Supporting your Neurodivergent Child

Written for parents, by parents

Supported and Funded by:

Essex Family Forum

SEND the right message

Herts Parent Carer Involvement

Takiwātanga supportservices.co.uk In his/her own time and space

NHS

Hertfordshire

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With thanks to the staff from Herts Parent Carer Involvement, our local voluntary sector providers, Hertfordshire County Council and local NHS organisations who have contributed to this amended and updated handbook

If you have any comments or feedback on this handbook, please email
EHCommissioning@hertfordshire.gov.uk

Hertfordshire Neurodiversity Support

On our **Neurodiversity Support page**, you'll find resources, support, and signposting on a whole range of things relating to ADHD and Autism. There are details of the Neurodiversity Support Hub - **Neurodiversity Support (hertfordshire.gov.uk)** - and links to courses for young people to help them to understand their ADHD and Autism, as well as pre recorded webinars for parents and carers.

You will also find links to practical strategies and resources to help your child at home and details of support groups and organisations in Hertfordshire who offer a variety of services to help neurodivergent children and young people and their families.

Contents

Introduction

When you first realise that your child experiences the world in a different way it can feel overwhelming. Once you begin to understand their particular way of processing their thoughts, senses and feelings, you will find it easier to support 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 see that much information is available, but finding the factually correct and relevant bits to your situation can be hard.

We wanted to share not only our experiences and tips, but also those of other families, who have been where you are now.

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 specificopics. We have also recommended some books, videos and blogs, which are all resources that we have used ourselves.

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. While books and websites can provide very useful guidance, 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. Therefore, we strongly encourage you to reach out to the various charities and support groups that we are lucky to have available to us in Hertfordshire.

This is not a replacement for a diagnosis, please seek professional guidance as you see fit.

Finally, we would like to thank all of the young people, parents and professionals who have provided input.

Good Luck on your journey!

Section 1

What is Neurodiversity?

What is Neurodiversity?

‘Neurodiversity’ is a term that describes the wide variety of human brains and the many different ways in which all our brains work.

Neurodiversity recognises the fact that there is no one correct or ‘right’ way of being and therefore differences are not necessarily deficits or problems.

What does Neurodivergent mean?

Brains that learn, behave and process differently to the majority are described as ‘neurodivergent’ and are also included and welcomed under the broad scope of neurodiversity. ‘Neurodivergency’ can be used to describe a wide range of differences in the ways that people experience and interact with the world around them such as autism, ADHD, Dyslexia, Dyscalculia, Dyspraxia and Tourette’s Syndrome.

While the idea of neurodiversity acknowledges that difference is not ‘wrong’, the world is nonetheless set up to suit the neuro-majority (sometimes called neurotypical people). Neurodivergent people, who are in the minority, therefore often face additional challenges that arise from being in a world that is not designed to suit them. Nurturing an understanding of what it means to be neurodivergent – bearing in mind that no two neurodivergent children are the same – is essential in order to minimize those challenges. It also helps us to support and encourage our neurodivergent child or young person so they can build on their individual strengths and passions, and celebrate being their true authentic self.

In the right environment and with the appropriate support there can be many positives to being neurodivergent:

- Great attention to detail
- Creativity
- Hyper focus
- Thinking outside the box
- Analytical thinking
- Passion for fairness and social justice
- Acceptance
- Questioning outdated ideas and ways of doing things

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

A Note on Terminology

As a parent of a neurodivergent child, discussions over the use of language are probably way down on your list of concerns. However using the right words can help people to feel included and respected while using words with subtly negative connotations can cause people to feel excluded and demeaned. Language is not only important for neurodivergent people and their families, but can also re-frame how society views and behaves towards neurodivergent people.

The terminology used to describe neurodivergency is changing, driven largely by the research and writings of neurodivergent adults. Within this handbook we have used the most up-to-date terminology favored by most neurodivergent adults. However, when you are speaking to neurodivergent individuals, be led by the terminology that they prefer – if in doubt, just ask!

Identity-first language

We have chosen to use identity-first language, such as “autistic child,” rather than person-first language like “child with autism.” This is the preferred terminology of most autistic adults, who view autism as an intrinsic part of themselves, much like having blonde hair or being left-handed. Autism is not an illness like cancer or diabetes and it cannot be ‘cured’. Individuals with autism do not “suffer from” autism, nor do they “live with” it in the same sense that one might live with a disease.

Why we shouldn’t use terms such as ‘high-functioning / low functioning’ or ‘Mild/ Moderate/Severe’

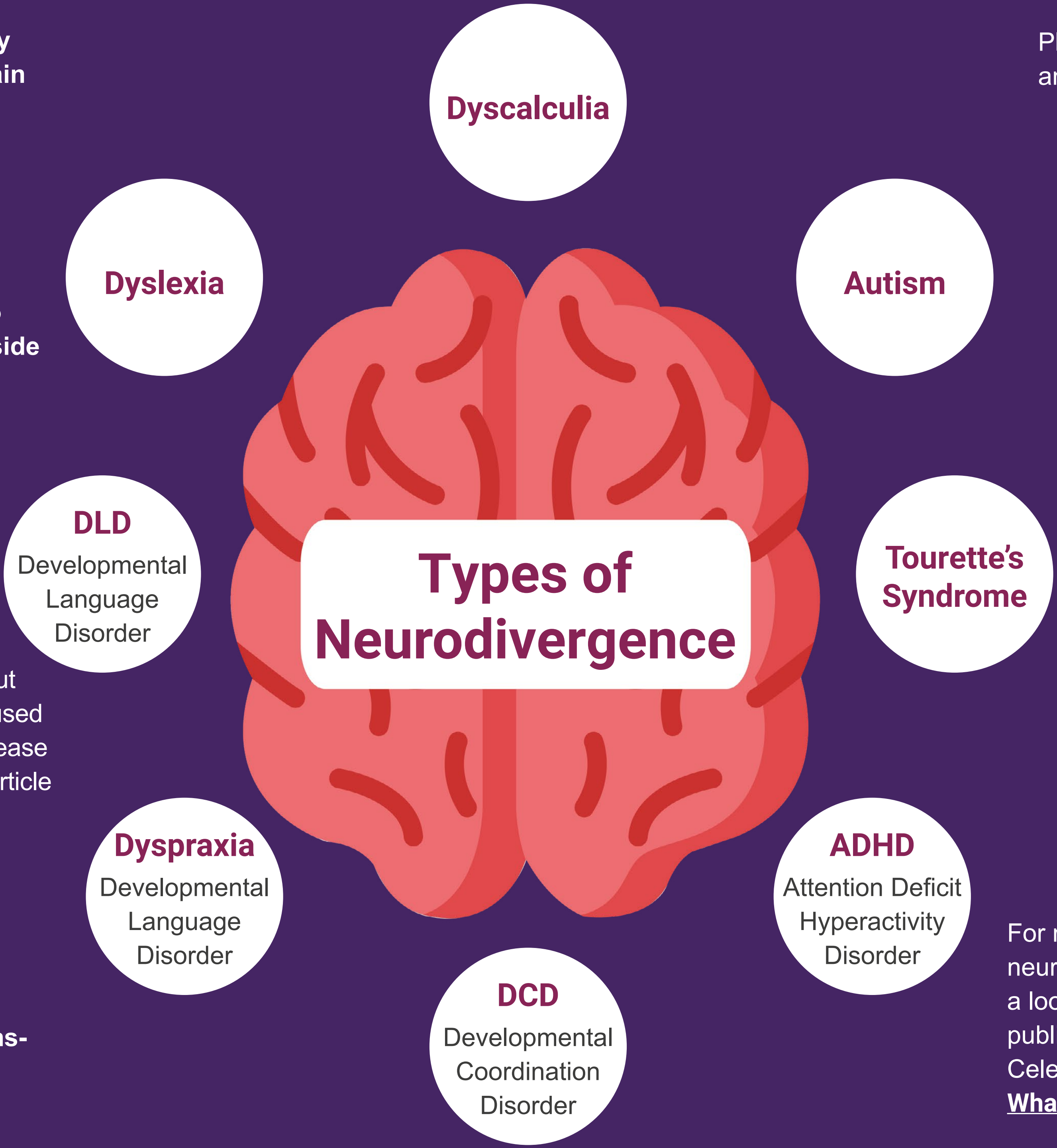
It is widely recognised that neurodivergent conditions are dynamic and can vary from day to day and throughout someone’s lifetime. Difficulties may be affected by, for example, stress, hormones and environmental factors such as noise, hunger or lack of sleep. Access to diagnosis, appropriate support and reasonable adjustments are also important factors. You cannot be mildly, moderately or severely diabetic or pregnant; you either are or you are not, and neurodivergence is the same. With individually tailored support everyone can thrive.

Asperger’s Syndrome

There is controversy surrounding the term ‘Asperger’s’ and clinicians no longer use this as an official diagnosis. Even so, the term is still used in some circumstances and by some practitioners. The diagnostic term was first used in the 1980s to describe autistic people without learning disability or language delay. It was named after Dr Hans Asperger, a scientist who extensively researched autism in children during the mid-twentieth century. People once regarded as having Asperger’s Syndrome would today be diagnosed as autistic.

“My ADHD is part of my neurotype, how my brain is wired. It impacts my life in different ways, both good and bad. It influences everything I do. I am ADHD, just as I am English; there is no version of me, no person,that exists outside of my neurotype.”

Please note, this is not an exhaustive list



Types of Neurodivergence

Dyscalculia

Autism

Tourette’s Syndrome

ADHD
Attention Deficit Hyperactivity Disorder

DCD
Developmental Coordination Disorder

Dyspraxia
Developmental Language Disorder

DLD
Developmental Language Disorder

Dyslexia

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)**

For more information about neurodiversity please have a look at the information published for Neurodiversity Celebration Week:
What is Neurodiversity

> “Some days my son seems more autistic than others.”

You may notice that the neurodivergent differences your child displays change **from day to day, due to a range of factors** such as how well they have slept, whether they have eaten, general levels of anxiety, etc.

Some days they can cope with situations they may find hard, e.g. loud noises, sitting still, speaking, being in crowded environments, or concentrating - other days they will find these things unmanageable.

Autism

Autism is a neurotype that leads to:

A cognition that is qualitatively different to that of most other people in the way that information specific to communication, social interpretation and interaction is processed and understood; and a perceptual reality of the sensory environment that differs considerably from that of most other people, and one from one individual to another.* Beardon, 2017

While autistic people share some overarching commonalities, each person experiences autism in a way that is specific and unique to them, often with considerable nuance and variability from one to another.

The extent of this variability has been expressed through the concept of 'the autism spectrum', although over time this has come to be misconceived as being some kind of scale by which 'levels' of autism can be measured. The autism spectrum is not linear, however, and there is no line from 'low' to 'high'; it is more accurately described as 'a constellation that circles in many spheres' (Caroline Hearst).

Within that constellation, each autistic individual has a unique profile of differences in a range of areas, some of which may require little support and others with significant difference that may require high levels of support. Very often it is the environment, situation or circumstance that determines an individual's support needs at that one moment. In the past, functioning labels have been used to try and explain 'where on the spectrum' a person is. We now know that functioning labels do not tell the full story, and can in fact be harmful. Describing a person as 'high functioning', for example, tends to lead to assumption that they have few support needs across all areas, which may lead to unrealistically high expectations and undue pressure to 'perform'. Similarly, describing a person as 'low functioning' tends to assume limited ability across all areas, which may lead to a lowering of expectation and a limitation on opportunities.

Most autistic people actually have what is called 'a spiky profile', which means that their profile of strengths and weaknesses is likely to be more extreme than that of most other people – the highs are higher and the lows are lower. When mapped, the autistic profile can look like a spiky mountain range, while most other profiles look more like gently undulating hills. This means that an autistic person may be very proficient in some areas but still find other areas to be extremely challenging. This can have great impact when it comes to academic learning – for example, being able to express thoughts and ideas articulately through speech but not being able to record or capture those thoughts and ideas in writing. Autism is not linked to intellectual ability, however...

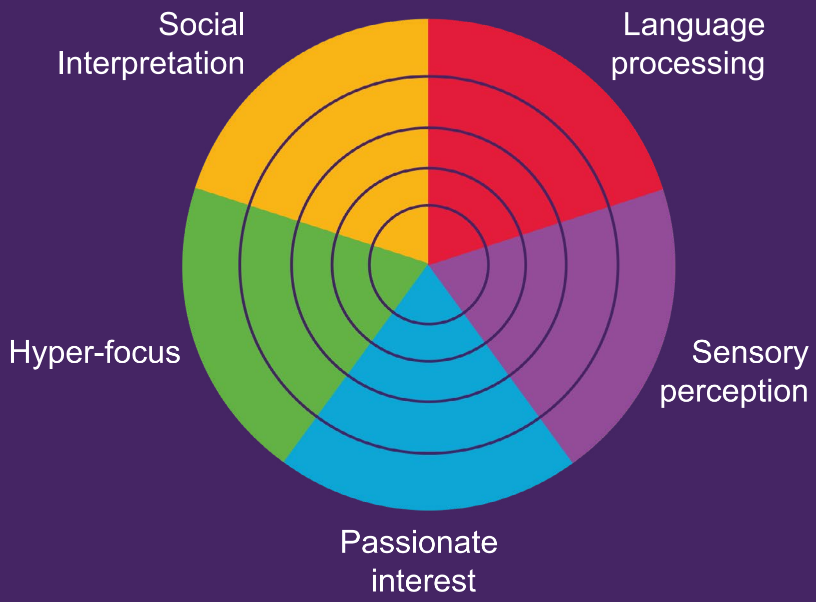
Autistic people are represented along the whole range of cognitive ability, from those with learning disability to those who are extremely clever. Additionally, it is incorrect to assume that a non-speaking individual is intellectually impaired.

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.

The Autism Spectrum

What people think the autism spectrum looks like:

What the autism spectrum actually looks more like:



Autistic people typically experience differences in the following areas:

1. Social Communication and Interaction

They may:

- Have a very advanced vocabulary or have a language delay, be non-verbal, non-speaking, or situationally mute (where their anxiety is sometimes so high that they cannot speak). For further information about speech delays and communication difficulties please see the section on Speech and Language).
- Prefer to use clear and direct language which may seem rude or abrupt to others.
- Assume other people say what they mean and therefore take
- words literally – may have difficulty understanding idioms, sarcasm or vague expressions like ‘in a minute’.
- Give their honest opinion to a direct question, not realising that the other person may have been looking for a compliment!
- Struggle to interpret facial expressions and body language cues, especially in larger groups, and find that neurotypical people misinterpret their expressions too e.g. a child may not respond in expected ways to a surprise gift.
- Find eye contact overwhelming or even painful, and therefore struggle to look at someone whilst also listening to them at the same time.
- Need time to filter, sort and process what other people say and do – often it takes a while (sometimes days) for them to realise that someone said something mean or inappropriate to them.
- Have a strong sense of justice and fair play, and become upset if others do not follow the rules.
- Like to feel in control to lessen their anxiety, and may appear assertive or defiant. Conversely may simply ‘follow the herd’ to avoid ‘getting things wrong’ and therefore be easily led.
- Find it difficult to initiate and maintain friendships and relationships due to frequent misunderstandings. May prefer to play alongside other children (parallel play), rather than with them, or to interact with objects, imaginary friends or animals – as there is no pressure to socialise in a “neurotypical” way.
- Appear intelligent and wise beyond their years (primary school), but may also be naïve which makes them vulnerable in their teens.
- Historically, it was often said that autistic people lack empathy - but it is becoming increasingly accepted that many autistics have an abundance of empathy but may not express this in expected ‘neurotypical’ ways.

“My son runs out of the room whenever the news comes on, he finds it distressing.”

2. Repetitive and Restricted Behaviours

They May:

- Prefer to have daily routines and may become distressed if the routine is changed.
- Like to strictly follow the rules and get upset if others do not.
- Use repetitive language.
- Mimic phrases they hear or tones of voice/ accents (this is called Echolalia) and repeat these.
- Sort things alphabetically.
- Follow a specific route to school and become stressed if their route or routine is changed.
- Want to wear the same thing every day.
- Line up objects by colour or type.
- Perform repetitive movements when stressed or excited, such as rocking, flapping hands, jumping, pacing or spinning (this list is not exhaustive – see the Section on Stimming).
- Want things to be kept in a certain place.
- Try to take control of their environment by cleaning and decluttering.
- Become fixated on objects, pieces of clothing, blankets, food and struggle if these are changed.
- Enjoy watching the same TV programme, film or Youtube video over and over again.

These behaviours may seem strange to you, but your child will use them to regulate and may find them soothing and enjoyable.

3. Sensory Processing Differences

Autistic children experience the world differently to neurotypical people and this can be across all their senses. Some may prefer loud noises and others will hate it!

As Sensory Processing is a challenge for so many neurodivergent 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 difficulties

- Being overly sensitive to loud noises, like hand driers in public
- toilets, school bells, fire alarms, big crowds.
- New clothes can be itchy, especially the labels.
- Some foods have too much flavor, or some foods are too bland.
- Due to auditory (sound) processing delays – there can be confusion when trying to keep up with conversations and interrupting other people.
- Tickled or hugged.
- Strong smells.
- Cleaning teeth – due to the taste and how it feels.
- Hair washing and brushing.

4. Intense Interests/Hobbies (sometimes referred to as “Special Interests”)

Your child or young person may be passionate about certain interests and give a lot of time and focus to these.

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. Often, they can be so absorbed in something that interests them that they forget to undertake self-care, such as remembering to eat or drink!

Their interest may be something like a passion for trains, dinosaurs, Minecraft, particular dolls, make-up tutorials or even reading fiction; it may be a person, a pet or a cuddly toy, or it might be something more unusual like vacuum cleaners. Sometimes their activity might be focused on organizing a collection of items or researching a particular topic, rather than actually ‘playing’ with things in expected ways. They may consider that anything which doesn’t include their special interest is not good use of their time and to some other people this may appear rude.

You may find that your child loves to talk about their passions at length - it is often the easiest way for them to connect with others and it makes them really happy so it’s important to value and embrace these interests. If you, or your child’s school, can find ways to work current interests into their education, it will help your child to focus and learn. Interests can also be used as a way to develop fulfilling friendships with like-minded individuals.

Further information

- Neurodiversity Support Hub (**hertfordshire.gov.uk**)
- SLP 136: Finding Autistic Joy & More - An Interview with Dean Beadle - Sue Larkey Podcast.
- **https://getpodcast.com/uk/podcast/sue-larkey-podcast/slp-136-finding-autistic-joy-and-more-an-interview-with-dean -beadle_ bb2790a0e6**)
- The benefits of special interests in autism.
- (**www.spectrumnews.org/features/deep-dive/the-benefits-of-special-interests-in-autism**)

“My daughter’s special interest is Harry Styles and she is so motivated to learn about him that she has been able to try lots of new things: researching a scrapbook project with facts about him; going on public transport to a concert; and connecting with other fans on social media and making ongoing friendships where they share an interest.”

Autistic Masking

It can be difficult to identify autism when a child's behaviour is not a cause for concern at school. But if you know them well enough you can often see how much energy they are having to put into trying to appear "normal" in front of others. This is called 'Autistic Masking'.

How this might affect your child?

While everyone may choose to project a different version of themselves in certain situations - e.g. attending a job interview as opposed to hanging out with friends - autistic masking is a very specific phenomenon which is quite different. Some autistic children quickly learn that who they are is not what other people want them to be.

They learn to suppress their autistic behaviours (e.g. stimming, talking about their interests, not maintaining eye contact etc.) as a response to the trauma of being constantly criticised and invalidated by the people around them. Although it may initially happen consciously, the person quickly learns to dissociate from the act and doesn't realise they are doing it.

In other words, autistic masking is a form of self-protection which involves projecting an acceptable version of oneself that others expect to see. For example, at school an autistic child may try to be the 'model pupil' which makes it more difficult for teachers to notice their needs. The longer someone suppresses their autistic self, the more stressed they become. So when that child returns home, all their pent up stress, exhaustion and frustration may come out as angry outbursts, sad tears, or complete withdrawal.

This 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 autism, even though a parent provides a long list of things that they a re concerned about. We have provided links to information about autistic masking, which you may wish to share with your school to help explain that this is a common problem.

The real danger is that repeated autistic masking, over a long period of time, denies a person the opportunity to be accepted authentically for who they are, which has a serious impact on self-esteem and mental health.

It also creates a barrier, which prevents the person from communicating their needs and getting those needs met, because no one can see that they are struggling. This may lead to autistic burn-out, with very serious long-term consequences.

Further information

- Neurodiversity Support Hub (**hertfordshire.gov.uk**)
- **Blog and latest book Girl Unmasked from local writer Emily-Katy**
- **Autistic Masking resources from Kieran Rose, The Autistic Advocate**

Ignoring Sensory Needs

Excessive self-monitoring behaviour

Trying to disguise or contain distressed behaviours

Worrying or overthinking previous conversations to understand what you did wrong

Trying to behave 'normally'

Copying gestures Learning scripts

Hiding Stims

Copying gestures Learning scripts

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 we 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 some girls, autistic traits may be clear but for others, the way that autism presents may differ significantly to the typical male presentation.

Historically more boys than girls were diagnosed as autistic, as research focused heavily on boys. As understanding of the typical female presentation of autism grows, more girls are being diagnosed (as well as some boys who also didn't display the typical male autistic traits).

Girls are more likely to:

- Have intense 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.
- Be more likely to become withdrawn than behave aggressively in public.
- Mask their differences. Many boys do this too, but it is a very common feature for girls.

Girls often have a group of friends who support and guide them through the primary years and can help to navigate difficult social situations.

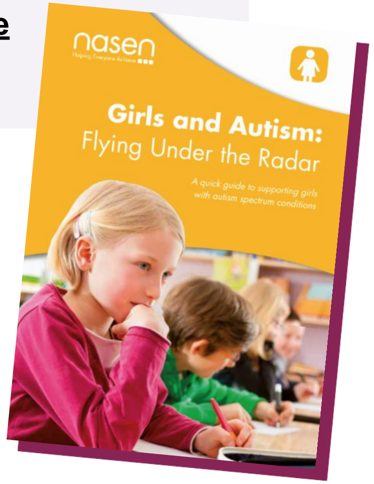
These relationships can change as girls grow up, some will mature quicker than others and their interests will change.

At primary school, that group of friends may have sat together in class and helped to interpret social cues and learning needs, but at secondary school, they are likely to be separated from their primary school friends and sometimes will struggle to make new friends.

Further issues can arise as seating plans change for each lesson and children are placed into sets for some subjects. So in addition to the pressures of secondary school, girls in particular may struggle from the lack of support from the friends that had previously been there to help them.

Further information

- Free mini guide - **Girls and Autism: Flying under the radar | Nasen**
- Book - Women and Girls with Autism Spectrum Disorder – Sarah Hendrickx - **Girls and Women and Autism: What's the difference? - Sarah Hendrickx**
- Resources from: **https://autisticgirlsnetwork.org/**
- **Girls and Women and Autism: What's the difference? - Sarah Hendrickx - YouTube**



Pathological Demand Avoidance (PDA)

Pathological Demand Avoidance (PDA), sometimes known as Extreme Demand Avoidance (EDA), falls under the autism umbrella. Individuals are generally diagnosed as 'autism with a demand avoidant profile'. It is a complex and challenging condition that is often misunderstood.

The key traits of a PDA profile are:

- resisting and avoiding the ordinary demands of life
- using social strategies as part of the avoidance
- appearing 'socially able' but this may mask underlying differences/difficulties in social interaction and communication
- experiencing intense emotions and mood swings
- appearing comfortable in role play, pretence and fantasy
- intense focus, often on other people (real or fictional)
- a need for control, often driven by anxiety or an automatic 'threat response'.

Conventional approaches to supporting autism are often ineffective.

Therefore it may be necessary to explore alternative parenting and teaching techniques.

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, their resistance is a way of managing acute anxiety.

By showing understanding, reducing demands and using a 'low arousal' approach at all times, their self-confidence and ability to cope will grow.

"Although the concept of PDA is not clinically recognised and so it is not possible to receive a standalone diagnosis of PDA, some people are diagnosed as autistic with a 'PDA profile' (or similar). However, the usage of this language in an autism diagnosis is not standardised; there is no standard assessment for PDA and usage of this terminology depends on whether the clinicians, practitioners or commissioners in your local area accept it."

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 else now” can be helpful.

Sanctions and consequences

- ‘My child has difficulties with sanctions 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:

- Kristy Forbes - Autism & Neurodiversity Support Specialist (**www.kristyforbes.com.au**)
- Sally Cat PDA (**www.sallycatpda.co.uk**)

Further information

- Understanding PDA: **www.priorychildrensservices.co.uk/news-blogs/understand ing-pathological-demand-avoidance-pda**
- Helpful approaches for parents and carers: **https://www.pdasociety.org.uk/wp-content/uploads/2021 /09/Helpful-approaches-for-parents-and-carers.pdf**
- Comprehensive guide to PDA: **https://www.pdasociety.org.uk/resources/understanding-pa thological-demand-avoidance-syndrome-in-children-a-guid e-for-parents-teachers-and-other-professionals -jkp-essentials/**
- PDA Guide for Young People: **https://pdaparenting.com/2019/01/16/me-and-my-pda-a-gu ide-to-pathological-demand-avoidance-for-young-people/**
- Personal experiences from a local parent: **https://www.stephstwogirls.co.uk/**
- Additional understanding: PDA Society Resources **https://www.pdasociety.org.uk/resources/sources-of-f urther-understanding/**

Autistic Strength

Autism can feel particularly challenging during childhood because our children struggle to understand and communicate their needs - and we may struggle to support those needs in a society which is set up to suit the neuro-majority. However, in adulthood, autistic people often have more choice about how they live their lives and are better able to create an environment which enables them to thrive.

Many autistic adults have fulfilling friendships, relationships and families of their own. And many discover that combining the ability to hyper-focus with intense interests has led to very successful career options. Throughout history, autistic individuals have made an enormous contribution to scientific and cultural advancements within society. These are just a few (although there are many more who do not have a formal diagnosis but self-identify as autistic):

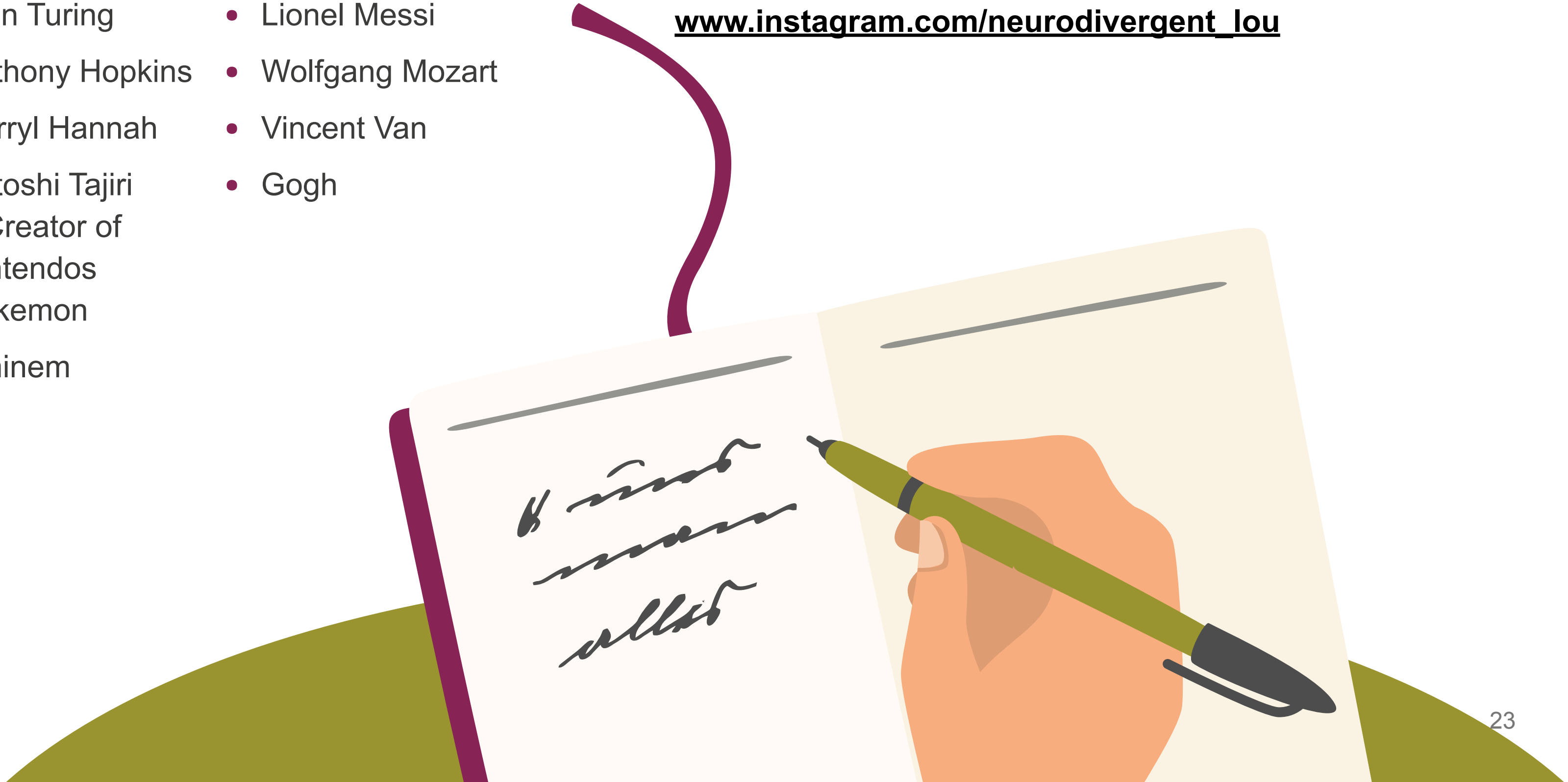
- Greta Thunberg
- Thomas Edison
- Elon Musk
- Albert Einstein
- Sir Isac Newton
- Thomas Jefferson
- Chris Packham
- Alan Turing
- Anthony Hopkins
- Darryl Hannah
- Satoshi Tajiri – Creator of Nintendos Pokemon
- Eminem
- Lionel Messi
- Wolfgang Mozart
- Vincent Van
- Gogh

> "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.

- Dean Beadle - **deanbeadle.wordpress.com/**
- Pete Wharmby - **www.patreon.com/pwharmbyautism**
- Ann Memmott - **http://annasautism.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 neurodivergent children. Autistic Not Weird Blog - Insights from an Autistic Teacher and Speaker **https://autisticnotweird.com/**
- Kieran Rose - **https://theautisticadvocate.com/about-kieran**
- Neurodivergent Lou - **www.instagram.com/neurodivergent_lou**



Further reading

- Neurodiversity Support Hub (**hertfordshire.gov.uk**)
- 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**
- Reframing Autism - Celebrating & nurturing Autistic Identity **https://reframingautism.org.au**
- Book - 'Start here: a guide for parents of autistic kids' – written by Autistic Self Advocacy Network (ASAN)
- Autism Education Trust- **www.autismeducationtrust.org.uk**

ADHD

Types of ADHD

ADHD usually presents in three different ways: hyperactivity (which means the need to move around more), inattention (difficulty concentrating or staying on task) or both, which is called Combined ADHD. These patterns of behaviour can interfere with development and day to day functioning.

The main features of ADHD as outlined in the diagnostic criteria are:

1. Hyperactive

- **A need for movement, fidgeting, squirming or struggling to stay seated**
- **Excessive talking**
- **Frequently interrupts others**
- **Overactive**
- **Loud interactions with others**
- **Struggles waiting turns**
- **Impulsive speech and actions**
- **Blurting out answers**

2. Inattentive

- **Makes careless mistakes**
- **Difficulty maintaining attention**
- **Often loses or misplaces things**
- **Avoids activities that require a lot of concentration or prolonged attention**
- **Has difficulty organising themselves, tasks and activities**
- **Difficulty following instructions**
- **Slow to process information**
- **Poor working memory**
- **Daydreams**
- **Shy or withdrawn behaviour**

3. Combined

- **The combination type means that the symptoms do not exclusively fall within the inattentive or hyperactive behaviour; instead, they are a combination of both.**

There are many more features of ADHD that could also have a significant impact on a child’s organisational skills and emotional well-being that are not currently listed in the diagnostic criteria, and we have listed some of these below.

Challenges

Children with ADHD may be labelled as naughty and disruptive for behaviour which they cannot control. They may experience problems with:

- Forgetfulness e.g. forgetting birthdays, plans or arrangements
- Time Management e.g. being late for plans or activities
- Time Blindness e.g. difficulty calculating time, very optimistic about how long a task will take, or daydreams and doesn’t realise how much time has passed
- Rejection sensitivity e.g being more sensitive to problems or criticism
- Overwhelm – due to struggling with task initiation and organisational skills they can become so overwhelmed with a long “To Do List” that they end up doing nothing at all. To others this can look like laziness, avoidance, and procrastinating.

Positives

There can also be many positives such as creativity, curiosity, willingness to take risks and the ability to think outside the box.

Hyperfocus - this is the ability to have intense concentration or fixation on a task or activity, but it has to be something that they enjoy. During hyperfocus, individuals with ADHD may become unaware of time, ignore those around them, and even neglect their own needs. ADHD people cannot always choose what they focus on.

“My brain doesn’t sit still, ever!”

ADHD Writers/Bloggers

- 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**)
- What's it like to have ADHD? (**www.youtube.com/watch?v=HI7Ro1PUJmE**)
- Ceri Sandford - ADHD Compassion Coach (**www.instagram.com/ceri.sandford**)
- Jak Levine-Pritzker (**www.instagram.com/authenticallyadhd**)

ADDitude - Inside the ADHD Brain: ADD Symptom Tests, Treatment, Support (additudemag.com)

Smart but Scattered: The Revolutionary "Executive Skills" Approach to Helping Kids Reach Their Potential by Richard Guare and Peg Dawson

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?

Literacy and Numeracy difficulties - including concerns about Dyslexia, Dysgraphia and Dyscalculia

A specific learning difficulty is a neurodevelopmental condition which can occur across a range of intellectual abilities.

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.

> “I feel like the spotlight is on me! I worry if I will get the information out of my brain in time.”

Different terms are used to describe the conditions:

Severe and Persistent Literacy Difficulties (SPLD) (including concerns about Dyslexia/ Dyscalculia and Dysgraphia)

People with SPLD/dyslexia may have difficulty connecting letters they see on a page with the sounds they make. As a result, reading becomes a slow, effortfull, and not a fluent process for them.

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 SPLD/dyslexia have difficulty with accuracy and fluency in word reading and spelling and 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 SPLD/dyslexia often try to avoid activities involving reading when they can, sometimes by being disruptive in class. They may find it easier to understand pictures, video, or audio rather than written words.

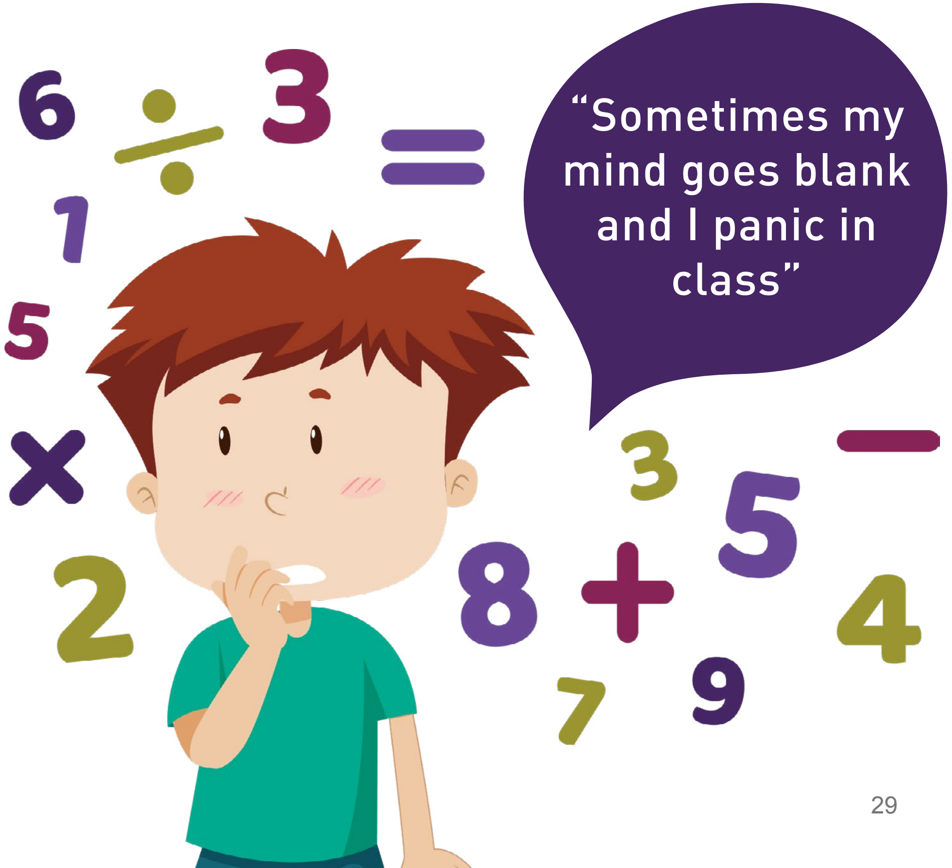
The British Dyslexia Association
https://www.nhs.uk/conditions/dyslexia/

Dysgraphia is a term used by some people for writing difficulties and can include having problems with spelling, grammar,

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

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.

Within the UK, most neurodivergent conditions have agreed diagnostic criteria (e.g., ASD, ADHD, Dyspraxia, Tourette’s); Dyslexia, Dysgraphia and Dyscalculia do not, which means that these terms are not used by some organisations.



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 Authorities' Education departments, to help schools and support your child and may include access to a literacy programme.

"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."

Did you know...
Henry Ford, Walt Disney, Steven Spielberg all had literacy difficulties. Henry Winkler has dyslexia and difficulty with maths.

Libraries

Libraries provide a welcoming and safe space for you and your child.

Many libraries will have a dedicated area for adults and children with literacy difficulties, they also have staff trained in understanding different needs and signposting help.

They may have a supply of Barrington Stoke literature, including books with a high interest level (e.g. age 12) and a lower literacy level (e.g. reading age of 6) – this is shown discreetly on the back of the book. They also have books in bigger or easier to read fonts/on coloured pages and audio books, etc.

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**)
- What is Dyscalculia? - The Dyslexia Association **www.dyslexia.uk.net/specific-learningdifficulties/dyscalculia**
- Dysgraphia - Psychology Today United Kingdom - **www.psychologytoday.com/gb/conditions/dysgraphia**

Local services

- East Herts,Broxbourne, Welwyn and Hatfield **EHBROX.ISLTEAM@hertfordshire.gov.uk**
- North Herts and Stevenage **NHSTEV.ISLTEAM@hertfordshire.gov.uk**
- St Albans and Dacourm **STADAC.ISLTEAM@hertfordshire.gov.uk**
- Watford, Three Rivers and Hertsmere **WAT3RIV.ISLTEAM@hertfordshire.gov.uk**
- SENDIAS Hertfordshire **info@hertssendiass.org.uk**

Developmental Language Disorder (DLD)

Developmental Language Disorder is a brain difference that makes talking and understanding language difficult.

DLD is hidden but common:

- 1 in 14 people have DLD
- 2 children in every class of 30 (7.5% of children) start school with DLD
- A further 2.34 % of children start school with a language disorder associated with another condition, such as autism, brain injury, Down’s syndrome, cerebral palsy, hearing impairment or learning disabilities.

People with DLD may experience challenges with:

- Understanding instructions
- Answering questions
- Learning new words
- Putting words together in sentences
- Reading
- Writing sentences

The prevalence of developmental language disorder

- Two children in every class of thirty, or **7.58% of children**, start school with DLD.[1]
- A further **2.34% of children** start school with a language disorder associated with another condition, such as autism, brain injury, Down's syndrome, cerebral palsy, hearing impairment or learning disabilities.[2]

If DLD is not identified and supported, it can affect literacy, learning, friendships, emotional well-being, employment and quality of life.

People with DLD are all different and have many strengths.

DLD is identified by a speech and language therapist but many professionals, such as teachers, can help to support people with DLD. With the right support, people with DLD can thrive and succeed in life.

See the following links for further support:

https://radld.org/ - Raising Awareness of developmental Language Disorder

https://www.rcslt.org/speech-and-language-therapy/clinical-informatio n/developmental-language-disorder/

Dyspraxia (Developmental Coordination Disorder - DCD)

Dyspraxia (also known as Developmental Coordination Disorder or DCD) affects the physical co-ordination of both fine and gross motor skills.

This can impact on everyday activities, such as:

- Writing and drawing
- Tying shoelaces and doing up buttons
- Eating food, drinking from a cup and using cutlery
- Speaking
- Riding a bike
- Playing sports

Some children may find some of these tasks physically painful and try to avoid doing them.

An Occupational Therapist can provide you with a number of strategies and/or exercises to help your child with these difficulties.

SEND SAS specialism areas also include sensory and physical neurological needs. We are a team of qualified teachers and specialists who support children and young people who have needs relating to neurodiversity, with specialisms in areas including speech, language, and communication needs (SLCN), autism, Cognition and Learning, Sensory impairment (Deaf, Blind, Deaf blindness) and physical/neurological impairment.

> “I felt so bad, I’d been constantly nagging my son to hold his cutlery properly and didn’t realise how painful it was for him to do that. He thought everyone’s hands hurt when they ate and that he was...

✓ 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

- www.dyspraxiafoundation.org.uk
- Dyspraxia: My life with the misunderstood condition - BBC News **(https://www.bbc.co.uk/news/uk-england-5769137)**

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 preceded 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.

The frequency, severity and functional impact of tics are not important considerations when diagnosing Tourette's. Some people may have just a few tics which do not interfere much with daily life, whereas for others, tics can be more frequent and complex with a significant impact. Although it is true that 'coprolalia' – the clinical term for involuntary swearing – is a symptom of TS, it doesn't affect everyone and it is NOT a criteria for diagnosis. It can however be one of the most difficult tics to manage.

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', come and go, with periods where people will have more or less tics, with no apparent pattern to this increase/ decrease in tic frequency. However, tics can also be 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. The sensory environment can also have an impact on tics, people often report that certain lights, sounds or temperatures can make tics worse. Tics can often 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 effortfull and may be exhausting. Tourette's is a lifelong condition, however around 50% of adults report that their symptoms have reduced following adolescence. In the majority of cases, the tics will improve and may go away completely by late adolescence/early adulthood.

TS is often associated with other neurodivergent conditions such as ADHD and Autism. It is also often associated with secondary mental health conditions e.g. Obsessive Compulsive Disorder (OCD) and Social Anxiety. Whilst an individual may not always have a co-occurring condition, they will almost always have features of the conditions. It is often most helpful to support children and young people with tics in managing these co-occurring features, as this can have a positive impact on the tics.

Getting a diagnosis for TS

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

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 for them (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.

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.

Certain activities can help to lessen tics e.g. physical activity, intense concentration, music - find whats works for your child.

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/155-elerarning.html**

Section 2

Related health difficulties

Co-Occurring Conditions (Comorbidities)

A lot of neurodivergent conditions are co-occuring, or overlap. It may be useful to understand more about these, to better understand your child's needs. This list is not exhaustive, but some examples are:

- **Hypermobility** - very flexible joints which may cause you pain. www.hypermobility.org/Pages/Category/join-a-support-group
- **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

Global Developmental Delay

- **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/
- **Irlen syndrome –** Differences in the way the brain processes visual information which can affect reading and printed information. It is not easily diagnosed via normal sight checks. www.learningdisabilitytoday.co.uk/irlen-syndrome
- **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
- **Learning Disabilities –** A person with an IQ under 20 would be described as having a profound learning disability. A person with an IQ of 50-70, mild learning disability.

Mental Health

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

However, neurodivergent 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

Burnout is often a consequence of masking, or feeling overwhelmed for extended periods of time.

Burnout may manifest as intense and serious anxiety and/or depression and it may involve increased autistic traits such as repetitive behaviours, increased sensitivity to sensory input, or difficulty with change. In extreme cases, it can go on for many months.

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/)

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 neurodivergent 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/)

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. This can involve school related trauma and be a consequence of bullying.

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

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/)**

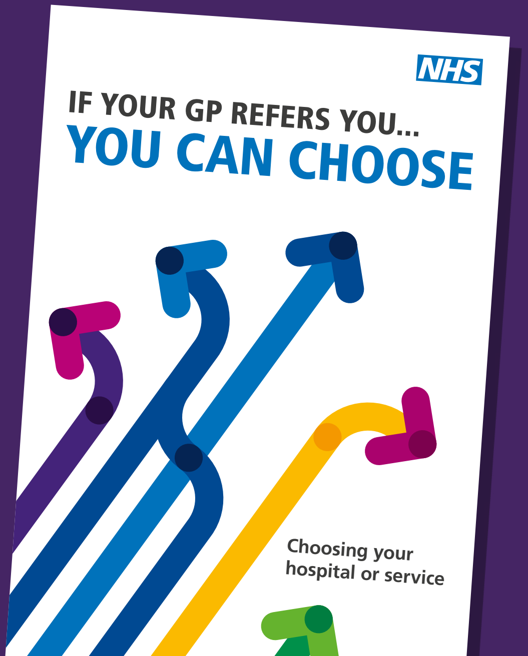
What professional help is available?

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?
- (**https://www.gov.uk/government/publications/the-nhs-choice-framework/the-nhs-choice-framework-what-choices-are-available-to-me-in-the-nhs**)



NHS

IF YOUR GP REFERS YOU...

YOU CAN CHOOSE

Choosing your hospital or service

Local services

Call HPFT’s freephone number: **0800 6444 101**

The quickest way to get help for a mental health crisis, day or night.

You can seek advice from 111 if you need help urgently, but it is not an emergency. In an emergency you should go to A&E or dial 999.

The mental health charity MIND has produced a guide on planning for a mental health crisis **www.mind.org.uk/information-support/guides-to -support-and-services/crisis-services/planning-for-a -crisis**

Waiting times to access mental health services can be long, please refer to the information in Section 9 for ideas on you can support your child while you are waiting

What if you have difficulties accessing help

For many neurodivergent 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/personalisedcare/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.england.nhs.uk/personalisedcare/personal-health-budgets/personal-health-budgets-for-people-with-learning-disabilities/**

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). To suppress the thought or lessen the anxiety, they will often repeat an action, again and again (compulsions).

There are two aspects to OCD

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.

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.

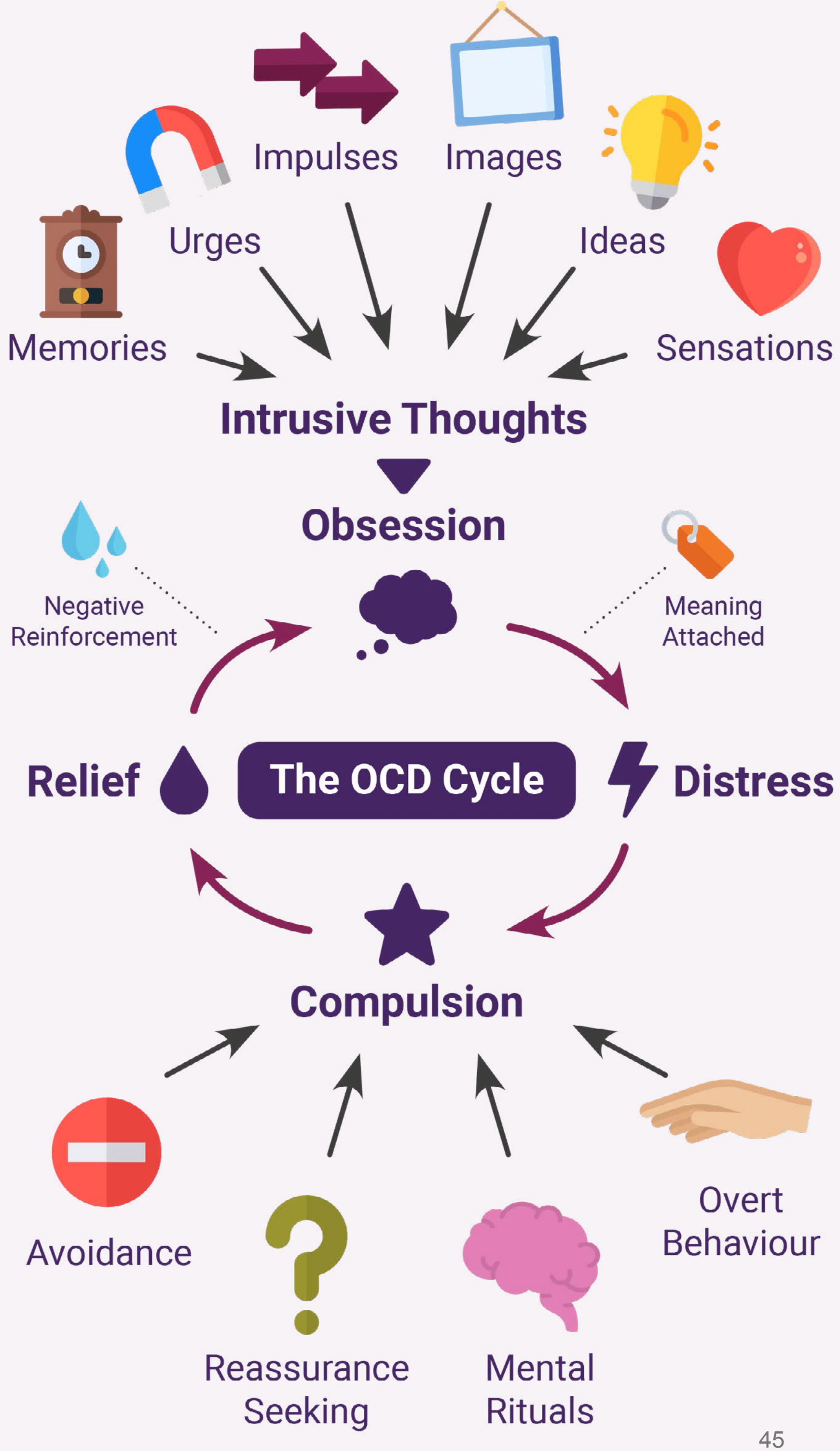
One of the greatest challenges if you have OCD, is to debunk the widely held belief that OCD is a mild or even “quirky” problem that is nothing more than hand washing. People might use the phrase “a bit OCD” without understanding what it really means.

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?



Eating Disorders

Disorders are more than simply problems with eating and are diagnosable medical conditions. Other mental health conditions may manifest through a relationship with food.

Anorexia Nervosa

Trying to keep weight very low by eating less or over exercising. **Atypical anorexia: Facing an eating disorder, Autistically by Reframing Autism.** (**https://reframingautism.org.au/atypical-anorexia-facing-an -eating-disorder-autistically/**)

Bulimia

Binge eating and then making yourself sick because of the fear of gaining weight.

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 neurodivergent 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. **Restrictive ARFID** – the person doesn't feel hungry or is easily distracted from eating.

There are a number of typical symptoms which may help you to identify whether your child has ARFID:

Behavioural symptoms

- Fear of eating – anxiety around meal times
- Refusal to eat some or all food
- Difficulty eating in font 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/P icky%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)

Section 3

Early Help and Where to Start

Introduction

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.

Some children may have neurological differences that are identified at birth or during their preschool years; while others may reach developmental milestones earlier or later than their peers, such as walking, talking, and toileting. It’s also possible for a child’s differences to become more noticeable as they progress through primary and secondary school, or during puberty.

It may be that you are not the first to notice differences. Some parents will 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 preschool/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. Youmay be referred to Speech and Language Services.

If there are differences that you are concerned about, you may wish to approach your GP or Health Visitor to discuss your concerns.

> “I felt no one understood my child. I didnt understand why my child was getting upset.”

Why might a diagnosis be important?

You may have been told that your child does not need a diagnosis to access support. Is this correct? By law, reasonable adjustments must be made for a child based on their needs, regardless of whether or not they have a diagnosis. However, it can be a ‘chicken and egg’ situation, as sometimes parents, carers, and relevant professionals do not know what a child’s needs are until qualified professionals have carried out an assessment.

It may prove more difficult to access support without having a diagnosis in place. If your child or young person receives a diagnosis they will be protected against discrimination under the Equality Act 2010.

Not every family will choose to seek a diagnosis, and that is perfectly fine - it's up to each individual family to make that decision. We asked parents why they sought a diagnosis for their child:

- 'To get help at school'
- 'To understand what was going on – was this a behavioural issue or something more?'
- 'To protect my child in the future'
- 'Because he was having a really hard time and needed help'
- 'So that she is protected by disability discrimination legislation'
- 'To know that I wasn't going mad as a parent'

First Steps

There are lots of things that you can do to help your child without a diagnosis:

- Speak to your school/nursery and see what help they can suggest Talk to other parents in a similar situation
- Keep a diary of differences or difficulties
- Read this book and follow the links to research areas of
- interest/concern
- Join support groups
- Find inclusive activities for your child

Every local Council will have a "Local Offer" online which will detail all the help and services available for children with special educational needs and disabilities in that area.

Useful links

- **Hertfordshire Local Offer** **https://www.hertfordshire.gov.uk/microsites/local-offer/the-hertfordshire-local-offer.aspx**
- **Neurodiversity Support Hub (hertfordshire.gov.uk)**

> "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

Keeping notes can help you to understand patterns and trends of your child's behaviour. Many neurodivergent children can have good days and bad days. This may enable you to recognise triggers and how you can best support your child. You can keep a record of sensitivity to smells, noises, examples of distressed behaviour, anxieties, unusual speech patterns and interactions with other children, struggling to concentrate, fidgeting, difficulty with handwriting or using cutlery, etc.

You can also include comments made by professionals, family members, childminders, teachers or friends, as this may help to validate your concerns.

It is useful to have these examples to hand when you are talking to professionals.

"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"."

Next Steps

Pre-school children

You can talk to your health visitor or nursery/preschool staff.

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 are'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.

Children aged 5-18

Visit your GP or speak to your school to discuss your concerns. See chapter 4.

✓ **Parent top tip**

Buy a folder and start keeping a record 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."

Section 4

Overview of the diagnostic process and what to expect

Discussing your Concerns

GPs and schools do not have the expertise to diagnose neurodivergent conditions, so they will refer you to a clinician who can undertake the diagnostic assessment.

Referral

GPs will include any information you provide when they make the referral, so it is important to share the records that you have been collecting. You can also include

- whether any relations are neurodivergent,
- relevant medical history etc.
- feedback or evidence from any professionals working with your child, this can include swimming teachers, childminders after school club leaders etc.

If your GP agrees that your child has sufficient indicators of neurodiversity, they will refer to the local health service provider that undertakes diagnostic assessments. Full details of the provision and process that will be followed are available on your local offer. Links to NHS and NICE guidelines are also shown below.

Finding it difficult talking to and being with other people

Having unusual or intense interests

Strongly preferring your usual routine

Sometimes finding noise, touch, taste and texture, lights or smells difficult to deal with

Developing more easily in some areas than others

Finding some situations and experiences difficult to cope with

Further information

- NHS guidelines autism **(www.nhs.uk/conditions/autism/getting-diagnosed)**
- NHS guidelines ADHD **(www.nhs.uk/conditions/attention-deficit-hyperactivity-ns/attention-deficit-hyperactivity-disorder-adhd/diagnosis)**
- NICE guidelines autism **(www.nice.org.uk/Guidance/CG128)**
- NICE guidelines ADHD **(www.nice.org.uk/guidance/ng87)**

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.
- Continue to update your records with examples of your child's difficulties.
- Consider applying for Disability Living Allowance which could help with the cost of providing

What to expect at the appointment

An assessment can take place with one professional, such as a paediatrician, or sometimes, it can be a multi-disciplinary team approach (MDT) and several professionals and clinicians can be involved as part of the assessment, such as:

- Paediatrician
- Specialist nurses
- Speech and language therapist
- Occupational therapists
- Educational psychologist
- Nursery Nurse

As well as the involvement of different professionals and clinicians, the type of assessments or "diagnostic tools" used can also vary depending on the condition being assessed for, and the age of the child. You will be advised ahead of any assessment the type of tools that will be used, and who will be conducting the assessment. If you have any questions, you can ask before the assessment takes place.

> "When I took my eight year old son for an assessment, and he heard all the things I had to say about this disabilities and how they affected him, he was so upset that later in the day he wet himself. I felt awful, I wish I had known I could speak to them beforehand, rather than in front of my son. He still remembers how sad he felt now."

Top tips

Make sure you bring your list of the signs you see (a timeline)

- ✓ 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.
- ✓ To avoid your child having to listen to you talk about their difficulties, you may wish to ask if you can contact them in advance to discuss the information that may upset your child while they are in the room e.g. a phone call in advance, or an email. Alternatively, if you bring a friend or partner to the appointment, you could ask them to come with you to the appointment, so that they can take the child out of the room at this point.
- ✓ Take a drink and snack for your child as well as a favourite toy for whilst they are waiting.
- ✓ Write down any questions you may want to ask in advance, to help you remember on the day.

Diagnostic Tools

Various diagnostic tools are used, depending on the specific condition, where you live, and the specialist that you see.

Autism diagnosis in Hertfordshire - A diagnosis of autism is usually confirmed by two or more clinicians, this may include a paediatrician, clinical psychologist, speech and language therapist or assistant psychologist. They will use the information gathered through the assessment and compare it to an internationally agreed set of criteria, such as the DSM5, as well as consider other information that is important when thinking about autism.

How the assessment is carried out may depend on the age of your child and their specific profile of strengths and challenges. For some children they may find coming into a clinic environment overwhelming and so an observation in their school or nursery setting or even at home may be better for them. For other children meeting with a clinician 1:1 in clinic will provide the best information so that they can communicate their experiences.

For all assessments, information from different settings is taken into account, for example how your child is at home, school and in the community. It is important that the clinicians have a good understanding of what your child is good at as well as any differences or challenges in various environments. The team will talk to you about the assessment and which tools will be used to gather information.

> ‘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.’

Your child has received a diagnosis

How do YOU feel?

Whatever you are feeling is entirely normal.

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.”

What can I do now?

It is common for parents and their families to react differently to a diagnosis, whether it brings feelings of overwhelm, shock, or relief. Once a diagnosis has been confirmed, it is important to do thorough research to gain a better understanding of your child's needs.

Remember that your child is still the same person they were before receiving the diagnosis, and allow yourself time to adjust to the news.

Local charities and support groups may offer on-line or in-person meet ups, as well as 1:1 support for parents and are a vital support network for families. Many will also offer activities for your child, giving them opportunities to meet other neurodivergent children and make friends.

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

Telling your child about the diagnosis

here 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**)

"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.

What do I do if my child is not diagnosed?

If a child does not receive a diagnosis, this is because the clinician assessing does not feel that there is enough evidence to meet the diagnostic criteria.

A lack of diagnosis should not mean that your child's needs are not supported by their school or other services. By law, reasonable adjustments must be made for a child based on their needs, regardless of diagnostic labels.

Sometimes difficulties can become more evident as children get older, especially for children who have learned to mask their differences in front of strangers. In these cases, continue to keep evidence and return to your GP to ask for a re-referral for a second opinion.

The charity Contact (contact.org.uk/help-for-families/information-advice-services/health-medical-information/all-about-diagnosis/getting-a-diagnosis) may be able to give you advice about your options for referrals, including private assessments.

"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."

Section 5

Education and School

Signs that your child may need extra help

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

Your child's school or pre-school may have already identified that your child needs extra support. However, you know your child and are their best advocate. If you notice that your child has 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
- Having a meltdown before or after school
- Hiding themself away and being unusually quiet
- Showing anxiety when you leave them
- Reluctance to go to school
- Getting into trouble at school for their behaviour
- Finding it hard to learn
- Struggling to follow instructions
- 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
- Finding it hard to move from one activity to the next

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)**.

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.
- A total communication approach where your child's understanding is supported by the use of visual tools, such as objects, pictures, signing or symbols and their communication strengths and preferences are encouraged.
- Sensory toys, weighted blankets, wobble cushions.
- Sensory breaks and a quiet place to go to if feeling overwhelmed.

Delaying School Admissions

If your child has development delays and you don't feel that they are ready to start school, you may have the option to delay if you feel that they need more time to prepare.

For instance, if your child turns 4 in August, waiting before sending them to school may be helpful but it is important to ensure your child is in full-time education by the time they reach compulsory school age.

If you decide that you would like to make a request to delay your child's start, a few options are available to you, including a part-time time-table, a delayed late admission (starting part-way through the year), or waiting a whole year, so that they start school in the next school year, in the September after they turn five.

Further information

Hertfordshire Summer Born Children - starting school.

https://www.hertfordshire.gov.uk/services/schools-and-education/school-admissions/primary-junior-and-middl e -schools/summer-born-children-starting-school.asp

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 neurodivergent 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..

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.
- ✓ Ensure that you discuss your child’s communication preferences with the school and that any supports are available (e.g. visual supports, understanding of signing etc).
- ✓ 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?
- 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?

> "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."

“My daughter and the school were worried about her attending a trip, so we worked together to find out more about the venue, e.g. where the toilets were. I was allowed to come along as an extra adult, which meant that she was able to enjoy the day with her friends.”

“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 policies on:

- SEND
- Supporting Children With Medical Conditions
- Behaviour and Discipline
- Inclusion
- Uniform
- Attendance

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.

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

1

Stage 1: Contact class teacher/key worker

Speak with your child's main contact at school (e.g. key worker, class teacher, Head of Year, Pastoral Lead, etc) to discuss your concerns and to understand whether the 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.

"I couldn't read what was on the board"

"I had no one to play with"

"I didn't eat much lunch today"

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 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.

The SENCo may also feel that the school require additional advice to ensure that the most appropriate support is put in place for your child. If so, the SENCo may choose to refer your child to the SEND Specialist Advisory Support Service (SEND SAS). This is a team of specialist teachers who work for Hertfordshire and provide advice, training and guidance to schools.’ Contact a SEND service (**hertfordshire.gov.uk**)

> “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
- Phonics, reading, writing
- Attention and concentration
- Developing social skills
- 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 your child requires more support, they will:

Primary School - Help the class teacher to fine turn their teaching to reflect your child's needs. This is sometimes referred to as 'Quality First Teaching (QFT).' QFT is a style of teaching that focuses on high quality and inclusive teaching for every child in a classroom.

Secondary School - Share the One Plan with all subject teachers, Head of Year and any other key individuals.

For Both - Some reasonable adjustments and small intervention groups 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.

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.

Reasonable adjustments

Education providers must make reasonable adjustments to ensure that neurodivergent children and young people are not disadvantaged. **Suggestions 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 and movement breaks.
- Being allowed to not go to assembly
- Sitting on a wobble cushion.
- Pencil/pen grips.
- Breaking down tasks into small steps.
- Tasks written as well as verbal instructions.
- It could be helpful if the teacher could inform students beforehand when they will be asked a question in class. Alternatively, the teacher could arrange not to ask certain students questions if they find it particularly challenging.
- Having a card to put on their desk or hold up if they are struggling, rather than verbally telling the teacher in front of the whole class.

Reasonable adjustments can help level the playing field for disabled pupils in the classroom. For example:

- A visually impaired pupil is seated to accommodate their field of vision
- Adjusting your snack policy to let a pupil with diabetes have a high calorie snack
- Adapting your school uniform policy for a pupil with allergies or sensory needs
- Letting a pupil go into the dinner hall before other pupils to help their sensory processing
- Allowing a disabled pupil to sit exams in a room for a smaller group of pupils
- Traffic light cards are available for a pupil to communicate who needs extra time
- Coloured paper is provided for a dyslexic pupil
- Allow a pupil with dyslexia and/or dyspraxia to use a laptop top write
- Providing ear defenders to a pupil who is very sensitive to noise to wear as appropriate

Department for Education information on Reasonable Adjustments

https://educationhub.blog.gov. uk/2023/04/10/what-are-reasonable-adjustments-and-how-do-they-help-disabled-pupils-at-school

Reasonable adjustment for exams

Several types of reasonable adjustments can be requested, depending on the reason. Examples include:

- offer alternative formats such as modified exam papers assessments that can be spoken rather than written, a scribe, and laptop use.
- compensate for cognitive processing variances or physical fatigue such as 25% extra time, a prompter, supervised rest breaks, use of a computer, and taking the test in a smaller room.

> "I asked for extra time for my autistic daughter when taking her tests and exams to allow for her cognitive processing speed. This was agreed upon for everything except the drama practical exam. The school told me it would be considered a reasonable adjustment in a written exam but unreasonable in a practical assessment such as Drama."

Reasonable adjustment for exams

If your education provider refuses to provide reasonable adjustments, you can contact them and ask for the reasons why.

- Why do they consider each request unreasonable?
- Who has made the assessment, and what is their role?
- If you have been advised the adjustment you have requested is an unfair advantage to your child, ask for the rationale behind this decision.

If you feel your requests for help are not being answered to your satisfaction, you can check the school's SEND policy and follow the school's complaints procedure.

Local services

Hertfordshire Local Offer

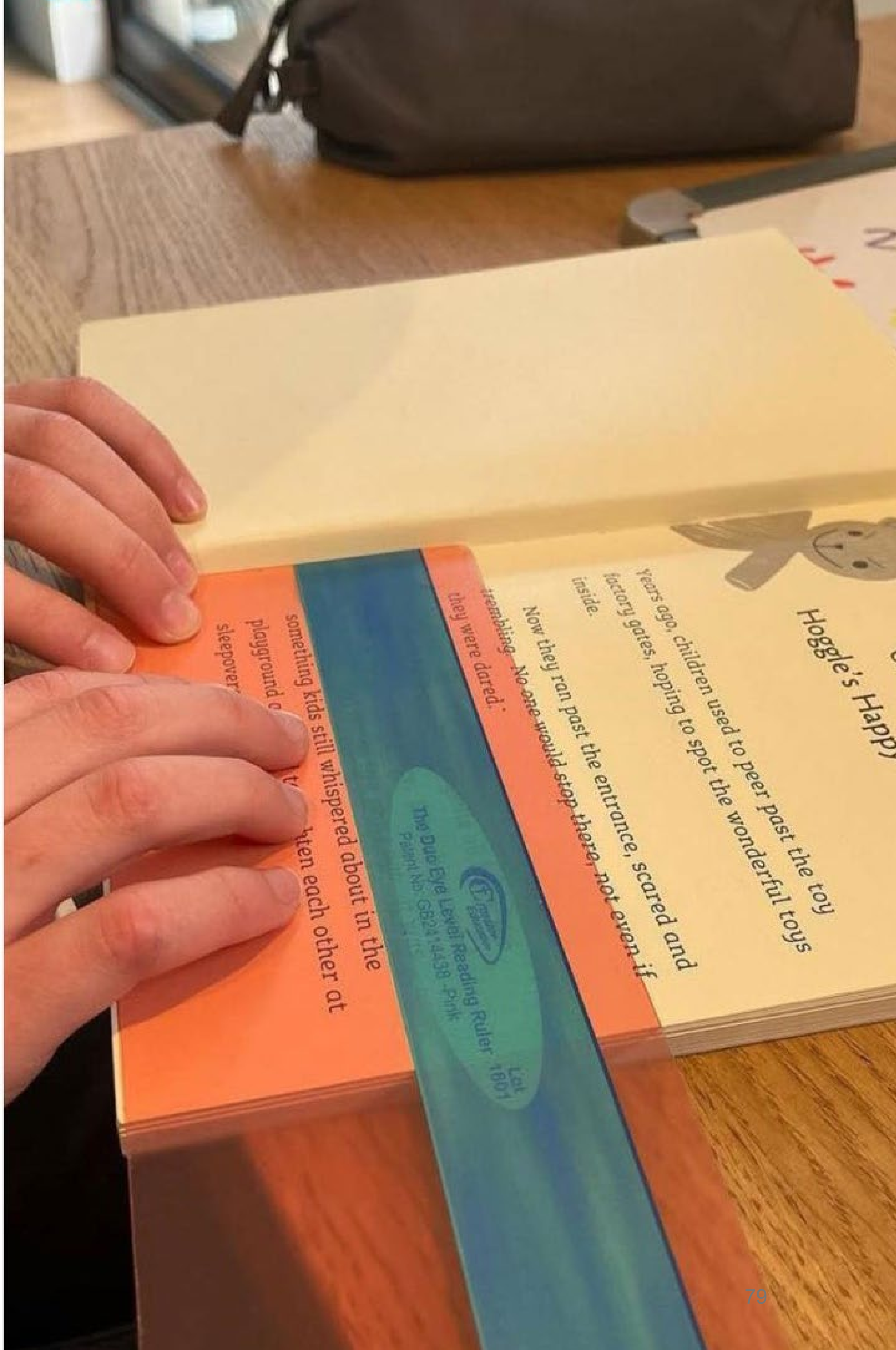
https://www.hertfordshire.gov.uk/microsites/local-offer/education-support/education-support.aspx

3

Stage 3:SEND Support and One Plans (Individual Education Plans, Learning Passports)

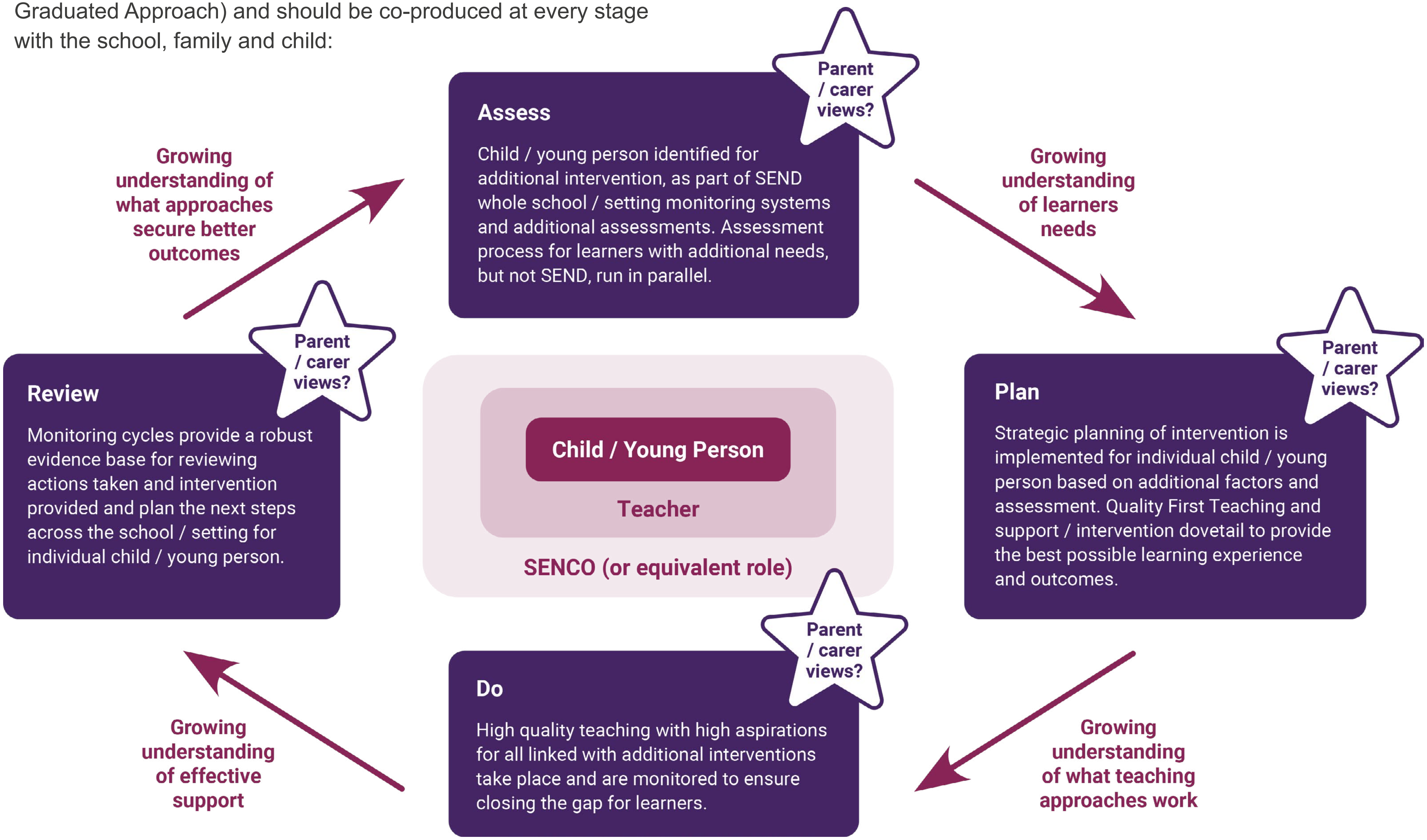
The next stage of help should be for children who need longer term SEND support to be placed on the school's Special Educational Needs register. Every school has a budget allocated for SEND support. It may sometimes be used to help groups of children, train staff working with SEND children or to help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

For children on the SEND register, an individualised support plan should be created, these may be referred to as One Plans, Individual Education Plans, Learning Passports or SEND Support. You, your child and school staff all contribute to the plan and progress is reviewed termly. One Plans/ SEND support should detail 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 including Communication and Interaction, Cognition and Learning, Social, Emotional and Mental Health, Academic Attainment and Sensory/Physical needs.



The 'Assess, Plan, Do, Review' Process

The One Plan process should be made up of a 4-part cycle of Assess, Plan, Do, Review (sometimes referred to as the Graduated Approach) and should be co-produced at every stage with the school, family and child:



Assess

Parent / carer views?

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.

Growing understanding of learners needs

Plan

Parent / carer views?

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.

Growing understanding of what teaching approaches work

Do

Parent / carer views?

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

Growing understanding of effective support

Review

Parent / carer views?

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.

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 (EHCNA).

4 Stage 4: Education and Health Care Plan (EHCP)

If you are concerned that this graduated approach has been tried with your child, but progress is still limited, requesting an Education and Health Care Needs Assessment could be the next step.

What is an Education and Health Care Plan (EHCP)?

An EHCP is a legal document that sets out a young person's special education needs and the support that they need. It covers birth until age 25 (if they remain in education and training) and can result in additional support and funding for a child or young person with special educational needs.

How do I get an EHCP for my child?

An Education, Health and Care Needs Assessment (EHCNA) is the first step owards getting an Education and Health Care Plan

(EHCP).

Who can request an EHCNA?

The following people can request an EHCNA:

- the child or young person's parents
- the young person themselves (i.e., someone over the age of 16) or someone on their behalf if they lack the mental capacity to do so
- a person on behalf of the child or young person's school
- professionals involved with the child or young person, such as foster carers, health and social care professionals, and early years practitioners.

Whilst the school usually makes the application, sometimes schools may not feel that an EHCP is necessary, for example, if a child masks at school. As a parent, you can request an

EHCNA if you feel your child is struggling in school or not making enough progress.

Criteria to apply for an EHCNA

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 EHCP.

There is additional guidance in the Send Code of Practice section 9.

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

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

- Nation-wide services:

Local Advisory Services

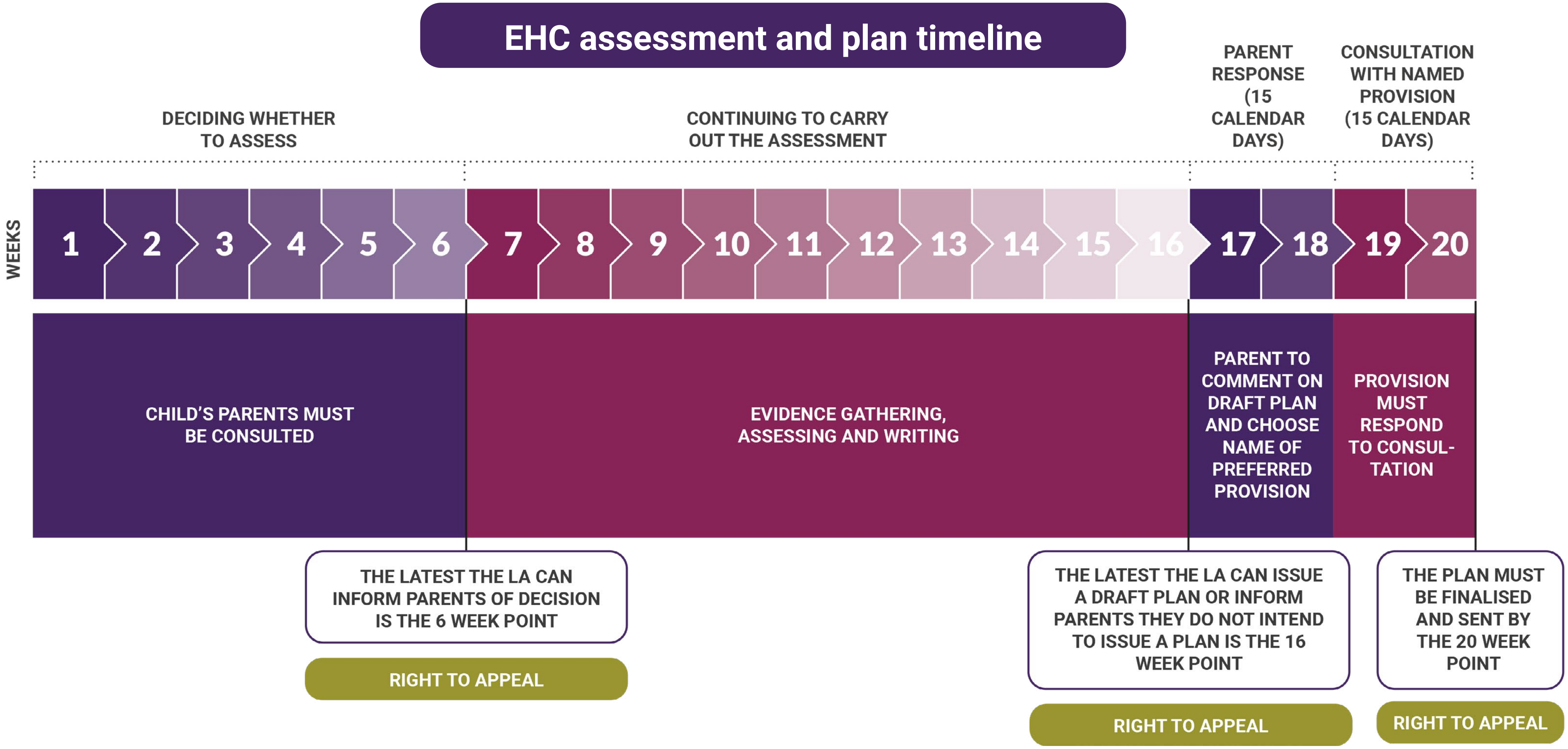
- SENDIASS Hertfordshire (**info@hertssendiass.org.uk**)

- IPSEA - Independent Provider of Special Education Advice (**www.ipsea.org.uk**)
- SOS SEN | The Independent Helpline for Special Education **Needs** (**www.sossen.org.uk**)
- Local charities and support groups which you can find on your Local Offer or search for on Google/Facebookr
- There are lots of individuals offering help with EHCPs, please check their qualifications and ask for recommendations from other parents before agreeing to pay any fees.

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. There are some exemptions to this such as school holiday dates. The application will be acknowledged when received by the Local Authority (LA) 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)

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 CONSULTATION

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

Overview of an EHCP

EHC plans are not standardised, as each local authority can adopt its own format. However, certain sections must be included to comply with the law.

Ipsea have created a really helpful overview: EHC Plan Checklist (**www.ipsea.org.uk/Handlers/Download.ashx?IDMF=afd8d11f-5f75-44e0-8f90-e2e7385e55f0**)

A The views, interests and hopes of the child and their parents or the young person

B The child or young person's special educational need (SEN)

C Health care needs relating to their SEN

D Social care needs relating to their SEN or to a disability

E What the outcomes of the support are hoped to be

F The special educational provision needed to meet their SEN

G Any health care provision needed to meet the child or young person's needs

H Any social care provision required from social services under the Chronically Sick and Disabled Persons Act 1970 and/ or to meet the needs of the child or young person

I The name of the school to be attended by the child or young person and the type of place of education (this should be left blank on the draft document and is only put into the final document)

J Details of any direct payments

K Copies of all the advice and information for the EHC needs assessment.

What do I need to do?

- Complete section A
- Check the draft EHC Plan
- Ensure outcomes are SMART
- Name your preferred school or education setting

Complete section A

When you write the parent section, think about including strengths and difficulties

Nobody knows your child better than you do.

There's no right or wrong way to complete this section but try to make the information as clear and concise as possible.

The views of children and young people are very important and will be included in the final EHC. It is useful to focus on areas that educational settings or other professionals writing reports may not be aware of.

Examples that some parents have shared:

- My child takes an adult by the hand to what they want
- When my child is older, she wants to go out and have fun like her friends
- My aspirations for him would be to enjoy his education, be fit and healthy, have friends, and maybe go to college or find
- employment.
- My daughter needs extra time and support daily and often relies
- on an adult to help her.
- He does not like certain foods, and I would love him to make and eat a sandwich independently.

Check 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.

Ensure outcomes are SMART

SMART goals are used to help guide goal setting. SMART is an acronym for Specific, Measurable, Achievable, Realistic, and Timely.

- **S** **Specific;**
- **M** **Measurable;**
- **A** **Achievable;**
- **R** **Realistic;**
- **T** **Time-bound.**

SMART goals 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 provided. Words and phrases like ‘regular or as required’ can cause particular difficulties o should be avoided.

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 is usually because the If the EHC assessment is declined information provided suggests that a young person's needs could be met at SEND 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. Remember that lots of first-time applications are declined but you can appeal. If you are considering appealing you must contact Mediation within 2 months of receiving the LA's decision letter.

Please see the IPSEA guide for details of the mediation and appeals process. **www.ipsea.org.uk/mediation-what-you-need-to-do**.

SEND Appeals

You can appeal to the Special Educational Needs and Disability Tribunal if you disagree with a decision your local authority has made about a child or young person's education, health, and care (EHC), needs or plan.

You can appeal if they:

- Refuse to carry out an EHC assessment or reassessment
- Refuse to create an EHC plan after carrying out an assessment or reassessment
- Refuse to change the sections of an existing EHC plan which are
- about education (sections B, F and I)
- Cease to maintain an EHCP

You have two months from the date on the Local Authority's decision letter not to issue an EHC plan to submit your appeal.

Check if you can get legal aid to help pay for legal advice: **www.gov.uk/check-legal-aid**

Contact details to make an appeal:

SEND Appeals
General enquiries
First-tier Tribunal (Special Educational Needs and Disability)
1st Floor, Darlington Magistrates Court
Parkgate, Darlington, DL1 1RU
United Kingdom

Email: **send@justice.gov.uk**

Telephone: **0300 303 5857**

Further information

- How to appeal a special educational needs (SEN)decision (**www.gov.uk/government/publications/how-to-appeal-a-special-educational-needs-sen-decision-send37**)
- Form SEND35a: Special Educational Needs and Disability Tribunal appeal a refusal to secure an EHC Needs Assessment (**www.gov.uk/government/publications/form-send35a-special-educational-needs-and-disability-tribunal-appeal-a-refusal-to-secure-an-ehc-needs-assessment**)
- Lots of useful information is available on the Ipsea website. Appealing to the SEND tribunal (**www.ipsea.org.uk/appealing-to-the-send-tribunal**)

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.
- Outcomes
- 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.

Outcomes

At the end of the review, there are three decisions the Local Authority can make:

1. To maintain the EHC plan in its current format (not make a any changes);
2. To amend the EHC plan;
3. To cease the EHC plan if, following consultation, they think it is no longer necessary for it to be in place.

If your child is coming up to a phase transfer (for example, moving from primary school to secondary school), the LA must carry out the review well in advance of the move.

For those transferring from secondary school to a post-16 provision, the EHC plan must be reviewed and amended by 31 March in the year of transfer; for all other phases of transfer, the deadline is 15 February in the year of transfer.

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**

> "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."

Home to School Transport

For children under 16

For children under 8 who live more than two miles away from their nearest suitable school (3 miles away for children over 8), Local Authorities must make free-of-charge travel

arrangements to facilitate the attendance at school of eligible children and young people of compulsory school age.

In addition, for children with SEND, if your child cannot

reasonably be expected to walk to school because of a special educational need, disability, or mobility problem, they may be entitled to free school transport, regardless of the distance they live from the school. Local Authorities will assess eligibility on a case-by-case basis. The Government Guidance provides some helpful examples on eligibility assessments).

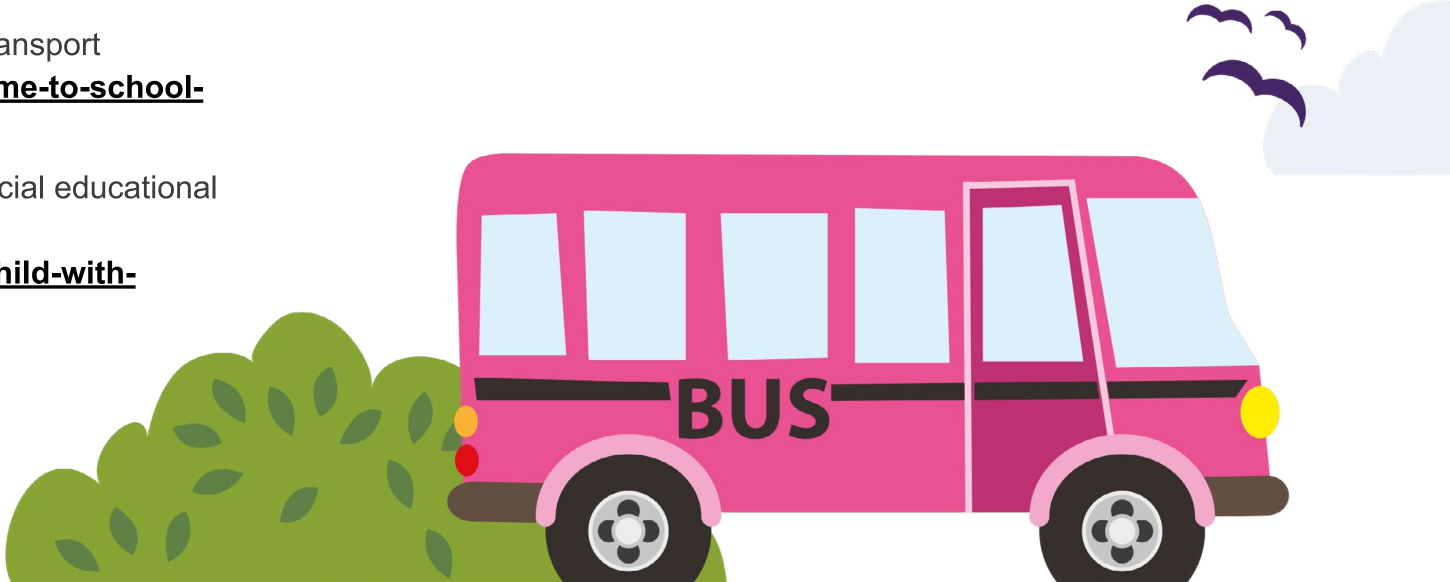
- Government guidance on Home to School Transport (**www.gov.uk/government/publications/home-to-school-travel-and-transport-guidance**)
- Apply for school transport for a child with special educational needs and disabilities (**www.gov.uk/apply-school-transport-for-child-with-special-educational-needs-sen**)

Local Advisory Services

- **Hertfordshire Local Offer -**

https://www.hertfordshire.gov.uk/microsites/local-offer/education-support/help-you-can-get-when-your-child-is-in-school/send-home-to-school-transport.aspx

Transport for eligible children must be suitable for their needs. These requirements are defined in sections 508A, 508B, and schedule 35B of the Education Act 1996



Post 16 transport

For young people aged 16 to 19, each local authority must publish it's own Transport Policy/Statement setting out the arrangements for specific groups of young people (as detailed in the Education Act s509AA).

The needs of young people with special educational needs and disabilities should be specifically considered, as well as those of the most vulnerable or socially excluded. They should consider individual circumstances and provide the necessary support to enable them to attend their educational establishment.

There is, however, no requirement to provide free-of-charge transport arrangements and most, Local Authorities have implemented a charge for 16-19 transport. It is likely that, even if your child does not change their education setting, you will need to re-apply for transport in addition to making the required payment. You should refer to your Local Authority's website and/or Local Offer for full details.

- Government guidance - Transport to education and training for people aged 16 and over (**www.gov.uk/government/publications/post-16-transport-to -education-and-training**)

Further Information

- Ipsea guidance - Young people aged 16 to 19 | (IPSEA) Independent Provider of Special Education Advice (**www.ipsea.org.uk/young-people-aged-16-to-19**)
- SENTAS – Special Educational Needs Transport Advocacy Service (**https://sentas.co.uk**)
- Transport - (**https://www.hertfordshire.gov.uk/microsites/local-offer/educ ation-support/help-you-can-get-when-your-child-is-in-school/send-home-to-school-transport.aspx**)

Travel training

Your local council may offer travel training' which can help young people to develop the confidence and skills or travel independently on buses, trains and walking routes.

You can also practice using public transport with your child and familiarise them with helpful walking routes.

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.

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

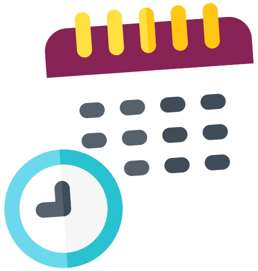
- **Transition workbook -** address differences between settings with a step-by-step approach. You can ask your existing setting to provide this.

- **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.



- 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.
- 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.

- Ask if the school could provide a timetable with pictures or icons instead of lots of text to make it easier to understand.

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.

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.

11. **If your child uses the Local Authority transport service,** speak to the transport provider to find out more about the journey, e.g. the route they will take, how many other children will be in the car, how long it will take, where the collections/drop- offs will be, will there be an LSA on board, who is the driver and what happens if traffic is bad and there are delays.

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.

- **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**)
- **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**
- **Square Peg** **www.teamsquarepeg.org**
- Check your Local Offer for support available in your area

Local Services

Education Access Team - if child has missed 15 days or will miss 15 days due to disability, medical, mental health or pregnancy, this team works with families to look at options - **find here**.

- **Hertfordshire SENDIAS and Home Education**

  call: 01992 555 847
  email: info@hertssendiass.org.uk

  visit; https://www.hertfordshire.gov.uk/microsites/local-offer/education-support/education-options/home-schooling.aspx

Education Other Than At School Vs Elective Home Education - What is best for my child?

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 (Education Other Than At School) package (**www.education-ni.gov.uk/articles/education-outside-school**) This includes all forms of education that take place outside the school environment, such as alternative provision.

- 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**)

Elective 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

- Check your Local Offer to see what support may be available in your area
- 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 fixed period exclusion.

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**)
- Child Law Advice (**https://childlawadvice.org.uk/information-pages/school-excl usion**)
- Exclusion from school (**https://contact.org.uk/help-for-families/information-advice-services/education-start/education-learning/exclusion**)

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 exclusion and what you should do. It also contains details of how to challenge the exclusion 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 fixed term exclusion, 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.

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 Equality Advisory Support Service (EASS) who provide information and advice about discrimination and human rights issues. EASS helpline:
- Telephone: 0808 800 0082 / Textphone: 0808 800 0084

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

What is an Educational Psychologist (EP)?

What we do

We provide independent professional advice to families, schools and other education settings. An EP applies psychology (the study of thinking, learning, emotions and behaviour) to support the learning, development and wellbeing of children and young people up to 25 years old. In Hertfordshire many EPs have specialist skills in areas such as autism, behaviour, literacy and mental health.

How we can help

An EP might be a good choice to help with significant learning, behaviour or other difficulties which are complicated, difficult to understand or have not improved with the support already in place. We work in a person-centred way to plan how to support a child or young person depending on their needs. This might include talking with the child or young person, psychological testing, observing in class and speaking with key staff and family members. This information will be used to plan what to do next. Sometimes we support in other ways, for example, by training the staff in the setting that the child or young person attends.

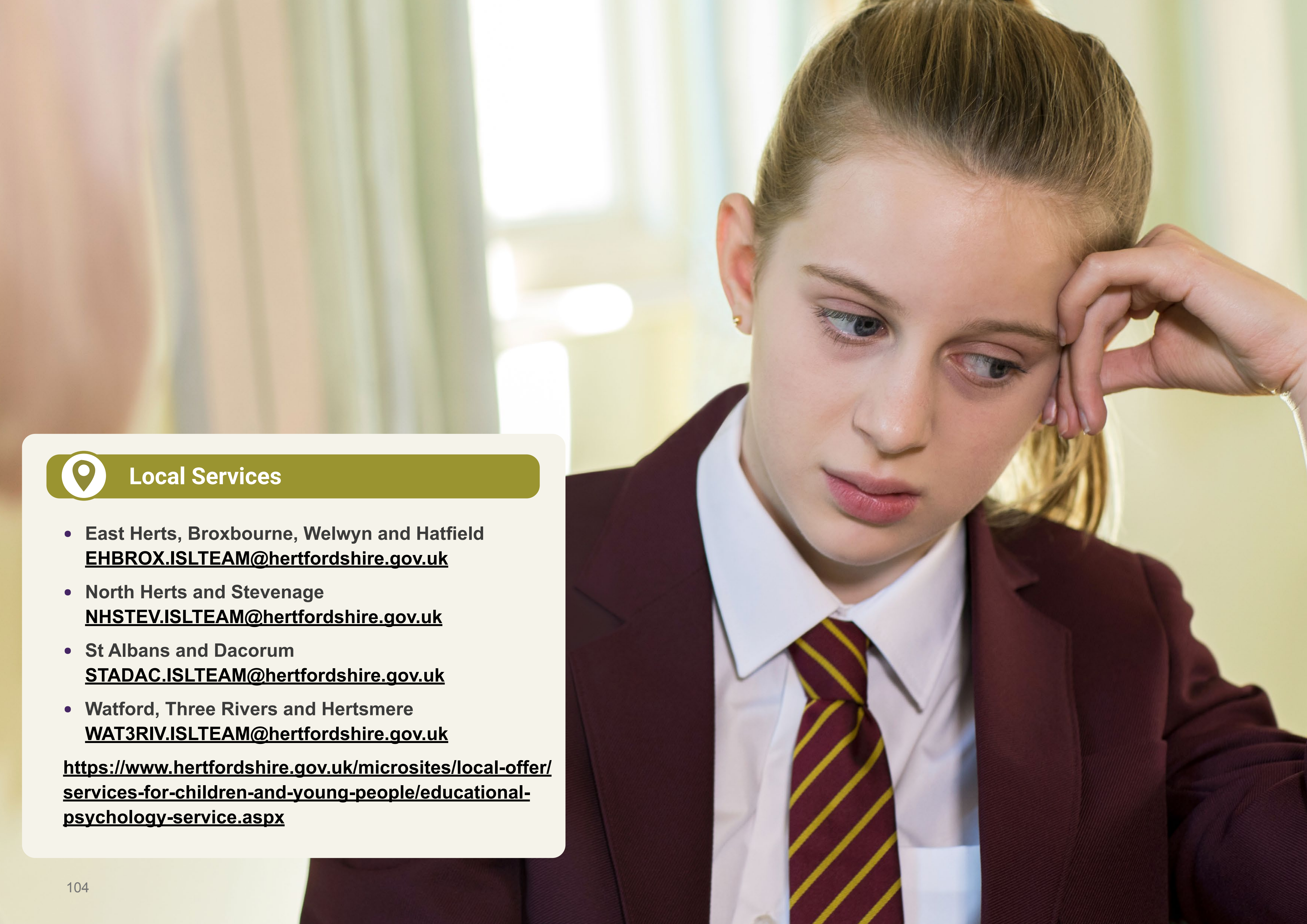
What is a Specialist Advisory Teacher?

What we do

We are a team of qualified teachers and specialists who support children and young people who have needs relating to neurodiversity, with specialisms in areas including speech, language, and communication needs (SLCN), communication and autism, and Cognition and Learning. We provide advice and guidance through meetings with schools and families, observations of, and discussions with, children and young people in school and whole-school support.

How we can help

An EP might be a good choice to help with significant learning, behaviour or other difficulties which are complicated, difficult to understand or have not improved with the support already in place. We work in a person-centred way to plan how to support a child or young person depending on their needs. This might include talking with the child or young person, psychological testing, observing in class and speaking with key staff and family members. This information will be used to plan what to do next. Sometimes we support in other ways, for example, by training the staff in the setting that the child or young person attends.



Local Services

- East Herts, Broxbourne, Welwyn and Hatfield
  EHBROX.ISLTEAM@hertfordshire.gov.uk
- North Herts and Stevenage
  NHSTEV.ISLTEAM@hertfordshire.gov.uk
- St Albans and Dacorum
  STADAC.ISLTEAM@hertfordshire.gov.uk
- Watford, Three Rivers and Hertsmere
  WAT3RIV.ISLTEAM@hertfordshire.gov.uk

https://www.hertfordshire.gov.uk/microsites/local-offer/services-for-children-and-young-people/educational-psychology-service.aspx

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 Services

Local authorities have teams that provide additional support to schools to help them to be inclusive.

- **Hertfordshire SEND team information https://www.hertfordshire.gov.uk/microsites/local-offer/education-health-and-care-plans/contacting-the-send-team.aspx**

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.

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.

Bullying

We all hope it will never happen to our own children and also that our children will never need to be considered a bully to others, 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.

https://anti-bullyingalliance.org.uk/tools-information/advice-and-s upport/advice-parents-and-carers

Unfortunately, due to their alternative communication styles, ways of thinking and moving, neurodivergent 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 screen shots of copies of messages on social media.

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

Young Minds (**https://www.youngminds.org.uk/young-person/coping-with-life/bullying/**)

Education post 16

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

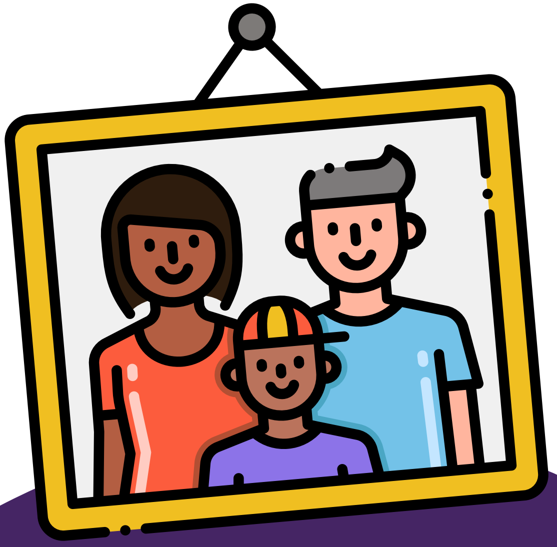
We have provided more details in the Growing Up section, and there is lots of useful information on the Contact website (**https://contact.org.uk/help-for-families/information-families/information-advice-services/education-learning/education-beyond-16**).

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 neurodivergent 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 – neurodivergent 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 neurodivergent. It appears to be more common in boys, but girls are more likely to mask and are often diagnosed at an older age.
- Autism and ADHD are not in themselves mental health conditions, but many autistic people/ADHD suffer from anxiety and/ or depression, due to a variety of reasons including unmet needs, inadequate support and social isolation.
- Being Neurodivergent 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 and some people thought it meant they were possessed by the devil. We now know that being left-handed is a neurological difference and not something that can be cured."

Sharing a diagnosis

Knowing that a child is neurodivergent 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 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 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.
- Being neurodivergent 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 needs.

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.

Autistic/ADHD individuals will display unique strengths and difficulties and experience characteristics of their disability in different ways.

> "If you have met one individual with autism...you have met ONE individual with autism."

Share the successes

hilst you will naturally share details of the challenges that you and your child may face, remember to share the achievements and fun moments too. Try to be patient, it may take a while for your family and friends to understand.

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 search on social media for your local town, the condition and SEND to find groups near you.

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!”

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.

Local Services

Further support for siblings can be found here:

- Hertfordshire Services for Young People - **https://www.hertfordshire.gov.uk/microsites/Local-Offer/Services-for-children-and-young-people/Services-for-children-and-young-p eople.aspx**
- Carers in Herts - **https://www.carersinherts.org.uk/?gad_source=1&gclid=EAIaIQobChMI8equ5abshQMVx5FQBh1xPAg-EAAYAiAAEgIPNfD_BwE**
- Neurodiversity Support Hub (**hertfordshire.gov.uk**)
- Hertfordshire Local Offer (**https://www.hertfordshire.gov.uk/microsites/local-offer/ the-hertfordshire-local-offer.aspx**)

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
- **https://www.sense.org.uk/**

Making Your Home Neurodivergent Friendly

Creating a warm and relaxing space which is sensory friendly can help provide a calm environment for your child. You can consider adaptations to support all the senses:

Sight

- You could paint walls in colours that your child finds soothing 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 and how we process information, function, and perform tasks.
- Avoid harsh or bright artificial lighting - yo could consider fitting dimmable lights.
- Create a calm environment by removing excess clutter and mess.
- Consider creating zones in your child's bedroom to distinguish between play, work, sleep, and storage areas.

Touch

- Experiment with various textures and materials when choosing furniture and furnishings – softness should meet support. If fabrics get too hot or too cold then that could be uncomfortable.
- Keep bedrooms cool.
- Choose fabrics that appeal - these could be different for everyone. Many children like soft and snuggly materials. Consider patterns and prints too and go for ones that are fun but not overly stimulating.
- Remove labels from bedding and night clothes, or try bedding and nightclothes made from other materials.

Sound

- Provide a warning that a noise is going to happen. E.g., hoovering.
- Consider that some lights can buzz, which may distract your child. Ask your child if anything bothers them and believe them when they tell you to change the bulb or provide headphones - their hearing may be more sensitive than yours.
- 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.
- Noise-cancelling headphones/earbuds can help reduce noise. Some children may like background noise, so you might want to try using a fan or listening to music through headphones.

Smell

- Limit the use of fragrances your child doesn't like, fabric conditioner, candles etc.
- Reduce smells coming into the room by closing the door fully or by using scented oils that your child finds relaxing
- Use an extractor fan or open a window in the kitchen to prevent cooking smells from filling up the house

Taste

- Try warm drinks like hot milk, hot chocolate, or herbal teas which some children find soothing
- Some children crave strong, spicy or salty foods, others prefer bland flavours.

Personalised safe spaces

Creating personalised spaces within your home can make your child feel more comfortable and supported.

- Consider creating a cosy corner or comfortable chair; add soft blankets, adjustable lighting, or a bookshelf stocked with their favourite books.
- Some children may prefer an area designed for movement with a yoga mat, a rocking chair or even giant bean bags.
- You could customise the space with items with emotional meaning or linked to specific interests, like photographs, artwork, or collectables, to make your young person feel more secure.
- In this safe space, your child can feel relaxed and comfortable tostim and self-regulate.

Being outdoors

Whether or not you have a garden, there are many benefits of having a sensory garden or area and spending time in nature.

Sensory gardens have all kinds of benefits for neuodivergent children and young people and provide an opportunity to

engage with nature on their terms, in their way, and at their own pace:

- Promotes play skills
- Helps with Sensory regulation
- Reduces stress
- Increases creativity
- Boosts Vitamin D from being outside
- Gardening can increase agility and co-ordination

Ideas to include:

- Butterfly garden
- A water play area with water features like fountains, a rain wall, a pond, or sprinklers to run through.
- A scent zone with fragrant herbs and vines like honeysuckle and jasmine
- An edible garden to explore taste.
- An area with bird feeders and plants that attract birds and wildlife.
- Music wall.
- Create window boxes or herb pots for balconies or window sills
- Children might enjoy growing and eating their own fruit and vegetables - explore local allotments or park gardening groups

Eating and Mealtimes

Thanks to Lucy Neary, 'The Early Years Dietitian' for writing this section and sharing her experience and expertise.

Having a child with feeding issues can feel isolating and parents often end up feeling judged for the way that their child eats.

There are many reasons for children to develop difficulties with eating a broad range of foods. Eating challenges are often seen in neurodivergent young people, but that this is not the only reason - there are likely to be other reasons your child eats in the way they do. Regardless of the reasons for your child's eating challenges there are many things you can do to help them to feel more confident and to reduce your stress levels.

Why do children become fussy eaters?

You may find that several reasons apply!

- **Medical issues:** previous illness, constipation, food allergies, reflux as a baby, chewing and swallowing issues
- **Sensory preferences:** eating uses all of our senses so when a child is sensitive to certain senses or has processing difficulties this can lead to strong food likes or dislikes.
- **Anxiety:** some children have anxiety that just presents itself around food and others have more generalised anxiety.
- **Personality:** Our general characteristics and personality traits affect the way we eat AND the way we are fed. Needing a lot of routine and structure, being highly emotional, being cautious in new situations or around new people are all characteristics that affect eating. They also affect parenting; if your child is likely to have a highly emotional response to a new food or a change to routine you are less likely to introduce change for fear of the outcome.
- **Neophobia:** This is a normal developmental phase that many children go through at around 15-18 months where new foods are rejected. When children reach this age, they naturally become more mobile and inquisitive. Throughout our evolution we have developed a reflex o prevent us from eating foods that we don't recognise because they may have been unsafe. Now, it's just a very real inconvenience for many parents.
- **Oral motor skills:** if there are any issues with chewing or swallowing this will affect the types of foods your child will eat. If they prefer soft and easy to chew foods or always leave the skin if they eat a piece of fruit, these can be signs that some textures are hard for your child to eat.

> "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!"

Common feeding challenges:

- Not wanting to eat around other people or in public spaces such as the school canteen or restaurants
- Eating only specific brands.
- Needing strict routines around food.
- Noticing and rejecting very tiny changes in food such as tiny specks of colour or blemishes.
- Eating a very limited range of foods.
- Having a preference for certain textures

Tips

1. Even if your child only eats a small range of foods, it can really help to try to rotate them as much as possible to prevent your child getting bored and dropping any. For example; for a child that eats crackers yoghurt and cereal bars you can vary it like this:
   - Day 1: 5 crackers + 1 yoghurt
   - Day 2: 3 cereal bars + 2 yoghurts
   - Day 3: 3 yoghurt + 1 cereal bar + 2 crackers
   - Day 4: 3 cereal bars + 3 crackers

2. If your child responds well to visual stories to prepare them for activities this can work well with feeding too.
3. Have a meal plan so that they know what to expect at each meal and snack can help to minimise mealtime anxieties.

4. If your child is happy to be around other food and you have a dinner table you can offer food using family style dining. Put all food in the middle of the table and allow everyone to serve themselves, ensuring there are at least 1 or 2 things your child would usually eat (but it doesn't have to be their favourite every time!) This method has several benefits
   - It exposes your child to new foods in a non-pressurised way.
   - Offering everyone's food together gives your child the message that all food is for everyone rather than a 'their food' and 'my food' mentality which can hold them back from exploring new foods.
   - It gives your child a choice to pick the amount of food that they want to eat.
5. Even though your child might eat differently to other children this doesn't mean that it needs 'fixing'. As adults we all eat differently but we just accept that fact. Aiming to meet your child's nutritional needs is important but if they do that with a handful of foods then that's ok. A good multivitamin is your friend if your child will take one!
6. Working on fussy eating is not a one size fits all; some of the strategies that work for other children may not work for your child. For example, it is a great idea to get your child involved with food preparation to help them to interact with food without the pressure of eating. However, if your child is hypersensitive to touch or smell they may find this difficult, and it coul actually put them off of trying foods. So always trust your judgement, you are the expert on your child!
7. Reduce any pressure for your child to eat certain foods as this will increase anxiety and mean they are less likely to eat. We know that anxiety decreases appetite so trying to keep worries to a minimum will help your child to have an appetite at mealtimes.

8 Think about your child's sensory preferences and think about anything that might make them feel more confident at meal times. For example:

- If they find noise difficult, let them wear defenders at mealtimes.
- If smells are difficult, put lids on, open a window or use a fan or give your child something sprayed with a scent they like to distract from any smells they find unpleasant
- If touch is hard, ensure your child has a tissue or cloth to wipe their hands or face.

9 Screens are a hot topic amongst parents! There are 2 ways to think about screens: If a screen has been introduced to encourage your child to eat and removing it will not cause too much stress then starting to have meals without it will help your child to be more engaged with their food. It will also help them to listen to their body; for example, knowing when they are full. If your child needs the screen because they find the process of eating stressful and they need to be distracted to put food into their mouth we wouldn't recommend removing the screen. Pick your battles – and this potentially isn't one to conquer straight away!

10 Try to have a structure to your child's day to allow them enough time to get hungry in between meals and snacks. If your child is grazing all day, it can stop them having an appetite at mealtimes

11 Try separating different types of food into separate bowls or using a plate with dividers as some children do not like different foods to touch.

Further information for siblings

- **Children's dietitian online, Essex & London - The Early Years Dietitian (https://theearlyyearsdietitian.co.uk)**
- **Fussy eaters - NHS (www.nhs.uk/conditions/baby/weaning-and-feeding/fussy-eaters)**
- **Understanding children's eating and supporting change | NELFT NHS Foundation Trust (www.nelft.nhs.uk/understanding-childrens-eating-and-supportig-change)**
- **magnificentmunchers.co.uk**

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.

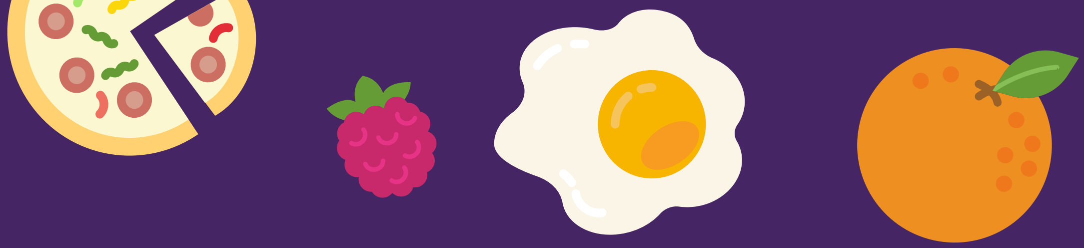
For a number of reasons, neurodiverse children are more likely to experience gastro-intestinal issues:

- 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.

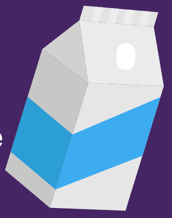
Further information

- **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!

Sleep

Why it can be difficult

Many neurodivergent people struggle with sleep-related issues and research has suggested a number of reasons for this:

- Other conditions may be present; including anxiety, depression, and gastrointestinal disorders, and these can make getting a good night's sleep more difficult.
- Extra sensitivity to certain things, such as light or noise, which can make it hard to wind down and relax.
- Melatonin is a naturally occurring chemical in the body which helps you to relax and fall asleep. Neurodivergent people often have issues with melatonin production, which means that they have trouble falling asleep, staying asleep and waking early.

Sleep Routine

A good sleep routine includes all the little things you do each night to help you get a peaceful night's sleep. It could be anything from taking a hot shower, brushing your teeth, having quiet - tech free time, doing some gentle exercise such as yoga, or slipping into your favourite cosy pyjamas.

It is important that your child makes these habits a part of their nightly routine, to help their body know it's time to relax and unwind ready for bed.

> "My son used to absolutely refuse to turn off his x-box before bed. Over time, I realised that it wasn't because he wouldn't turn it off when I asked, it was because he wouldn't leave in the middle of a game – he felt he was letting his team mates down. I have now built in a half an hour window to allow him to finish the game. This flexibility on my side has resulted in far fewer arguments between us!"

Every child is different and it will probably be a case of trial and error before you get the routine right. For instance, if your child gets particularly upset by brushing their teeth, don't do this immediately before bedtime.

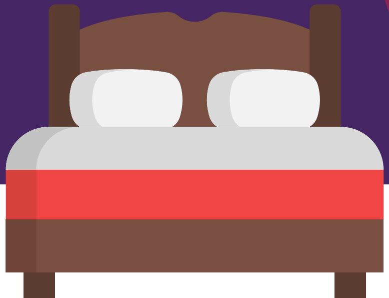
Bedtimes can become a very stressful time between parents and children, so sometimes it can be helpful to have some flexibility, especially if you or your child are particularly stressed or low on energy. On these days, having a strict and rigid routine could be unachievable, so skipping certain activities, like changing clothes or showering, can help to make getting to bed more manageable.

Hints and tips

Environment

The environment and surroundings can play a role. Not everything works for everyone, but it may help to:

- ✓ Make the bedroom more comfortable, tidy and ordered;
- ✓ Block out light using dark curtains or black-out blinds;
- ✓ Make sure the bedroom is not too hot or too cold – your child may struggle to recognise or regulate their own temperature, so you could need to do this for them.
- ✓ Experiment with white/brown noise. Lots of children benefit from a fan being on all year round to provide white noise, which blocks out other background noises and helps to slow down racing thoughts.
- ✓ You could try reducing noise using a thick carpet or rug, shutting doors entirely, turning off appliances, and moving your child's bed away from a wall if there is noise on the other side. You could also block out noises by letting your child use earplugs or listen to music through headphones.
- ✓ Remove labels from bedding and night clothes, or try bedding and nightclothes made from other materials.



- ✓ Reduce unwanted smells coming into the room by closing the door fully or by using scented oils or scents 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).
- ✓ Limit sugary foods, fizzy drinks, and other stimulants near bedtime.
- ✓ Melatonin naturally occurs in various foods including dairy products, bananas and cherry juice, so you could try introducing these foods in the evening.

You may find other stategies that work for you.

> "A couple of things that helped us were –
>
> 1. Allowing my son to sleep inside a duvet cover, wearing the corner bit like a hood and wrapped up like a cocoon, with a soft blanket over the top when it's cold.
>
> 2. I learnt how to do a head massage, like you get at the hairdressers and my eldest found this very relaxing at bedtime. I would also put pressure on his limbs, by pushing them gently into the bed, starting from his feet and working up to his shoulders."

If these simple changes don’t help, then there are other things you can consider:

- Purchase memory foam mattress toppers and pillows for comfort
- Painting the walls a different colour, if there is a colour that helps your child. Soft blues and greens are often suggested as relaxing colours.
- Using a sensory projector. Some children can find them overly stimulating, but others like to follow the shapes, and it can help them to doze off to sleep.
- Weighted blankets or compression sheets work for some children, but be sure to check the retailer’s guidelines and age limitations and get the correct weight for your child.
- Some children will benefit from medication to help them sleep, but it is really important to figure out if a lack of melatonin is what is causing your child’s sleep troubles. Speak to your GP for more information if you think that medication may help.

Further information

Many sleep/relaxation apps are available:

- How to Help Kids Sleep Better – Headspace (**www.headspace.com/sleep/better-sleep-kids**)
- Moshi – Sleep and Mindfulness App Meet Moshi Your New Superpower. (**moshikids.com**)
- **https://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 www.circadiansleepdisorders.org**
- National Sleep Helpline - The Sleep Charity (**thesleepcharity.org.uk/national-sleep-helpline**)
- SG Autism and Sleep V3.pdf - Google Drive (**https://drive.google.com/file/d/1MAP2t6eHyzwiCQKoIYiEA38Sk_sLA-jM/view?pli=1**)

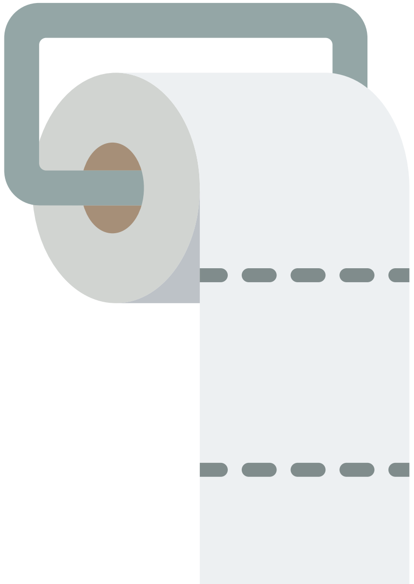
Toileting

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.

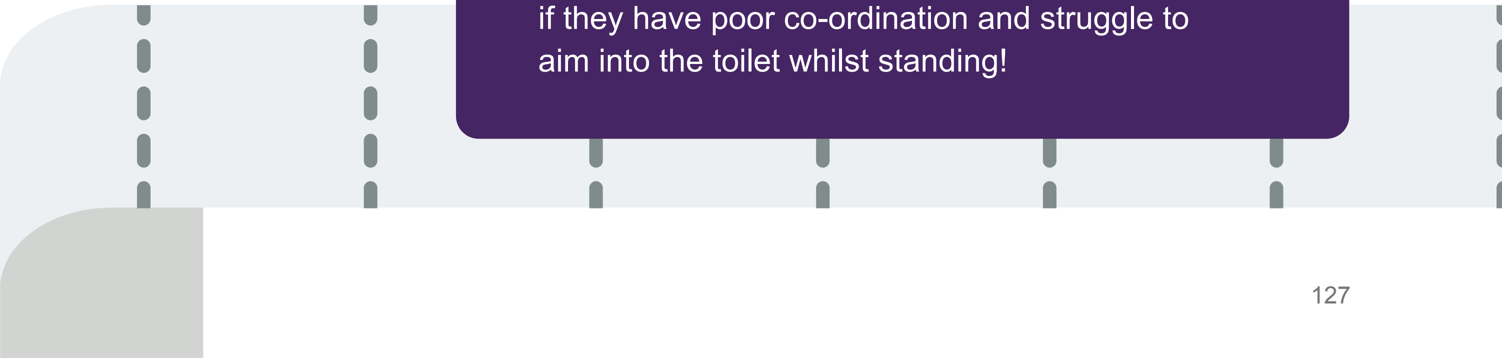
Some children don’t have a natural desire for that independence, but it can make day–to–day living, particularly outside the home, difficult for them and you.



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.
- ✓ 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**

Teeth Cleaning and Dental Health

Neurodivergent people often have additional sensitivity in their mouth and this can make everything teeth-related particularly challenging.

Teeth cleaning can be difficult - most of us can adjust the pressure while brushing our teeth to avoid hurting our gums, and learn to tolerate the taste of toothpaste, but this can be difficult for many neurodivergent children.

Hints and tips

You could try a social story or a storybook which will help your child understand what happens while brushing their teeth. You can also show what can happen if you don't brush your teeth. There are some excellent free resources available online which could help:

- I Can Brush My Teeth Social Situation (teacher made) (**www.twinkl.co.uk/resource/t-s-3767-i-can-brush-my-teeth-social-stories**)
- I Can Brush My Teeth- Social Story - Autism Adventures (**www.autismadventures.com/i-can-brush-my-teeth-social-story)**
- It could be helpful to have visuals that show step-by-step instructions
- Experiment with different toothpastes to determine what flavour your child likes best. There are lots of different flvours available: apple, peach, strawberry, unflvoured etc. as well as the traditional mint.

Hints and tips

- ✓ It could be easier to learn new habits with someone else. You could brush your teeth together and show your child what to do.
- ✓ You can introduce ways to make it fun – for example,asking your child to brush your teeth or using a musical timer.
- ✓ Allow your child to take a break if they find it too uncomfortable.
- ✓ Allow them to go at their own pace – don't rush them,but you can encourage them to slow down if needed!
- ✓ 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.
- ✓ It can help to develop a routine and have a set number of brush strokes for each tooth. This also gives a definite end point for children who find it hard and is a good distraction.
- ✓ 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 stiff, a baby toothbrush with softer bristles might help. If even this is too uncomfortable, using your finger is better than nothing!

"I hadn't realised that sensory toothbrushes are a thing – there are loads of different types available and I was surprised by just how much easier it made things."

"We use flavourless toothpaste – it's expensive but worth it."

"My child used to absolutely refuse to go to the dentist. I spoke to the dentist and he was actually really understanding and helpful. He said that the most important thing we could do was 'prevent, prevent, prevent' by minimising or even cutting out sugar, and that even if my child had days where he couldn't clean his teeth, cutting out sugar would minimise problems."

Visiting the dentist

Regular dental check-ups are essential to maintain dental health and hygiene, However there are a number of factors which can make a trip to the dentist challenging, for example, cold metal instruments entering the mouth may be painful, and the noise of the drills and other instruments may be distressing, the taste and feel of mouthwash and dental paste can be uncomfortable and the dentist standing very close might feel like an invasion of their personal space.

There are things that you can do to make visits less stressful:

- Start from an early age.
- Speak to the dentist in advance to let them know about any particular difficulties.
- Take your own sunglasses and ear defenders or headphones.
- Help prepare for the visit by reading books about it, or showing them photographs of what to expect.

‘We always book extra time for appointments so we feel comfortable and can take a break whenever needed.’

‘I hold my daughter’s hand and she squeezes it if she needs the dentist to stop. The dentist doesn’t mind at all and it gives her a sense of being in control of the situation.’

‘My dentist always explains each step of the process clearly. For instance, they might say, “I am going to check your teeth to ensure they are in good condition”, or “I will be using a small mirror to examine your teeth.’

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?

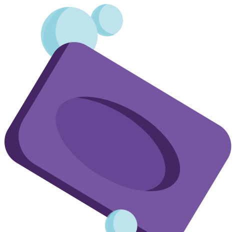
https://autismlittlelearners.com/losing-tooth-story-for-children

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!

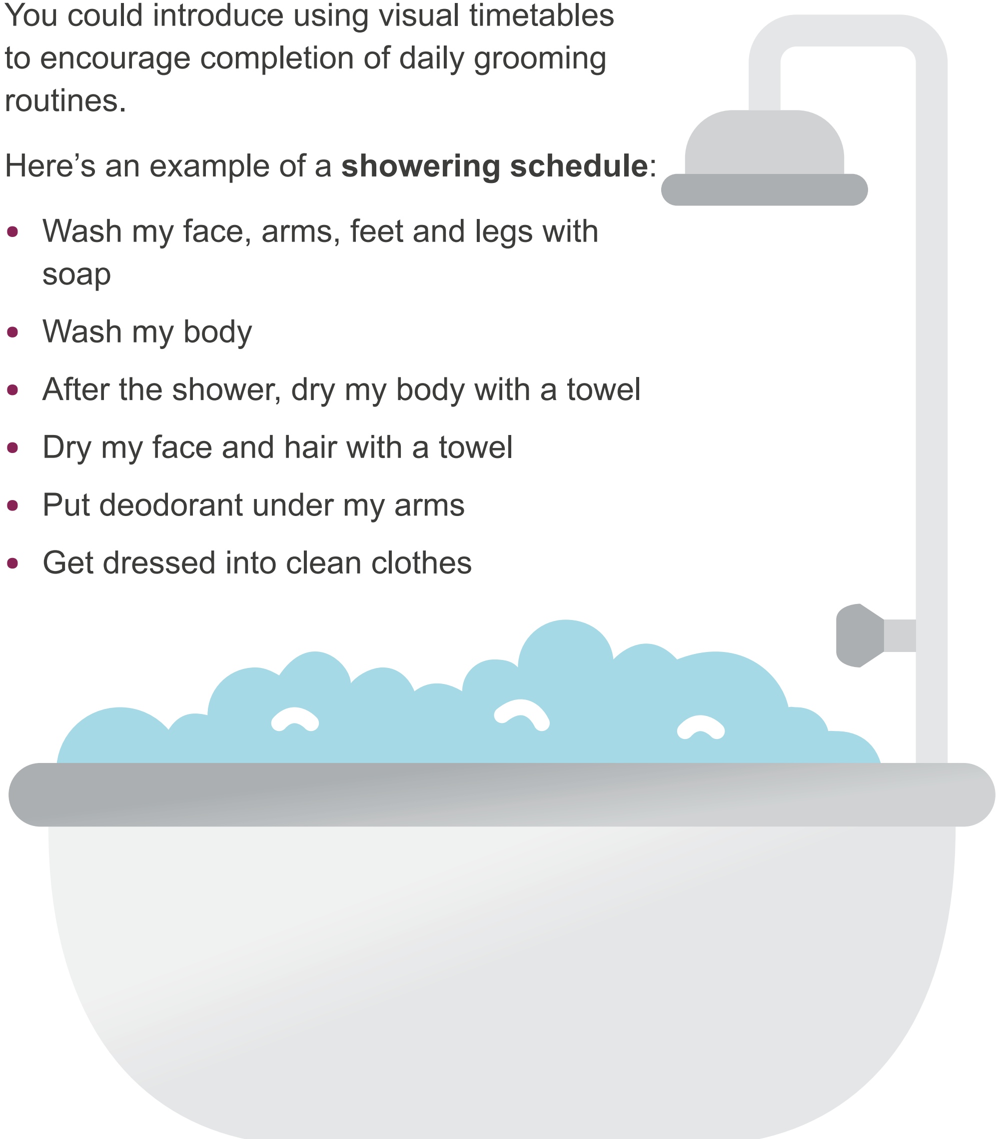


Showering Schedule

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 Essex.
   - Disabled toilet key **www.cheapdisabilityaids.co.uk/disabled-toilet-key-205-p.asp**
   - Apply for a Changing Places key **www.shortbreaks.essex.gov.uk/apply-for-a-changing-places-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.”

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, extra universal credit or other benefits

DLA isn’t affected by your earnings, other benefits or savings.

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. DLA recognises extra care needs, day and night, and the difficulties you may have with mobility and going out with your child

This guide from charity Cerebra is an excellent resource to help you: **www.cerebra.org.uk/download/disability-living-allowance-dla-guide/**

To apply, see: **www.gov.uk/dla-disability-living-allowance-benefit**

PIP

At 16, the young person may be eligible for Personal Independence Payment (PIP) instead of DLA. Although it still covers daily living and mobility, the assessment is different and is based on a point-scoring system. For more information see www.gov.uk/PIP and for help with completing the claim form, see the PIP guides on **www.hertfordshire.gov.uk/benefits**

You can find more information here - www.gov.uk/pip and here www.citizensadvice.org.uk/benefits/sick-or-disabled-people-andcarers/pip

Carer’s Allowance

If your child receives DLA Care at the middle or higher rate, or PIP for daily living at either rate, you may be able to claim Carers Allowance. It is not means-tested so your savings and partners income aren’t taken into account. However, if you earn over £151 a week after tax, NI and certain expenses (April 2024 figure), you wont get any carers allowance for that week. If you are on universal credit, you can get a carer element added to your benefit if you are a carer, no matter what you earn. For more information see **https://www.carersuk.org/help-and-advice/financial-support/carer-s-allowance/**

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.”

Local Libraries

There are lots of free events held at local libraries, throughout the year.

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**

Foodbanks

There are a variety of organisations that run Food Banks - the following links will give you details of what they provide:-

- The Trussell Trust **www.trusselltrust.org**
- The Salvation Army **www.salvationarmy.org.uk**
- Peabody Trust **www.peabody.org.uk/cs-services**

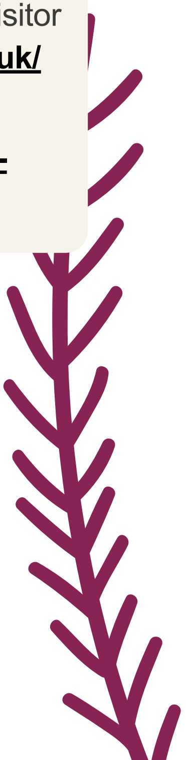
You can also contact your local council to find out what is available in your area.

Save on the cost of food and cut down on waste

There are a variety of Apps available to help you find cheap food and reduce food waste, such as Too Good To Go, where restaurants, cafes and bakeries list leftover food that would otherwise be thrown away. Users can then browse the map for food near them and pick up a ‘magic bag’ for a fraction of the original retail cost. Registration to **the app is free and users can specify their dietary requirements.**

Useful Links

- **Money - https://www.hertfordshire.gov.uk/microsites/Local-Offer/ Money/Money.aspx**
- **Disability Access Fund - https://www.hertfordshire.gov.uk/microsites/local-offer/ early-years-0-5/disability-access-fund.aspx**
- **Early Years Inclusion Fund - https://www.hertfordshire.gov.uk/microsites/local-offer/ early-years-0-5/early-years-inclusion-funding.aspx**
- **Baby Basics** Provide some of the basics needed for vulnerable women with a newborn baby. They provide starter packs for those in need, including moses baskets, baby clothes, nappies, etc. They do not accept self-referrals, but you can contact, your mid-wife, health visitor or social worker to refer you. **www.baby-basics.org.uk/**
- **SEN Funding in Education - https://www.hertfordshire.gov.uk/microsites/local-offer/ early-years-0-5/early-years-inclusion-funding.aspx**



Short Breaks

The Short Breaks schemes are run by every Local Authority to provide activities for disabled children and respite care for families with disabled children.

https://www.hertfordshire.gov.uk/microsites/local-offer/courses-and-activities-in-hertfordshire/short-breaks.aspx

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

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**

Access Card

This card provides evidence of your child's disabilities and can help you to secure discounts at many theme parks and attractions. **www.accesscard.online**

Brainwave Charity

https://brainwave.org.uk/

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

Looking after yourself

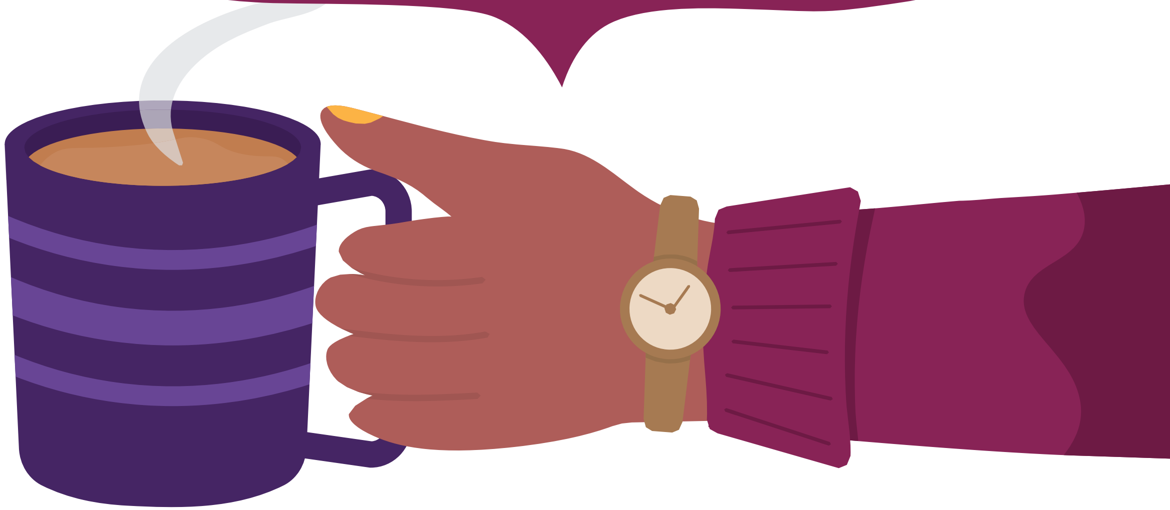
Most parents and carers find it hard o make time for themselves, but to be able to support everyone else in the family, you need to keep well.

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!

"I have recently started to homeschool my 2 children. My husband recognises how challenging this is for me and how important it is that I can 'fill my cup'. Unfortunately it isn't always possible to go out together as a family or to do things as a couple as we have limited childcare options – but he looks after the children to give me time to do whatever I need to do to recharge. It isn't always the same thing, sometimes it is sitting in a coffee shop with a book, sometimes it is seeing friends, sometimes it is talking to other parents who understand, and sometimes it is doing something challenging so that I can keep my own sense of identity. It's no one thing but it is so important for me to have that opportunity to fill my cup."

"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."



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.

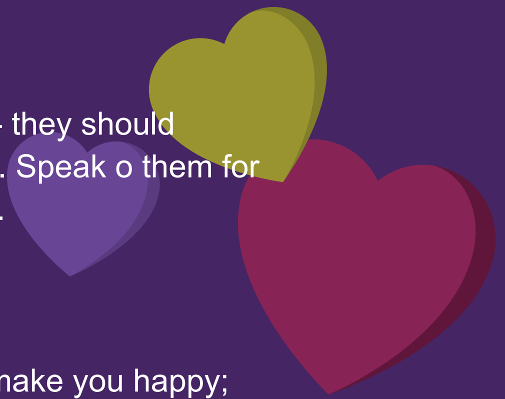
Say YES to offers of help - it is not a sign of weakness.

“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 o keep seeing if you are going through a difficult time yourself. Equally, sometimes the feed can seemoverwhelmingly sad and difficult. It is ok o take a break – or to switch off altogether. If you explain to friends that you are doing it then they will find another way o contact you if needed.to contact you if needed.

Speak to Your GP



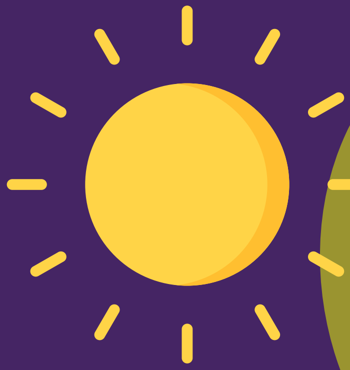
Tell your GP that you are a carer - they should amend your records to reflect this. Speak o them for help to keep you healthy and well.

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.

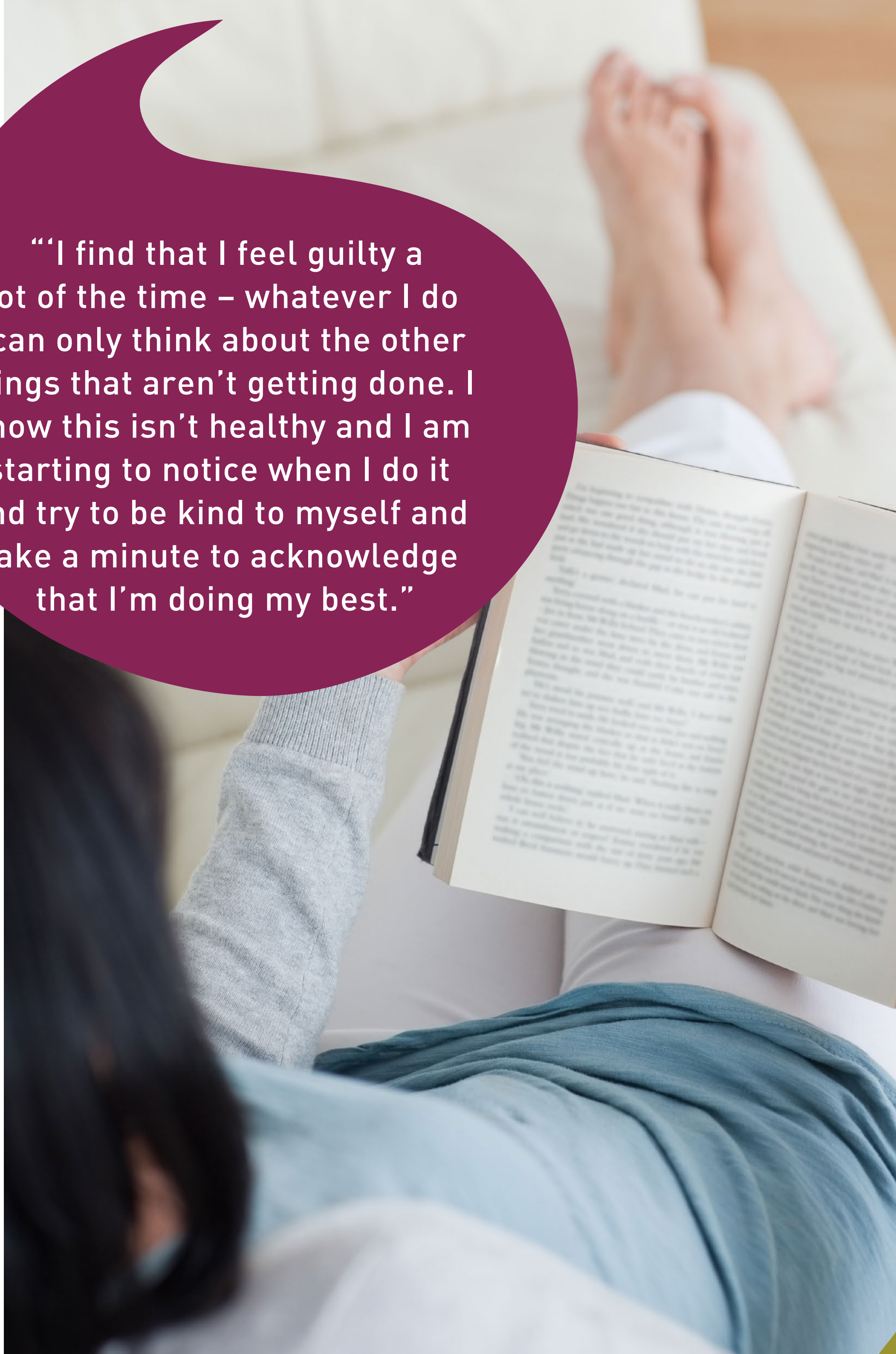


“I volunteered to take the rubbish to the skip. The queue was huge and I sat for 30 minutes – but it was so calm and I really enjoyed just listening to music on the radio by myself with the sun on my face!”

Further Support

There are a number of charities who provide support specifically for unpaid carers. They organise events and can provide respite care.

- **Hertfordshire Services for Parents, Carers and families - https://www.hertfordshire.gov.uk/microsites/Local-Offer/Services-for-parents-carers-and-families/services-for-parents-carers-and-families.aspx**
- **Mental Health and Wellbeing Support for Parents and carers https://www.hertfordshire.gov.uk/microsites/local-offer /services-for-parents-carers-and-families/mental-healt h-and-wellbeing-services-for-parents-and-carers.aspx**
- **Short Breaks - https://www.hertfordshire.gov.uk/microsites/local-offer /courses-and-activities-in-hertfordshire/short-breaks.aspx**



> “‘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.”

Section 7

Communication, Speech and Language

Communication, Speech and Language

Neurodivergent children may show differences in their development of speech, language or communication and at times this can cause challenges. This may include differences in:

- Speech sounds – how someone produces sounds and coordinates them in words.
- Understanding – how someone processes language and understands words and meaning in phrases
- Expressive language – how someone communicates using spoken words or other means, how they put words together to make sense to others
- Narrative skills – how someone puts ideas together to retell events
- Social communication – how someone uses their communication with other people, including how they play together, have conversations, negotiate etc
- Fluency – for example someone may have a stammer when speaking
- Situational mutism/non-speaking – describes how someone may use verbal communication in one context and is not able to in a different context
- Higher level language – how someone understands non-literal language, such as making inferences, predictions, understanding idioms etc
- Vocabulary and word finding – how someone learns new words and uses them when speaking

Some children follow different paths when developing language and learn in different ways. You may hear that your child is developing using Gestalt language processes, which describes someone who is developing language in 'chunks' and this may be when you see echolalia (repeating words) or someone using learnt phrases. You can speak with a speech and language therapist to discuss how to support your child's development and understand more about their style of processing.

A Total Communication environment is the most enabling for most children to develop communication. This means that all forms of communication are used to support understanding and all forms of communication are accepted when the child is expressing themselves. In Hertfordshire, neuro-affirmative approaches are supported, whereby a child's communication preferences are respected and supported and behavioural means are not used to try and change this.

What professional help is available?

If you are concerned about your child's speech, language or communication then speak with your GP, health visitor or school and they can advise on how to make a referral to the speech and language therapy team.

- Parents can also contact the dedicated advice line. Please visit **https://www.hct.nhs.uk/children-and-young-people-speech-and-language-therapy-parents for further information.**
- You can also find lots of advice and webinars on the speech and language therapy website: **www.hct.nhs.uk/children-and-young-people-speech-and-language-therapy**

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**

Local Speech and Language Services

- Speech, Language and Communication **https://www.hertfordshire.gov.uk/microsites/local-offer/servic es-for-children-and-young-people/speech-language-and-communication.aspx**
- Services for Children and Young People **https://www.hertfordshire.gov.uk/microsites/Local-Off er/Services-for-children-and-young-people/services-for-children-and-young-people.aspx**
- Speech, Language, Communication & Autism Team **https://www.hertfordshire.gov.uk/microsites/local-of fer/services-for-children-and-young-people/communication-and-autism-team.aspx**

Further information

- 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
  - https://www.specialneedsjungle.com/speech-therapy-terminology-what-does-that-mean/
- **files/assets/documents/speech_language_and_communication_needs_brochure.pdf**

"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."

Further information

- Information for parents - Speech and language therapy | Hertfordshire Community NHS Trust (**hct.nhs.uk**)
- **https://www.hct.nhs.uk/children-and-young-people-speech-and-language-therapy-parents**

"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 8

Sensory Needs

Sensory Processing and Integration

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 is Sensory Processing?

Sensory processing is the brain's ability to process, interpret and filter sensory input received from the senses to organise and prioritise our responses to the constant environmental demands appropriately.

Some people refer to sensory processing difficulties as 'Sensory Processing Disorder' and many neurodiverse people experience this, not just autistics.

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.

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)

> “When I wear those other itchy trousers, it’s just too distracting for me to do my work.”

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.responses may be intense; the input is registered as irritating at best, and as painful at worst.

Top Tip

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.

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.

Top Tip

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

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.

Top Tip

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 o process visual information over verbal instructions; this is related to communication issues rather than sensory processing.

“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.

Top Tip

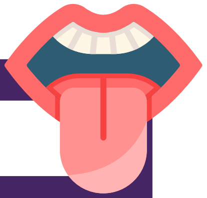
If the child’s sense of smell is under-responsive/ sensitive, you could help by creating a routine around regular washing and using strong-smelling products to distract your child from inappropriate strong-smelling stimuli. If they are over-responsive/sensitive to smell, you could use unscented detergents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

“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.

"My son hates sticky food but loves crunchy cereal"



Top Tip

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.

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!"

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

Top Tip

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.

Top Tip

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 oppers 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.

“My daughter is always hungry. It is like she can’t understand when she is full.”

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.

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.

What professional help is available?

- There are no quick fixes or cures for sensory pocessing 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 appoaches are usually used as part of a goal-focused and occupation-centred approach
- Many OTs offer parent workshops, with useful information about the principles of sensory processing. This approach helps educate parents about sensory needs and recognises that everyday interventions by parents can have the biggest impact.

Local Speech and Language Services

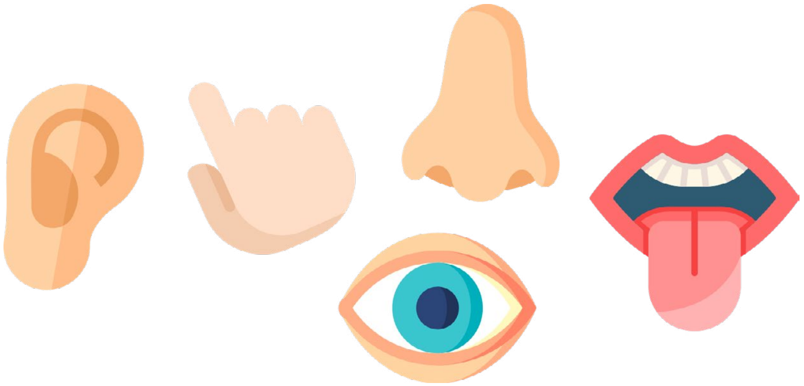
- **Physical and Neurological Impairment Team**
  www.hertfordshire.gov.uk/microsites/local-offer/services-for-children-and-young-people/physical-and-neurological-impairment-team.aspx
- **HCT and Young Peoples Sensory Services**
  www.hct.nhs.uk/sensory-service
- **Contact a SEND Service**
  www.hertfordshire.gov.uk/microsites/local-offer/contact-a-send-service.aspx

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 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.

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 9

Understanding and Supporting your Child’s Social and Emotional Development

Understanding

Being neurodivergent means that your child's brain is wired differently and as a result, they may require additional support to develop new skills, participate in education, recognise and regulate their emotions, make friends, understand social norms and communicate their needs.

It is now widely accepted that parenting style is not a contributing factor to the development of neurodivergent children. Instead, the condition is rooted in genetics and emerges from various factors. However, to give them the support that they need, it may be helpful to think about how you speak to your child (including your tone, volume and the words used), your parenting traditions/style, and how you organise your home and trips elsewhere.

Along with these challenges and different ways of thinking, your child may have strengths in other areas such as creative arts, problem-solving, "thinking outside the box", pattern recognition, or attention to detail. As a parent, it's essential to embrace and celebrate your child's differences and provide them with the support and resources they need to thrive. Low self-esteem and constant criticism for things they find much harder to do than the average child can lead to burnout, anxiety, and depression.

It's important to be flexible with your strategies and adapt to your child's needs as they grow. What counts is that your child feels included, loved and has a safe-haven at home. You don't have to be an expert to help your child succeed - simple strategies can make all the difference.

> "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."

In this chapter, we have overviewed some of the challenges you will face, some helpful strategies and models of support, under the following headings:

- General Tips
- Recognising and Regulating Emotions
- Anxiety
- Meltdowns and Distressed Behaviour
- Organisational Skills
- Social and Communication Differences

General tips

- ✓ **See the funny side** – this isn't always possible, but there may be times that you can use humour to help diffuse a difficult situation. This can help to create a good, fun relationship between you. However, there may be occasions that this doesn't work, so be responsive to your child's mood.
- ✓ **Ask yourself** – Is this a can't or a won't situation? For example, is your child refusing to use cutlery just to be defiant, r is it because they struggle with fine moor skills and can't do it? Has your child deliberately forgotten their PE kit, or do they lack the executive functioning skills to remember it?
- ✓ **Don't say, "Because I told you so!"** - explain why. A lot of neurodivergent children and young people struggle with following nonsensical rules and demands which don't make sense to them - they need to understand the reasoning behind it.
- ✓ **Spend quality time together** – this is especially important in the teenage years to keep a positive connection between you. Try to do something every week and make it a moan-free event! This doesn't need to be a formal event, just something that you can both do together, e.g. go for a walk, drive around the area playing your favourite music, watch a TV programme together, take them out for ice cream – whatever encourages them to feel closer to you. Try to avoid mentioning anything they've done wrong that day/week during these times. Be their safe person – let them know they can tell you anything, and you won't shout or criticise, and you will help them solve the problem.
- ✓ **Communicate clearly and briefly** - If you attempt to communicate too much information at one time, your child can quickly become overloaded (in fact, anyone can become overloaded!). Try to give one or two options rather than a long list, and minimise the number of instructions you want them to follow.
- ✓ **Take a break** - If your child becomes angry or overwhelmed, it's often best to delay the discussion until everyone has calmed down.
- ✓ **Pick your battles** – sometimes, it can feel like you disagree about everything. If there are arguments about things that don't matter, sometimes it is helpful to let those go.
- ✓ **Provide positive directions** – if you tell your child what to do rather than what not to do, this gives them a start rather than a stop direction, and can make it easier for them to follow.
- ✓ **Believe your child** when they say that something is too loud, too smelly, too bright – see sensory section
- ✓ **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 of 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 neurodivergent children might be a good compromise.

Recognising and Regulating Emotions

Extensive research has been conducted into models and strategies that can help understand dysregulation and find ways o help our children recognise, moderate and regulate how they feel.

Many neurodivergent people struggle to recognise their emotional state and be able to describe it – this condition is known as Alexithymia, which translates into English as “no words for emotions”. For instance, they may struggle to see the difference between being excited (about something good) and scared, as the body reacts similarly to both scenarios.

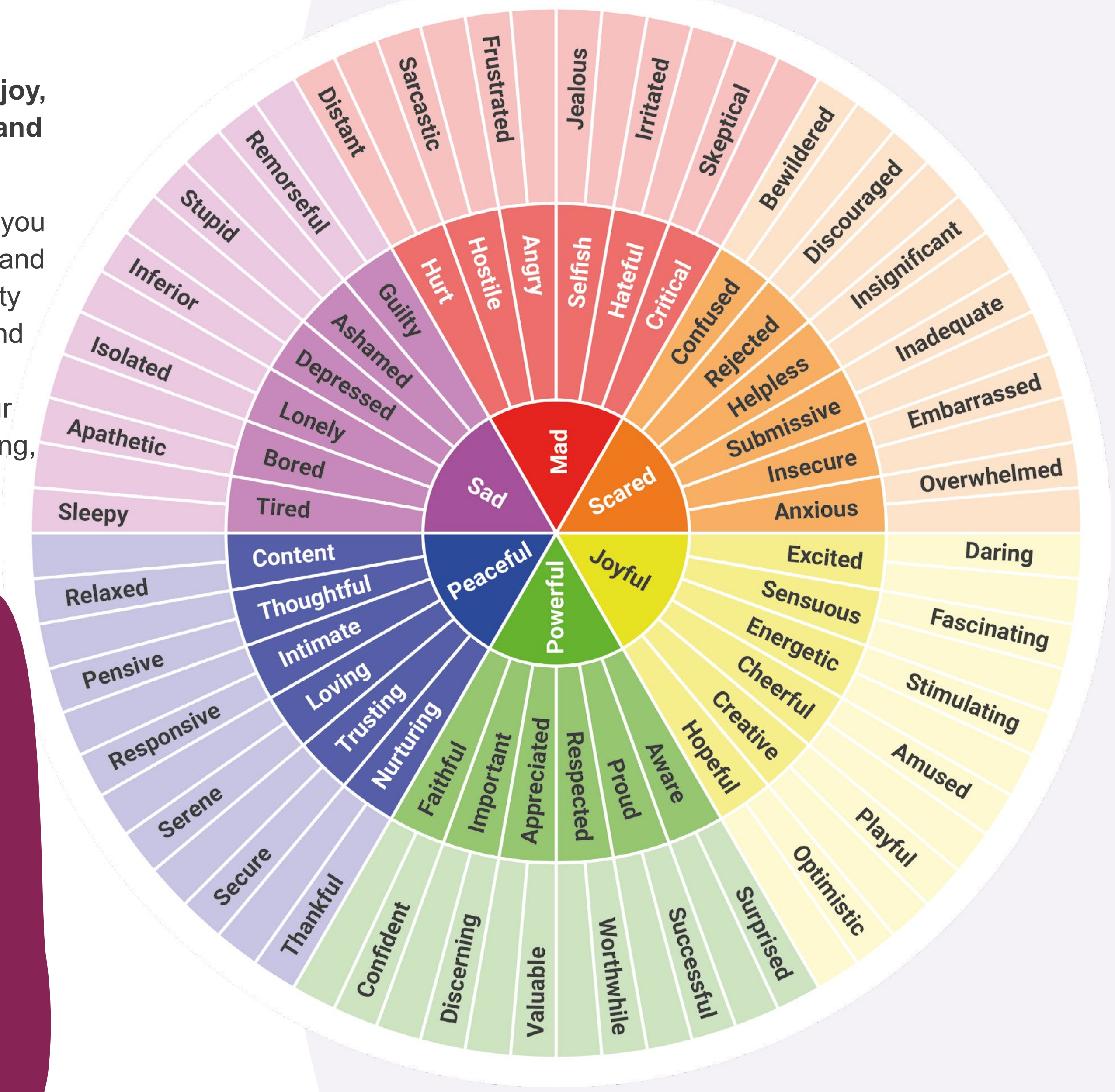
To help them, it’s important to start by recognising and talking about emotions (you could use the wheel of emotions) Once we understand our feelings, we can start breaking down the situation into smaller, more manageable parts and it is easier to work on navigating tricky social situations and feel more confident in interactions with others.

If you think this is an issue for your child, there are a number of ways you can help, which we have listed below.

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.

The wheel of emotions can help identify which emotions you are experiencing in a precise way. Labelling, identifying, and recognising feelings can reduce confusion and uncertainty – it can also help to make sense of stressful situations and start to understand it. Knowing what you are feeling and why, is incredibly empowering. We can start to accept our emotions as we feel them, instead of ignoring, suppressing, or rejecting them.



> "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."

Two other ways to help your child to recognise and regulate their emotions are the 5-Point Scale and Zones of Regulation. They are based on similar ideas, so it's best to choose which works best for you and then stick with one, or it could become confusing.

The 5-Point Scale

Downloadables – THE INCREDIBLE 5-POINT SCALE (www.5pointscale.com/downloadables.html)

The 5-Point Scale helps your child to discuss situations they find stressful and gives them tools to deal with their emotions.

5 = This could make me lose control.

4 = This can really upset me.

3 = This can make me nervous.

2 = This sometimes bothers me.

1 = This never bothers me.

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. Many schools also use Zones of Regulation as a strategy, if they do, it can be helpful to have a joined-up approach between home and school – **www.zonesofregulation.com/index.html**

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**

Stimming – how your child might regulate themselves

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 neurodivergent people,as their types of stim and the frequency with which they carry them out, are deemed less socially acceptable.

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 can regulate emotions and help us to manage stressful situations. It also helps to process sensory input and provides important clues to you that your child is dysregulated. 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 such as chewy pencil tops, fidget cubes, putty and squishies, can be kept in a pocket and can help your child to regulate in a controlled way.

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

Anxiety

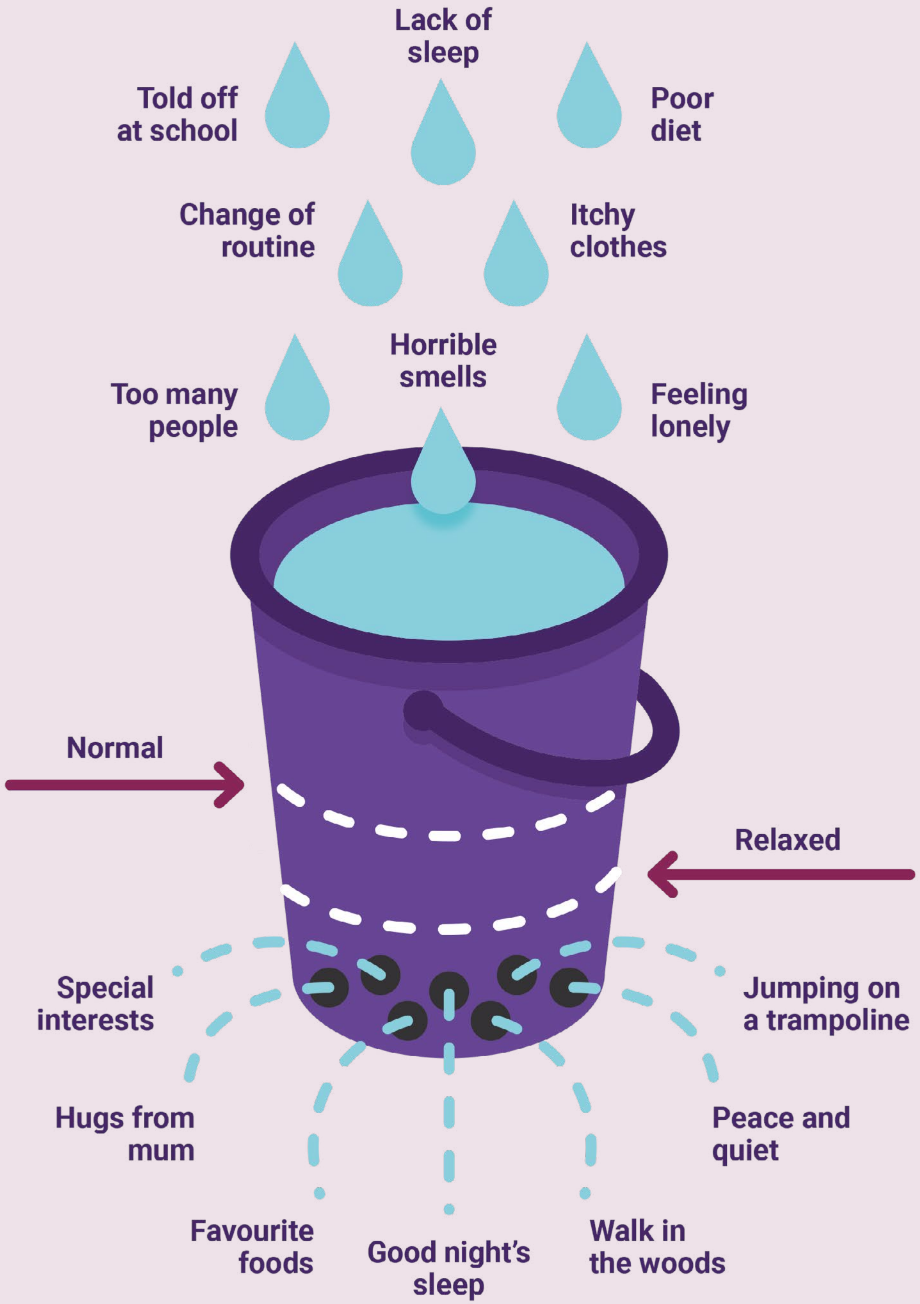
The stress bucket analogy - Brabban and Turkington (2002).

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 neurodivergent 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.

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:



Filling the Bucket - are things which sap energy, or create anxiety e.g., going to school, brushing teeth, trying new foods, seeing relatives or socialising. These may be activities which your child enjoys, but still finds stressful, or emotionally draining.

Emptying the Bucket - are things that replenish energy or make them happy, e.g. having quiet time alone, playing with a pet, reading a book or playing computer games.

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.

Books on Managing Emotions and Anxiety

For adults:

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

K.I Ghani has written some very useful illustrated books 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)**
- **The Red Beast: Controlling Anger in Children with Asperger's Syndrome**
- **The Panicosaurus: Managing Anxiety in Children Including Those with Asperger Syndrome**

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**.'

"My son used to bolt all the time. He still does occasionally, but doesn't go far. We stop the running mostly by letting him know we can see he's upset, naming the trigger if we know it and telling him we are here when he needs us. Avoid eye contact. Keep speech quiet and calm. Limit words. When he shows signs of calming, we sympathise with him, acknowledging the difficult situation he was in. When we're out, we always agree on a safe place to go, which is usually back to the car with no one talking. We always let him know that if things become difficult we will leave together. Knowing he has our full support to exit quickly usually means he doesn't panic. This works for us."

Managing a meltdown

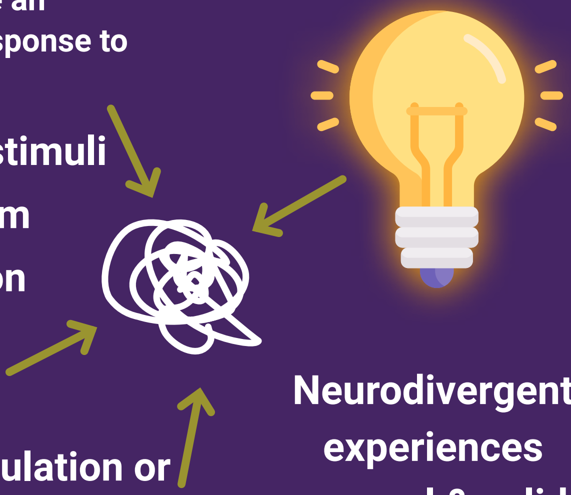
Tantrums vs meltdowns

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**



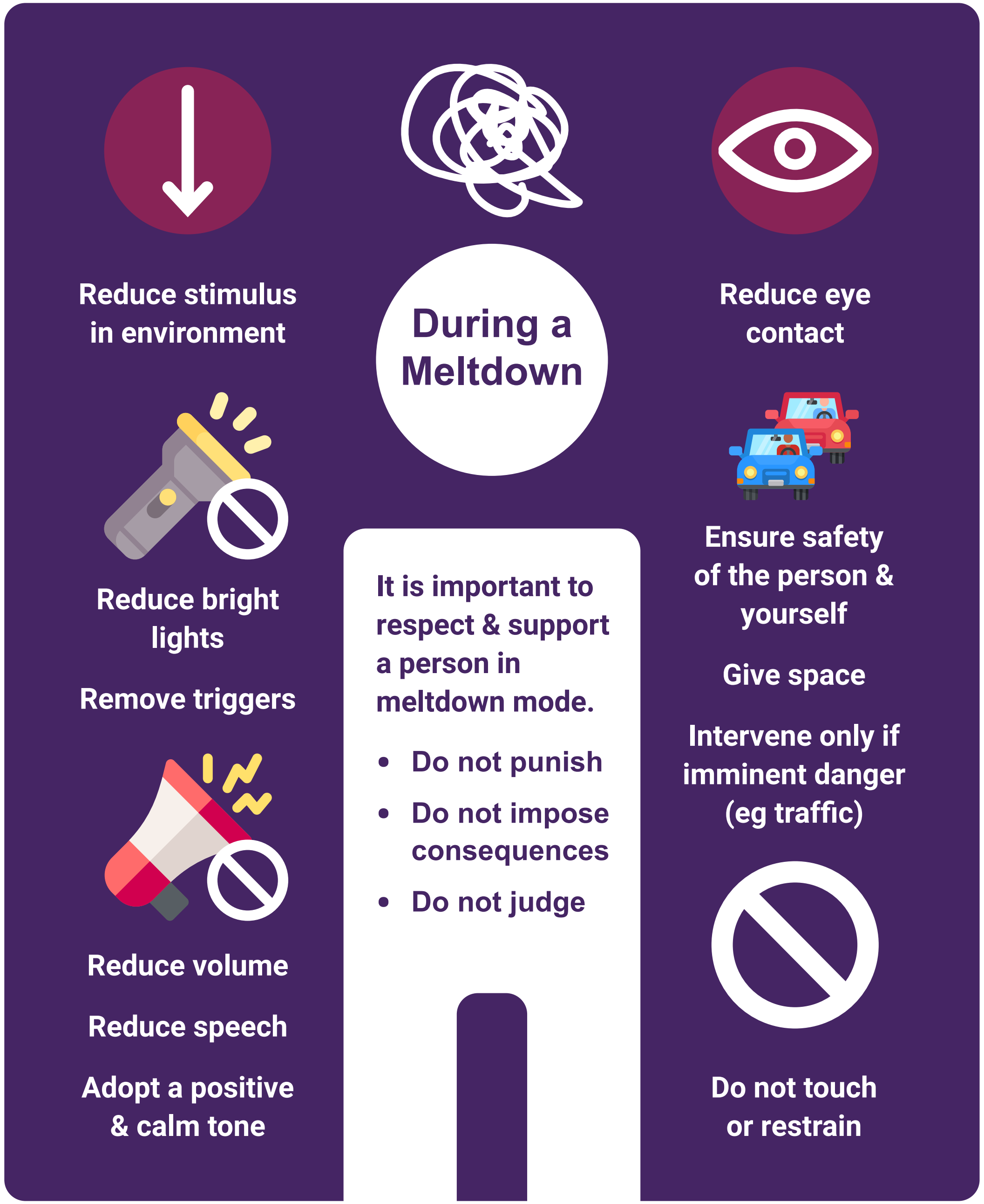
Neurodivergent experiences are real & valid

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.
- 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.



During a Meltdown

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

> "It took me a while to understand that they are not being defiant, they are overwhelmed and upset. Don't take it personally and definitely don't join in - it will make it 10 times worse and last twice as long."

Remove all triggers

Recovery time

Unlimited access to calming or favourite activity is crucial

Drink & snack

Create a safe space

Validate emotions

Further information

There are lots of theories and research about emotional regulation and heightened anxiety and fight/flight/freeze responses in neurodivergent people. If you are interested in finding out more we would recommend the following:

- What is the polyvagal theory? **https://therapist.com/brain-and-body/polyvagal-theory**
- Yvonne Newbold supports parents and professionals to reduce violent, difficult and dangerous behaviour in children and young people with a disability and/or additional needs **www.newboldhope.com**
- Neurodiversity Support (hertfordshire.gov.uk)
- Hertfordshire Local Offer (**https://www.hertfordshire.gov.uk/micr osites/local-offer/the-hertfordshire-local-offer.aspx**)

After School Restraint Collapse

Children who mask at school become ‘wired and tired’ because they use a lot of cognitive energy to maintain control throughout the day.

School can tire neurodivergent children out mentally. Children feel most relaxed and home is often the best place for them to unwind and express themselves in a safe and relaxed environment.

Your child might feel mentally drained, making concentrating and returning from challenges harder. This is sometimes known as cognitive load.

1. Avoid immediately asking your child about their day. Offer a snack and drink.

2. Encourge your child to regulate by having quiet tie alone with their thoughts. Avoid engaging in lengthyy conversations or mmaking demands

3. Let your child decompress at the end of the day and allow them to take charge of when and how they want to interact.

Some children prefer to decompress through physical activities such as trampolining, wrestling, running around outside, or riding bikes.

What might it look like?

- Refusing to do as asked.
- Absorbed in computer games (this isn’t a bad thing – this may be their way to relax).
- Throwing, ripping or breaking things around the house.
- Falling asleep at dinner.
- Extreme emotional responses .
- Too tired to do homework.

How can we help at home?

- Use simple language.
- Avoid immediately asking your child about their day.
- Offer a snack and a drink.
- Allow time for processing and self-regulation.
- Encourage your child to regulate by having quiet time alone with their thoughts.
- Avoid engaging in lengthy conversations or making demands.
- Create space for them to relax.
- Some children prefer to relax through physical activities such as trampolining, wrestling, running outside, or riding bikes.

Organisational Skills (Executive Function)

Executive functioning is the way that our brain processes, organises and remembers information.

Executive dysfunction is a term used to describe weaknesses in these cognitive processes which can impact upon the ability to prioritise tasks, manage time efficiently, and make decisions. Children and adults with executive dysfunction may misplace papers, reports, and other items. They might have problems keeping track of their things or keeping their bedroom organised.

These are fundamental skills which help our children to think, plan, self-monitor, control themselves, be organised and manage their time and working memory.

What is Cognitive Load?

Cognitive load is the amount of information that our brains can process at any one time.

What is cognitive overload?

Cognitive overload occurs when there is too much information or too many demands on working memory. It happens when you handle multiple tasks, complex information, or deal with new technology, or for our children if they have to concentrate at school all day, undertake a new activity or visit a new place.

These main causes can be broken down into the following:

- **Multitasking** - Trying to complete several tasks simultaneously can make us less productive. Our brains can struggle to switch between tasks when we multitask.
- **Information overload** - Being overloaded with the fast pace of the curriculum and daily academic activities at school, or receiving too much information through emails, social media, and digital channels
- **Poor time Management** - When our children have difficult managing their time, they might put off important tasks, making them feel anxious and overwhelmed. This often happens when they don’t have enough time to complete things or if there’s a deadline coming up.
- **Complex tasks** - Learning complex or challenging things can take time, and sometimes it can be overwhelming.

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

Emotional age vs biological age

The emotional age of a child is not tied to their birthday or their intelligence, but to their emotional maturity and executive functioning skills.

Activities to help with time management:

- Helping with chores that involve sorting and categorising, like putting away dishes, matching and folding laundry, storing groceries, etc.
- Writing weekly, monthly, and even yearly plans can help children visualise abstract concepts like time.
- Use things that ding! This includes timers, phone apps, watch alarms, clocks, etc.
- Posted schedules, especially those with eye-catching visuals or colours.
- Daily whiteboards: Encourage your child to jot down the month, day, day of the week and year, and also include any events that are coming up or have recently passed. It’s a fun way to help them practice their writing skills and keep track of important dates.
- Time estimation games: how long will it take to drive to the supermarket?
- Learning a musical instrument.

Activities to help with Planning & Problem-Solving:

- Rubik’s Cubes
- Brain teaser puzzles & logic problems
- Strategy-based board games (Battleship or Chess)
- Geocaching and/or orienteering
- Scavenger hunts

Activities to help with Attention:

- Yoga
- Martial Arts
- Dancing
- Jump rope games
- Hide & seek
- Laser Tag
- Learning a musical instrument
- Reading books like I Spy

Activities to help with Working Memory:

- Matching card games
- Singing in a choir
- Guessing games
- Hand clapping games (pat-a-cake, a sailor

Moving from one task to another

If your child has difficulty sopping 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 plays. Some games can be saved immediately, some can only be saved at a certain point, and many on-line based ones often can't be saved at all and may instead work as separate rounds or games and involve teammates.

Your child may react badly to being asked to leave an on-line game immediately, as they could be letting their team down, or they might be about to win! 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."

Social and Communication Differences

Literal language

Neurodivergent people tend to communicate directly, interpreting language literally. This means that even if you use slang or make a joke, they might take your words literally. Similarly, if you use approximations, like saying “Give me a minute,” they may not understand that you mean “I’m almost ready, just wait a little while.” This can be confusing, and they may think that you want us to literally give you a minute, or start counting from 1-60 seconds, expecting you to be ready at the end of the count.

To avoid this, it’s important to check understanding regularly to ensure that your child knows what you mean.

This can also be a trigger at school, if a teacher doesn’t explain something clearly and your child misinterprets a request and does the opposite.

We’ve included some examples below that parents have shared with us. Although they are amusing in hindsight, at the time our children can become very upset that they have been told off and don’t understand why – when in their minds they did what they were told.

“Jump in the car”

“Run the hoover around the house”

“Throw me my bag”

Social Stories and Comic Book 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. They can be personalised to the interests of each child and can be presented in a logical, literal way and help to take away some of the child’s anxiety around new experiences.

Comic strip conversations can be a fun and helpful way for neurodivergent children to understand complex social situations. Parent Carers or adults supporting your child can use drawings and visual aids; these conversations can make learning about social situations much more enjoyable and engaging.

Further information

- Social Stories - Home - Carol Gray - Social Stories (**https://carolgraysocialstories.com**)
- Helping autistic children & adults make sense of the social world **www.siobhantimmins.uk**
- Social stories and comic strip conversations (**www.autism.org.uk/advice-and-guidance/topics/communic ation/communication-tools/social-stories-and-comic-strip-co versations#What%20Are%20Social%20Stories%20for?**)

Info-dumping

Info-dumping is a neurodivergent trait where your child will get really excited about their special interests or specific topics and tend to share a lot of information about them during conversations which others may find boring. It can be helpful to explain to your child that not everyone shares the same interests that they have. People with similar interests maybe happy to discuss the subject at length, but other people can become annoyed.

> It is important to bear in mind that your child will have their own natural way of communicating and socialising and this is equally valid.

Top Tips

Make friends - seek out other SEND families at your child's school or in the area – there are often SEND-specific times at play centres or inclusive activities. Your child is likely to have particular interests they love – find other children with similar interests and encourage those friendships.

Visit social events tailored to neurodivergent children – this relieves the pressure on our children to conform to neurotypical behaviour. Often, children may hide their natural behaviour, like stimming, being anxious about joining activities or struggling with sensory overstimulation. Inclusive activities and events offer a safe space for children, young people and families to be themselves without fear of judgment or discrimination.

Ask school to help - if your child is finding establishing friendships difficult at school, you could ask the school for help. They could support your child to find like-minded children whoenjoy similar interests and support them to share these in a quieter environment, for example at break or lunch time.

Maintain friendships – "Out of sight, out of mind" can be a problem factor for neurodivergent minds. You will probably have to act as your child's social secretary, arrange play dates, and remind them to contact their friends on weekends and during the school holidays.

Quality, not quantity – choose your people! Remind them that they don't need to be friends with everyone.

Types of friendship – teach them the difference between an acquaintance, friend and best friend. Some children will think

Neurotypical people usually share the same communication style and understand their social rules

But when they try to communicate or meet socially there can be a lot of misunderstanding.

In the past neurodivergent people have been told that their ways of thinking and communicating is wrong and they should learn to be more neurotypical - but it would benefit everyone if both NTs and NDs would learn to understand each other better.

Some people used to think that having a lack of empathy and/or interest in others was a core feature of autism e.g.finding it hard to see something from someone else's point of view or thinking that everyone has the same interests and values as you. **This was referred to as Theory of Mind**.

This theory has been challenged by extensive research carried out by Dr Damian Milton and others, who have developed their own theory called the Double Empathy Problem. This states that the lack of empathy for others goes both ways because people who experience the world in different ways often find it difficult to understand – or empathise with – each other. When we try to empathise with someone, this is much easier if we have been in a similar situation ourselves. Therefore, while neurodivergent people may struggle to understand and empathise with neurotypical people, equally neurotypical people may struggle to understand and empathise with neurodivergent people. In other words, the empathy gap is a double problem which can lead to a breakdown in mutual understanding.

The impact of the empathy gap

While this empathy gap is experienced by both parties, they are not equally affected by it. The experience of the neuromajority is assumed to be typical, expected and preferable. So the burden of responsibility to close the empathy gap falls on the minority group. Neurodivergent people are pressured to learn 'majority' ways of thinking and communicating, without similar and equal expectation for neurotypical people to understand neurodivergent culture. The lack of empathy towards neurodivergent people can lead to the creation of significant challenges for them, including suppression of their natural and authentic ways of being.

The Double Empathy Problem in action

As an example of a breakdown in mutual understanding, consider an autistic child who loudly announces that a woman in the supermarket is fat, and is told off for hurting the woman's feelings and being rude and 'inappropriate'. The child's view is that it is a clear and obvious fact that the woman is fat and the woman must know she is fat since she has to buy large clothes. Therefore saying she's fat is a simple fact such as 'the sky is blue' or 'the grass is green' - it would not, for the child, be an emotionally-triggering comment. The parent's reaction doesn't make sense to the child, who is left confused about what they have done wrong, and potentially anxious about getting it wrong again in the future.

Why does this matter?

These theories are all well and good, but what does this have to do with your child? The Double Empathy Problem is at the heart of the neurodiversity affirming movement – encouraging acceptance of differences, rather than pressurising everyone to think, socialise, communicate and behave in the same way. Spreading awareness and acceptance and dispelling some of the myths associated with neurodiversity will make a difference to how society views it and hopefully provide our children with a future where they feel different, not less.

Further information

Milton's 'double empathy problem: A summary for non-academics from Re-framing Autism

https://reframingautism.org.au/miltons-double-empathy-problem-a-summary-for-nonacademics/

Milton's 'double empathy problem: An Introduction To The Double Empathy Problem, written and narrated by Kieran Rose and animated by Josh Knowles Animation

https://www.youtube.com/watch?v=qpXwYD9bGyU

Section 10

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.

Useful Resources

- **ADHD Foundation Teenager Booklet** www.adhdfoundation.org.uk/wp-content/uploads/2023/05/AD HD_TeenagerBooklet_London.pdf
- **Family Life and Relationships** – www.autism.org.uk/advice-and-guidance/topics/ family-life-and-relationships

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**

Top Tip

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.

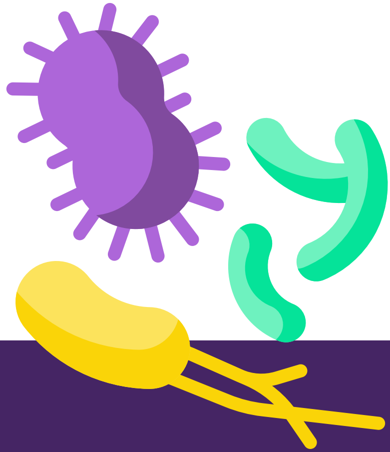
Lots of sensory issues can be triggered by sanitary products. It is worth trying out a variety of products. A growing number of parents are recommending period pants, so they are definitely worth a try.

Further information

- The Autism-Friendly Guide to Periods by Robyn Steward

Personal Hygiene

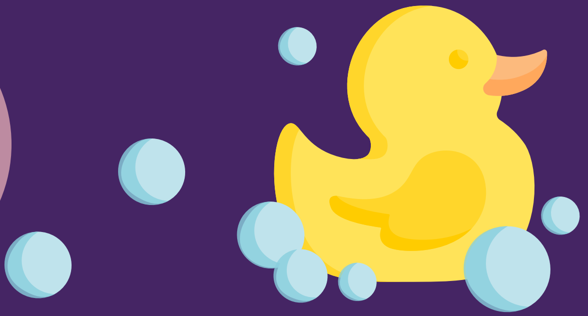
Developing self-care skills such as shaving and personal hygiene can be difficult and sensory differences can make these tasks uncomfortable. Many may have to be convinced of the need to develop good personal hygiene habits!



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.

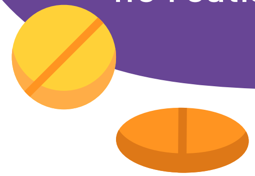
If you use a visual timetable or break down hygiene tasks for your child, (refer to the section on day to day life) remember to update this to include the additional tasks that will need to be included as they are growing up.



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.”



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.

Sex Education

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.brook.org.uk/your-life/adhd-and-navigating-sex-and-relationships**

Top Tips

- ✓ 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
- Encourage your young person to advocate for themselves and ask for help. They know and understand their own needs far more than anyone else ever could.

> "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 at last' 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 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.

Books for Young People

- 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
- Lauren Melissa (**www.instagram.com/autienelle/**) - Lauren chronicles her life as a woman on the autism spectrum, on Instagram, providing #Autietips along the way.
- Paige Layle (**www.instagram.com/paigelayle/**) – an autistic advocate who posts on Tik Tok and Instagram. Layle offers a lot of insight into neurodiversity and can help anyone gain more awareness of the misconceptions they might have about the autism spectrum.
- Neurodivergent Rebel (**https://neurodivergentrebel.com**)
- **https://jennhasadhd.com**

Neurodiversity and LGBTQIA+

(Lesbian, Gay, Bi-Sexual, Transgender, Queer/ Questioning, Intersex, Asexual)

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.

Sometimes being neurodivergent and LGBTQIA is referred to as being "under the double rainbow".

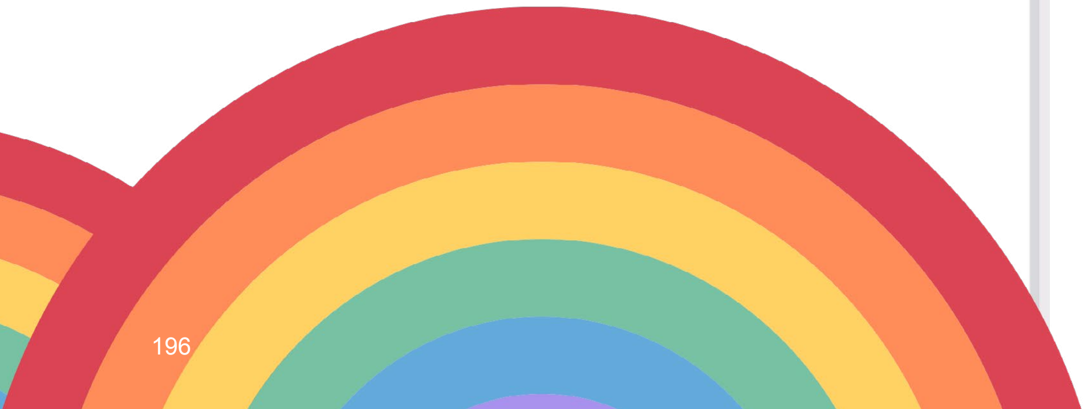
www.twainbow.org is an autistic led charity for those who are both autistic and LGBTQIA.

> "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"

Gray-by David Gray-Hammond (www.rainbowaim. com/2021/02/11/a-world-full-of-bullies-being-autistic-and-lgbtqia)

Further information

- Queerly Autistic: The Ultimate Guide for LGBTQIA+ Teens On The Spectrum by Erin Ekins
- The Anxiety Book for Trans People by Freiya Benson - Jessica Kingsley Publishers - (uk.jkp.com)
- www.genderedintelligence.co.uk
- www.mermaidsuk.org.uk
- www.theouthouse.org.uk



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.

> "My son really struggled in years 7-11 and honestly hated school. He decided to go to sixth form at the same school, only really because he didn't know what else to do! However, sixth form really suits him. He no longer has to wear a uniform and gets scheduled free periods / study breaks where he can complete his homework, and he is studying only the subjects that interest him."

Local Speech and Language Services

Other education providers and charities helping with the transition to adulthood

- ACL - offer numerous support services to help ongoing education to be accessible. This includes lots of inclusive practices and they can work in small groups.
- Hamelin Trust - Can support at home, in their centre and or support into employment - for example they run their own cafe.
- Services for young people https://www.servicesforyoungpeople.org/
- Services for Young People LDD Team https://www.servicesforyoungpeople.org/support-for-young-people/support-for-young-people-with-learning-difficulties-and-or-disabilities/the-services-for-young-people-ldd-team/
- Youth Work Projects for Young People with Learning Disabilities https://www.servicesforyoungpeople.org/support-for-youn g-people/support-for-young-people-with-learning-difficultie s-andor-disabilities/youth-projects-for-young-people-with-l earning-difficulties-andor-learning-disabilities/

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

Whether or not you have a Preparing for Adulthood Advisor, the Local Authority, schools and colleges have an important role in supporting all young people with special educational needs or disabilities (SEND). They work with them to understand their inspirations and help them achieve their goals. They also make sure that they receive impartial guidance on career choices and provide assistance in transitioning to the next stage of their journey. It is important to remember that 'learning' can take place in different settings, including school, college, through work with training, bespoke programmes, or even volunteering.

Information should be provided covering the following options:

For 16+ (Years 12-14)

- **·A Levels**
- **·BTEC Qualification**
- **Supported Learning**
- **–Traineeships/Internships, Apprenticeships, Volunteering, Foundation Courses**

For 18+ (Adulthood)

- **·Further Education (FE)**
- **·Higher Education (HE)**
- **18+ Apprenticeships**
- **Employment**
- **Volunteering**

For young people with an EHC Plan moving from secondary school to a post-16 setting or apprenticeship, the review and any amendments to the EHC plan (including specifying the post-16 provision and naming the college, etc.) must be completed by the 31 March in the calendar year of the transfer.

Further information

- Preparing for Adulthood - All Tools & Resources: www.ndti.org.uk/resources/preparing-for-adulthood-all-tools-resources
- www.contact.org.uk/help-for-families/information-advice-services /education-learning/education-beyond-16/
- www.nationalcareers.service.gov.uk
- Supported employment - www.base-uk.org

"Volunteering has helped improve my son's sense of worth. He feels accepted and enjoys being around adults. He finds it rewarding – but it also teaches him important lifeskills."

Local Speech and Language Services

- Hertfordshire Preparing for Adulthood - https://www.hertfordshire.gov.uk/microsites/Local-Offer /Preparing-for-adulthood/preparing-for-adulthood.aspx

"My child was really unhappy at school, and became too anxious too attend, which meant he didn't achieve his potential and left with only a couple of GCSEs. He finds it difficult now to apply for jobs that reflect his abilities – it's hard for him."

Section 11

Useful information

The ‘Local Offer’ contains information relating to SEND services from your local authority

- Hertfordshire Local Offer
- https://www.hertfordshire.gov.uk/microsites/local -offer/the-hertfordshire-local-offer.aspx

Preparing for Adulthood

- Hertfordshire Preparing for Adulthood -
- https://www.hertfordshire.gov.uk/microsites/Local-Off er/Preparing-for-adulthood/preparing-for-adulthood.aspx

Educational Psychology Services

- East Herts, Broxbourne, Welwyn and Hatfield EHBROX.ISLTEAM@hertfordshire.gov.uk
- North Herts and Stevenage
- NHSTEV.ISLTEAM@hertfordshire.gov.uk
- St Albans and Dacorum
- STADAC.ISLTEAM@hertfordshire.gov.uk
- Watford, Three Rivers and Hertsmere WAT3RIV.ISLTEAM@hertfordshire.gov.uk
- https://www.hertfordshire.gov.uk/microsites/local-of fer/services-for-children-and-young-people/ educational- psychology-service.aspx

Social Care

- https://www.hertfordshire.gov.uk/services/Childrens-social-care/childrens-social-care.aspx

Elective Home Education

- https://www.hertfordshire.gov.uk/microsi tes/local-offer/education-support/educati on-options/home-schooling.aspx

Occupational Therapy

- Physical and Neurological Impairment Team www.hertfordshire.gov.uk/microsites/local-offer/s ervices-for-children-and-young-people/ph ysical-and-neurological-impairment-team.aspx
- HCT and Young Peoples Sensory Services www.hct.nhs.uk/sensory-service-

Speech and Language Services

- Speech, Language and Communication https://www.hertfordshire.gov.uk/microsites/local-off er/services-for-children-and-young-people/speech-language-and-communication.aspx
- Services for Children and Young People https://www.hertfordshire.gov.uk/microsites/Local-Of fer/Services-for-children-and-young-people/ services-for-children-and-young-people.aspx
- Speech, Language, Communication & Autism Team https://www.hertfordshire.gov.uk/microsites/local-off er/services-for-children-and-young-people/ communication-and-autism-team.aspx
- https://www.hertfordshire.gov.uk/services

Special Education Needs and Disabilities Information and Support Service (SENDIASS)

- **SENDIASS Hertfordshire (info@hertssendiass.org.uk)**

SEND Schools

- https://www.hertfordshire.gov.uk/microsites/lo cal-offer/education-support/education-options /special-schools-filter-tool/special-schools-an d-specialist-provision-in-hertfordshire.aspx?s

School Transport

- Hertfordshire Local Offer - https://www.hertfordshire.gov.uk/micr osites/local-offer/education-support/help-y ou-can-get-when-your-child-is-in-school/se nd-home-to-school-transport.aspx

Neurodiversity support page

- https://www.hertfordshire.gov.uk/microsite s/local-offer/resources-for-parents-and -professionals/the-neurodiversity-hub.aspx

Useful Websites

General Help

- 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/
- SNAP Charity useful resources including a fantastic Christmas survival and summer survival guide
https://www.snapcharity. org/need-support/informing-you-online/ resources-2

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
- Dyslexia Society
  https://www.bdadyslexia.org.uk/dyslexia/about-dyslexia/what-is-dyslexia
- 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/
- 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
  https://www.hypermobility.org/what-are-hypermobility-syndromes
- Foetal Alcohol Spectrum Disorder
  www.nhs.uk/conditions/foetal-alcohol-spectrum-disorder/
- National FASD
  www.nationalfasd.org.uk

Neurodiverse Websites/ Facebook/Instagram/ Youtube Pages

- Autistic Not Weird - Insights from an Autistic Teacher and Speaker - Chris Bonnello
  https://autisticnotweird.com/
- The Autistic Advocate - Kieran Rose
  https://theautisticadvocate.com/
- Pete Wharmby
  https://www.patreon.com/pwharmbyautism
- Sara-Jane Harvey, Agony Autie
  https://www.youtube.com/channel/UCN9fwlmPnx16e8-eThlKCWQ
- Dean Beadle
  https://www.facebook.com/dean.beadlespeaker
- **Emily@21andsensory**
- **https://www.instagram.com/21andsensory/**
- How To ADHD
  https://www.facebook.com/howtoadhd
- Neurodivergent Rebel
  https://neurodivergentrebel.com/
- Rene Brooks ADHD
  https://blackgirllostkeys.com/rene-brooks/
- Lauren Melissa **-**
  https://www.instagram.com/autienelle/
- 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/
- Neurodivergent Lou
  www.instagram.com neurodivergent_lou/

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

Notes

The Essex Family Forum is a well-informed, connected and empowered community of families that includes children and young people up to the age of 25 with disabilities or additional needs. We work in partnership with organisations, our Local Authority and health commissioners aiming for quality outcomes that meet the needs of all our families. We are also part of the Eastern region (ERPCF) and national network of parent carer forums (NNPCF).

www.essexfamilyforum.org

SEND the Right Message is a charity that provides support services and training for families with special education needs and /or disabilities (SEND) in Southend and the surrounding areas.

www.sendtherightmessage.co.uk/services

Takiwātanga is a Maori word for autism and translates to ‘In their own time and space.’ Takiwātanga Support Services is a South Essex based, registered charity, providing support to parents of autistic children and activities tailored for autistic children and those with social anxiety and/or sensory issues. Your child does not need a diagnosis to access any of our services.

www.takiwatangasupportservices.co.uk