- **Attention and concentration**
- **Social communication skills**
- **Physical skills, including fine-motor (small movements such as handwriting or getting dressed) or gross-motor (large scale movements such as riding a bike, catching a ball) development**

Once the Senco has identified the areas where more support is required, they will aim to help the class teacher fine tune their teaching to support your child (this is sometimes referred to as High Quality First Teaching). Intervention groups (individual or small group support) may also be suggested.

> **"My child's school has been supporting us since we got confirmation of her place. From making adjustments like a time out card for anxiety, being allowed to doodle in lessons for focus and a toilet card to reduce toilet anxiety, to helping through school refusal, they've just been great. Being able to contact individual teachers by email is fantastic."**

Top tips: Preparing for a meeting with the Senco

- ✓ Understand your child's views.
- ✓ Plan what you are going to ask and what you want to discuss – list these in order of importance knowing what your priorities are and what doesn't matter as much.
- ✓ Have a clear idea of what outcomes you are trying to achieve.
- ✓ Write down the questions you want to ask, for example.
  - Is my child making progress?
  - How does my child interact with their peers and staff?
  - What help does my child receive in school?
  - Does the school share the same concerns?
  - How can I support my child at home?
- ✓ Be realistic in what you are asking for.
- ✓ Bring a notebook and pen.
- ✓ You are entitled to take someone (often referred to as an advocate) with you for support, to take notes and to help remember everything that is said. An advocate may be a family member, friend, a local charity offering advocacy services or someone independent provided by the Local Authority if you wish.

Further information about advocates

- **www.legislation.gov.uk/ukpga/2014/23/part/1/crossheading/independent-advocacy-support/enacted**
- **www.mind.org.uk/information-support/guides-to-support-and-services/advocacy/legal-rights-to-advocacy**
- **https://childlawadvice.org.uk/information-pages/advocacy**

After the meeting

- Tell your child what has been agreed.
- Recap the conversation with an email or letter so it is documented or if someone else was making notes, ask for a copy.
- Complete any actions that you were given and make a diary note to ensure other actions are completed as agreed.
- Make sure that a follow-up meeting is arranged if this is required.

3

Stage 3: SEN Support

The next stage of help should be for children who need longer term SEND support to be placed on the school's Special Educational Needs register., where they have one. Every school has a budget allocated for SEN support. It may sometimes be used to help groups of children, train staff working with SEN children or to help deliver strategies for your child.

As part of a graduate response, for children on the SEN Support the school will write an Assess Plan Do and Review (APDR) document, working with parent carers. (It can be called different things in different schools). It will set out the child's needs and what support will be put in place to meet short term and long-term targets. Targets should be for progress in all elements of SEND, not just for academic progress. https://fis.peterborough.gov.uk/kb5/peterborough/directory/localoffer.page?familychannel=8-6&loboolean=1

What people like and admire about me...

Photo

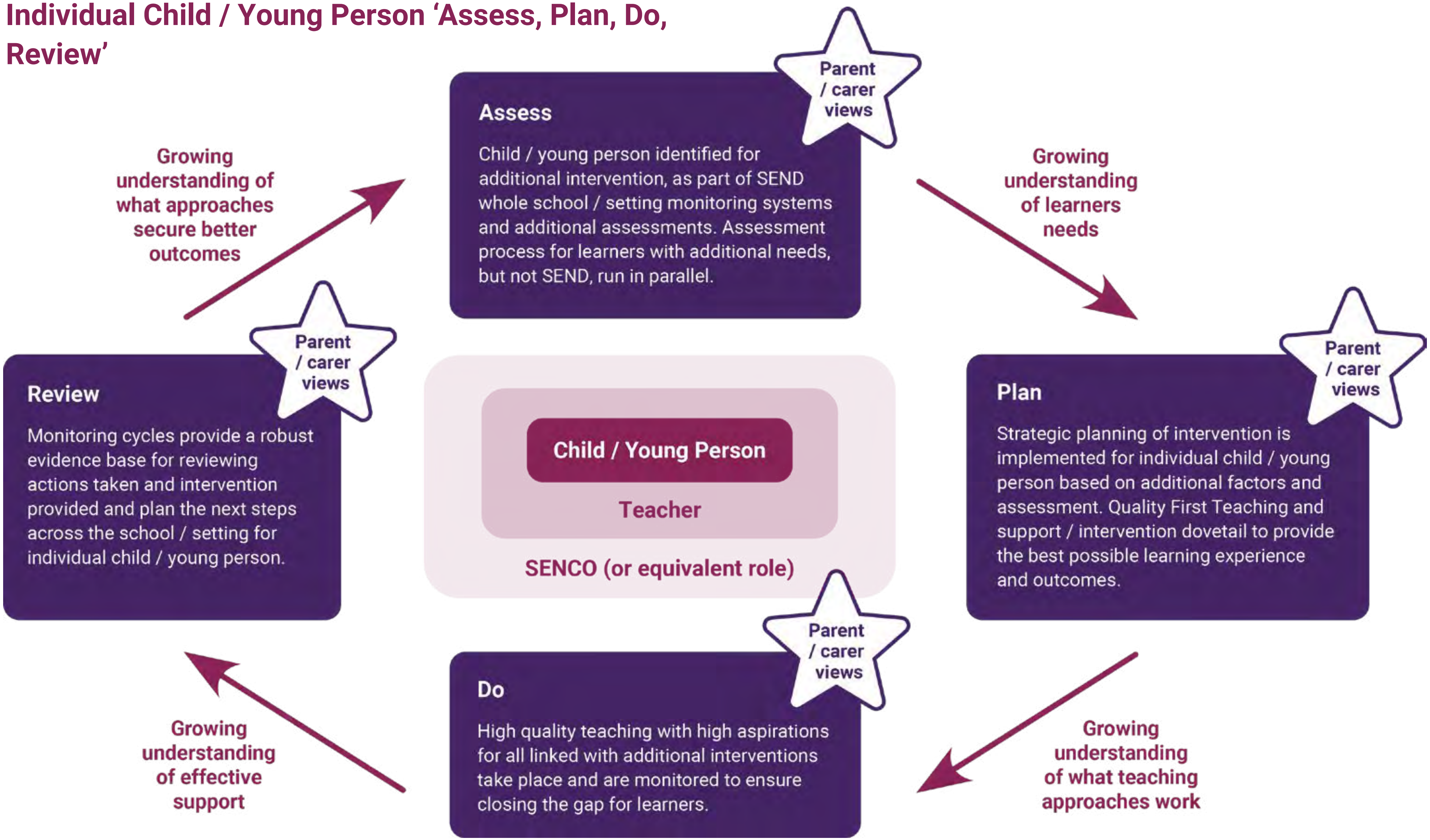
What makes me happy

How I want to be supported...

You can find one page profiles at https://www.sheffkids.co.uk/resources/

The Assess, Plan, Do, Review process should be made up of a 4-part cycle and should be co-produced at every stage with the school, family and child:

Individual Child / Young Person 'Assess, Plan, Do, Review'



Assess

Child / young person identified for additional intervention, as part of SEND whole school / setting monitoring systems and additional assessments. Assessment process for learners with additional needs, but not SEND, run in parallel.

Parent / carer views

Growing understanding of learners needs

Plan

Strategic planning of intervention is implemented for individual child / young person based on additional factors and assessment. Quality First Teaching and support / intervention dovetail to provide the best possible learning experience and outcomes.

Parent / carer views

Growing understanding of what teaching approaches work

Do

High quality teaching with high aspirations for all linked with additional interventions take place and are monitored to ensure closing the gap for learners.

Parent / carer views

Growing understanding of effective support

Review

Monitoring cycles provide a robust evidence base for reviewing actions taken and intervention provided and plan the next steps across the school / setting for individual child / young person.

Parent / carer views

Growing understanding of what approaches secure better outcomes

Child / Young Person

Teacher

SENCO (or equivalent role)

“My son’s school have really involved him in the meetings and asked him how they could help him, as well as asking us as parents. This made him feel he could open up and be honest with his struggles. They have been very supportive for us both since he started in September - even though we don’t have a diagnosis.”

If your child is still not making progress, academically, socially, or otherwise, you or the school should consider asking the Local Authority to undertake an Educational Health and Care Needs Assessment (EHC Needs Assessment).

4

Stage 4: Education Health and Care Needs Assessment

An Education, Health and Care needs assessment is the first step towards getting an Education and Health Care Plan (EHC Plan) An EHC plan can result in additional support and funding for a child or young person with special educational needs.

An EHC plan is a legally-binding document outlining a child or young person's special educational, health, and social care needs. The document must:

- List all of the child's special educational needs,
- Show the provision to meet each of the needs which should be specific, detailed, and quantified,
- Name the setting.

To get the most comprehensive view of your child's needs, and because many of the assessments take place within school, it is best to work with the school/setting to make the application. The school will ask you to give your consent and ask for your and your child's views to support the application. You may wish to:

- Include examples from your child on their most difficult day.
- Include personal statements from extra-curricular club leaders which can be very helpful.
- Include a photo of your child.
- Create your own one-page profile.
- Keep the information succinct and to the point.
- Include your child's SEND across all areas of need.
- Organise your supporting documents in date order and number the pages.
- Keep a duplicate of everything you send with your application for your own reference.

The more high-quality supporting evidence you have, the stronger your application will be.

The Local Authority (LA) refer to The SEND Code of Practice and Children and Families Act to decide whether to proceed with an assessment. The LA will consider: -

Academic Attainment – is the child working at, below or above the expectations for their age.

Communication and interaction – e.g., difficulties with use of language, social skills, rigid thinking, difficulties with transitions, using non-verbal behaviour to communicate difficulties, etc.

Cognition and learning – e.g., executive function difficulties; specific learning difficulties such as literacy and numeracy difficulties, changes to routine, etc.

Social, emotional and mental health – e.g., sleep disturbance, feeding or eating disorders, anxiety, OCD, school refusal, self-harm, nervous tics, poor self-esteem and stress, behaviour that challenges etc.

Sensory and/or physical needs – e.g., fine/gross motor problems; balance issues, sensory integration difficulties; personal space issues, sight/hearing issues; feeding or toileting etc.

Parent request for EHC needs assessment

There may be occasions when a parent application is appropriate, for example, if you have a different opinion to the school about the level of help that your child needs, for example if they mask their behaviour at school, or if the school is unable to progress the application within an agreed timeframe.

The Local Offer has details about how to apply and IPSEA (Independent Provider of Special Education Advice) has a wealth of information and template letters to assist parents:

https://fis.peterborough.gov.uk/kb5/peterborough/directory/site.page?id=KfRVLCQJHRs

A model letter can be downloaded to help you apply for an EHCP and can be found here:

Making a request for an EHC needs assessment: Model letter 1 (IPSEA) (www.ipsea.org.uk/making-a-request-for-an-ehc-needs-assessment)

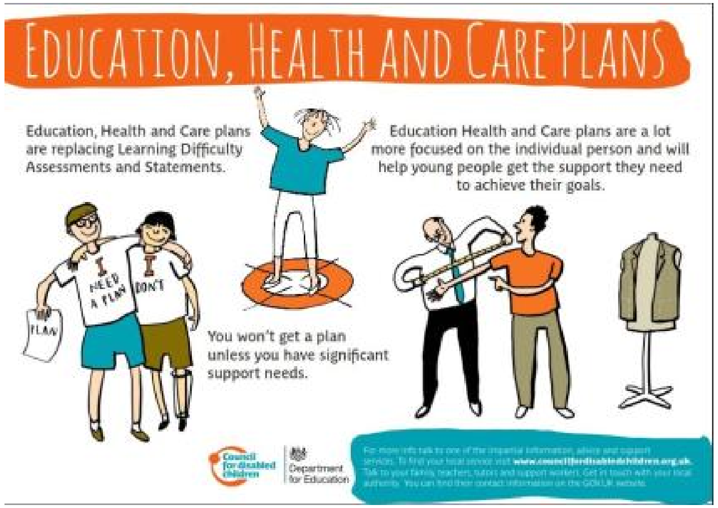
It is a good idea to keep school informed of your intentions to apply, so they can support the application with extra evidence if requested to do so.

The EHC Assessment Process

In law (section 36(8) of the Children and Families Act 2014), the following are the only questions the LA should ask when considering whether or not to carry out an EHC needs assessment:

- whether the child or young person **has or may have** special educational needs (“**SEND**”); and
- whether they **may** need special educational provision to be made through an EHC plan.

If the answer to both of these questions is yes, the LA must carry out an EHC needs assessment.



EHC Needs Assessment Myths

There are a few myths and confusing views surrounding the EHC assessment process. Here are a few of them...

- Your child must have a diagnosis
- Your child must be x years behind academically
- You must have x number of One Plans via the process of Assess, Plan, Do, Review
- The school must have spent £6,000 on help for your child
- Children need to be in school for a given period of time before you can apply

Local Authorities can set their own guidance to help them decide when an assessment is necessary, but they must not apply a ‘blanket’ policy, as every child’s needs are different and should be considered individually.

The process can be quite technical, but there is lots of help available

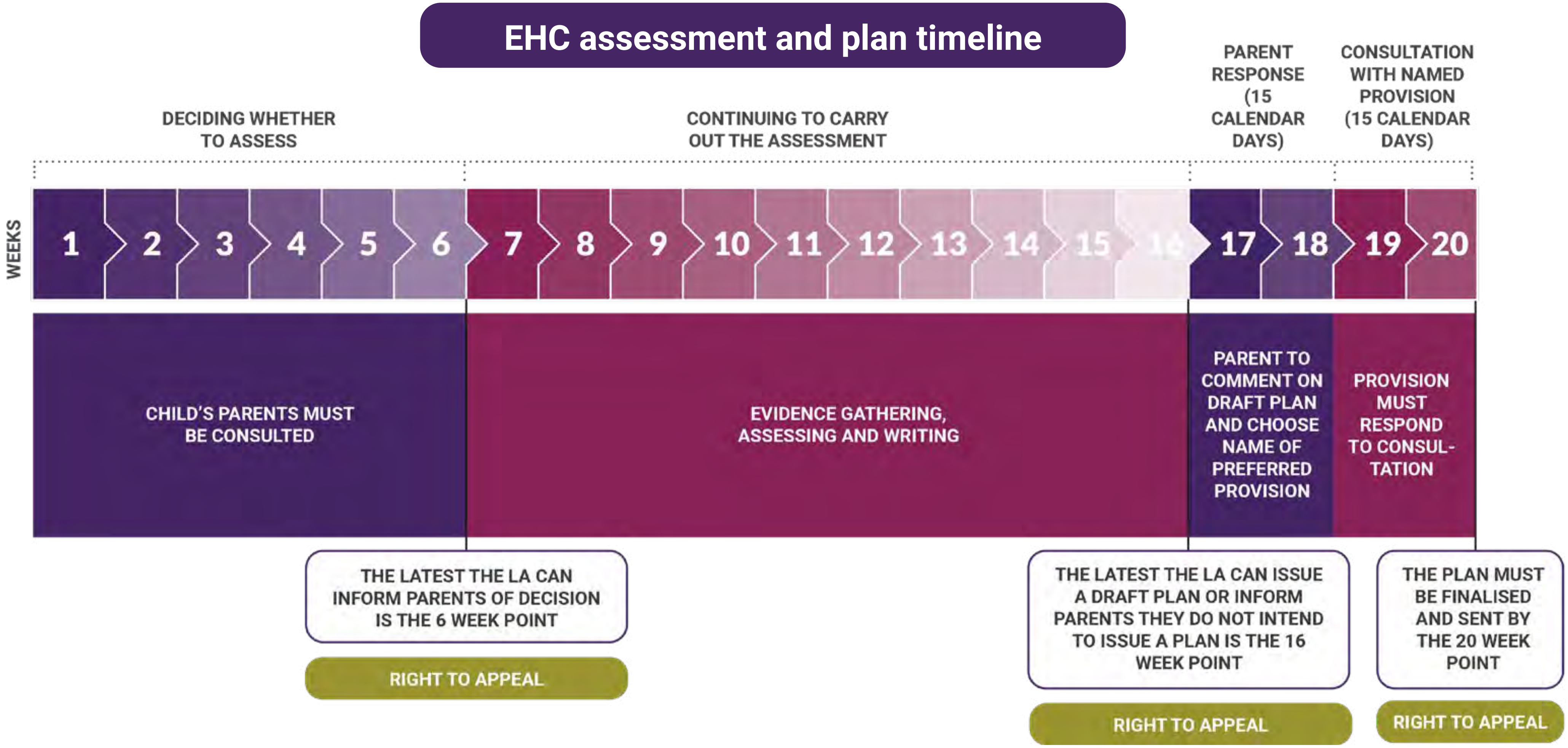
- Local advisory services: SENDIASS, IPSEA, SOS SEN

  - SEND Information, Advice and Support Service (SENDIASS) https://fis.peterborough.gov.uk/kb5/peterborough/directory/service.page?id=E1PbUIt6ObU
  - IPSEA - Independent Provider of Special Education Advice (**www.ipsea.org.uk**)
  - Contact A Family www.contact.org.uk/help-for-families/information-advice-services/our-helpline/
  - SOS SEN | The Independent Helpline for Special Education Needs (**www.sossen.org.uk**)
  - Family Voice has information and signposting on its website: www.familyvoice.org
  - Local charities and support groups which you can find on your Local Offer or search for on Google/Facebook.

Overview of the process

If the assessment and plan are agreed, it should take no more than 20 weeks from the point when an assessment is requested by the parent/school until the final EHC plan is issued. The application will be acknowledged when received by the Local Authority and progressed in line with the timeline. You may wish to make a note of the dates so that you can track the application.

Local authorities must tell you whether they will carry out an EHC needs assessment. within six weeks of receiving the request. IPSEA provide guidance on what to do should this not happen (**www.ipsea.org.uk/complaining-if-the-la-does-not-respond**).



EHC assessment and plan timeline

DECIDING WHETHER TO ASSESS

CONTINUING TO CARRY OUT THE ASSESSMENT

PARENT RESPONSE (15 CALENDAR DAYS)

CONSULTATION WITH NAMED PROVISION (15 CALENDAR DAYS)

WEEKS

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

CHILD'S PARENTS MUST BE CONSULTED

EVIDENCE GATHERING, ASSESSING AND WRITING

PARENT TO COMMENT ON DRAFT PLAN AND CHOOSE NAME OF PREFERRED PROVISION

PROVISION MUST RESPOND TO CONSUL-TATION

THE LATEST THE LA CAN INFORM PARENTS OF DECISION IS THE 6 WEEK POINT

RIGHT TO APPEAL

THE LATEST THE LA CAN ISSUE A DRAFT PLAN OR INFORM PARENTS THEY DO NOT INTEND TO ISSUE A PLAN IS THE 16 WEEK POINT

RIGHT TO APPEAL

THE PLAN MUST BE FINALISED AND SENT BY THE 20 WEEK POINT

RIGHT TO APPEAL

If the EHC needs assessment is agreed

The assessment is a chance for professionals to look more closely at your child's special educational needs and disabilities and the support that they need to help them develop academically, socially and emotionally.

The LA is required to seek input from all of the following (as a minimum)

- You and your child
- Educational advice (usually from the Senco or class teacher);
- Medical advice and information from a health care professional;
- Psychological advice and information from an educational psychologist;
- Advice and information in relation to social care;
- Where the child or young person is in or beyond year 9, advice and information in relation to preparing for adulthood; and
- Advice and information from any person that you reasonably request the LA to seek advice from.

Any existing evidence for example, private reports from professionals, submitted by parents **must** also be considered.

Further information

- **www.ipsea.org.uk/what-happens-in-an-ehc-needs-assessment**
- **www.specialneedsjungle.com/faq/can-a-local-authority-refuse-to-consider-an-independent-report**

EHCP assessments should consider all education, health and social care needs, although the focus is often on education in the first instance. More details about social care or health assessments can be found here:

- **www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment**
- **Peterborough Carers Assessments:**
  https://www.cpft.nhs.uk/carers/
-
- **Caring for an adult 18+**
  https://fis.peterborough.gov.uk/kb5/peterborough/directory/adult.page?adultchannel=8
- **Caring Together : www.caringtogether.org/support-for-carers/**
- **www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment**

Checking the draft EHC plan

If it is agreed that an EHCP should be issued, you then have 15 days to suggest any amendments and to express a preference for an educational setting. The IPSEA guide (**www.ipsea.org.uk/what-sections-should-an-ehc-plan-have**) contains lots of useful information but it is also important to check the draft EHCP, to ensure that the provisions/outcomes for your child are clearly set out and defined. If there are words which are vague, these could be misinterpreted, and may dilute the provision that is needed. Words and phrases like 'regular or as required' can cause particular difficulties so should be avoided.

- Saying that a child should have ‘access to a learning support assistant.’ fails to identify how much support the child will have, or what training and experience the Learning Support Assistant should have to support the child, so this information should be included.
- Saying that a child ‘requires a structured programme to develop their motor planning coordination skills.’ does not provide enough detail as to what is required. Details of the programme must be set out; including who will deliver the programme and how often, what the duration should be and how it will be assessed and reviewed.

With regard to the outcomes detailed in the EHCP, these need to be SMART:

S **Specific;**

M **Measurable;**

A **Achievable;**

R **Realistic;**

T **Time-bound.**

Example of a smart outcome

John will develop his social skills to enable him to self-manage difficult situations with friends, both in person and online.

This will be achieved by:

- Daily check-ins with his key worker
- Weekly attendance at the nurture group with no more than 4 pupils, which will include structured activities such as role plays and coaching from the nurture group leader, as well as the chance to discuss strategies and with other members of the group.
- Following the Zones of Regulation strategies

Progress will be reviewed with John, his parents, his key worker, and the nurture group leader on a termly basis including:

- Tracking any incidents of friendship difficulties at home or school; and
- Completion of two Zones of Regulation modules per term.

Refer also to: **What makes a good outcome in an Education, Health and Care Plan? - Special Needs Jungle (www.specialneedsjungle.com/what-makes-good-outcome-education-health-care-plan)**

Naming your preferred school, college, or provision

The provision will be named at the draft EHCP stage. You can ask the LA to consider:

- A maintained school or nursery (mainstream or special)
- An Academy (mainstream or special)
- A Further Education setting
- A non-maintained special school
- A section 41 (independent) school.

The draft plan is then sent to the named school or provision to see if they can meet the child's needs.

If the LA decline to consult with the school of your choice, you can follow IPSEA guidance: **www.ipsea.org.uk/complaining-when-the-la-will-not-consult-with-the-school-or-college-you-request**

You have a legal right to request that a particular school or college is named in an EHCP.

If the EHC assessment is declined

If the request is declined, this could be because the information provided suggests that a young person's needs could be met at SEN Support level, which is why it is so important to ensure that the LA has accurate information about both the support that is needed and also the type and amount of support that is currently in place. You could ask school for a meeting to explore what more they could be doing at SEN Support. They could complete more Assess, Plan, Do Review and resubmit. They could look at what further information would help the panel, using Peterborough's ECHA Guidance **https://fis.peterborough.gov.uk/kb5/peterborough/directory/site.page?id=KfRVLCQJHRs**

If they feel the wrong decision has been made they, or you, can appeal. The appeal must be made within 2 months of the date of the LA's covering letter, or within 30 days of the date of the mediation certificate and you can send in any further information for the Local Authority to consider.

More information about making an appeal

- **Click below to find more information about how to appeal - SENDIASS and IPSEA can support you to do this:**
- How to appeal a special educational needs (SEND) decision (SEND37) - **(https://www.gov.uk/government/publications/how-to-appeal-a-special-educational-needs-sen-decision-send37)**
- **Click below to download the appeal form:**
- Form SEND35a: Special Educational Needs and Disability Tribunal appeal a refusal to secure an EHC Needs Assessment - **(https://www.gov.uk/government/publications/form-send35a-special-educational-needs-and-disability-tribunal-appeal-a-refusal-to-secure-an-ehc-needs-assessment)**

School Transport

If your child attends a SEND school, a mainstream school within a certain distance of your house, or you are on a low income, you may be entitled to free school transport.

These are the links for information setting out the criteria for accessing support with transport.

- Peterborough School Transport https://fis.peterborough.gov.uk/kb5/peterborough/directory/service.page?id=cCDSUjTKliA
- General Information - (**www.gov.uk/apply-school-transport-for-child-with-special-educational-needs-sen**)

Peterborough Blue Badge Scheme

https://www.peterborough.gov.uk/residents/parking/blue-badge-parking-scheme

Finally, if you are experiencing difficulties with accessing or using School Transport, you can visit the Special Educational Needs Transport Advocacy Service (Sentas) for help (**https://sentas.co.uk**)

Annual reviews

Once agreed, EHC plans must be reviewed by the LA annually (as a minimum) to revisit and review the outcomes and the effectiveness of the provisions in place to achieve them.

Before the annual review meeting, parents, professionals, and the education setting that your child attends share their thoughts about what is going well, what is not going well, aspirations and anything that they think may need to change within the plan. The information should be gathered and shared two weeks before the meeting.

All professionals that provide the support detailed in the EHC Plan should be invited to contribute and to attend the meeting.

Preparing for an annual review

- Read through all the comments submitted. You should receive this at least two weeks before the meeting. If you don't feel you have enough time to prepare then you can ask for the meeting to be deferred.
- Make a note of any questions that you would like to ask. There can be a lot of information shared in these reviews so it's really helpful to have a written list to refer to.
- Take notes during the meeting so you have a record of what was discussed and agreed.
- Consider taking an advocate, family member or friend with you for support.

Further information

IPSEA and Special Needs Jungle provide an excellent overview of the annual review process, how things should work, timelines and what to do if things don't go as planned.

- www.specialneedsjungle.com/wp-content/uploads/2021/03/Annual-Review-Flow-Chart_21.png
- www.ipsea.org.uk/annual-review

> **"In my daughter's EHCP she had sensory breaks which really helped her to regulate her emotions during the day at school. Things were going so well, school decided that these breaks were no longer needed, but this resulted in my daughter having problems again. It is really important to recognise what is working well and keep these measures in place."**

Transition from primary to secondary school

What is different about secondary school?

A child with SEND may take a long time to get used to the new school environment and may need additional help to support them throughout this period.

If there has been insufficient preparation for the huge changes that occur between primary and secondary school, this can result in difficulties accessing the curriculum and make it harder to make friends. The first few weeks are crucial in developing the new peer group and poor preparation can result in lasting damage throughout their secondary school years.

Here are some of the changes that your child might notice:

- Classes may be larger.
- Need to move around the school between different lessons.
- Different teachers for each subject and being split into sets, which means you may not be with friends in every class.
- Bigger school environment and not all teachers will be aware of your child’s difficulties.
- Coping alone in the playground a break and lunchtimes, with fewer teachers supervising.
- No personal desks.
- The use of lockers to store belongings.
- Independent travel to school.
- Homework – greater volume and increased expectations.
- The need for greater organisational skills and meeting deadlines.
- Career choices at a time when the child may not see they have any strengths.

Without planning and support, the cumulative effect of all these changes may lead to your child becoming increasingly anxious. They could feel out of control in their new environment, after seemingly being able to cope in primary school.

Spend time talking to your child about all of these things so that they can understand what to expect and have a chance to ask questions about anything that may be worrying them. Refer to the transition information regularly in the period leading up to the move, to help refresh the information and trigger questions.

There are other children who struggled at primary school but who enjoy and adapt well to the independence and increased responsibility at senior school.

> **"I hated junior school. We were forced to make eye contact and sit completely still and if I didn't finish my work, I had my break taken away. Senior school is so different. I get a break between lessons when we move classes and I'm much happier now."**

Top tips for moving to secondary school - working with the school

- **Transition workbook -** address differences between settings with a step-by-step approach. You can ask your existing setting to provide this.
- **Phased transition –** is it possible for your child to have additional visits? This can help to become familiar with the new school by finding their way around, noticing new sounds and smells and asking questions? Ask your new Senco or ask your existing teacher for advice.
- **Meeting key members of staff -** for both you and your child.
- **Photos of the new school and key staff -** ask your new Senco at the new school for photos of key members of staff that will be working with your child and of the new building, you can include a map of the school if there is one. You can also look for additional information about the new setting, for example the school's website and social media, and share this with your child.

- **Lockers –** speak to the new Senco about whether having a locker at school may help your child to organise their equipment. A locker may be a good place to keep spare stationery.
- **School day plan -** you can create a visual overview of what your child can expect.
- **Timetable -** ask your new school for a sample Year 7 timetable or if the school have a school app which loads timetables or homework. Start looking at this in the summer break.
- **A buddy system -** ask your new Senco if there is a buddy system that your son or daughter could have for at least the first two terms.
- **Gain the views of your child -** Talk to your child. Ask them if anything is worrying them and see what you can do to help.
- **Share one-page profile –** Ask your existing Senco to share your child's up to date one-page plan with all staff that will be working with them.
- **Communication –** find out the best way to communicate with staff at the school – for example, having a named contact, and whether it is best to communicate via phone or email.

- **Reasonable adjustments –** consider anything that the school may be able to do to help your child access the full curriculum and reduce anxiety. Here are some strategies that you could consider:
  - If your child struggles to change quickly for PE, perhaps they could wear a clip-on tie, or wear adapted PE equipment.

  - If your child is anxious taking tests in the classroom, perhaps they could take the test in a small group in a different room.
  - If your child may be easily distracted in class, discuss potential seating options.
  - If your child has dyspraxia, pencil grips, adapted rulers and protractors etc. may help.

  - If your child struggles with homework, ask whether there are options to complete homework at school either in a homework club, or during the school day.
  - If your child may feel overwhelmed in class, or if they struggle knowing when they need to go to the toilet, consider a time out or toilet card so that they can easily leave the classroom.

  - If your child finds it difficult to write notes during a class, see if handouts could be provided to capture the key points.
  - Ask if there is a quiet place your child can go to at break and lunch times, such as the school library or SEND department.

Strategies for supporting executive functioning needs

- Have homework written down in the same spot every day
- Explicitly teach executive functioning and study skills
- Give an extra 3-5 minutes to organise before transitions
- Schedule a weekly organisation time
- Create routines and practice them often
- Incorporate movement during instruction
- Create an end-of-the-day checklist to remember materials
- Provide brain breaks during and after instruction
- Clearly explain academic and social expectations
- Keep an extra set of books at home and in the classroom
- Use countdowns and time checks during work periods
- Have students set up homework binders

Your Senco will probably have lots of other suggestions too!

“My sons school took him out of French in year 7 and he does ‘support lessons’ instead. They have also arranged for him to go into school early, so he isn’t at the gate with noise and crowds. He has a 5-minute early pass to avoid the busy corridors and to leave school before the bell. He only had to choose two options instead of three.”

What you can do to help at home - top tips

1 **Get everything ready the night before.** Get everything ready that they are going to need in advance including backpack; uniform; PE kit; stationery; books etc. and decide whether they are going to have a school lunch or packed lunch.

2 **Getting Dressed for School -** Children with sensory issues can be overly sensitive to the way different textures of clothing feel on their skin. They might not be able to tolerate the feeling of new shoes because the material is too stiff. Their reactions to items like itchy sweaters or stiff trousers can range from annoyance to outright refusal to wear something. Being aware of what triggers negative reactions in your child can help. For instance, cut off clothing labels if they bother your child. Small adjustments could reduce complaining—and help to get you out of the door faster.

Top tip – some clothing retailers offer sensory-friendly school uniform options.

3 **Set a bedtime routine.**

> **“I’d suggest getting up 30 minutes before you think you need to!”**

4 **Organise your morning routine.** It is important to set rules or routines in advance, and these can be very detailed if that is needed. You can arrange a routine that includes timescales, for getting up, getting ready, eating breakfast, having some down time, preparing to leave, and even includes the route that you will take to school.

5 **Stock up on school supplies and buy spare uniform if possible.** A second set of school supplies, uniform and equipment should be kept at home that is the same as the one that the child is using. This will be very important if your child loses anything during the school day.

6 **School day plan -** have a copy of your child’s timetable and talk to your child about what they will be doing each day. If the timetable is available on-line or via an app, consider writing it out for them so that they have the reassurance of having a visual copy too.

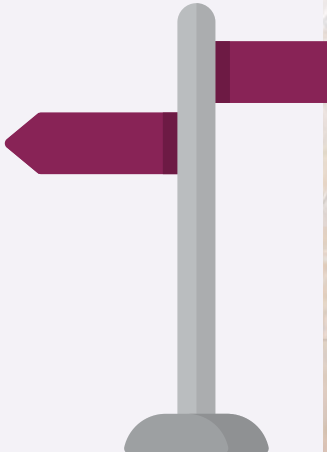
7 **Decompress -** have calm and quiet time after school so your child can self-regulate.

> **“I bought a cheap whiteboard and wrote out the timetable for the next day so that my daughter could see it when she woke up.”**

8 **Create a safe place** at home where your child feels safe and can retreat for some down time.

9 **Accept that your child is different** and let them lead on how they feel, cope and what they feel able to do. Always validate your child’s feelings and emotions.

10 **Travelling to school** – Take the journey with your child between home and school, whether you walk, drive, or take public transport, as many times as you can and you could also film the route or take photos to help your child become familiar with the route. This will help to make the journey more predictable, which will help children who experience anxiety or hyper vigilance in unfamiliar surroundings.
If your child uses the Local Authority transport services to school, speak to the transport provider to find out more about the journey – for example: the route that will be taken, how many other children will be in the vehicle, how long the journey will take with the collections/ drop-offs of the other children etc.



What happens if your child is unable to attend school?

If a child is struggling getting into school, there are a number of services and groups that can help.

- **Peterborough SEND Information Hub**: https://www.peterborough.gov.uk/residents/schools-and-education/attendance
- **Not Fine in School** is a parent/carer led organisation set up in response to the growing number of children and young people who struggle with school attendance (**https://notfineinschool.co.uk**)
- **Contact A Family:** www.contact.org.uk/help-for-families/information-advice-services/education-learning/attendance-absence-medical-needs/handling-absence-from-school/

- **Define Fine:** Parent Peer Support for School Attendance Difficulties (**https://www.facebook.com/groups/773420163493553**)
- **IPSEA** provides further advice here **www.ipsea.org.uk/getting-temporary-education-put-in-place**

Education other than at School (EOTAS)

If you already have an EHCP, before you consider elective home education (**www.gov.uk/government/publications/elective-home-education**), you may wish to ask your Local Authority about an

EOTAS is offered when no alternative education pacakage can be found. This includes all forms of education that take place outside the school environment, such as alternative provision.

- **Peterborough and Cambridgeshire EOTAS Directory:** www.cambslearntogether.co.uk/cambridgeshire-services-to-schools/alternative-education-provision-directory
- **You can find more information on the IPSEA website:**- Home schooling and 'education otherwise' | (IPSEA) Independent Provider of Special Education Advice (**www.ipsea.org.uk/home-schooling-and-education-otherwise**)

Home Education

Some parents decide that a formal education within school is not suitable for their child. Others may see it as the only option due to circumstances, such as a lack of places at specialist schools.

If you home educate, you will be responsible for all the associated costs, including stationery, books, tutor costs, educational trips and exam fees.

Further information

- **Peterborough EHE: https://www.peterborough.gov.uk/residents/schools-and-education/home-education**
- **Book - The Brave Learner:** Finding Everyday Magic in Homeschool, Learning, and Life by Julie Bogart
- **Ross Mountney's Notebook** | parenting, home education, thoughtful living (**https://rossmountney.wordpress.com/**)

Exclusion

This isn't a pleasant topic, but unfortunately it is a necessary one because government statistics show that exclusion rates are higher among special educational needs (SEND) pupils It is 5 times more likely that a pupil with SEND will receive a suspension.

Under the law, head teachers can only exclude pupils for breaches of the school's behaviour policy and where allowing the pupil to remain in school would seriously harm the education or welfare of the pupil or others in the school.

They cannot exclude a pupil for behaviour resulting from having special educational needs, or because they cannot meet their needs. If you think an exclusion has occurred for one of these reasons, you could make a claim under the Equality Act 2010 and suggest a managed move to a provision which can better meet their needs.

Further information

- School exclusion helpline (**https://www.autism.org.uk/what-we-do/help-and-support/school-exclusion-service**)
- Exclusion from school | (IPSEA) Independent Provider of Special Education Advice (**https://www.ipsea.org.uk/pages/category/exclusion-from-school**)
- Peterborough Local Offer **https://www.peterborough.gov.uk/residents/schools-and-education/school-admissions/fair-access-protocol**

My child has been excluded. What do I do?

1. Try to remain calm so that your child can see that you are in control of the situation.
2. Don't immediately make a judgement about what has happened. Emotions are likely to be running high for you and your child, but they need to know that you are there to support them.
3. You will receive a letter from the school, giving information about the length of the suspension and what you should do. It also contains details of how to challenge the suspension if you do not agree with it: School discipline and exclusions: Challenging exclusion - (**www.gov.uk/school-discipline-exclusions/challenging-exclusion**)
4. Write to the school to ascertain exactly what happened, how your child breached the Behaviour Policy and the circumstances surrounding the incident. Keep records of all correspondence, emails and conversations. Follow up all conversations in writing, setting out what was said and agreed and asking for the school to confirm the contents are a true reflection of the conversation.
5. After a suspension, a re-integration meeting is usually held to help the child/young person adjust back into school. Consider the circumstances which led to the exclusion and whether additional support may be needed to minimise the chance of this happening again.
6. If your child has been permanently excluded then it is the responsibility of the LA in which you live to provide full time education from the 6th day since exclusion.
7. Speak to IPSEA or the National Autistic Society exclusion team for advice.

What the school can't do – illegal exclusions

- A school cannot ask you to collect your child following an incident at school, without following the proper procedures. For an exclusion to be lawful a letter has to be sent to the child's parents, immediately after the exclusion,
- A school cannot ask you to collect your child due to a staff member being off sick, or if there is an activity that your child will not engage in, or because they cannot meet their needs.
- If the school suggests that your child attends school on part time basis, they can only do this with your agreement. There should be clear review dates set and an expectation that you will work together to support your child in their return to full time education as soon as possible.
- If you feel that your child has been discriminated against because of their disability, you can contact the Disability Discrimination Advice's Helpline via -Telephone: 0808 800 0082. You can also use this form if you feel that this may be necessary and as a last resort.

www.gov.uk/government/publications/form-send4a-disability-discrimination-claim-by-a-parent

What is an Educational Psychologist (EP)?

What we do

Educational pyschologists apply psychology (the study of thinking and learning) to support children / young people (0-25 years) who are having difficulties within an educational setting. They aim to look at how learning, development and emotional well-being can be enhanced. They provide independent professional advice to families, schools and other education settings.

How we get involved

The Educational Psychologists (EPs) are all registered with the Health Care Professions Council. They have specialist training and qualifications in Child Development, Psychology and Education.

Peterborough also has a team of specialist teachers and practitioners who work with the EPs to offer advice to schools and settings, helping them to support children.

For more information see

https://fis.peterborough.gov.uk/kb5/peterborough/directory/site.page?id=Vke5T9THiS4

How we can help?

Educational Psychologists work together with parents, schools and other professionals to determine what the child or young person's strengths and difficulties are. Educational Psychologists review a child's development and progress across 4 areas:

Communication and Interaction;

Cognition and Learning;

Social, Emotional & Mental Health;

Physical & Sensory.

Educational Psychologists use this information to make recommendations to support children and young people in order for them to make progress across these areas of need, where there has been a clear need identified for the child. We take into account and value the strengths of the child or young person, what they are doing well, to help inform this process. Educational Psychologist apply their educational and psychological knowledge throughout this process and gathering information might be done in a variety of ways.

Further information

- You can find out more from the leaflets the service produce: . https://fis.peterborough.gov.uk/kb5/peterborough/directory/localoffer.page?familychannel=8-6

Promoting Inclusion and overcoming issues

Inclusion

Section 100 of the Children and Families Act 2014 places a duty on schools to support pupils with SEND at school. This means that they must ensure that all children with medical conditions, (physical and mental health), are properly supported in school so that they can play a full and active role (be included) in school life, including school trips and physical education, remain healthy and achieve their academic potential. Local authorities have teams that provide additional support to schools to help them to be inclusive. The Peterborough offer from the inclusion team is for those children who do not have an Education Health and Care Plan.. Those who need this help and who do have a Plan can get support from the Statutory Assessment Team.

- **Peterborough 's Inclusion Offer:** https://fis.peterborough.gov.uk/kb5/peterborough/directory/results.page?familychannel=8-6-7

If you notice that your child is not fully accessing the curriculum; for example, is regularly being taken out of class, not being allowed on school trips, receiving sanctions etc., this may be an indication that more help is needed. To avoid the situation escalating, consider applying for an EHCP if your child does not already have one. If your child has an EHCP, you can ask for an urgent review/one planning meeting.

Bullying

We hope it never happens to our children and also that our children are never called a bully, but children with SEND are three times more likely to be bullied than their non-disabled peers, according to research carried out by the Anti-Bullying Alliance.

Unfortunately, due to their alternative communication styles, ways of thinking and moving, neurodiverse children are often targeted by other children for being different. Their lack of understanding of social rules can often mean that they aren't even sure if the other children are being nasty or playing, and find the concept of "banter" particularly confusing. To help understand any patterns of behaviour which may be affecting your child, consider keeping a record of incidents and taking screenshots of copies of messages on social media.

You can be proactive in promoting diversity and inclusion by asking the school to help to support inclusion of all students in lessons and assemblies, to teach all the children to be accepting of people's differences, including neurological ones. You can also work with your school to help to boost your child's self-esteem, helping them celebrate their uniqueness.

Dealing with bullying - a guide for parents and carers (**https://www.autism.org.uk/advice-and-guidance/topics/bullying/bullying/parents**)

Education post 16

The Preparing for Adulthood Team will support your child into employment or further education.

We have provided more details in the **Growing Up section**, and there is lots of useful information on the **Contact website (https://contact.org.uk/help-for-families/information-advice-services/education-learning/education-beyond-16)**.

Section 4

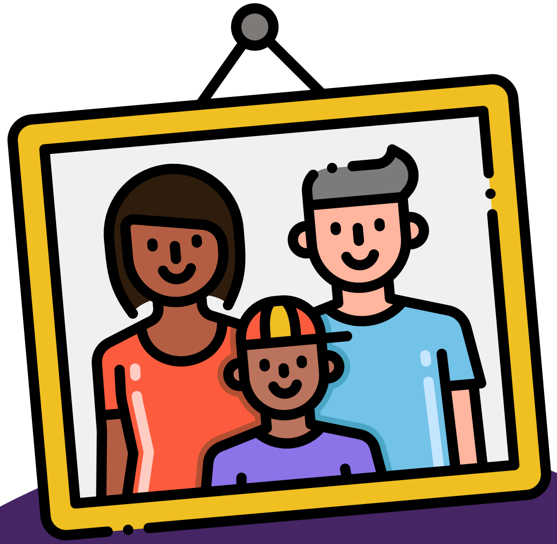
Day to Day Life with a Neurodiverse Child

Family and friends

This section is full of hints and tips from other parents to help you manage personal relationships and day to day activities.

Extended family and friends can offer you a great deal of support, but having a neurodiverse child can change the way that you interact with your family and friends. Give it time! Be patient, it may take a while for your family and friends to understand. Some people will naturally be inclusive and understand, and there are others who for a number of reasons may find it more difficult to be accepting.

You can share the information in this pack with family and friends to help them understand your child's needs and the challenges that you face.



> **"Some members of our family do not believe the diagnosis. I absolutely see it now. But it is frustrating that some people think I'm neurotic when I didn't think a diagnosis was needed in the first place. Outside professionals did, and they were right."**

Understand how family and friends may be feeling

Try to understand how others may be feeling. Relationships often change when we have children – but this may be more apparent when you have a child with SEND because we have to be their advocate and adjust our lifestyle and habits to meet their needs. This may mean that you have less time to spend with other people and may have to cancel or change plans at the last minute. You may not have the time, energy or resilience to be able to support your family and friends in the same way that you did in the past. You shouldn't feel guilty about this, but it can be helpful to recognise that it happens so that you can work together to maintain a positive relationship throughout any challenging times.

Although some people know about autism or being neurodiverse, there are also many people that have no experience at all or have preconceived ideas from newspapers/films/TV that are inaccurate. Be careful not to give too much information at once; the key to building support is helping family and friends to understand how your child is affected, and to help them feel included.

A Grandparent’s perspective

We asked some grandparents what advice they would give to other grandparents:

“Celebrate and enjoy successes - no matter how small.”

“Be a natural part of their lives if you can.”

“Initially I was angry and upset, then I wanted to do as much as I could to help. A few years on, I realise that it’s my son and daughter-in-law that need as much help as possible because they are going 24 hours a day and need some respite and leisure time.”

“Accept and enjoy them for who they are.”

“Get the parents to recognise that their own health needs, both mental and physical, are important and if you can, give them a chance to have a break to get time on their own.”

“Expect that the parents will be very stressed and maybe resentful or frightened.”

“Find things that they like that you can do together – like going out for a cake.”

Dispelling the myths

Awareness and acceptance of neurodiversity is growing but there is still a lot of confusion around what causes it and how it affects people in different ways.

Some of the misinformation that you may encounter and wish to address:

- It is not a curable disease and you do not grow out of it – it is a lifelong condition that with the right help can be effectively supported.
- We know it is not caused by vaccines. (2013 Centre for Disease Control study showed that there is no link between MMR and autism and the theory was discredited)
- It is not caused by bad parenting – neurodiverse children can present with behaviour that challenges as a result of sensory and other needs which are not being effectively supported. Parenting courses tailored to SEND children may help improve understanding.
- Not only boys are neurodiverse. It appears to be more common in boys, but girls are more likely to mask and are often diagnosed at an older age.
- Neurodiversity is not a mental health condition. It is a neurodevelopmental difference.
- Neurodiversity is not caused by a bad diet, but certain artificial additives and food sensitivities can exacerbate symptoms in some children.

"I found it useful when talking to grandparents to point out that back in the day children were punished for being left-handed. We now know that being left-handed is a neurological difference and not something that you should try to cure."

Sharing a diagnosis

Knowing that a child is neurodiverse can trigger a range of emotions and reactions in others in the same way that it will for you. Some common reactions that you may encounter:

- Sometimes it is a relief because it gives an explanation.
- Sometimes relatives may feel sad or worried.
- They may be in denial and reject the diagnosis, which may make you feel isolated and hurt.
- They may be judgmental and blame you – for example if they don't see difficulties themselves because your child masks, or if they blame your parenting style.
- Neurodiversity is often a genetic condition, so it may be that when a child receives a diagnosis, other people in the family may start to be aware of their own quirks.

Let your family and friends express their views and feelings, but it is also important for you to feel supported so you can say that you welcome their support and understanding.

Educate friends & families

General information

There is a lot of information available so be careful not to overwhelm them.

Information specific to your child

The information in this pack is helpful as background but the most useful information you can share with others is to let them know the things that are important to your child – the things that will help and comfort them, and the things that they will find difficult.

Talk through their routine and how it is important to stick to it where possible. Let them know of sensory issues and particular routines for example, around time, food, noise, smells, bedtime routine etc.

Share the successes

Whilst you will naturally share details of the challenges that you and your child may face, remember to share the achievements and fun moments too.

Be patient, it may take a while for your family and friends to understand.

> **“If you have met one individual with autism... you have met ONE individual with autism.”**
>
> **Dr. Steven Shore**

Case studies

Families have shared some of the difficulties that they faced, which may help you to plan in advance how you could prepare for similar situations.

"My child always liked to eat lunch at 11.30. We went to my in-laws for Sunday lunch - which they always had at 1pm. They refused to let my son snack beforehand in case it ruined his appetite. Needless to say, we had to go home before 1pm!"

"I took my daughter for a play date with a friend, when we arrived, she had invited another friend too. My daughter hadn't expected it and was really upset and completely unable to speak to the other girls. It was really difficult and we just had to go home"

"My son went to a friend's house for a playdate when he was 5. When I collected him, the mum said 'it's been awful'. I was so embarrassed and spent the whole night dreading the school run the next day. We got over it though, and now she understands she has become a good friend."

"Every time I started to explain my child's difficulties, I found my parents were judgmental. I got defensive and upset and it ended up in an argument. In the end I shared their one-page profile from school and it really helped. I have since created one for home that I have given to my sister and also to helpers at various clubs."

"My parents used to get really upset when my son bounced on the settee and it became a real bone of contention between us, even to the point that I no longer wanted to go to their house. However, when we understood more about why he did this, I explained to my mum and they bought him a little mini trampoline, which he loves, and no more bouncing on the settee!"

Make New Friends for Yourself and Your Child

Joining a support group in your local area can help you to understand more about your child and validate how you are feeling. You will also meet other like-minded parents and carers who can provide non-judgmental advice and emotional support. You can google or search on social media for your local town, the condition and SEND to find groups near you.

Help for Siblings

Your other children will have questions that they may ask you:

- Why does my brother or sister act in a way that seems strange to me?
- Why does my brother/sister get more of your time and attention than I do?
- Why are you stricter with my brother/sister than me?
- Why don't they have to do chores around the house like I do?
- How can I play with my brother or sister? It makes me sad that I don't know what to do.

They may also be embarrassed if their brother or sister acts differently, particularly in public or if they are at the same school or out with friends.

It is important to let your other child/children know that you don't love them any more or less. Try to make sure that they see their sibling's neurodiversity in a positive way. You can help to find activities that they can both enjoy together. Sometimes your neurodiverse child may need more support but look for opportunities to spend time with all of your children individually if you can.

Useful Links

Local support for siblings can be found here:

- **Centre 33 offer a young carers programme of support** https://centre33.org.uk/help/caring/
- **Caring Together all support young carers** www.caringtogether.org/support-for-carers/young-carers/

Further information for siblings

- Action for Family Carers (https://affc.org.uk/services/young-carers)
- Sibs – Facebook group for siblings of children with disabilities (https://www.facebook.com/SibsCharity)
- Dragon and His Friend: A Dragon Book About Autism - Steve Herman
- My Brother is Special, My Brother Has Autism: A story about acceptance - Schmidt-Mendez, Marta M, Mironiuc, Andreea
- My Brother is Different: A Book for Young Children Who Have a Brother or Sister with Autism - Gorrod, Louise, Carver, Beccy
- Sam and the Spider: A story of friendship and kindness that hopes to change the perception of children with special educational needs - Yusuf, Genevieve, Philip, Ms Shermain

Creating a Neurodiverse Friendly Home

Allow time for processing & transitions

- Use visual timetables and transition cues between activities. Give them time to shift focus, process questions or requests.
- Avoid cognitive overload by breaking instructions down and giving one step instructions.

Add regulating sensory experiences

- Create a safe space they can go to if needed.
- Encourage non-harmful stimming.
- Have an on-the-go sensory toolkit.
- Provide sensory activities and sensory input e.g. slime, bubbles, trampoline.

Structure daily activities

- Use visual timetables.
- Label and colour code to make routines and activities visually organised.
- Help to keep track of time visually by using a timer.
- Be consistent – e.g., Computer games must go off by 6pm everyday.

Minimise potentially overwhelming sensory experiences

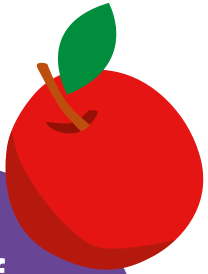
- Provide a warning that it’s going to happen. E.g., hoovering.
- Avoid harsh or bright artificial lighting.
- Consider that some lights can buzz and this may be distracting for your child. If they comment, change the bulb or provide headphones - their hearing may be more sensitive than yours.
- Could you install dimmable lights?
- Black out curtains could be useful.
- Explore the colours that your child finds soothing and you could paint walls in those colours. Often colours such as reds, oranges, yellows and whites are over stimulating whereas blues, greens, purples, browns and blacks are soothing and comforting. Colours can affect mood, how we process information and how we function and perform tasks.
- Choose fabrics that appeal - soft and snuggly, cotton or flannel and consider patterns and prints that are fun but not overly stimulating.
- Noise cancelling headphones/earbuds, can help reduce noise. Some children may actually like background noise, in which case you might like to try using a fan. or listening to music through headphones or having a fan on

- Have a cool room with no screens or mobile phones at bedtime.
- Consider creating zones in your child’s bedroom to distinguish between areas for play, work, sleep and storage.
- Create a calm environment by removing excess clutter.
- Reduce noise using thick carpet, shutting doors fully, turning off appliances, and moving your child’s bed away from a wall with activity happening on the other side.
- Remove labels from bedding and night clothes, or try bedding and nightclothes made from other materials.
- Reduce smells coming into the room by closing the door fully, or by using scented oils that your child finds relaxing.

Mealtimes

Why it can be difficult

Neurodiverse children can have a variety of issues with mealtimes, for a number of reasons, depending on their particular preferences. Some may have sensory issues around the taste, smell or texture of certain foods, some may hate having to sit still at a table during a meal, and some may struggle with you for control of the situation.



> **"It's important to pick your battles. Food battles cannot be won. A lot of food issues appear to be about the child wanting to feel in control, and they quickly realise that no-one can make them swallow. The best thing to do is to pretend that you don't care if/what they eat, but it's so hard!"**

www.autism.org.uk/advice-and-guidance/topics/behaviour/eating

Hints and tips

- ✓ Forcing your child to eat does not work. Try the 'Shared Plate' approach: presenting all the food in the middle of the table, making sure there is at least one or two things you know the child will eat, then everyone helps themselves. That way, the child learns/sees that the foods are safe to eat, and will one day, eventually, after lots of opportunities, touch some different foods.
- ✓ Try and keep to set mealtimes,
- ✓ Get children involved in the food preparation, and to help tidy up.
- ✓ Let them explore food and textures with their fingers, so it isn't a surprise when it goes in their mouth.
- ✓ Try making the plate one colour so your child isn't put off or distracted by patterns on the plate.
- ✓ Use a small plate, so the child isn't overwhelmed by the amount of food.
- ✓ Try separating different textures and tastes into separate bowls or using a plate with dividers.

Please see the section on **Diet and Exercise** for help you can receive if your child develops an eating disorder or has a particularly restricted diet.

Sleep

Why it can be difficult

Neurodiverse people can often have trouble getting to sleep and with disturbed sleep. There is a range of reasons for this including difficulties with relaxing or winding down and irregular melatonin (sleep hormone) levels. Young people may:

- have difficulty settling, winding down and going to sleep;
- wake repeatedly during the night, or have difficulty getting back to sleep after waking up to go to the toilet;
- be anxious or be unable to relax causing insomnia;
- have social cueing problems and not make the connection between others in the house going to bed and their own need to sleep;
- have a neurological condition such as epilepsy;
- have increased sensitivity to blue light from smart phones, laptops and other screens, or sensitivity to certain sounds or white noise, which may be upsetting or distracting and keep them awake;
- have food allergies, which could cause tummy problems and discomfort, or increased sensitivity to caffeine or other stimulants, which can disturb sleep;
- sleep too much (hypersomnia) - they could be exhausted because of the additional stress from social situations.

"J often listens to something called ASMR on YouTube. He says you have to have headphones to get the full effect. It's just people talking in different tones about all sorts of different things. There are Minecraft ones etc. It's really relaxing."

What professional help is available?

Medication

Melatonin is a naturally occurring hormone which our bodies produce when it gets dark to help us sleep. Synthetic Melatonin supplements are only available on prescription in the UK. For more information, you should speak to your child's GP or paediatrician.

Peterborough has a sleep service called "Sleep Right".

https://fis.peterborough.gov.uk/kb5/peterborough/directory/service.page?id=AykzPEe0FUI&familychannel=8

Hints and tips

The environment and surroundings can play a role. It may help to:

- make the bedroom more comfortable, tidy and ordered;
- block out light using dark curtains or black-out blinds;
- get a fan for hot nights; this can also provide white noise which helps some people to sleep
- reduce noise using thick carpet, shutting doors fully, turning off appliances, and moving your child's bed away from a wall with activity happening on the other side;
- block out noises by letting your child use ear plugs or listen to music through headphones;
- remove labels from bedding and night clothes, or try bedding and nightclothes made from other materials;
- reduce smells coming into the room by closing the door fully, or by using scented oils that your child finds relaxing;
- remove distractions, such as electronic devices near the bed and pictures on the wall (unless the person finds these relaxing), and consider a different colour on the walls;

- consider using a sensory projector. Some children can find them overly stimulating but others like to follow the shapes and it can help them to relax;
- use relaxation techniques such as having a bath, massage, quiet time or gentle exercise such as yoga, to help your child wind down before bedtime;
- limit sugary foods and fizzy drinks and other stimulants near bedtime.
- weighted blankets or compression sheets work for some children, but be sure to get the correct weight for your child
- there are a number of sleep/relaxation apps available, such as How to help kids sleep better - Headspace (**https://www.headspace.com/sleep/better-sleep-kids**) and Moshi – Sleep and Mindfulness.

Further information

- **www.cerebra.org.uk/wp-content/uploads/2019/07/Sleep-cards-Cerebra-charity-for-children-with-brain-conditions.pdf**
- **www.scope.org.uk/advice-and-support/keeping-sleep-diary/**
- **https://www.circadiansleepdisorders.org/**

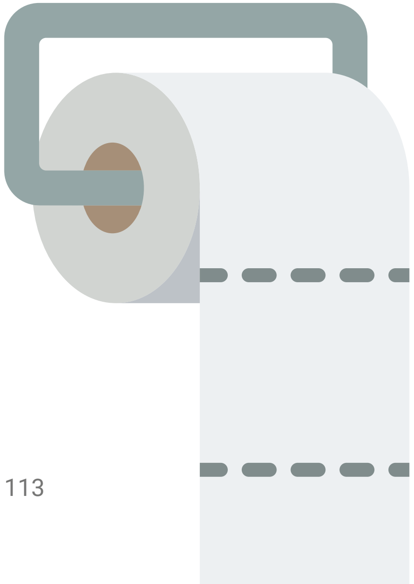
Toileting

Establishing an independent toileting routine can be difficult for all children, but for neurodiverse children it can take longer and there may be other challenges.

How this might affect your child.

For children who want to use the toilet in the same way as their peers, this can be embarrassing, so it is important to help them establish independence.

Some children don’t have a natural desire for that independence, but it can make day–to–day living, particularly outside the home, difficult for them and you.



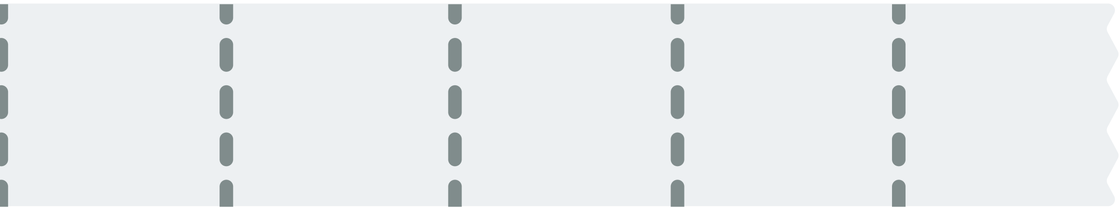
Hints and tips

It can be helpful to establish structure and a routine around going to the toilet and changing. The following ideas may also help:

- Use the bathroom to change your child so that they link toileting activities to the bathroom.
- Make sure that everyone helping your child adopts the same approach.
- Dress your child in clothes and pants that are easy for them to remove if they are in a hurry.
- See if you can work out a regular time that your child needs a wee or a poo (for example immediately after eating), and prompt then to visit the bathroom at these times. This develops a habit which may help even if your child still struggles to understand the physical signals of needing a wee or poo. Perhaps give your child a drink 20 minutes before a scheduled toilet visit to increase the chances of success!
- Boys may sometimes struggle to distinguish between when they need a wee or poo; if this is the case for your child, encourage them to sit down. You may also want to get them to sit down if they have poor co-ordination and struggle to aim into the toilet whilst standing!

Hints and tips

- ✓ Use visual aids in the bathroom to help your child understand what they need to do and in what order, for example, undress, sit on the toilet, wee/poo in the toilet, wipe (you may need to show how many squares of paper to take), get dressed, flush the toilet and finally wash and dry hands.
- ✓ Keep to the same routine and order every time you help them to go to the toilet.
- ✓ Make sure that they like going into your bathroom – they are unlikely to go independently if there are smells that they don't like (for example air freshener) or if they don't like the soap that you are asking them to use. Make the bathroom as child-friendly as possible – consider buying foaming soap or something that will be an incentive for them. If you have an extractor fan, consider if that sound is difficult for them – perhaps turn it off when they use the bathroom.
- ✓ It may or may not be appropriate to praise or reward your child – you know your child the best and will know how best to reinforce a successful trip to the bathroom.



> **"my son used to get so engrossed in his special interests that he would forget to go to the toilet - I still have to remind him sometimes!"**

Night-time toileting issues

If your child is dry during the day but has accidents at night then try the following:

- Have a set bedtime routine – go to bed at a similar time each evening.
- Limit the amount that your child eats and drinks leading up to bedtime.
- Try taking your child to the toilet when you go to bed or at different times during the night.
- Use mattress protectors to protect bedding.
- Many children need to wear a nappy (or night pants for older children) at night for a long time – it can be reassuring to know that there are other children in a similar situation but if you are worried, talk to your GP.

School toileting issues

Schools should not refuse to admit a child because there are difficulties with toileting- a school that does this may be at risk of disability discrimination.

Smearing

Some children smear their poo. This could be for medical, sensory or behavioural reasons including:

- feeling unwell or being in pain.
- being reluctant to wipe because toilet paper is too harsh.
- seeking out sensation from texture, smell or movement of arms during smearing action.
- seeking attention/wanting a reaction.
- fear of toilets.

If you have any concerns about sleep or toileting talk to your GP, your health visitor or school nurse.

Hints and tips

- ✓ Visit the GP to make sure that there are no physical reasons involved, like being in pain.
- ✓ If you think it could be a sensory issue, provide an alternative substance with a similar texture, e.g., papier-mâché, Gelli Baff, gloop (corn flour and water), finger painting, play-dough.
- ✓ Replace toilet paper with a wet wipe.
- ✓ Teach them the wiping process, 'hand over hand' i.e., putting your hand on top of their hand as they wipe.
- ✓ Provide alternative activities at times when the smearing usually takes place.
- ✓ Avoid asking your child to clear up after themselves, or telling them off, as this may reinforce the behaviour. Try to avoid paying too much attention.

Further information

- **Bladder & Bowel UK - bladder and bowel problems information and advice www.bbuk.org.uk**
- **On Autism and Toileting www.neuroclastic.com/on-autism-getting-dressed-and-toileting**

Dental Care

Brushing teeth can be a challenge for many neurodiverse children. When we brush our own teeth, we can feel how hard to brush and how to avoid hurting our gums but this can be challenging for many of our children. It is important to validate how they are feeling and show that you understand it is something that they really don't like. Fledglings (www.fledglings.org.uk/) have lots of alterantive toothbrisuhes and non-flavoured toothpaste that can help. Some children may need specialist help and dentists can refer to the special dental service https://fis.peterborough.gov.uk/kb5/peterborough/directory/service.page?id=9VOadobfQ4Q

Hints and tips

- ✓ Allow them to go at their own pace – don't rush them but you can encourage them to slow down if needed!
- ✓ It can help to develop a routine and have a set number of brushstrokes for each tooth. This also gives a definite end point for children who find it really hard and is also a good distraction.
- ✓ Encourage your child to do as much as they can themselves - even if they don't do a great job, you can go over it again afterwards.
- ✓ Experiment with different toothpastes to find out what flavour your child likes best.
- ✓ Offer mouthwash after each brush - some children enjoy the sensation of using this.
- ✓ Consider using an electric toothbrush - these can give a better clean and the vibration can also help to detract from any discomfort in their mouth. If bristles are too hard, a baby toothbrush with softer bristles might help. If even this is too uncomfortable, using your finger is better than nothing!
- ✓ Allow your child to take a break if they are finding it too uncomfortable.
- ✓ You can introduce ways to make it fun – for example, asking your child to brush your teeth or using a musical timer.
- ✓ For younger children you could have a reward chart and give a sticker every time they do a good job – and then give them a small reward every time they reach a certain number of stars.

Losing teeth

The process of wobbling teeth can be extremely uncomfortable for some children. Explain to your child what is happening and why teeth are replaced to help them understand what is happening. You can also explain that it is a natural process and that the wobbling will end when the new tooth comes through.

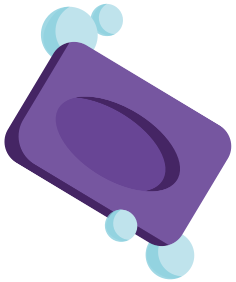
Some children will view their teeth as part of their body and find it difficult to come to terms with the fact that a tooth has fallen out. They may want the tooth fairy to visit but not want part of their body to be taken away - so consider whether the tooth fairy could make an alternative arrangement in these cases, maybe they could leave the tooth but give a reward based on how clean the tooth is?

Keeping Clean

Challenges getting children to wash, shower and get in the bath vary at different ages.

We have talked in this section about creating the right environment in the bathroom and in the growing up section about puberty but there are other things you can try:

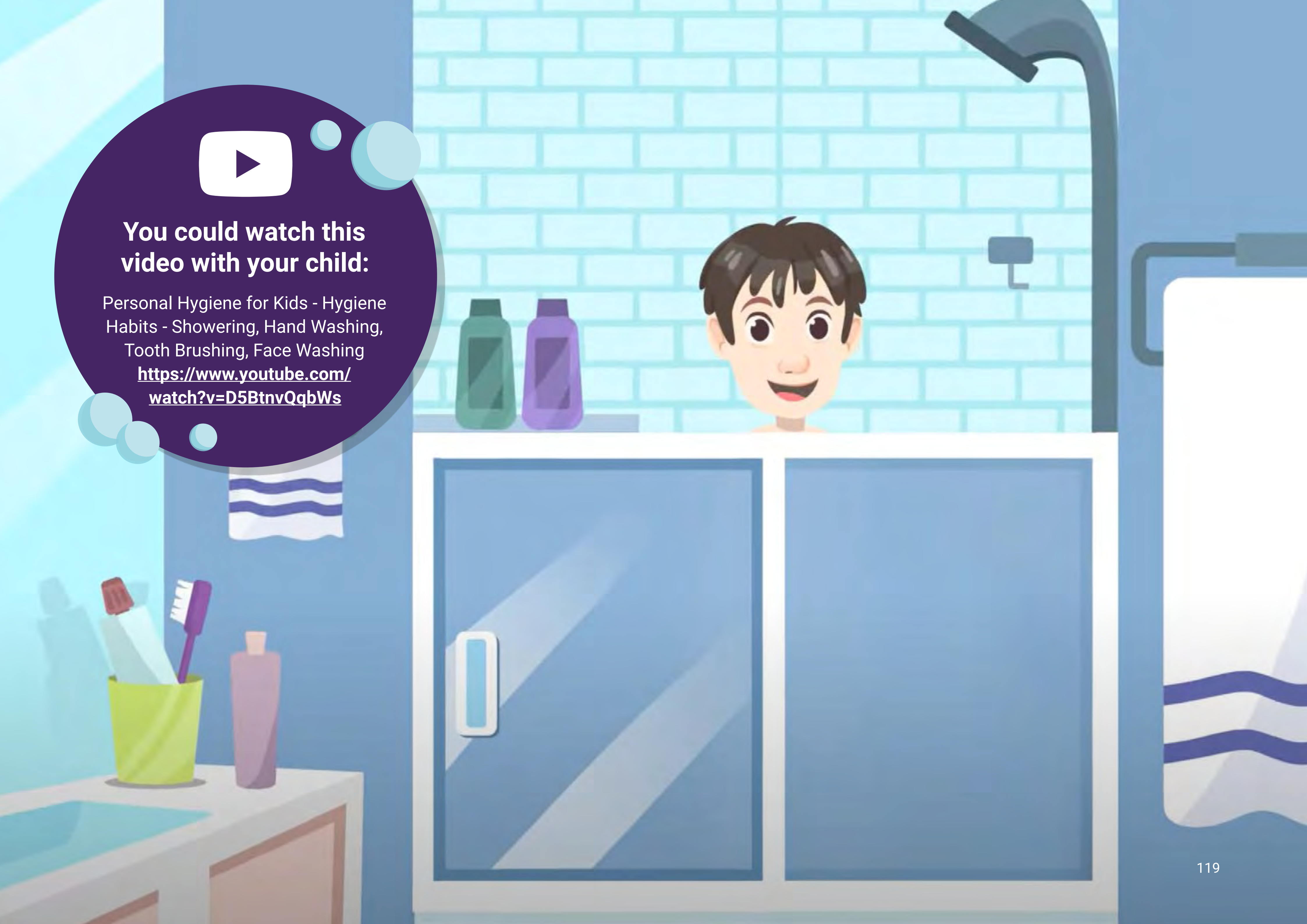
- For children that love different smells, let them choose their own products. Their idea of what smells or feels good may differ to yours.
- There are lots of toiletries that can help make washing more fun: squirty shower gel, bath bombs, bath slime etc., and these can help meet sensory needs.
- Have a range of toys that will help make bath time more fun.
- If you have a child that wants to spend a long time in the shower or bath, you could build your morning or evening routine around this to make sure everyone has enough hot water and everyone knows when their allocated slot will be!



You could introduce using visual timetables to encourage completion of daily grooming routines.

Here's an example of a **showering schedule**:

- Wash my face, arms, feet and legs with soap
- Wash my body
- After the shower, dry my body with a towel
- Dry my face and hair with a towel
- Put deodorant under my arms
- Get dressed into clean clothes



You could watch this video with your child:

Personal Hygiene for Kids - Hygiene Habits - Showering, Hand Washing, Tooth Brushing, Face Washing
https://www.youtube.com/watch?v=D5BtnvQqbWs

Out and About

Planning can often help to make trips out easier and there are many things that you can do to limit uncertainty and address in advance the things that you know your child may find difficult.

Here are some of our top tips:

1. **Research** – try to anticipate the things that your child might find difficult, or that it might help to know about in advance. For example, if you are visiting a theme park or other attraction, can you get a map in advance and highlight the location of the toilets? If you are out and about in a city, can you plan stops to favourite restaurants, where you know the food will taste similar to what they have had before? Many chains have apps or information on their website that can help you to plan a visit. The Google Earth App is a great way to see places in advance and you can virtually walk/drive a journey.

2. **Changing and accessible toilets.** Consider purchasing a Radar key to access disabled toilet facilities. You can also apply through Shortbreaks for a Changing Places key which gives access to clean and accessible toilet and changing facilities across

   - Disabled toilet key **www.cheapdisabilityaids.co.uk/disabled-toilet-key-205-p.asp**
   - Keys can also be purchased from Disability Rights UK. **www. shop.disabilityrightsuk.org/products/radar-key**

3. **Plan lots of breaks** – in an unfamiliar environment and faced with the uncertainty of new things, your child will probably get tired quickly. Help by keeping them fed and watered and plan in lots of breaks. As above, if you know that having an ice cream or drinks break is a treat for your child, you can schedule in these stops to encourage them to rest.

4. **Take some familiar items** – take some things from home that might reassure your child. This could include a tablet, special toy, ear defenders, puzzle books etc. You can also take snacks and drinks that you know they will eat and drink.

5. **Useful Apps** – help alleviate stress with these recommended sensory Apps - Sensory Fidget Toy, Fluid, Heat Pad, SafeSpace.

6. **Social Stories** – can help to give an understanding of what will happen when and what is expected from your child during the visit. They are also a way to provide reassurance that you will go home at the end of the trip. Books available from Carol Gray and Siobhan Timmins.

7. **Phoning ahead** – it can help to phone ahead and speak to staff to get more information about the place that you are visiting and let them know of any additional things that they could do to help make your visit go smoothly. for example, if you are booking a table in a restaurant, you could ask for this to be in a quiet area.

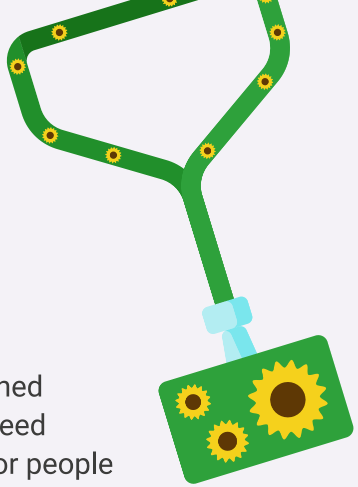
8. **Shopping** – some children love shopping; other children hate it and can find it overwhelming. If your child does not enjoy shopping consider whether you need to go at all. This can mean changing your own habits, but online grocery shopping is now increasingly accessible and it is easier to buy shoes and clothes online too. If you do need to go into a shop, there are some things that may make it easier:

- Tesco give free fruit to children to eat whilst they are in the store;
- You could give your child their own mini shopping trolley;
- Let them sit in the main part of the trolley and help to organise the food as you put it in;

- Ask for their help ticking off items from your shopping list as you put them in the trolley;
- Try using ear defenders, headphones and other distractions and avoid the areas with harsh smells such as the fish counter!
- If you do want to have shoes fitted, Clarks offer an appointment system and if you phone ahead, they can help to identify quiet times in the shop which can make your visit less stressful.

9 **Condition alert cards** – these are business cards which briefly outline your child's condition and can help to explain in difficult situations if you need to give information quickly. - for example, if you need to help your distressed child. Older children may also choose to keep one to use to ask for help without using words.

- I am autistic card (**www.autism.org.uk**)
- ADHD card - Stickman Communications (full range of needs are covered) **www.stickmancommunications.co.uk/product/adhd-card/**



10 **Sunflower lanyards** – these were designed to let people know that someone may need extra help. The scheme was originally for people with a non-obvious disability or condition, but throughout the pandemic some people started using the lanyard as form of exemption from wearing a face covering, which is now having an impact on those with hidden disabilities who use the lanyard. However, you may still find it useful and can order from a number of places including the hidden disabilities store. The Hidden Disabilities Sunflower (**www.hiddendisabilitiesstore.com**)

11 **Car journeys** – there are lots of special car seats and adaptations available to stop your child from wriggling out of their car seat. Always make sure you have the child locks on your doors to prevent your child from opening them while you are driving. Children's Car Seats & Safety Advice in the UK & Ireland - ICSC (**www.incarsafetycentre.co.uk**)

12 **Flying**– you can use a sunflower lanyard at most airports to help avoid the worst queues. Spotter books can help show what will happen at the airport and then give your child things to do whilst waiting. When you are on the plane you could have a lucky dip bag with lots of small treats; fidget toys; games, sweets etc. which they can pick one at a time to keep them amused on the flight.

Financial help

Having a child with additional needs can put a strain on the family finances, due to having to reduce working hours or pay extra for equipment or activities for your child, but there are a number of ways to secure help.

> **"Applying for DLA is a depressing experience, as you have to list out all your child's difficulties, but the extra money each month has made up some of the money lost when I had to cut my working hours to make sure I am there after school to collect my son."**

Benefits

You may be elegible for a range of beenfits. The Turn To Us website (www.turn2us.org.uk/jargon-buster/Means-tested-benefits) has a tool to help you find out what would apply to you.

Disability Living Allowance (DLA)

You can apply for DLA without a formal diagnosis as this is based on an assessment of needs. As well as receiving a DLA payment, this can also unlock other ways to save money or increase income. For instance, if you currently receive Tax Credits, they will go up if you are also awarded DLA. DLA is not means tested.

Some parents feel they shouldn't apply for this benefit, as they don't feel their children are "disabled enough". However, it is worth making a note of how many hours a day you spend helping your child to do everyday tasks, as it may surprise you. A neurotypical child may take 10 minutes to get in the shower and once in there wash themselves properly, whereas a neurodiverse child (especially with sensory issues) may need to be persuaded and reminded for an hour to do the same task. You may spend 2 hours a night calming your child and getting them to sleep, whilst other parents are relaxing in front of the TV.

The DLA form is long and can seem daunting, but this guide from charity Cerebra is an excellent resource to help you: **www.cerebra.org.uk/download/disability-living-allowance-dla-guide/**

You can apply for a paper form to complete, or download a pdf form that you can edit and save and then print out and post: **www.gov.uk/dla-disability-living-allowance-benefit**

Carer’s Allowance

If you receive DLA at the middle or higher rate you can also claim Carer’s Allowance, but it is means tested. If you earn more than a set amount (as at October 2021 £128 a week after tax, National Insurance and expenses) you cannot claim Carer’s Allowance, but you may be able to secure Carer’s Credit instead.

Carer’s Allowance Eligibility **www.gov.uk/carers-allowance/eligibility**

Theme Parks/Theatre Trips/Days Out

Before arranging any days out, it is always worth checking the website of the place you will attend to see if they provide free adult carer tickets, or allow you to avoid queues if this is something that your child will be unable to do.

> **“We had some awful experiences at theme parks when queue times were just too long for my son to manage, especially when people were standing too close to him. Someone told me about the disability access scheme and it made all the difference, and we could just do everything at our own pace.”**

Disabled Facilities Grant

A Disabled Facilities Grant can be applied for via your Local Authority to help towards the cost of making adaptations to your home. The adaptations must make it easier for you to care for your disabled child or increase their level of independence at home. It will only be awarded if your LA believes that the changes are necessary to meet your child’s needs and the work is both reasonable and practical depending on the age and condition of your property. More information on the criteria and how to apply can be found here: **www.cerebra.org.uk/wp-content/uploads/2021/05/Disabled-Facilities-Grants-May21.pdf**

Family Fund

Family Fund is a charity that provides grants to low-income families, with disabled or seriously ill children, to help pay for items such as sensory equipment, days out, holidays, technology etc: **www.familyfund.org.uk/grants-england**

Peterborough Short Breaks

If your child or young person doesn't receive services from social care and has high rate Disability Living Allowance (Care Component) or the enhanced rate Personal Independence Payment (PIP), they have an automatic entitlement to our local short breaks offer. You will receive a personalised budget that can be used for agreed activities and support as identified in your child's short break plan.

If your child or young person has a disability and will require lifelong support from statutory services, their social care assessment may indicate that they are eligible for short break / Early Help funding. You will receive a personalised budget that can be used for agreed activities and support. For some Early Help Plus enables an increased personal budget to meet assessed needs.

Peterborough city council
https://fis.peterborough.gov.uk/kb5/peterborough/directory/site.page?id=iDoiJa0Zlr0

Vivacity Peterborough
https://vivacity.org/things-to-do/short-breaks-send-holiday-clubs/

Family Voice Peterborough caravan
https://familyvoice.org/caravan/

CEA Card

The CEA Card enables you to a free adult carer cinema ticket, whenever you purchase a ticket for your child. It is accepted at most cinema chains: **www.ceacard.co.uk**

Disability Aids etc.

Better Mobility have listed a variety of charities that you can apply to for help with disability aids, therapy, sensory equipment, etc.

Charity Funding Options - Better Mobility - Wheelchairs, Powerchairs, Scooters and Living Aids: **www.bettermobility.co.uk/charity_funding_options.php**

Discounts For Carers

This is an on-line shopping discount scheme for carers. You can secure discounts by clicking through to retailers via their website: **www.discountsforcarers.com**

The Cauldwell Trust

The Trust provides equipment, treatment and therapies for sick and disabled children. Apply for Support - **www.caudwellchildren.com/apply-support/**

The Handicapped Children's Action Group

This organisation provides specialist equipment for children with disabilities, learning difficulties and other special needs: **www.hcag.org.uk**

Section 5

Communication, Speech and Language

Difficulties with Communication, Speech and Language

Thanks to Michelle O'Brien, Speech and Language Therapist for providing input and advice on this section.

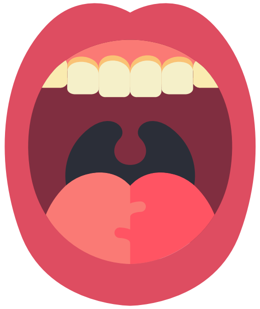
What do we mean by speech, language and communication?

Speech

- Speech sounds, saying sounds accurately and in the right place
- Speaking fluently
- Speaking with expression, for example, pitch, volume

Language

- Talking and understanding
- Having words to describe objects and actions
- Using words to build sentences
- Following grammar rules so things make sense



Understanding

- Processing and making sense of what people say
- Understanding the words being spoken
- Understanding the rules of grammar

Many neurodiverse children have difficulties with speech, language or communicating including:

- being non-verbal
- mild, moderate or severe learning difficulties
- language delay
- specific difficulties in producing sounds
- a hearing impairment
- stammering
- voice disorders
- situational/selective mutism
- misunderstanding and taking things literally

Finding ways to help your child communicate their wants, needs, sensory issues and anxieties is a really important part of regulating their emotions and frustrations and helps to limit behaviour that challenges.

"Despite having no words, life with J is far from quiet. He is constantly vocalising, it's just the sounds he makes are unlike any words that you or I would know. It's like he has his own language; a language that he truly understands, but the rest of the world doesn't. Sometimes I can see that he is really trying to communicate, and he looks at me shocked that I don't know what it is he's trying to tell me. Somewhere in the connection between his brain, vocal chords and tongue, there is something that isn't working properly. Instead, I've learnt to become a detective to the tone of his sounds. I can tell with each noise he makes how happy he is, if he is trying to communicate with me, jabbering away to himself, or if a meltdown is on the way. His understanding of language, when we are talking to him, has improved significantly, able to follow various instructions when he chooses to. However, his frustrations at not being able to relay his own thoughts are clear to see. Over the last 4 years these frustrations have gradually become more and more physical."

Taken from **Home - Stories About Autism** a blog written by James Hunt, an Essex based dad to two amazing autistic boys - **www.storiesaboutautism.com**

What professional help is available?

If your child has any of these difficulties, their school, paediatrician, GP, or health visitor will usually make a referral for your child to see a Speech and Language Therapist (SALT). The SALTs work together with children and their families, and other professionals to carry out assessments and plan a personalised therapy programme plan to meet child's communication and swallowing needs.

Further information

Local Speech and Language services:

- **Local speech and language drop-in clinics / online advice and assessments.** Drop-ins are held around the county for any parent concerned about their child's speech and language.
- **CPFT https://www.cpft.nhs.uk/speech-and-language-therapy-children/**

Learning to Communicate

The usual learning process of communicating is shown in the Pyramid of Communication and there are a variety of ways to assist your child to reach each stage.

Every child learns at their own pace, but there are things that you can do at home to support communication, developing attention and the foundations of communication through play and fun activities.

“From as early as one and a half I was worried about my daughter’s speech as she had lost words, and was making beat box noises instead. When she was about 18 months old, I phoned my health visitor who gave me the times and days of our local speech therapy clinic drop in. At the clinic, they asked me if I knew what autism is and I went home and googled it and she had every single sign and I knew she had autism. From there it snowballed, assessment after assessment and she was diagnosed just a few months after her 2nd birthday.”

Hints and tips

- ✓ **Role play** can be a great way to show your child appropriate frameworks for social interaction and to explore how things can go wrong/what to avoid.
- ✓ Try to **say less** by making your questions short and specific. Speak slowly and repeat your instructions.
- ✓ Give your child **time** to process the information that you have given them and time to respond– wait, wait and wait for a response!
- ✓ Find opportunities to **encourage** your child to communicate, for example, by providing small food portions or treats and encouraging them to ask for more; or offer them choices.
- ✓ **Joint attention** – follow your child's lead and use their interests to spark conversation; encourage them to copy your actions and sounds; help them to participate in stories and songs, join in with your child's play; take photos and videos of you with your child and watch them back together, and ask family members and friends to provide photos that you can use to talk about them with your child.
- ✓ **Share** lots of picture books with your child and point to the pictures as you say the corresponding words.
- ✓ **Allow your child to take the lead** when you play, observe, wait, watch and allow them time to develop thinking and language
- ✓ **Set aside a time** when there will be no distractions
- ✓ Interactions don't have to be long, **little and often** works well
- ✓ Use Alternative and Augmentative Communication which are systems and devices that aid communication for people, supporting understanding and communication. Speech and Language therapists will provide advice of any AAC suitable for your child. AAC does not have to mean high tech computer technology, it includes signing, gestures, written words, symbols and picture books.
- ✓ **Visual aids** – can be really helpful to help a child communicate without the need for words.
- ✓ **Makaton** is a unique language programme that uses symbols, signs and speech to enable people to communicate. Makaton can be really fun too; the resource page has lots of nursery rhymes you can share and learn. www.makaton.org
- ✓ **Picture Exchange Communication System** (PECS) aims to teach functional communication. www.pecs-unitedkingdom.com
- ✓ Children who find it hard to communicate their feelings may find these **Communication Fans** a simple way for them to express how they are feeling. The fans contain 10 pictures and words with symbols for sensory situations such as 'it's too crowded, noisy, or smelly etc'.

Literal Language

Neurodiverse people often take language literally and can be confused by non-literal or colloquial language such as:

- ‘I feel like my head is going to explode’ - meaning ‘I am angry’
- ‘I’ll be with you in a minute’ - meaning ’I won’t be long’
- ‘You drive me up the wall’ - meaning ‘you are making me cross’
- ‘Get lost’ - meaning ‘go and disappear for a while’
- ‘I’ve got your back’ - meaning ’I will look after you’
- ‘Have you lost your marbles?’ - meaning ‘that’s a silly suggestion?’

They may not understand things said sarcastically such as:

- ‘Hah-ha, funny’ - meaning ’you are not funny at all’!

You can help avoid misunderstanding by using factual, specific language:

> **I am friends with my child’s teacher and we laugh about the time that she asked the class to sit down. Everyone else sat on their chair but my son sat straight on the floor. Luckily, she knew him well enough to understand that he wasn’t being cheeky - he just hadn’t understood what she wanted him to do**

If you are asking your child to do something for you, don’t phrase it as a vague question, as they will think it is optional, rather than non-negotiable. They aren’t necessarily being rude, they are just giving you an honest answer!

“Would you like to tidy your room?”

“No!”

Further information

- **Book: More Than Words - A guide to helping parents promote communication and social skills in Children with ASD by Fern Sussman**
- **www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/visual-supports**
- **www.blacksheeppress.co.uk - Lots of free picture resources to use at home**
- **Speech Apps - Splingo, Rainbow Sentences, Articulation Station**
- **www.communicationmatters.org.uk**
- **www.specialneedsjungle.com/speech-therapy-terminology-what-does-that-mean**

“We felt helpless that our son wasn’t communicating, especially when he seemed sad and we couldn’t work out why. Knowing what to do to get real help would have given us some focus and reduced stress for the whole family.”

“Everyone assumed she was choosing not to talk, not that she couldn’t talk - no one appreciated her difficulties in speaking. Everyone said that she would talk when she had settled in, but I don’t think she ever ‘settled in’ anywhere. Friends tell me they thought she was just being rude when she couldn’t speak to them. She wouldn’t even be able to talk to me, if someone else was around. But when we were on our own, she couldn’t stop talking - tripping over her words as they tumbled out of her.

She desperately wanted friends, but not being able to talk to them, she couldn’t join in and quickly got left out of social groups.

Selective mutism is such a debilitating condition, that is so poorly understood. There is some argument for it to be called Situational Mutism, as the word selective implies choice. Also, in my experience, my child can speak freely to me on my own, but the introduction of another person can cause such anxiety, they can’t even manage to look at me.”

Section 6

Sensory Needs

Sensory Differences

Researching your child's sensory needs can help you understand how they experience the world. This section has been written by Jenne Seibolt, a Children's Occupational Therapist from The Great Little OT Practice..

What are Sensory Differences?

There are five well-known senses - sight, hearing, touch, taste and smell, which the conscious part of the brain is very aware of; it continuously checks information obtained by these senses in order to experience our environment. There are other, equally important sensory systems, essential for normal body functioning; however, these are not so easily recognised because the nervous system keeps the input unconscious: proprioception is the sense of the position of body parts in space, the vestibular sense is the balance system that provides information about our movement and orientation in space and interoception is the messages sent from the body to the brain that regulate temperature, hunger, pain and many other functions of the body.

How you process that information from your senses is often called sensory processing. It is how the brain processes, interprets and filtesr sensory input received from the senses to organise and prioritise our responses to the constant environmental demands appropriately.

Some people need a lot of stimulus through their senses whilst others need very little. This can show in what we find comfortable and uncomfortable - lots of touch and very little light / lots of noise but a dislike of strong smells etc. For some, these feelings can be overwhelming and can even cause pain. For many, these are managebale sensations with the right adjustments,

Some people refer to sensory processing difficulties as 'Sensory Processing Disorder' and many neurodiverse people experience this, not just autistics. Currently, there is no separate diagnosis for sensory processing difficulties as such, which is conversely what the word 'disorder' implies.

There are two important factors to remember when it comes to sensory processing:

1. Firstly, all autistic children and some neurodiverse children are likely to experience some differences in sensory processing, but they don't always lead to major difficulties. But it's good to become a detective for your child and identify their sensory needs so they can be considered when there is a practical problem, such as accessing a toilet (smell, sound), wearing certain clothes (touch) and accessing busy places from assemblies to supermarkets (sound, touch and sight). It is useful, as a parent, to understand the issues and principles behind sensory processing to support the child in a) minimising unhelpful sensory input, and b) providing the sensory input they need to function best.
2. Secondly, our sensory processing skills impact greatly on our ability to regulate our behaviour and, to an extent, our ability to regulate our emotions. We all use movement breaks to regulate our concentration and attention, and the link between physical activities and emotional well-being is well established. Children with sensory processing differences require more input to the vestibular and proprioceptive systems to help them with regulation – this is not a quick, one-off fix to a problem, but an ongoing, long-term need.

How this might affect your child

Everyone is different in how they process sensory information. It doesn't always lead to problems, but most autistic people have differences in sensory processing. This means that they may be over- or under-responsive (over- or under-sensitive) to input received from the sensory receptors. The child can be over-responsive in one or more of their senses and be under-responsive in one or more of the others at the same time. It is also worth noting that responsiveness is not constant and is affected by many factors, such as physical well-being and the social environment – we are all more bothered by loud noises if we are ill, and most people will feel less bothered by sensory input if they are in their familiar home environment as opposed to, say, a shopping centre.

In your child, the over- or under-responsiveness may show, as follows: (this is not an exhaustive list)

Touch

The child may struggle with wearing clothes, especially with labels and seams, and especially in tickly places, such as feet. They may struggle (or used to when they were younger) with nail cutting, hair washing and hair cutting. They may dislike being touched lightly or become disproportionately upset when someone brushes past them. Small injuries to the skin may either seem the end of the world or go unnoticed. The responses may be intense; the input is registered as irritating at best, and as painful at worst.

Sound

To the child, some noises are magnified and some are not heard; they are likely to find it difficult to prioritise one noise over the other, e.g. the teacher's voice over the general noise of the classroom. Sudden loud or unusual noises may trigger tears and/or a 'fight or flight' response. Background noises may be really distracting.

Sight

The child may be over-responsive to bright lights. They may be able to spot small difference others easily miss. Some objects may be magnified, some blurred. Children may enjoy looking at specific objects more than you would usually expect.

"My daughter loves her room clean and tidy and having her projector light on when she goes to sleep."

Smell

Although this is relatively rare, the child may find certain smells unbearable (e.g., cooking smells, strong perfume or a trip to the zoo), some may actually gag. Others may not notice bad smells at all.

"My child can not stand the smell of fish, but loves the smell of the beach"

Taste

The child may seek or avoid hot, spicy, cold, bland, mushy or crunchy foods. The child may try to eat non-food items, although this may relate to non-sensory aspects. Please note that most food issues in children relate to the texture of the food, rather than its taste and, therefore, relate to the sense of touch: how the mixed textures feel inside the mouth.

Eating non-food items is referred to as Pica.

"My son hates sticky food but loves crunchy cereal"

Vestibular (balance)

The child may rock back and forth, in standing or sitting. They may enjoy spinning, jumping, enjoy being upside down, or literally, climb the walls. On the flip side, they may avoid any activities that involve rapid change of position, such as playground swings and roundabouts, and become travel sick quickly.

"My twins are so different. One like seesaws while the other feels sick. One always falls over and can't ride a bike while the other is really good at football!"

Proprioception (awareness of our own body in space)

The child may seek movement all the time. They may love tight hugs and to squeeze into tight corners behind sofas and beds. They may like heavy weighted things or people on top of them. Reduced registration from proprioceptive input is also associated with motor co-ordination difficulties: the child may appear clumsy and have a poor sense of personal space. They may struggle with fine motor skills such as using a pen or tying shoe laces.

"My child loves climbing so we take him to Bouldering Club every week. His posture has really improved along with strengthening his joints.

"My daughter is always hungry. It is like she can't understand when she is full."

Interoception

Interoception is a fairly new area for discussion in sensory integration; interoception is how our body tells our brain what is going on inside our body, when we are hungry or feel full, when we need to use the toilet, when our heart is beating fast or when we have that sensation of butterflies in the stomach. Just as there are receptors in your muscles and joints, there are also receptors inside your organs, including your skin. These receptors send information about the inside of your body to your brain. This helps regulate our vital functions like body temperature, hunger, thirst, digestion, and heart rate. For children with sensory processing issues, the brain may have trouble making sense of that information. They may not be able to tell when they're feeling pain or when their bladder is full. An itch may feel like pain, or pain may feel ticklish.

Children who struggle with the interoceptive sense can also have trouble "feeling" their emotions. They may not be as tuned in to the body cues that help interpret emotion. Without being able to feel and interpret those body sensations, it's harder to clearly identify the emotion.

What professional help is available?

There are no quick fixes or cures for sensory processing difficulties. However, Occupational Therapists (OTs) have developed an understanding and expertise around sensory processing skills, which can be helpful to access.

Children's Occupational Therapists enable children and young people with special needs to participate in and successfully manage the activities that they want or need to do at home, at school or work and during their free time. They have the skills and expertise to identify the personal, task and environmental factors that support or inhibit children's development, participation and achievement.

OTs tend to address sensory processing issues alongside motor skills as part of a child-centred, goal-focused approach to develop the child's level of independence with day-to-day activities such as dressing, eating, toileting at home and learning activities at school.

OTs recognise that a child needs to be in the right state of alertness to be able to function and learn – mostly a 'calm and alert' state – and OTs can provide strategies to help children to increasingly achieve the right state for each situation they encounter.

Most OTs use an educational approach, providing the children, parents and school staff with the understanding of the underlying principles of sensory processing and providing lots of sensory strategies to be incorporated into the child's daily life.

Some OTs use sensory-based intervention, some use a specific approach called Ayres Sensory Integration (ASI), which requires additional qualifications, both these approaches are usually used as part of a goal-focused and occupation-centred approach

As with all OTs, for the referral to be accepted, the sensory processing difficulties need to impact significantly on the child's ability to complete their day-to-day activities and/or school work.

Most services offer parent workshops or videos with very useful information about the principles of sensory processing. This is an educational approach to make the parent become an expert, which recognises that everyday interventions by parents have the biggest impact.

Video of a child's prespective : https://www.youtube.com/watch?v=D1G5ssZIVUw&ab_channel=Easterseals-GoodwillNorthernRockyMountain

Fledglings have items that can help children with their senses:www.fledglings.org.uk/

If you prefer to find a private OT, which means you will have to pay for this yourself, you can find a directory on the website of the Royal College of Occupational Therapists for information on therapist working in your area: **www.rcotss-ip.org.uk/ ind**

What is a Sensory Diet?

This is a term used for a schedule or programme of activities to help a person to manage the demands from their sensory environment, which they may find overwhelming. The activities are usually devised to provide intense input to the proprioceptive and/or vestibular system, which are known to have a modulating (or regulating) effect. The underlying purpose is to meet the person’s sensory processing needs, and, over time, improve their sensory processing skills. It is intended to be used ‘little and often’, i.e. in short five-minute bursts several times during the school day, as well as at home. These are sometimes referred to as Sensory Breaks.

Sensory Diets are often recommended by Occupational Therapists, as a strategy towards the child accessing learning activities – they are a tool, a means to an end, not an end in themselves. However, if a child uses a sensory diet schedule, it must be followed and not withheld; **it must never be used as a reward or consequence.**

Most children, especially young children, benefit from the type of activities included in the Sensory Diet to improve attention and concentration.

Hints and tips

Many neurodiverse children and young people have difficulty processing sensory information. Any of the senses may be over- or under-responsive/sensitive, or both, at different times. These sensory differences can affect behaviour, and can have a profound effect on a person’s life.

Small changes and adaptations can be made to limit the impact of sensory processing difficulties:

General:

- Make sure that all people working with and looking after your child are aware of their issues and don’t misinterpret them. There is a wealth of information on sensory processing difficulties available on the internet, with many statutory and independent providers offering online training on sensory processing for free or for a small fee, accessible to parents, grandparents and school staff alike – knowledge is power and nurtures understanding of the child’s world.
- When a child is displaying a sensory-based behaviour, it usually meets a need for the child: it helps them to regulate and cope in the time and place they find themselves in. It usually doesn’t work to simply suppress these behaviours – they will show in other ways. If a behaviour is unsafe or undesirable/inappropriate, try and work out what sensory need is being met by it, and find a suitable replacement; however, this is sometimes easier said than done. Use the support systems around you to ask for advice. This display of sensory behaviour is often called **Stimming (Self Stimulatory Behaviour)** or stereotypies.

Touch:

- If the child is over-responsive/sensitive to touch input, ensure you cut out labels from clothing and try wearing socks inside out. There are specialist suppliers for seamless clothes, if necessary. Some children prefer tight fitting clothes, such as leggings, which move less on the skin when they move, others will prefer loose fitting clothes – you will have to experiment. One way to help a child with under/over sensitivity to touch is to warn them if you are about to touch them and always approach them from the front. If nail cutting is an issue, do it while the child is fast asleep. Many children don't like having their hair cut, since the small hairs find their way into the clothing and tickle and itch – you can try to make the hair wet before cutting so it clumps together. Alternatively, if you are cutting it, you can do it with the child sitting in the bath. It can be useful to slowly introducing different textures to touch and, if children enjoy certain touch experiences too much, you can offer suitable alternatives to smearing, such as playdough.

> **"When I wear those other itchy trousers, it's just too distracting for me to do my work."**

Sound:

- If the child is over-responsive/sensitive to sound input, you could pre-warn your child before going to noisy places. Some like to use ear defenders/head phones/ear plugs to block out some of the noise. Try to avoid peak times, if possible.

Sight:

- If the child is over-responsive to visual input, you could make changes to the environment, such as reducing fluorescent lighting, providing sunglasses and peaked caps, or using blackout curtains. At school, it may help to minimise colourful displays and to create a workstation in the classroom to minimise visual distractions.
- Most children benefit from visual support in their schedule, since they tend to find it easier to process visual information over verbal instructions; this is related to communication issues rather than sensory processing.

Smell:

- If the child's sense of smell is under-responsive/sensitive, you could help by creating a routine around regular washing and using strong-smelling products to distract your child from inappropriate strong-smelling stimuli. If they are over-responsive/sensitive to smell, you could use unscented detergents or shampoos, avoid wearing perfume, and making the environment as fragrance free as possible.

Taste:

- Some children may limit themselves to bland foods or crave very strong-tasting food. As long as someone has enough dietary variety, this isn't necessarily a problem – if they are growing, they are probably doing okay. Unlike adults, who need a fairly even amount of calories each and every day, children are able to spread their calorie intake over 4-8 days (yes, days, it's really true!). This is perfectly normal. Also, remember that eating issues may relate to the food texture rather than the taste, and therefore to the sense of touch. The child may struggle with the sensory input of two or more food textures in the mouth at the same time – which is why many children prefer to keep the components of their dinner separate, i.e. sausage on one plate, chips on another, with the beans in a separate bowl – make it happen if you can. You can get plates with separate sections, if you prefer. Many children like to have a bit of control over their food, try and get them involved 'hands on' as early as you can and as they can tolerate. A great way to expand the food range is to eat 'old fashioned family-style', with bowls of food in the middle of the table and everyone helping themselves, with no pressure to eat anything. Children are given control and see that the food is safe to eat, since you are eating it, too.

Movement sensors (vestibular and proprioceptive):

These senses are less well known and operate in the background; nonetheless, providing the right type of input to these sensory systems – and avoiding the wrong type – can have a big impact on the child. All children require movement breaks to release energy and to re-focus their concentration. Children with sensory processing differences often need this with higher frequency, duration and intensity than others; often, they are under-responsive in these senses.

- They may be un-coordinated and feel 'spaced out' since they can't tell where their body is within their environment. Lots of movement activities, such as bouncing on a trampoline, running, using playground equipment, etc. will feed into these sensory systems. Remember that all physical activities need the appropriate adult supervision to keep your child safe.
- If your child is overstimulated, avoid spinning movements, but you can try short, linear movements, such as rocking, which may calm them. Swings can provide regulating sensory input; you can do this with two adults and a blanket at home.
- Many children like being squashed and squeezed with tight hugs or rubbed in a towel after a bath. This will provide them with lots of pressure to the muscles, making them more aware by providing sensory movement input.

- ✓ Some children use chewing on clothes and pencils etc. as a strategy. Biting uses the jaw muscle, which provides lots of proprioceptive feedback, which is calming: you may have experienced it yourself, when you clench your teeth in a stressful situation to help you cope. You can offer your child crunch foods such as carrot sticks, apples and bread sticks instead, or find chewable pencil toppers and bracelets made from food-grade silicone as a safe replacement. Pica is a more extreme sensory behaviour, whereby children eat non-food items. A top tip for dealing with Pica is to make up a snack box with lots of different foods that match, in texture, the non-food that the child was eating e.g. hair is replaced with alfalfa, sand with crushed up biscuits, twigs with twiglets. Every time the child eats non-food stuff the parent / school can offer the alternative to provide the same, or similar, texture experience.

Interoception isn't as well-known as other sensory processing issues. Experts are still learning what techniques can help children who struggle with it. Some think that mindfulness activities like meditation can help children become more aware of interoceptive sensations in their bodies. Heavy work and a sensory diet may be helpful as well.

What is Sensory Overload?

Sensory overload is a term used to describe a point where the sum of all the sensory input a child/person experiences becomes too much for them to process.

The best way to avoid sensory overload is to detect early signs of it building up, such as irritability, restlessness and discomfort, and to remove/minimise the sensory input.

The National Autistic Society has made a short video to illustrate what it may feel like for a child: www.youtube.com/watch?v=aPknwW8mPAM

Section 7

Emotional Regulation

Emotional Regulation & Dysregulation

What is emotional regulation?

Emotional regulation, sometimes called self-regulation, refers to the way we deal with big feelings like anger, excitement, frustration, anxiety or low mood.

Our children can often have difficulty regulating and recognising their emotions and, if not supported, this can lead to frustration and them becoming overwhelmed.

Sometimes children will try to regulate themselves by using self-stimulatory behaviour, also known as stimming.

What is Stimming?

Stimming is short for 'self-stimulatory behaviour'. Many people use stimming as a means of regulating emotions and processing sensory information, but it tends to be more visible in neurodiverse people, as their types of stim and the frequency with which they carry them out, are deemed less socially acceptable. These used to be referred to as stereotypies.

Some examples of stims that are common to many people are:

- biting the end of a pen
- tapping your fingers or toes when agitated
- twirling hair around your fingers
- biting your lip
- talking to yourself
- stress eating.

How this might affect your child

Stimming regulates emotions and manage stressful situations. It also helps to process sensory input. It acts as a communication tool and a valve to let out excess emotion in a controlled way, whether that is excitement, fear, happiness, or anxiety. If the stimming is stopped or punished the emotions will still be within your child and will come out at a later stage, probably in a meltdown or shutdown. Therefore, stimming shouldn't be stopped or reduced, unless it becomes dangerous, e.g. head-banging or other self-harming behaviour, in which case you need to find different ways to help them release their emotions or experience the same sensory input. Sensory toys are very useful, such as chewy pencil tops, fidget cubes and squishies, that can be kept in a pocket.

If a child is stimming a lot in school, it is a good indication that they are anxious. Working with the child and the school to understand what exactly has caused the increased stimming is the best way to help your child.

Some forms of stimming have different names, for example:

- **Echolalia** - this is repetition of another person's spoken words or repeating the same word over and over again. The sounds can be comforting to your child and/or it can help your child to process the information they have been given.
- **Visual** - staring at lights; repetitive blinking, staring at spinning objects.
- **Auditory** - listening to the same song or noise on repeat, playing with their ears and clicking fingers.
- **Tactile** – touching objects, or rubbing the skin with hands, or scratching/picking at skin.
- **Taste/smell** – sniffing or licking objects or people.
- **Physical** - rocking, swinging, jumping, pacing, running, flapping hands, tip-toeing or spinning, chewing on non-food items, or grinding teeth – all of which help release pent up emotional energy and provide connection to the physical world.

> **"If you see an autistic child flapping their hands because of stress, and your first reaction is to teach them to stop flapping their hands.....what you end up with is an equally stressed autistic child, who is now growing up with one fewer method of communicating that they're stressed. Address their actual needs first. I'm surprised this is even a discussion"**

Chris Bonnello,
www.autisticnotweird.com

Further information

- **Respectfully Connected - www.respectfullyconnected.com**

Managing Emotions and Reducing Anxiety

Anxiety affects most neurodiverse children and young people: www.youtube.com/watch?v=rPD_yzMHJls

How you can help your child regulate their emotions and reduce their anxiety

1. Zones of Regulation

A complete social-emotional learning curriculum, created to teach children self-regulation and emotional control, using different colours to represent different emotions. There are often talks given on Zones of Regulation, so it is worth searching for this term on Eventbrite or Facebook. Many schools also use Zones of Regulation as a strategy so it can be helpful to have a joined-up approach between home and school - **www.zonesofregulation.com/index.html**

2. Mindfulness or yoga

Mindfulness or yoga can teach children calming techniques, which can help them to focus on how their body is feeling and in turn recognise their emotions.

- Calm - The #1 App for Meditation and Sleep - **www.calm.com**
- How to Be More Present - Headspace - **www.headspace.com/articles/how-to-be-more-present**
- Cosmic Kids Yoga - **www.youtube.com/user/CosmicKidsYoga**

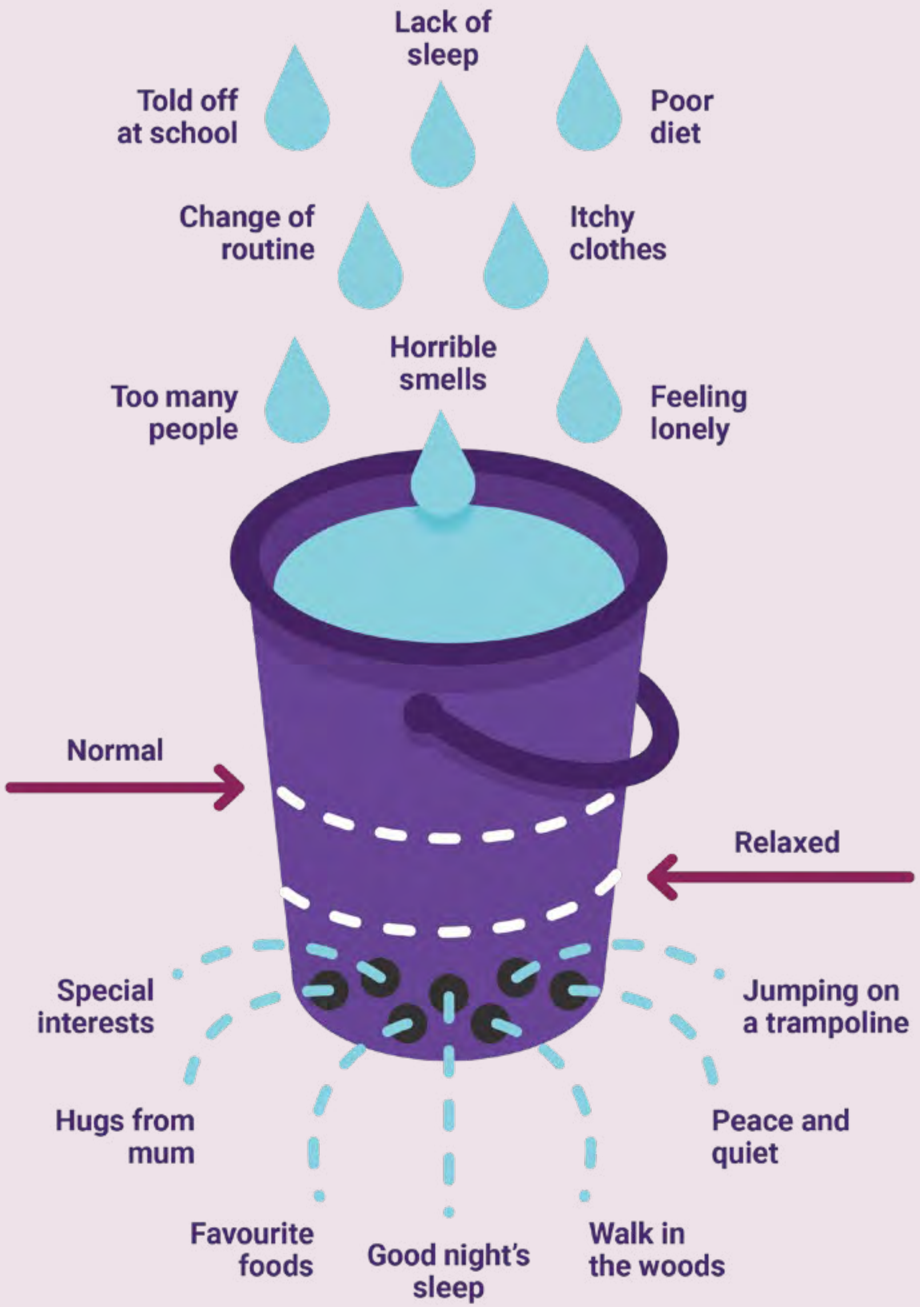
3. Reduce their overall anxiety

The stress bucket analogy - Brabban and Turkington (2002).

Anxiety is one of the most significant challenges for our children, and the stress-bucket analogy is a helpful way to think about how you can help them to manage and control their levels of anxiety in daily life. Being in a state of high anxiety is often caused by the gradual build-up of worries. A useful metaphor for understanding this is the 'stress bucket' where worries drip into it, one on top of the other, until it overflows and results in extreme anxiety and highly distressed behaviour.

A lot of people experience anxiety, but neurodiverse children are more likely to fill their 'stress bucket' at a much faster rate and more often, due to the many challenges that they experience every day. Sometimes it only needs the smallest of drops to make the bucket overflow – for example, sometimes giving your child the wrong type of cereal, or the wrong coloured cup can be enough to cause a meltdown; it isn't the cereal or cup that has caused the problem; using the analogy of the stress bucket, that is the drop that caused the bucket to overflow, or using another analogy 'the straw that broke the camel's back'.

The stress bucket analogy is a helpful way to think about how we can try to control the build-up of stress in our children's lives – for children already managing a lot of anxiety, their bucket may be close to full a lot of the time.The size of the bucket varies from person to person and can change on a day-to-day basis.



It can be helpful to spend some time with your child making two lists:

A List A) activities and things which sap energy, or create anxiety (**Filling the bucket**) e.g., going to school, brushing teeth, trying new foods, seeing relatives, socialising. These may be activities which your child enjoys, but still finds stressful, or emotionally draining.

B List B) things that replenish energy or make them happy; (**Emptying the bucket**) e.g., having quiet time alone, playing with a pet, reading a book.

You can then monitor the stressful things that have happened to your child each day and make sure they have plenty of bucket emptying activities, to help keep their anxieties under control.

Top tip

- ✓ The Molehill Mountain app has been developed in collaboration with autistic people to help them understand and self-manage anxiety, and is recommended by SET CAMHS for neurodiverse people with anxiety - **www.autistica.org.uk/molehill-mountain**

4. Give your child permission to do less or say no

You may feel that your child needs to socialise more with other children at after school clubs or playdates, but bear in mind that if your child has been at school all day long with lots of other people, for many of them that is enough socialising for one day.

You have to weigh up the benefit in terms of your child socialising, with the cost to their emotional well-being if they are too stressed out to socialise. Finding an after-school activity that is very relaxed, where they aren’t forced to join in and can mingle with other neurodiverse children might be a good compromise.

> **“My daughter was really good at gymnastics but she got so nervous before going, complaining of headaches and tummy aches, even though she loved it when she was there. The anxiety started to really impact on our lives. We discussed it with our paediatrician who suggested that we encourage her to stop or take a break. It was sad to stop doing something that she enjoyed, but it immediately lifted a huge weight, and she was more able to cope with school and other daily pressures.”**

5. Help them to move from one activity to another

If your child has difficulty stopping an activity they are enjoying it helps to give them frequent warnings that the activity is going to come to an end. You could use a visual timer but sometimes they will need more if it is something they particularly love and they may not even realise you are talking to them and giving them a countdown. In this case sit with them and ask them questions about what they are doing. This will gradually bring them out of their hyper-focused state and back into the “real world”. You can then say to them that they only have a limited amount of time left on that activity. It is a much gentler way of bringing them out of their intense focus.

If your child gets engrossed in computer games, it can help to learn a bit about the specific games your child gets obsessed with. Some games can be saved, but on-line based ones often can’t be and may instead work as separate rounds or games and involve team mates. Your child may react badly to being asked to leave an on-line game immediately as they will be letting their team down. You have to try to use the right terminology with your child when asking them to finish their game, so that they understand when to turn it off.

> **“You have to enter their world for a little while, in order to help them to leave it.”**

6. Social stories (trademarked) and comic strip conversations

Social stories were created by Carol Gray and are a useful tool to help explain a new social situation or activity in a simple, visual way, and they can be personalised to the interests of each child. They present information in a logical, literal way and help to take away some of the child's anxiety around new experiences. Dr Siobhan Timmins, based in Essex, has also written some great Social Stories and often holds talks and training events for parents.

- Social Stories - **www.carolgraysocialstories.com/social-stories**
- Helping autistic children & adults make sense of the social world - **www.siobhantimmins.uk**

Books on Managing Emotions and Anxiety

- **Avoiding Anxiety in Autistic Children: A Guide for Autistic Wellbeing** by Luke Beardon

Some very useful illustrated books have been written to help children understand and regulate their emotions:

- **The Disappointment Dragon: Learning to cope with disappointment** (for all children and dragon tamers, including those with Asperger syndrome) **by K.I. Al-Ghani**
- **The Red Beast: Controlling Anger in Children with Asperger's Syndrome by K.I. Al-Ghani**
- **The Panicosaurus: Managing Anxiety in Children Including Those with Asperger Syndrome by K.I. Al-Ghani**

Meltdowns and Distressed Behaviour

Following these hints and techniques can help to manage low level difficult behaviours and avoid your child getting to a point where they feel unable to cope.

However, the cumulative effect of the challenges of day-to-day life can lead to a child feeling overwhelmed.

Your child may:

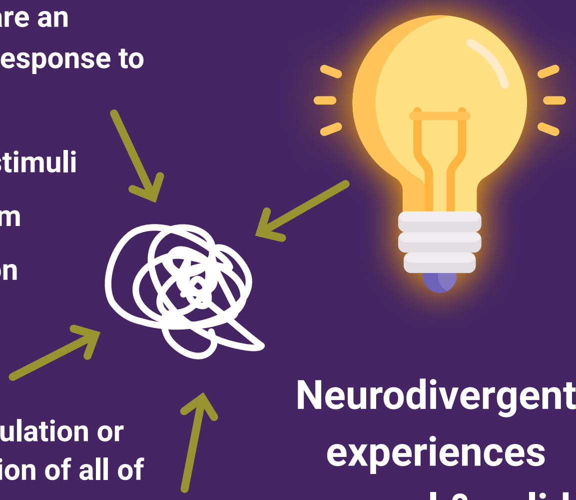
- cover their ears, close their eyes, and tuck their arms and legs in as much as possible, hide, possibly under a table or bed, bury themselves in your arms, or retreat to the corner of a room. – this can sometimes be called '**shutdown**' or '**withdrawal**' or '**freeze**';
- run and try to escape from the situation at hand...without any regard for their safety This is sometimes referred to as '**flight response**';
- kick, scream, hit, bite, spit, throw things. This can sometimes be referred to as a '**meltdown**', '**fight response**' or '**violent challenging behaviour**.'

Managing a meltdown

Tantrums vs meltdowns

Meltdowns are not tantrums. A tantrum is typically a result of frustration for not getting something that a child wants, it can occur more frequently if a child is tired, hungry or feeling unwell and usually ends when the dispute is resolved. A meltdown occurs when your child is overwhelmed and cannot control themselves. If you get cross or impose punishments your child's behaviour is likely to get worse and the meltdown/shutdown will intensify and last longer.

What does a Meltdown look like?



Meltdowns are an involuntary response to overloads

- **Sensory stimuli**
- **Overwhelm**
- **Exhaustion**
- **Anxiety**
- **Change**
- **Or accumulation or combination of all of the above**

Neurodivergent experiences are real & valid

Managing a meltdown:

- Help your child find a safe, quiet place to de-escalate, for example: “Let’s leave the busy shopping centre and sit in the car for a few minutes.”
- Provide a calm, reassuring presence without talking too much to your child. The goal is to limit sensory overload.
- Sometimes the reaction from other people can add to the stress of the situation. It can be helpful to carry awareness cards to quickly explain your child’s difficulties to by-standers: **www.autism.org.uk/shop/products/merchandise/alert-card**
- When a child is having a meltdown, they find it very hard to process and understand what you are saying and doing, so keep actions and communications short and clear and prioritise safety.
- This is not the time for a reasoned discussion – that can come later when they have calmed down.

> **“When I see my son upset I feel start to feel panicky too, especially if he is behaving dangerously towards himself or someone else – it has taken practice but I know that I have to keep calm myself and be the one to help him calm down – but once the urgency of the situation has passed, it can take hours, and sometimes days for me to really recover.”**

- Encourage deep breathing.
- If your child likes physical reassurance, give them a hug.
- Try to get them to a ‘safe place’ such as their bedroom, a dark den or other place where they feel comfortable.
- If the child responds well to swinging, encourage calming rhythmical movement.

After a meltdown

- After a child has had a meltdown, they are likely to feel exhausted – give them time and space to calm down. The feeling of losing control can be traumatic for children – this may leave them feeling embarrassed or scared. You might be feeling embarrassed, scared, angry, or anxious too – so be sure to give yourself some quiet time to decompress.
- When your child is feeling better, follow up with a sensory activity that you know they will find calming, for example:
- Heavy hard work such as pushing a wheelbarrow or shopping trolley;
- Resistive sucking/blowing/chewing...such as blowing bubbles or eating a chewy snack or sucking a smoothie through a straw;
- Continue to keep the environment quiet and calm for a while.
- Also recognise that you may be feeling upset and exhausted after supporting your child through a meltdown. When you can, take some time for yourself to recover.

Facts & tips

Reduce stimulus in environment

Reduce bright lights

Remove triggers

Reduce volume

Reduce speech

Adopt a positive & calm tone

It is important to respect & support a person in meltdown mode.

- **Do not punish**
- **Do not impose consequences**
- **Do not judge**

Reduce eye contact

Ensure safety of the person & yourself

Give space

Intervene only if imminent danger (eg traffic)

Do not touch or restrain

Positive praise and compliments

A compliment to some neurodiverse children can make them self-conscious, particularly if they are socially anxious. They may:

- Receive a compliment and perceive it as a demand.
- Imagine that everyone is looking at them or judging whether they deserve the praise or reward.
- Not know how to respond to a compliment or praise.
- Freeze when they receive praise because they do not know what to say

Top tips

- ✓ If you know that your child does not like to be recognised publicly, they may prefer private compliments or a note or a nonverbal cue like a thumbs up.
- ✓ Tell your child that a compliment or praise is like a gift. Teach them that the best way to respond can be simply to say ‘Thank you’ and smile.

> **“My child struggles with this. He explained that saying ‘you are amazing’ made him feel pressured to live up to the expectations.”**

Remember all neurodiverse children are different and some may love praise and thrive on it!

Distressed behaviour

For all the reasons covered throughout this information pack, neurodiverse children and young people may be unable to communicate their needs or feel overwhelmed.

In these situations, they may display behaviour that puts themselves, or someone else, at risk. This is commonly known as a 'behaviour that challenges' or 'distressed behaviour'. Common examples include:

- Physically challenging behaviours - such as hitting, biting, spitting, or pulling hair.
- Emotionally challenging behaviours - aggressive shouting, anger or using unkind language.
- Self-injurious behaviour - behaviour that may harm them, such as head-banging, picking scabs, punching walls, biting hands or arms.
- Pica - which means eating things other than food. This can become dangerous if someone eats potentially toxic or sharp objects.
- Smearing - when young child or person smears their poo on walls or objects.
- Pathological demand avoidance (PDA) - this is a behaviour profile within the autism spectrum that is characterised by resistance to everyday demands. What constitutes a demand can look different to every individual.

"I feel like going down into a hole and staying there!"

Strategies to try:

- Rule out any medical causes.
- Keep a behaviour diary and making notes on any links to environment or particular events.
- Refer to the information in this section of meltdowns and sensory overload for lots of hints and tips.
- It can be very upsetting when your child exhibits distressed behaviour, especially if it is directed towards you. Try to give yourself time and space to recover.

Further information

- **www.yvonnenewbold.com**
- How Collaborative and Proactive Solutions Changed My Family - **www.neuroclastic.com/how-collaborative-and-proactive-solutions-changed-my-family-2/**
- Meltdowns and shutdowns - **www.ambitiousaboutautism.org.uk/information-about-autism/behaviour/meltdowns-and-shutdowns**
- **Peterborough SEND Information Hub https://fis.peterborough.gov.uk/kb5/peterborough/directory/service.page?id=ieu2KYigGXk**

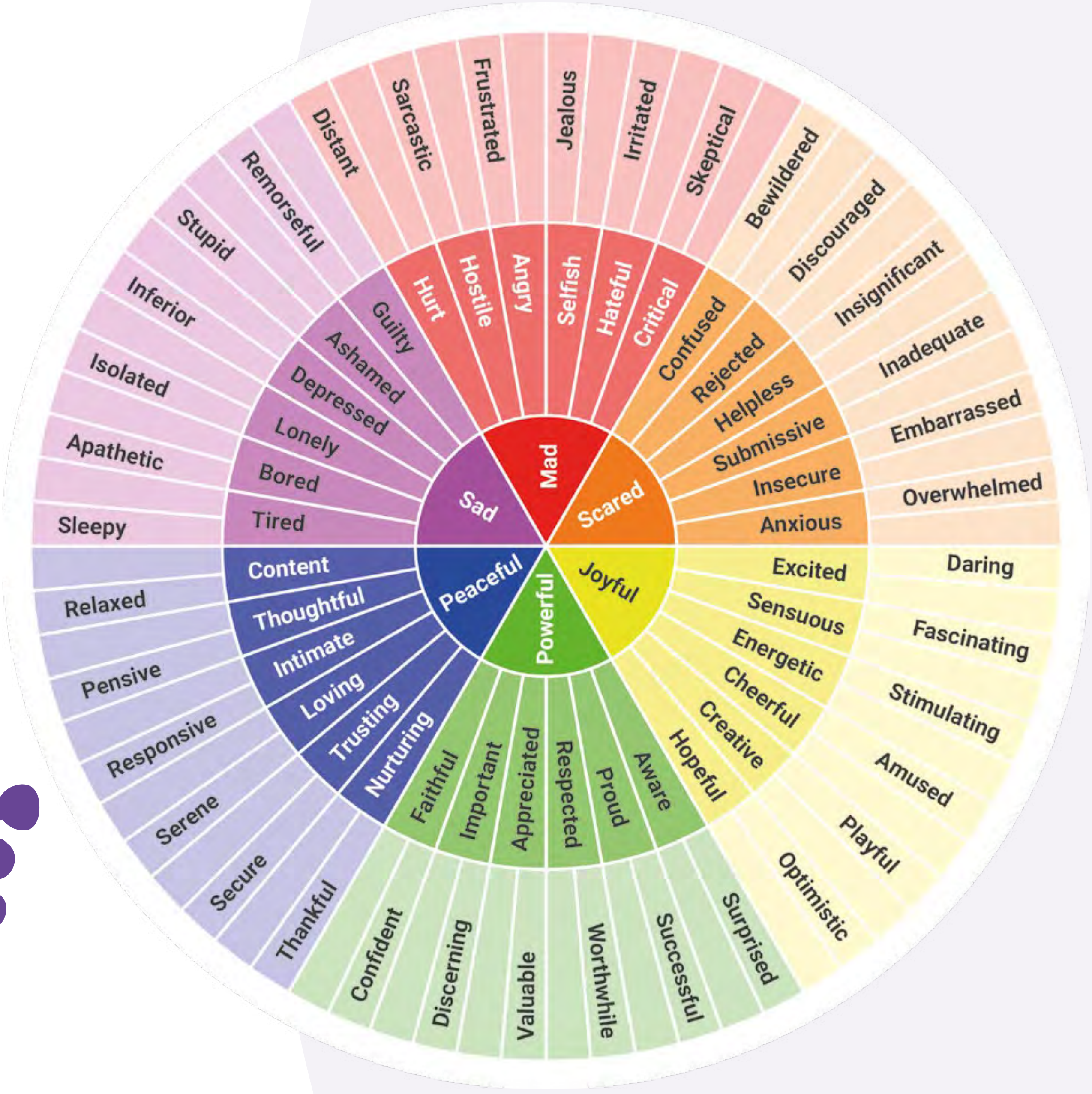
broken glass for the last 2 days - pictures being thrown down the stairs and walls punched. We have only just had our walls replastered from the last time!"

The wheel of emotions

American psychologist Dr. Robert Plutchik studied emotions and proposed that there are eight primary emotions that serve as the foundation for all others: joy, sadness, acceptance, disgust, fear, anger, surprise, and anticipation. (Pollack, 2016).

The wheel of emotions can help you identify which emotions you are experiencing in a precise way. Labelling, identifying, and recognising feelings can reduce confusion and uncertainty for neurodiverse people. It can also help you make sense of a stressful situation and start to understand it.

For neurodiverse children, young people and even adults, knowing what you are feeling is incredibly empowering. We can start to accept our emotions as they come, instead of suppressing or rejecting them.



What next?

- ✓ Learn to listen to what your child's emotions are telling you.
- ✓ Be patient with your child.
- ✓ Learn to understand why they are feeling this way.
- ✓ Learn how to accept negative emotions. Validate their emotions.
- ✓ Use strategies in **Section 5** Managing Difficulties with Communication, Sensory Issues and Emotional Regulation.

We hope this may help your child or young person identify their feelings and whether it is emotional or sensory (see the **Sensory Processing** section)

For more information find American psychologist Dr. Robert Plutchik studied emotions and devised the Emotional Wheel (Pollack, 2016)

"It may sound simple, but labelling your emotions can have a positive effect on the power that they have over you, because then you know what you're facing and whether they are an enemy or friend. When you know what you're facing, you can learn how to respond. When you are somewhere on the spectrum of anger, you know to take a "time out," or find a quiet spot to cool down. When you are anxious, you know to practice meditation or grounding. Overwhelming things tend to be so much less overwhelming when you've figured out a strategy or a plan to respond to them."

"we use the emotions wheel at home with my older child. It's a useful tool to help manage his emotions by learning to identify them."

Section 8

Health and Wellbeing

Diet and Exercise

There are a variety of issues that can stem from a poor diet, and lack of exercise, ranging from temporary problems like increased inattention, tiredness etc. to serious conditions like diabetes and food disorders.

For a number of reasons, neurodiverse children are more likely to experience gastro-intestinal issues:

- Their brain might not correctly interpret messages from their gut about being hungry or thirsty.
- Your child may be so engrossed in what they are doing that they forget to eat or drink.
- Those with sensory issues relating to food may have a restricted diet.
- The symptoms of Irritable Bowel Syndrome (IBS) can be exacerbated during times of high anxiety.

Further information

- **Constipation, Witholding, Overflow - Bowel Problems & Autism (https://autismawarenesscentre.com/constipation-witholding-and-overflow-a-deeper-dive-into-bowel-problems-for-individuals-with-asd/)**

Hints and Tips

- ✓ Exercising can help children to regulate their emotions, manage weight, improve self-esteem and better engage in the environment around them.
- ✓ It is not always easy to provide your child with the recommended mix of food types, vitamins and minerals; you can consider offering multivitamin supplements.
- ✓ It can be useful to keep a food diary to keep track of what is being eaten each day and noting if there is a change in behaviour or mood when certain food or drinks are consumed.
- ✓ Some parents report that a gluten free diet works for their child, whilst others have tried and say it makes no difference. Remember, everyone is different and what works for one, will not necessarily work for anyone else. In the first instance seek advice from your GP or Health visitor and discuss any concerns about potential allergies or food intolerances.

- ✓ Set regular times for food and drink breaks and remind your child to take a snack if they don't recognise the need themselves.
- ✓ If your child needs reminding to drink or eat at home, make sure you include this in any One Plan/SEND Support/ Individual Education Plan/Learning Passport or EHCP documentation, so that snack breaks can be incorporated into the school day.
- ✓ Let children explore the texture of food with their fingers so it isn't a surprise when they put food in their mouth.
- ✓ Ask your child to help prepare food. This can help them to feel more included in mealtimes and if they engage their other senses, for example smelling the raw ingredients, kneading dough etc. they may be more prepared to try what they have made. Helping can also equip them with other useful skills such as planning, safety etc. as well as helping to regulate senses.
- ✓ Exercise can be difficult for some neurodiverse children, particularly if they have dyspraxia and have poor co-ordination, or if they have had a bad experience such as being selected last for a team in PE at school. If they dislike team sports, try swimming, trampolining or even going for a family walk. Everyone has different preferences and all exercise is good!

ARFID (Avoidant Restrictive Food Intake Disorder)

ARFID is a serious eating condition where food consumption is restricted or avoided altogether. ARFID is diagnosed either by a paediatrician or multi-disciplinary team assessment

It is more common for neurodiverse children and young people and there are 3 types:

1. **Avoidant ARFID** - certain foods are excluded because of sensory issues such as smell, taste or texture
2. **Aversive ARFID** - eating all or certain foods is distressing, normally because of an event such as choking, illness or pain associated with that food.
3. Restricted ARFID - little-to-no interest in food. They may forget to eat, have a low appetite, exhibit extreme pickiness, or regularly get distracted during mealtime.

Behavioural symptoms

- Fear of eating – anxiety around meal times
- Refusal to eat some or all food
- Difficulty eating in front of others
- No or very reduced appetite
- Forgetting to eat
- Limited number of foods that your child will eat

Physical symptoms

- Delayed growth against expectations
- Stomach complaints
- Vomiting, choking or gagging when eating

What professional help is available?

If you have concerns, speak to your GP or health visitor, who may refer you to a dietician, a sensory feeding workshop for parents or in some areas FAST (Feeding & Swallowing Team) nutritionist Children's feeding and swallowing- BSBWTK | NELFT NHS Foundation Trust (**www.nelft.nhs.uk/services-childrens-dietetic-resources**)

Useful links

- National Autistic Society advice - Supporting autistic people with eating difficulties (**https://www.autism.org.uk/advice-and-guidance/professional-practice/autism-eating**)
- Advice to help teens try new food - **https://youngwomenshealth.org/wp-content/uploads/2018/09/Food-Chaining-for-ARFID.pdf**
- Understanding picky eaters vs problem feeders - **https://www.spdstar.org/sites/default/files/file-attachments/Picky%20Eaters%20vs%20Problem%20Feeders_2.pdf**
- Practical strategies for picky eating - Extreme Picky Eating Help (**https://www.extremepickyeating.com**)

“Through concerns about my son’s eating and weight loss I was referred through the GP to the Feeding and Swallowing Team. (FAST) They worked out that he had acid reflux, prescribed meds, concluded he had no swallowing issues and that his food selection and reduction was based on his sensory issues plus common autism trait of feeling that certain foods were only “safe” in certain environments. He was then referred to a nutritionist who asked me to keep a food diary for a week. He checked that my son was getting something from each food group, said calories were more important than content if he was reducing intake (which is linked to stress). Keep an eye on food groups and come back if he drops a group entirely. We get him involved with choosing food etc. but he has to first see it outside of meal time, at a time which is not food time, he then touches and plays with it. Then it will be offered on a side plate near him at a future mealtime, but never next to his food. No fuss, no commenting, which yes is really hard. He still has his food separated on different plates and bowls. He’s 9.”

Pica

Pica is the eating of non-food items, such as dirt, plaster from walls or sticks. It is usually a sensory need, rather than an actual desire to eat non-food items. The child often wants the sensory feedback from crunching or chewing, not the taste of the non-food.

Top tip

- ✓ Make up a snack box with lots of different foods that match in texture the food that the child is eating. E.g., hair replaced with alfalfa, sand with crushed up biscuits, twigs with twiglets. Every time the child eats non-food stuff the parent / school can offer the alternative to provide the same, or similar, texture experience.

Useful links

- Pica - Beat (**https://www.beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/types/other-eating-feeding-problems/pica/**)

“My daughter is autistic and non-verbal and has an eating disorder, severe selective eating, and Pica, which is eating non edibles. I would say Pica is one of the harder aspects of her autism as she eats the plaster on her bedroom walls and the 3 beds we had for her, and the wood frames. We now have a softplay bed and are getting her room made safe with softplay material on the walls. Our garden is also out of use for the time being as she eats the plants, leaves and berries, so we are hoping to remove all plants and trees so there would be just grass and patio.”

Did you know...

that anyone aged 14 or over, with a learning disability, is entitled to an annual health check with their GP? Learning disabilities - Annual health checks - NHS (www.nhs.uk/conditions/learning-disabilities/annual-health-checks)

Mental Health

Feelings of anxiety are entirely normal and all children will benefit from support to help them manage their feelings and worries from time to time.

However, neurodiverse young people are more likely to experience feelings of anxiety, depression, burn-out and low self-esteem, so may need additional specialist support.

The National Autistic Society undertook a study of **130 young people with autism and found that 80% reported concerns with their mental health**, partly as a result of the pressure to act 'normal' in a neurotypical world.

If you have any concerns about your child's mental health, consider that the earlier on that any issues are identified, the quicker support can be accessed and this can often stop problems from escalating and becoming more serious. Speak to your GP if you become worried about your child.

There is also an increased focus on mental health in schools and work is underway to increase resources, training and information available, so speak to your child's teacher or SENCO as soon as you have any concerns and they may be able to refer them for help with mental health support, which can sometimes be offered at school.

Whilst not directly helping your child, you can help to educate the community around you to help promote inclusion - educate everyone you meet about neurodiversity! The more that people understand that it is a neurological difference, rather than something to be ashamed of, or that needs to be cured, the more accepting they will become.

Understanding the reasons for our children's difficulties can help us to find ways to provide the right support. Below is a brief overview of the more common mental health difficulties, some of which you may not have heard of – see the further information at the end of this section for where you can go for help.

Anxiety

Anxiety is commonly talked about as feeling worried or afraid and is how we feel when we are feeling out of control or threatened. High anxiety can lead to feelings of panic and panic attacks. Unsupported, high anxiety over a period of time can lead to chronic stress or autistic burnout. Please see **Section 7** for further information about anxiety, its causes and tips to help.

Autistic Burnout/Depression

Some autistic people experience this as an overwhelming sense of physical exhaustion. They may have more difficulty managing their emotions than usual and be prone to outbursts of sadness or anger. Burnout may manifest as intense anxiety or contribute to depression. It may involve an increase in autism traits such as repetitive behaviors, increased sensitivity to sensory input or difficulty with change.

Autistic burnout, explained | Spectrum | Autism Research News (https://www.spectrumnews.org/news/autistic-burnout-explained/)

Body Dysmorphia

Body Dysmorphia is high anxiety about body image and can lead to obsessional and compulsive behaviours to do with appearance.

What is body dysmorphic disorder (BDD)? | Mind, the mental health charity - help for mental health problems (www.mind.org.uk/information-support/types-of-mental-health-problems/body-dysmorphic-disorder-bdd/about-bdd/)

Eating Disorders

Eating Disorders are more than simply problems with eating (as described in the section on diet and exercise above) and are diagnosable medical conditions. Other mental health conditions may manifest through a relationship with food. For example; anorexia nervosa – trying to keep weight very low by eating less or over-exercising; and bulimia, which is binge eating and then making yourself sick because of the fear of gaining weight.

Atypical anorexia: Facing an eating disorder, Autistically by Reframing Autism (https://reframingautism.org.au/atypical-anorexia-facing-an-eating-disorder-autistically/)

Low Self-Esteem

This is the way that we view and value ourselves. It can be impacted by any other mental health conditions but is also common where children perceive that they are different to others, or have difficulty with common tasks – so it is very common for neurodiverse children to have low self-esteem.

Most Effective Ways to Build Self-Esteem in Kids with Autism (https://inclusive-solutions.com/blog/most-effective-ways-to-build-self-esteem-in-kids-with-autism/)

Rejection Sensitive Dysphoria

Being rejected by friends or family is a difficult experience for anyone to deal with, but most people have instinctive ways to help them deal with the sadness and pain. Autistic people and those with ADHD may not have those in-built coping mechanisms and in these situations of rejection, may feel overwhelmed by the loss of social support and the impact on their self-esteem and resilience. This can build up over time, resulting in the neurodiverse child reacting badly to any perceived criticism.

This article from ADDitiude Magazine gives a great overview: **What Is Rejection Sensitive Dysphoria? ADHD and Emotional Dysregulation (https://www.additudemag.com/rejection-sensitive-dysphoria-adhd-emotional-dysregulation/)**

Self-Harm

Deliberately harming/injuring yourself.

Autism and self-harm https://www.autism.org.uk/advice-and-guidance/professional-practice/self-harm

Trauma (PTSD)

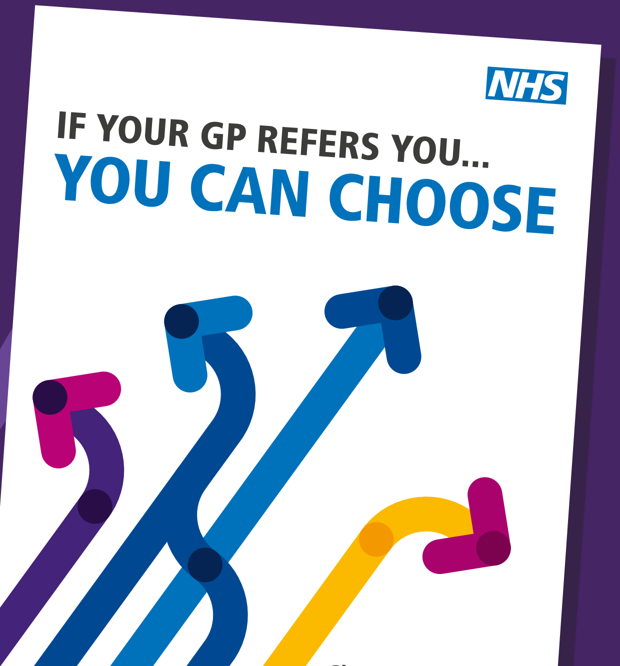
Going through stressful, frightening or distressing events can cause trauma and long-term harm.

The link between autism & PTSD | Embrace Autism (https://embrace-autism.com/the-link-between-autism-and-ptsd/)

What professional help is available?

You can talk to your GP, paediatrician or self- refer to a specialist mental health service if you believe that is what your child needs.

There is often a wait to access the help that they provide, so consider approaching these services as soon as you have any concerns. Don't forget that you can request a specific service provider (especially if your child needs to see someone urgently) using your Patient Choice rights, which are outlined in the nhs patient choice leaflet (**https://www.nhs.uk/NHSEngland/patient-choice/Documents/patient-choice-leaflet.pdf**) with more detailed information available here The NHS Choice Framework: what choices are available to me in the NHS? - GOV.UK (**https://www.gov.uk/government/publications/the-nhs-choice-framework/the-nhs-choice-framework-what-choices-are-available-to-me-in-the-nhs**)



IF YOUR GP REFERS YOU...

YOU CAN CHOOSE

Cambridgeshire's Children's and Adults Mental Health (CAMH) Service

This is a free National Health service is for anybody aged between 0 -18 and 18+. The service is also for young people with special educational needs (SEN) up to the age of 25. In Cambridgeshire its call the Younited Service. https://www.cpft.nhs.uk/younited/

Your child may be referred to CAMHS by your doctor if they have one or more of the symptoms listed below:

- Mood and anxiety disorders
- Behavioural and conduct disorders
- Emerging personality and attachment disorders
- Eating disorders
- Psychotic disorders
- Deliberate self-harm and suicidal thoughts
- Substance misuse
- Autistic spectrum disorder (ASD)
- Attention-deficit hyperactivity disorder (ADHD)
- Neurodevelopmental disorders
- Prolonged bereavement problems

Keep Your Head

www. keep-your-head.com/

All of Peterborough's mental health services in one place

What if you have difficulties accessing help?

For many neurodiverse children, their social, communication and other difficulties can mean that traditional strategies such as talking therapies and group therapy sessions are less suitable, so it is helpful to know that other information, strategies and groups are available.

- Mental health of people with autism | Mind (**https://www.mind.org.uk/about-us/our-policy-work/equality-and-human-rights/mental-health-and-autism/**)
- Mental health in young autistic people (**https://www.autism.org.uk/advice-and-guidance/professional-practice/mental-health-young**)
- ADHD and mental health - ADHD Aware (**https://adhdaware.org.uk/what-is-adhd/adhd-and-mental-health/**)
- Book - **The Guide to Good Mental Health on the Autism Spectrum** by Emma Goodall and Jane Nugent

If you are finding it difficult to access services like mental health support and your child has continuing care or an EHCP, you can request a Personal Health Care Budget. This enables your Clinical Commissioning Group (CCG) to identify private services that fill a gap and can meet your child's SEND needs.

What is a personal health budget?

https://www.nhs.uk/nhs-services/help-with-health-costs/what-is-a-personal-health-budget/

The NHS guidelines provide useful information for families and professionals.

NHS England - Personal health budgets for people with a learning disability or autism or both https://www.england.nhs.uk/personal-health-budgets/personal-health-budgets-for-people-with-learning-disabilities/

Further Information

- The NHS have produced an A-Z of charities who can support with mental health issues - **https://www.nhs.uk/mental-health/nhs-voluntary-charity-services/charity-and-voluntary-services/get-help-from-mental-health-helplines/**

Looking after yourself

How long can you hold a cup of coffee at shoulder height? Answer – it doesn't matter how long, if you take regular short breaks you will be able to hold it much longer.

Most parents and carers find it hard to make time for themselves, but to be able to support everyone else in the family, you need to keep well and resilient yourself.

This can be especially hard if you are juggling the support you need to give your child alongside numerous appointments, work and other family commitments.

Often, we make time for everyone else at the expense of doing things that we enjoy, or which can help us to manage our own stress to keep healthy. We feel guilty taking time for ourselves when there are so many other pressures – and often that can take the joy from activities, even if we manage to do them!

> **"It used to really annoy me when family members would say that I needed to take time for myself – how? But actually, I realised that if I got up 15 minutes earlier and had that quiet time to start the day, then I was in a much better position to cope with whatever happened next."**

Be kind to yourself

Before thinking about what you can do, it is worth thinking about your mindset towards yourself. There are numerous self-care and self-help books available, but some common advice is to recognise our own importance and treat ourselves in the same way that we would advise a friend in a similar situation.

Recommended reading

- **Self-compassion** by Kristen Neff
- **Day by Day: Emotional Wellbeing in Parents of Disabled Children** by Joanna Griffin

> **“‘I find that I feel guilty a lot of the time – whatever I do I can only think about the other things that aren’t getting done. I know this isn’t healthy and I am starting to notice when I do it and try to be kind to myself and take a minute to acknowledge that I’m doing my best.”**

Things you can do:

Reduce the pressure on yourself

If you don’t want to do something, give yourself permission to say no. Or if you are tired and need to duck out of plans then that is ok. Friends will understand.

“Just deleting the Facebook app felt very liberating!”

Social media

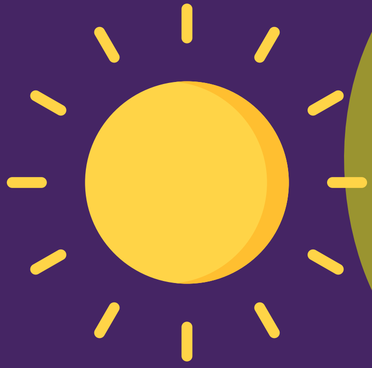
Social media can be full of false pictures of domestic harmony - and this can be difficult to keep seeing if you are going through a difficult time yourself. Equally, sometimes the feed can seem overwhelmingly sad and difficult. It is ok to take a break – or to switch off altogether. If you explain to friends that you are doing it then they will find another way to contact you if needed.

Friends

Spend time with the friends who make you happy; that you feel comfortable around with your child and with whom you can be yourself.

Be present

It’s a skill that you need to learn, but if you can focus on the current moment, then it can help you to manage anxiety about the future. There are lots of great resources available – many of which are free. **Headspace How to Be More Present** (**www.headspace.com/articles/how-to-be-more-present**) is a subscription service but does include some useful sessions which are free.



“I volunteered to take the rubbish to the skip. The queue was huge and I sat for 30 minutes – but it was so calm and I really enjoyed just listening to music on the radio by myself with the sun on my face!”

Find something that you enjoy doing

Many activities claim health benefits which can help you to decompress and de-stress. We have listed some ideas below but it doesn't matter what it is - as long as you enjoy doing it!

> **"I love ironing because it's my one time in the week that I get to choose what is on TV."**

Physical

- Sleep
- Walking
- Group exercise
- Running
- Nutrition
- Yoga
- Mediation

Emotional

- Listening to music
- Learning new skills
- Journaling
- Therapy
- Reading

Hobbies

- Making things - to eat, to wear, to look at
- Spending time in nature
- Seeing friends
- Pets

Further Support

If you are a carer you are entitled to a free carers assessment www.caringtogether.org/help-advice/carers-assessment/

- **Caring Together** an offer you practical advice, support www.caringtogether.org/

- Cambiridgeshire's online carers directory: www.caringtogether.org/carers-directory/

A Carers Card enables you to let someone know you are a carer and can help in emergency situations: www.caringtogether.org/support-for-carers/adult-carers/carers-card/

.

Section 9

Growing Up

Tween and Teenage Years

Our children can often find the teenage stage an extremely difficult time.

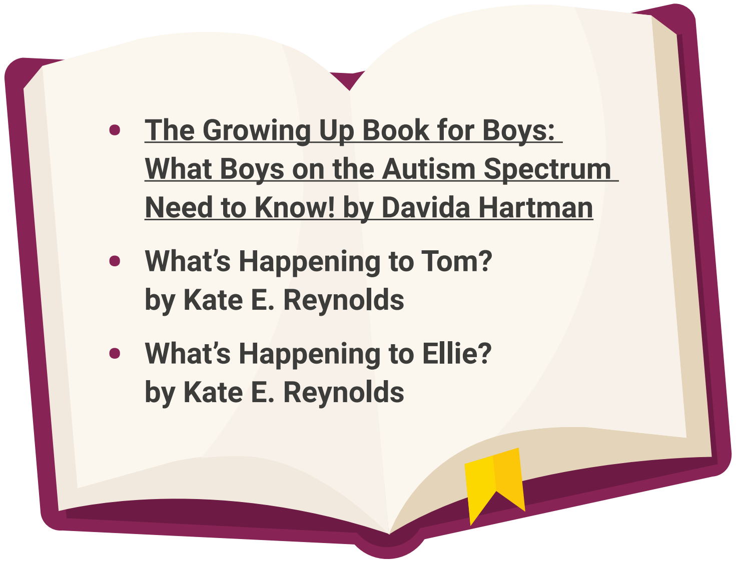
- They often struggle to interpret or engage in more complex relationships with their peers. Friendships from primary school can begin to falter as they change school and undergo puberty.
- At home, our children may still need help with daily activities even though they desire independence.
- **And**, demands are increased as they move to secondary school.

Preparing for Puberty

Puberty is a time of physical change which many of our children find difficult and some will not want to accept that it will happen to them at all.

You will best know how and when to approach discussions about how their body will change as they get older.

It can be beneficial to normalise it by talking about changes from as young an age as possible. You don't need to mention sex but can start to point out that as they get older they will get taller, hairier and their body will change. You can add more detail as they mature. You could introduce the topic by showing them that most things change over time, including plants and pets. Point out that the change is a slow process, so they aren't scared that they will wake up one day and discover that they have turned into an adult overnight!



- **The Growing Up Book for Boys: What Boys on the Autism Spectrum Need to Know! by Davida Hartman**
- **What's Happening to Tom? by Kate E. Reynolds**
- **What's Happening to Ellie? by Kate E. Reynolds**

Some children will, point blank, refuse to discuss the subject, and in these cases it can help to leave an age-appropriate book lying about the house which might make them curious!

"My daughter absolutely refused to talk to me about growing up, whenever I approached the subject she became angry and upset. I bought a book and left it in her room and noticed that she had been reading it. I also told her that she could text me if there were things that she found too difficult to talk to me about, and when her periods started she did this and it worked really well for us."

Periods

Top tips

- ✓ Try and establish a way to talk to your daughter about what will happen;
- ✓ Prepare an emergency period pack for school, as periods are often irregular and unpredictable and it will give your daughter peace of mind to have everything to hand. To avoid embarrassment, try to make the pack as small and discreet as possible.
- ✓ Liaise with the school and consider asking for a toilet card that they can show the teacher, to allow them to leave class.

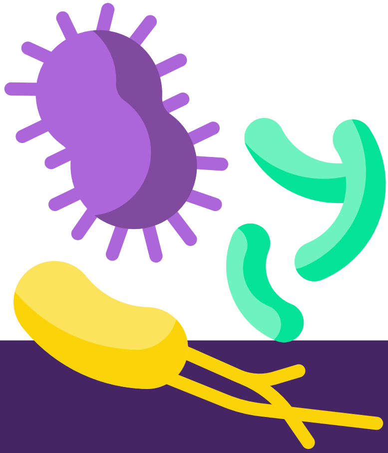
Lots of sensory issues can be triggered by sanitary products. It is worth trying out a variety of products. A growing number of parents are recommending period pants, so they are definitely worth a try.

Further information

- The Autism-Friendly Guide to Periods by Robyn Steward

Personal Hygiene

Developing self-care skills such as shaving and personal hygiene can be difficult and sensory differences can make these tasks uncomfortable. Many may have to be convinced of the need to develop good personal hygiene habits!



Top tips

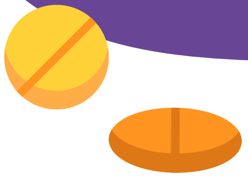
- If deodorant from an aerosol is too much of a shock on the skin, try a roll-on.
- Triggers - Try to identify triggers that may be causing problems, for example you may need to change a shampoo or shower gel brand.
- Involve your child in selecting their own toiletries, finding textures and smells that they like, or which are unperfumed.
- Tell them how important it is to keep clean – you can use their special interest to help with this – e.g., if they like logic and fact then explain how bacteria can be harmful. If they are sociable, tell them other people may not want to be around them if they smell unpleasant.

- If your child does not like the sensation of water on their skin in the shower, encourage them to take a bath.
- If you use a visual timetable or break down hygiene tasks for your child, (refer to the section on day to day life) remember to update this to include the additional tasks that will need to be included as they are growing up.

Issues with Medication

It's quite common for teenagers to push back against taking prescribed medication – for a number of reasons; they don't like being told what to do, don't like being seen to be different, are in denial about their condition or don't like the side-effects. Keep an eye out for this as it can be dangerous to suddenly stop some medications. It is important to be sure your child understands and accepts their diagnosis. Explain to them why the medication works but validate their feelings about taking it. You could talk to your GP/paediatrician to find out if a medication "holiday" would be possible so that you and your teen can assess the impact or see if a different medication may work better and have fewer undesirable side-effects.

"It was a heartbreaking time for me, watching my teen struggle in school and missing career opportunities as he exercised his right to not want to take medication. After being off the meds for a while he realised the benefit."



Finding a place in the world and developing relationships

For children who already find social situations difficult, there are additional challenges as they grow up and become more independent, and you aren't around as much to support them. They may:

- Prefer to spend time on their own, rather than with their peers and family.
- Have trouble understanding the social rules of teenage friendships.
- Make social mistakes like invading personal space and getting too close to others.
- Have trouble relating to children of their own age, preferring to spend time with younger children or adults.
- Give in to peer pressure without realising the consequences.
- Become a target of bullying due to poor social and communication skills.
- They may not understand what is acceptable 'banter' or teasing and what can be construed as inappropriate sexual or racist language, and what they should not accept being said to them.
- The 'dating game' can also be hard to interpret, and they may not always pick up on cues or misinterpret them.

Health education, including learning about relationships (for primary children) and relationships and sex education (for secondary pupils) is statutory in schools so young people at school should be receiving lessons that are age appropriate and differentiated. The sex education forum has lots of useful resources which you may find helpful, particularly if your child does not attend school.

Useful resources

- **www.sexeducationforum.org.uk**
- **www.dhiverse.org.uk/**

Ideas to help your tween/teen

- ✓ Give them their own space but try to ensure they don't retreat from family life altogether. Set aside some time together every week to do something fun and relaxing. Make sure you involve your child in the planning. You could even set a budget and let them organise the whole thing, to help with their executive functioning skills.
- ✓ To encourage your teen to talk to you, sometimes it's easier to talk to them while they are engaging in an activity they enjoy, like walking the dog, or speaking to them while you are driving in the car, this way the focus is not on them, and they aren't having to make eye contact.
- ✓ Pick your battles - take a stand on the important issues. Recognise and be alert to the important risks for teenagers, for example, internet use, social media or peer pressure – but be prepared to compromise on matters that are less important. This can help to show your child that you value their opinion and what they want to do.
- ✓ Allow them to make mistakes and help them to learn from them. Teenagers have to learn about the consequences of their behaviour - this is the beginning of learning adult responsibility. However, a neurodiverse teenager may make more mistakes before the lessons are learned so may need additional support.

"On the rare occasion that your teen comes to you to talk, drop everything to spend time with them."

- ✓ Use lots praise and try not to criticise every little thing they do wrong, as many of our children already have low self-esteem. Some children dislike being singled out and given praise, often because they don't feel they deserve it.
- ✓ Try and find clubs where there are other neurodiverse teenagers or find opportunities for them to volunteer to help build confidence.
- ✓ Find out if there is a Neurodiverse or Autistic Pride event near you and if they would like it, take them along.
- ✓ For those that like gaming, invite other teens they play on-line games with to your house for a gaming night.
- ✓ Encourage them to follow young neurodiverse bloggers/writers on social media to increase their exposure to positive role models.
- ✓ It is an important part of growing up for your child to make their own friendship choices. Your son or daughter might have experienced difficulties making friends in the past, therefore, support them now by encouraging friendships and helping them to maintain them. Accept their friends but be aware that your child may be easily led or taken advantage of, so get to know the people they are mixing with.

- ✓ Support their independence. This might be hard for us as parents, but it is essential that you raise your child to become as independent as possible. You can try:
    - ✓ Giving your child a role or a regular job;
    - ✓ Reducing the instructions you give;
    - ✓ Providing time and space for your teenager to work out how to do the task for themselves.

  Whatever the result of this, recognise the effort.
- ✓ Respect their privacy. Every teenager needs their own space.
- ✓ Do not punish the behaviour you want to see.

> **“I have made a really conscious effort to change my behaviour towards my son. It’s so tempting to still be annoyed or sarcastic when you ask 10 times for him to do something and he finally does! I used to say ‘thanks for joining us finally’ or when he finally brings down the plates from his room, I’d say ‘Great, I’ve only asked you 5 times to do that!’ But changing the way that I speak to him and encouraging him when he does do something positive has made him a lot less resentful towards me and keener to help. He said ‘I felt I was being punished when I didn’t do something, and would then be punished again when I did. I felt that I couldn’t win. ”**

Developing a positive identity

- For many neurodiverse children, emotional development and regulation can be delayed by two or three years, and doesn’t tend to even out until their 20’s. However, being a little emotionally immature doesn’t affect intelligence.
- Growing up, neurodiverse children may be criticised and have a sense of not fitting in. As a result shame often forms a large part of their upbringing and can affect their self-image and self-esteem.

What you can do to help:

- Assume competence. Many parents worry about their children but it can help their esteem and confidence if you start from a place of thinking that your child can do something. You may find that what you assumed they couldn’t do, they actually can, but in a way you wouldn’t have thought of.
- It is important that they develop an understanding of why they may behave a certain way and you can support them in learning how to explain their neurodiversity to other people. This may help reduce feelings of shame for being the person that they are.
- Having a strong personal identity and feeling proud of who you are is one of the key factors that can help protect a child’s mental wellbeing and develop resilience.
- Emphasise the positives and the things that they can do instead of the things that they find difficult.

Neurodiversity and LGBTQIA+

(Lesbian, Gay, Bi-Sexual, Transgender, Queer/ Questioning, Intersex, Asexual +anyone who doesn't feel they fit into the previous descriptions)

According to a number of studies (www.sparkforautism.org/discover_article/autism-lgbtq-identity/) neurodiverse people are 2-3 times more likely to be LGBTQIA+ and this figure is higher amongst females than males.

Throughout their childhood, it is important to understand your child and to create an environment where they can talk to you about difficult topics so that you can help. If they don't find it easy to discuss, it doesn't mean that you have failed, it's just that this can often be a difficult topic for young people.

It is worth doing a bit of research to be informed, so that if your child has questions you are able to discuss this with them.

> **"If you teach your children nothing else, please teach them that who they are is good enough and worthy of love. Teach them that no matter what the bullies say, the world has a place for them just as they are. Teach them about different identities and why it's okay to not fit in with the mainstream. Most importantly, teach them to love themselves"**

by David Gray-Hammond **(www.rainbowaim.com/2021/02/11/a-world-full-of-bullies-being-autistic-and-lgbtqia)**

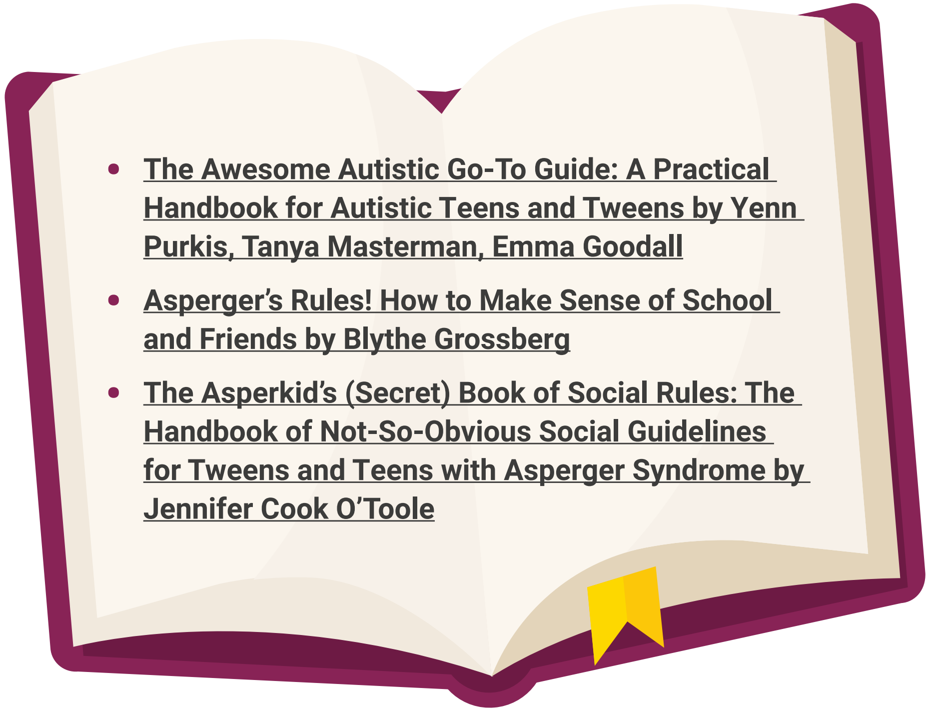
Sometimes being neurodiverse and LGBTQIA+ is referred to as being "under the double rainbow".

www.twainbow.org is an autistic led charity for those who are both autistic and LGBTQIA+

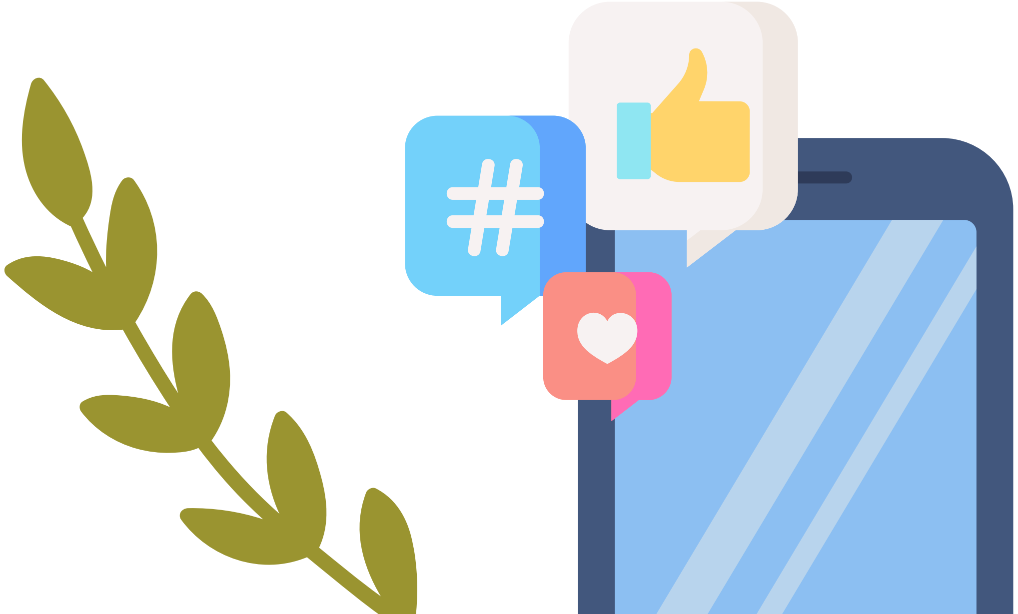
Further information

- **Book: Queerly Autistic: The Ultimate Guide for LGBTQIA+ Teens On The Spectrum by Erin Ekins**
- **Book: The Anxiety Book for Trans People by Freiya Benson -Jessica Kingsley Publishers - (uk.jkp.com)**

Books for Tweens/Teens to Read Themselves



- **The Awesome Autistic Go-To Guide: A Practical Handbook for Autistic Teens and Tweens by Yenn Purkis, Tanya Masterman, Emma Goodall**
- **Asperger's Rules! How to Make Sense of School and Friends by Blythe Grossberg**
- **The Asperkid's (Secret) Book of Social Rules: The Handbook of Not-So-Obvious Social Guidelines for Tweens and Teens with Asperger Syndrome by Jennifer Cook O'Toole**



Neurodivergent Social Media - please note some of these may not be suitable for under 15's

(there is a more comprehensive list in the **Useful Information Section** at the end of this pack)

- **Emily@21andsensory** (**www.21andsensory.wordpress.com**) – autistic blogger/graphic designer who also has sensory processing disorder
- **Dean Beadle** (**www.facebook.com/dean.beadlespeaker**) - Autism Advocate, highly entertaining public speaker, LGBTQIA+, singer, Dr Who fan.
- **Rene Brooks** (**www.blackgirllostkeys.com/rene-brooks/**) – ADHD Blogger and Advocate

16 and Beyond

Your child's school should begin helping them with careers advice from Year 8 onwards and for those with an EHCP from Year 9 onwards their annual reviews should include plans for transitioning to adulthood.

In the SEND Code of Practice, it states that support should continue after the age of 16 for those with an EHCP and this continues until they are 25, provided they stay within education/ training (this does not include higher education – so if they go to university from 18 their EHCP will end).

If your child has never had an EHCP but you think that they may now need one to provide extra support into adulthood, you (or your child) can ask the LA for an EHCP Needs Assessment.

What help is available?

If your child has an EHCP, in Year 9 a Preparing for Adulthood Advisor will contact your child and may attend their Annual Review meeting. They will assist your child by providing up to date information about:

Living independently

Contributing to society and the local community

Higher education

Friendships and social life

Employment

Physical and Mental Health inc. diet and exercise

Further information

- Peterborough local offer https://fis.peterborough.gov.uk/kb5/peterborough/directory/site.page?id=WN_GJoZFanc

- Caring together parent`s guide https://www.caringtogether.org/wp-content/uploads/2022/06/preparing_for_adulthood_-_a_parents_guide_may_2022.pdf

Further information

- **www.contact.org.uk/help-for-families/information-advice-services/education-learning/education-beyond-16/**
- **www.nationalcareers.service.gov.uk**

Considering University? – Bukky's story

Bukky Owoaje is an incredible young man who was diagnosed with Kabuki when he was a baby and dyslexia/dyspraxia in his teens.

After having difficulties at school, he successfully managed the move to university and has shared his story along the way.

Check out his blog at: **www.lifeentertainment1993.wordpress.com**

Bukky's learnings

1 Normal stands for 'Nothing Original Round My Actual Life':

N **Nothing**
O **Original**
R **Round**
M **My**
A **Actual**
L **Life**

It's my description of normal for people who have been considered not 'normal'.

2 Uni was incredible it's like a roller coaster of emotions - you meet new people, you learn new things and you find out more about yourself.

3. I found out I had dyspraxia and dyslexia in my first year at uni for which I received a massive amount of learning support from my student wellbeing officer.

4. I would tell myself it's ok to stand out from the crowd and be not the same as everyone else and I should just be me and not someone I shouldn't be. People would love me for me and others who don't that's life.

5. I struggled massively when I was at school but when I left school and got into college and uni I found out what I was good at and it's the case for many.

6. If you are struggling at uni with your mental health, the best thing to do is to talk to people - a friend, the wellbeing team, a mentor, family, halls staff or a lecturer. I learnt if I keep all my struggles to myself it wouldn't go away.

The support I got from uni was :

- Mentor,
- Notetaker,
- One to one support worker.

Further information

- Bukky's story: **www.kabukiuk.org.uk/bukky**

Huge thanks to Bukky for sharing his experiences with us.

Section 10

Useful information

The ‘Local Offer’ contains information relating to SEND services from your local authority

- Peterborough City Council is our Local Authority. Each Local Authority must have a "local offer"

https://fis.peterborough.gov.uk/kb5/peterborough/directory/localoffer.page?familychannel=8

Special Education Needs and Disabilities Information and Support Service (SENDIASS)

Provides free confidential and independent advice on all things SENDSEND Information, Advice and Support (SENDIASS)

SENDIASS Peterborough & Cambridgeshire
Sand Martin House,Bittern Way
Peterborough
PE2 8TY

sendiass@peterborough.gov.uk

Confidential helpline open during term times: 01733 863979

Outside of term time please leave a message as a small number of staff are available to answer queries but it will take time for them to respond to your enquiry.

https://fis.peterborough.gov.uk/kb5/peterborough/directory/service.page?id=E1PbUIt6ObU

All areas

- IPSEA – Independent Provider of Special Education Advice **https://www.ipsea.org.uk**
- SOS SEN **https://www.sossen.org.uk**
- Contact A Family **www. contact.org.uk/**

Activities/Holidays for SEND Children

- Peterborough's Short Breaks Offer **https://fis.peterborough.gov.uk/kb5/peterborough/directory/site.page?id=iDoiJa0ZIr0**
- Max Card in Cambridgeshire **www.spectrum.org.uk/max-card/**

Educational Psychology Services

- Educational Psychology Service **https://fis.peterborough.gov.uk/kb5/peterborough/directory/site.page?id=Vke5T9THiS4**

Elective Home Education

- **https://www.peterborough.gov.uk/residents/schools-and-education/home-education**

Children's Learning Disability Service (EPUT)

- **https://fis.peterborough.gov.uk/kb5/peterborough/directory/service.page?id=x-7D8s9OApM**

- **https://fis.peterborough.gov.uk/kb5/peterborough/directory/service.page?id=shbmee-mXq0**

Children's Mental Health Services

- Cambridgeshire Children's Mental Health Service: **www.cpft.nhs.uk/service-detail/service/child-and-adolescent-mental-health-services-camhs-63/**

—

- Kooth
  www.kooth.com
- Centre 33 **www.centre33.org.uk/**
- **www.keep-your-head.com/**
- **Cambridgeshire and Peterborough Key Worker Collaborative**

Occupational Therapy Services

- Peterborough's Children's Occupational Health
  https://www.cpft.nhs.uk/occupational-therapy-children/

Preparing for Adulthood

Peterborough's Local Offer

https://fis.peterborough.gov.uk/kb5/peterborough/directory/localoffer.page?familychannel=8-7

Contact A Family - Education beyond 16
contact.org.uk/help-for-families/information-advice-services/education-learning/education-beyond-16/

Thera Trust
www.thera.co.uk/

Information on The Mental Capacity Act and 16+yrs of age:
www.ipsea.org.uk/mental-capacity-and-decision-making

- Mencap
  https://www.mencap.org.uk/advice-and-support/children-and-young-people/transition-adult-services

- Social Care Institute for Excellence
  https://www.scie.org.uk/care-act-2014/transition-from-childhood-to-adulthood/

- NICE
  https://www.nice.org.uk/guidance/qs140

- National Careers Service
  https://nationalcareers.service.gov.uk/

Schools

- All schools
  https://www.peterborough.gov.uk/residents/schools-and-education/all-schools-colleges

School Transport

- Peterborough's School Transport
  https://www.peterborough.gov.uk/residents/schools-and-education/school-transport

- Special Educational Needs Transport Advocacy Service
  https://sentas.co.uk/

Social Care

- Peterborough's Local Offer
  https://fis.peterborough.gov.uk/kb5/peterborough/directory/localoffer.page?familychannel=8

- Peterborough safeguarding and child protection
  https://www.peterborough.gov.uk/healthcare/safeguarding-children

- Peterborough's Disability Social Care
  https://fis.peterborough.gov.uk/kb5/peterborough/directory/service.page?id=shbmee-mXq0

- NHS Social Care nformation
  www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment/

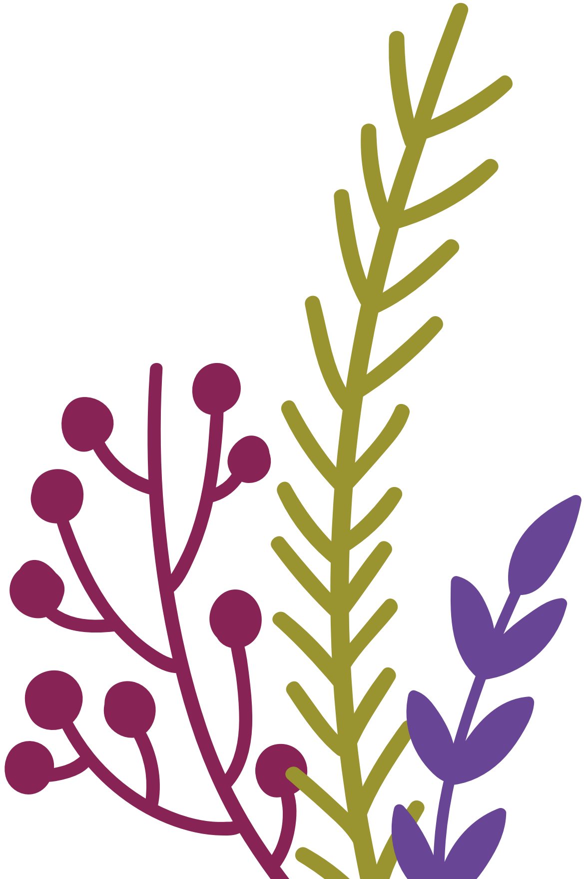
- Contact – How to Access Social Care Guide
  https://contact.org.uk/help-for-families/information-advice-services/social-care/how-to-access-services/needs-assessments/

Speech and Language Services

- Peterborough's Speech and Language **https://fis.peterborough.gov.uk/kb5/peterborough/directory/service.page?id=OyLb7r5yC6A**
- Speech and Language Uk **www.speechandlanguage.org.uk/information-and-support/**

Support for Family Carers/ Siblings

- Centre 33 Young Carers Support **www.centre33.org.uk/**
- Caring Together **www.caringtogether.org/**
- NHS Young Carers **www.cpft.nhs.uk/young-carers/**
- Sibs (Sibling Support) **www.sibs.org.uk/**
- Action for Family Carers **https://affc.org.uk/**
- Carers UK **https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment**



Useful Websites

General Help

- Family Voice Peterborough
  www.familyvoice.org
- Special Needs Jungle
  https://www.specialneedsjungle.com
- Cerebra
  https://cerebra.org.uk
- Contact
  https://contact.org.uk/help-for-families/information-advice-services/get-in-touch/our-helpline/

Visual Resources and Social Stories

- Social Stories by Carol Gray
  https://carolgraysocialstories.com/social-stories/
- **https://www.thepathway2success.com/parent-support-executive-functioning/**
- Social Stories – Siobhan Timmins
  https://siobhantimmins.uk/
- Ultimate List of Free Visual Supports for Autism and Why They Work - The Sensory Toolbox
  https://thesensorytoolbox.com/visual-supports-for-autism/
- Zones of Regulation
  https://www.zonesofregulation.com/index.html
- BSP, speech & language resources for schools, therapists & parents
  https://www.blacksheeppress.co.uk/

Condition Specific Sites

- National Autistic Society
  https://www.autism.org.uk/
- Autism Education Trust
  https://www.autismeducationtrust.org.uk/
- Autism in Girls - Girls and Women and Autism: What's the difference? - Sarah Hendrickx
  https://www.youtube.com/watch?v=yKzWbDPisNk
- Tony Attwood - Aspergers in Girls
  https://www.youtube.com/watch?v=wfOHnt4PMFo

- ADHD
  https://www.adhdfoundation.org.uk
- ADHD UK
  https://adhduk.co.uk/
- ADHD in Girls
  https://www.verywellmind.com/adhd-in-girls-symptoms-of-adhd-in-girls-20547
- OCD-UK | A national OCD charity, run by, and for people with lived experience of OCD
  https://www.ocduk.org/
- Dyspraxia Foundation
  https://dyspraxiafoundation.org.uk/
- British Dyslexia Association
  https://www.bdadyslexia.org.uk/
- PDA Society
  https://www.pdasociety.org.uk
- Tourette's Syndrome
  https://www.tourettes-action.org.uk
- Avoidant/Restrictive Food Intake Disorder - ARFID
  https://www.arfidawarenessuk.org/
- Hypermobility Syndromes Association
  https://www.hypermobility.org

Neurodiverse Websites/ Facebook/Instagram/ Youtube Pages

- Autistic Not Weird - Insights from an Autistic Teacher and Speaker **https://autisticnotweird.com/**
- The Autistic Advocate
  https://theautisticadvocate.com/
- Pete Wharmby
  https://www.patreon.com/pwharmbyautism
- Sara-Jane Harvey, Agony Autie **https://www.youtube.com/channel/UCN9fwImPnx16e8-eThlKCWQ**
- Dean Beadle
  https://www.facebook.com/dean.beadlespeaker
- How To ADHD
  https://www.facebook.com/howtoadhd
- Neurodivergent Rebel
  https://neurodivergentrebel.com/
- Rene Brooks ADHD
  https://blackgirllostkeys.com/rene-brooks/
- Kristy Forbes - Autism & Neurodiversity Support Specialist
  https://www.kristyforbes.com.au/
- Ann Memmott - Ann's Autism Blog
  http://annsautism.blogspot.co.uk/
- Autistic Inclusive Meets (AIM) **https://autisticinclusivemeets.org/**
- NeuroClastic
  www.neuroclastic.com
- Stories About Autism
  https://www.facebook.com/storiesaboutautism/
- Sally Cat PDA
  http://www.sallycatpda.co.uk/
- Non-Speaking Autistic Speaking
  http://nonspeakingautisticspeaking.blogspot.co.uk
- Yo Samdy Sam
  https://yosamdysam.com/

Useful Books

General

- **10 Rules** by Damian Milton
- **The reason I Jump** by Naoki Higashida
- **An Insider's guide to Asperger Syndrome** by Ian Hale
- **Nerdy, Shy and Socially Inappropriate: A User Guide to an Asperger Life** by Cynthia Kim
- **It's an Autism thing** by Emma Dalmayne
- **Fall Down Seven Times Get Up Eight: A young man's voice from the silence of autism** by Naoki Higashida
- **Pretending to be Normal: Living with Asperger's Syndrome (Autism Spectrum Disorder)** by Lianne Holliday Willey
- **I Think I Might Be Autistic: A Guide to Autism Spectrum Disorder Diagnosis and Self-Discovery for Adults** by Cynthia Kim
- **Neurotribes** by Steve Silberman
- **Fingers in the Sparkle Jar** by Chris Packham
- **Can You See Me?: A powerful story of autism, empathy and kindness** by Libby Scott and Rebecca Westcott
- **Asperger's Syndrome: A Guide for Parents and Professionals** by Tony Attwood

Education

- **Inclusive Education for Autistic Children: Helping Children and Young People to Learn and Flourish in the Classroom** by Dr. Rebecca Wood
- **Lost and Found: Helping Behaviorally Challenging Students (and, While You're At It, All the Others) (J-B Ed: Reach and Teach) 1st Edition** by Ross W. Greene, PhD
- **More Than Words - A guide to helping parents promote communication and social skills in Children with ASD** by Fern Sussman

Girls/Women

- **Women and Girls with Autism Spectrum Disorder: Understanding Life Experiences from Early Childhood to Old Age** by Sarah Hendrickx
- **Girls and Autism** by Barry Carpenter
- **Camouflage: The Hidden Lives of Autistic Women** by Dr. Sarah Bargiela
- **Autism and Girls** by Tony Attwood, Temple Grandon, et al
- **Nobody Nowhere: The Remarkable Autobiography of an Autistic Girl** by Donna Williams

- **Understanding Girls with ADHD: How they feel and why they do what they do** by Patricia O. Quinn and Stephen Hinshaw

Mental Health

- **The Guide to Good Mental Health on the Autism Spectrum** by Contributions
- **Trauma, Stigma and Autism: Developing Resilience and Loosening the Grip of Shame** by Gordon Gates
- **Avoiding Anxiety in Autistic Children: A Guide for Autistic Wellbeing** by Luke Beardon

Parenting

- **The Explosive Child: A New Approach For Understanding And Parenting Easily Frustrated, Chronically Inflexible Children** by Ross W. Greene, PhD
- **Raising Human Beings: Creating a Collaborative Partnership with Your Child** by Ross W. Greene, PhD
- **Treating Explosive Kids: The Collaborative Problem-Solving Approach 1st Edition** by Ross W. Greene, PhD
- **Unconditional Parenting: Moving from Rewards and Punishments to Love and Reason** by Alfie Kohn
- **Punished by Rewards: The Trouble with Gold Stars, Incentive Plans, A's, Praise, and Other Bribes** by Alfie Kohn
- **The Parents' Practical Guide to Resilience for Children aged 2-10 on the Autism Spectrum** by Jeanette Purkiss and Emma Goodall

Teens

- **The Parents' Practical Guide to Resilience for Preteens and Teenagers on the Autism Spectrum** by Dr. Emma Goodall and Jeanette Purkiss
- **The Asperkid's (Secret) Book of Social Rules: The Handbook of Not-So-Obvious Social Guidelines for Tweens and Teens with Asperger Syndrome** Jennifer Cook O'Toole
- **The Anxiety Workbook** by Clare Ward and James Galpin
- **Asperger's Rules!: How To Make Sense of School and Friends** by Blythe Grossberg
- **The Awesome Autistic Go-To Guide: A Practical Handbook for Autistic Teens and Tweens** by Yenn Purkis, Tanya Masterman, Emma Goodall
- **Thriving with ADHD Workbook for Teens: Improve Focus, Get Organized, and Succeed** by Allison Tyler

Books for Children

- **The Disappointment Dragon: Learning to cope with disappointment**
- **The Red Beast: Controlling Anger in Children with Asperger's Syndrome**
- **The Panicosaurus: Managing Anxiety in Children Including Those with Asperger Syndrome** all by K.I. Al-Ghani
- **All Cats Are On The Autism Spectrum**
- **All Birds Have Anxiety**
- **All Dogs Have ADHD** all by Kathy Hoopmann
- **What to Do When Your Brain Gets Stuck: A Kid's Guide to Overcoming OCD** by Dawn Huebner and Bonnie Matthews
- **Underdogs** by Chris Bonnello (Autistic writer) - stories are about a group of neurodiverse children
- **The Dog Man and Captain Underpants Books** by Dav Pilkey (who has ADHD)
- **The Tourettes Survival Kit: Tools for Young Adults with Tics** by Tara Murphy and Damon Millar

www.familyvoice.org

https://www.facebook.com/fvpcommunity

Family Voice Peterborough is the Parent Carer Forum for Peterborough. We support parent carers of children and young people aged 0 -25 years with additional needs or disabilities. As a parent carer forum, we enable the Local Authority to fulfil its statutory requirement to listen, engage and work together with parent carers for the benefit of children with Special Educational Needs and Disabilities (SEND) and their families.

Family Voice:

Help parents engage with professionals across Health, Education and Social Care.

Facilitate participation in service delivery.

Provide a voice for parents at strategic level meetings.

Hold informative events.

Help parents and carers have access to the information about what services are available to them.

Signpost parents and carers to other agencies/ organisations who provide specific services that we do not.

Provide family based trips and activities.

Run a community centre.

Provide short breaks.

The Essex Family Forum

SEND the Right Message Charity (STRM)

MyOTAS – My Own Time And Space

We wanted to record our thanks again to the Essex Alliance who created and shared this booklet. The power of parent carers working together to support other parent carers cannot be underestimated.

We are greater by working together and together we can achieve more. Thank you.

Cambridgeshire & Peterborough
Integrated Care System

family voice
peterborough
together improving services