APPEER

Connecting autistic girls and women

Parent and Carer Tool Kit

appeer.org.uk

Contents

Welcome to the Appeer Community

Foreword

Appeer was conceived to connect autistic girls, women and those assigned female at birth, to offer genuine peer groups, facilitate mutual support and provide a safe space to enjoy shared interests and talents.

As parents of autistic girls ourselves, we continue to learn from our peers and know how helpful it can be to meet others, exchange experiences, to understand and get to know our daughters better and to find our place in the autistic community.

That's why supporting parents and carers of autistic girls is central to Appeer's mission. We provide facilitated peer support sessions alongside all our offerings for young people.

But, we didn't create this Tool Kit - you did! It aims to bring together the wealth of knowledge, strategies and support that Appeer parents and carers have brought to each other and to us, as well as assorted insights from specialists who have kindly shared their expertise.

We hope you find something that rings true with you and helps you in your and your daughter's journey.

Welcome to the A Team

Starting your journey

Adjusting to a diagnosis and the new perspectives it brings takes time. Formal support is lacking, but there is a vast, knowledgeable, and supportive lived experience community out there, and you will soon find your feet. Here we offer some advice and tips for ‘newbies’, based on our work with hundreds of individuals and families.

Explaining the diagnosis to your daughter

Take it at your daughter’s pace of understanding and willingness to understand. She might not be ready to learn about it yet. Be there when she is ready to learn more.

The key to helping her thrive is to learn about ASC (Autism Spectrum Condition) yourself, developing and deepening your understanding of how she sees and processes the world. Then you can find effective and nurturing ways of operating within the family and advocate for her support elsewhere, like school, university or in the workplace.

There is a lot of information online from autistic girls and women themselves; it will be more enriching to learn from sources which are validating and open-minded rather than those focused on ‘cures’ or making autistic people mask

You will find many book recommendations given by parents and autistic women in the photos section of the **Appeer Facebook Page** and in the following section on Autism in Girls/Women. Some other great starting points include:

- **The Girl with the Curly Hair project**, informative visual guides for autistic girls and loved ones
- Books like **"M is for Autism"** and **"Blue Bottle Mystery"**, novels which can help a younger daughter understand autism, even if you don’t directly tell her she is autistic at first.
- Female vloggers such as **Paige Layle and Amythest Schaber**, who talk engagingly about their autism.
- **Chloe Farahar and Viv Dawes** talk engagingly about their autism online.

Reassure your daughter that the diagnosis is hers alone, to share or not; in any given situation or with any particular person or organisation or at any stage of her life. You could explore the pros and cons of sharing a diagnosis in each situation. It is not a judgment; it is a passport.

Support for the family

There is little formal support for autistic girls and their families, but several organisations which can support generally include:

National Autistic Society

Your area may have a local brand run by volunteers which you can link into for newsletters, support groups, email forums, information or family support.

Local Authority Family Information Services

Check out your county council website; they often have a database of services available for SEND families and individuals.

Appeer

We work to connect autistic girls and women and those around them including professionals and families.

Local Support

Explore local support groups or Facebook Groups for parents of autistic girls or young people. It really helps to hear others’ stories, and other parents/carers offer a wealth of experience and support.

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Your starter for 10!

If you are new to autism, here are a few things you may want to consider or learn more about:

Anxiety A common comrade and often explains meltdowns, shutdowns and ‘acting out’.

Executive functioning Planning/organising can be a real challenge with ASC. It’s not laziness.

Masking Sometimes called camouflaging, trying hard to fit in by ‘masking’ is mentally, emotionally, and physically exhausting. They may need recovery time after school or social events.

Change Most autistic people struggle with changes in routine or expectations. Preparing for it can help.

Mental Health More autistic people experience mental health problems than the rest of the population. Watch. Listen. Be an ally.

ADHD At least 30% of autistic people are thought to also have ADHD, but the latter is often overlooked.

Self-criticism Autistic people can be self-critical to the point of paranoia. Go lightly on correction/criticism.

Actions speak louder Bringing home her favourite drink may ‘say’ **love** more clearly than the spoken word.

Details The more specific you are, the less uncertainty she experiences.

Different not less Your daughter’s brain is amazing. It is different, not defective.

Autism and Girls/Women

Including those assigned female at birth who may be gender questioning and/or non-binary.

The amount of information out there can seem overwhelming at first. In case it is helpful we have marked with an asterisk (*) a few resources in particular that may be useful starting points.

Personal Accounts and Insights:

***Curly Haired Project books** website and company started by Alis Rowe, a young autistic women. Wide range of books, seminars and resources for autistic people and those around them.

What Every Autistic Girl Wishes Her Parents Knew by Autism Women's Network, USA.

***M is for Autism** by Vicky Martin - Written by two young autistic girls from Limpsfield Grange School to give their perspective.

Can You See Me by Libby Scott and Rebecca Westcott - A fictional tale of an autistic 11 year old girl based on the real experiences of Libby.

***Aspergirls** by Rudy Simone – Edited insights by adult autistic women interspersed with her own account of growing up as an undiagnosed autistic person. Moving and validating.

Blue Bottle Mystery by Kathy Hoopmann. A children’s mystery adventure about a boy who discovers his autism along the way and the enlightenment of his family about Asperger’s Syndrome.

Aspertools A Practical Guide to Understanding and Embracing Asperger’s, ASD and Neurodiversity written by Harold Reitman, MD - A father's perspective on supporting his autistic daughter

Information and Advice:

Been There, Done That, Try This, An Aspie's Guide to Life on Earth by Tony Attwood - Practical advice for autistic challenges, by autistic people and professionals; very down to earth.

Women and Girls with Autistic Spectrum Disorder by Sarah Hendrickx, autistic author and expert.

The Complete Guide to Asperger's Syndrome by Tony Attwood

The impact of diagnosis and self discovery:

Several valuable talks and presentations are available online:

Niamh McCann's TED talk, reflecting on her life as a young autistic women, about her childhood experience and figuring herself out.

Elisabeth Wiklander's TED Talk "Neurodiversity: The key that unlocked my world"

Paige Layle's content on being diagnosed and how it helped as a teenager.

Carrie Beckwith-Fellows' TEDx talk on undiagnosed autism, Invisible Diversity: A Story of Undiagnosed Autism.

Voices of autistic girls and women

Video Content Creators:

Paige Layle

Young Canadian advocate and vlogger, talks about her experiences and insights with a touch of humour.

Amythest Schaber

Creator of the helpful 'Ask an Autistic' series

Stephanie Bethany

Educational content on various autism topics, including a video on“25 Autistic YouTubers”

Professional Advocates and Educators:

Kristy Forbes (InTune Pathways)

Autism and Neurodiversity support specialist for individuals and families. Great sense of humour, authentic, experienced and skilled.

Dr. Chloe Farahar

British autistic advocate and educator, founder of aucademy.co.uk

Kieran Rose (Autistic Advocate)

Blogs and website resources

Tony Attwood and Sarah Hendrickx

Professional speakers with extensive YouTube content

Additional organisations offering support:

Australian Asperger/Autism Network

Extensive information and help

Autistic Women and Nonbinary Network (AWN)

Offers welcome packets for newly diagnosed individuals and parents

#TakeTheMaskOff campaign - Advocacy focusing on authentic autistic expression

Top Tips for Parents and Carers

Support you can access now

Register at your GP as a carer

Awareness of your responsibilities allow your doctor to support you so you can support your loved one.

Carers Short Breaks (also GP Carers Fund)

Apply through your GP for this grant, for a break away or for support like counselling etc

Disability Living Allowance (DLA)

A monthly, tax free benefit for children up to 16 in the UK, to help with care and potential mobility costs.

Personal Independence Payments (PIP)

Above for those over 16.

Carers Allowance

A taxable benefit for someone who cares for someone with a disability or illness Citizens Advice
A free, confidential service that offers advice and support to those facing a range of problems.

Turn2Us

Charity providing practical information and support to those facing income shocks and financial insecurity.

Useful Basic Strategies

We have to be creative and innovative in the way we support our autistic daughters. Here you will find some simple strategies which we can use to ease our daughter's anxiety (and our own) to make our lives, and theirs, calmer.

When and Then" Approach

"When you have got dressed then you can have a snack/walk/more time on the Switch." **It assumes they are going to do what you have asked – try swapping asking them to do something for just assuming they are going to do it.**

E.g., *"When you have your shoes on then you can have your tablet back/When you have finished this game then you can have one of these delicious donuts I just bought!"* And so on.

"Thank You vs Well Done" Method

Claire Truman, an expert on PDA, suggests treating your daughter like your mother-in-law. If your mother-in-law sets the table or empties the dishwasher you would say *"Thank you"* not *"Well done Doris, that's amazing work!".* By saying well done we set an element of expectation for our daughters. Even their own expectations of themselves are overwhelming. They know they should clean their teeth every day, they want to, but the pressure of the demand might just be too great. Examples you could use are:

"Thank you for getting dressed, that's really helped me because I am pushed for time today,"

"I noticed you fed the cat earlier – thank you so much – it totally slipped my mind."

End Time

An end time is just as important as the start time.

E.g., "We are going to Grandma's – leaving at 10am – and then we will leave her house no later than 6pm."

Stick to the end time, even if you have just started eating. You will need to explain to family or friends that this is how your family have to operate to ensure your daughter isn't distressed.

Understanding Co-occurring Conditions And Presentations

- **Anxiety**
- **ADHD**
- **Rejection Sensitive Dysphoria (RSD)**
- **Pathological Demand Avoidance**
- **Selective Mutism**
- **Hypermobility**

Anxiety

What is anxiety?

Anxiety is the brain and body's natural defence system. When a threat is perceived, the body quickly gears up to deal with it, whether through running away, fighting, or freezing. The brain releases the hormones adrenaline and cortisol, raising the heart rate, shortening breath, increasing muscle tension and energy, and shutting down the rational part of the brain to allow quick action by instinctual, emotional responses. It becomes hard to think rationally or clearly whilst anxious.

It is helpful to note that the word comes from the Latin 'angere' which means 'to choke'. A person's risk of anxiety comes from a combination of their inbuilt vulnerability plus stressful things in their environment.

Autism and anxiety

Anxiety is more common in autistic individuals than others. In fact, 40% of children with autism meet the criteria for several anxiety disorders (Van Steensel & Bogels, 2011) and around 20% of autistic adults (42% across the lifetime), compared to fewer than 9% of non-autistic people (Nimmo-Smith *et al*., 2020). This higher rate is thought to be due to many autistic people's additional and often persistent stressors of:

- **Difficulty recognising emotions**
  Leading to uncertainty around the intent and meaning of others, hence potential threat.

- **Sensory sensitivities**
  When overwhelmed, the nervous system is already highly charged for threat

- **Intolerance of uncertainty**
  Necessitating persistent danger alertness.

Anxiety is often considered a common companion to autism, the flip side of our heightened sensitivity and attention to detail.

Managing anxiety

The first line of dealing with anxiety is prevention.

- Try to identify and remove/reduce triggers for anxiety in your daughter and/or develop systems of advance warning and preparation. If it seems she *"goes from 0 to 60"*, she was probably already at 55, even if you can't see it (for example, worrying all half-term about returning to school). It is also helpful to pace the stimulation and stressors she experiences and make time for exercise and enjoyable activities.

- When a person is mildly anxious, soothing the mind and body to lower the threat response is helpful, perhaps through breathing or grounding techniques or distraction. There are many websites with information on these. It is best to discuss these with your child when anxiety is low. They may like to develop their own tools or visual prompts to support these exercises when needed.

- Validating your child's feelings is key. Feelings do not need to be fixed but heard. Simply naming them helps dampen the overexcited amygdala and puts space between your child and 'the anxiety'.

- They might not always know what they are feeling; you can help by suggesting, for example, "I can see why you might feel sad you couldn't play your favourite game at playtime."

As anxiety rises, it becomes less helpful to try to eliminate it and more helpful to simply be with your child whilst they 'ride the wave'. As a physiological response, anxiety rises and falls, it physically cannot spiral on endlessly. Here are some useful phrases you could use in high anxiety situations:

This feeling is your body responding to anxiety

What does the worry look like?

Your body has felt this before.
It can get through this again.

What do you want to say to your anxiety? What might it say back? Then what?

Do you want to dance or run around to get rid of the worried energy?

Let's wait together. Anxiety always passes.

I'm here with you. You're safe.

Match your breaths to mine.

If anxiety turns into a panic attack, remember even these have a life cycle - up to 30 minutes - and being calm and quietly reassuring for your child during this time is important. Their minds will not be able to process rational discussion or questions. They may not want to be touched or to be alone, so just stay near and ride it out with them (provided they are not putting themselves or others in danger). At another time, talk to them about what would help in future so you can both be prepared.

When the panic attack ends, keep in mind that their bodies are still at high alert, so any small stressor could ramp it up again. Think of how long it takes a just boiled kettle to cool and give them the time they need to return to themselves in whatever way works for them - being left alone, being distracted, exercising. They usually know what they need. See our note about autistic burnout later in the Tool Kit.

Finding Support

For persistent anxiety, therapy can be effective. Your first port of call is usually your GP, who can refer your child to a counsellor or psychologist. Many schools now also have free counsellors who pupils can access. Some people seek private support due to waiting times. It can be worth asking therapists if they have discounted places for those on low income; many do. The **Psychology Toda**y website has a list of therapists in private practice is searchable by type and location.

Other helpful resources

Books

Hey Warrior by Karen Young is great for those aged 6-16

Helping your child with fears and worries by Cathy Cresswell, a good general book for parents of primary age children

Overcoming anxiety by Helen Kennerley, suitable for older teens and adults

How to raise a happy autistic child by Jeesie Hewitson

Online

- Dr Martha DC
- kooth.com
- youngminds.org.uk
- mind.org.uk

Attention Deficit Hyperactivity Disorder

ADHD is a complex brain condition that affects the brain's self- management system. It is not a mental illness, or strictly speaking a learning disorder, nor a behavioural problem. ADHD is thought to occur in just over 5% of the general population i.e. 1 of 20 schoolchildren (World Health Organisation, ADHD Foundation).

ADHD commonly co-occurs with autism; up to 40% of autistic people are estimated to have ADHD, and vice versa.

ADHD includes:

- **Inattention**
  Not being able to keep focus and finding it hard to remember information)
- **Hyperactivity**
  Excess movement, needing to fidget a lot and be on the go
- **Impulsivity**
  Often doing or saying things hastily in the moment without thinking and finding it challenging to regulate feelings, thoughts and actions).

A combination of these can be experienced by those with ADHD, and someone may have a hyperactive, inattentive or combined profile. Many also may struggle with executive functioning and with regulating and managing emotions.

This condition is often misrepresented.

It's not that those of us with ADHD have a deficit of attention; often we have lots of it. It's more like a dysregulation of attention, as we don't always direct our attention to the things that we or other people want us to, and it can be hard to redirect focus or retain our focus.

It's also important to remember that as with autism, aspects of ADHD are in fact valuable strengths, such as:

- **Creativity**
- **Versatility**
- **Spontaneity**
- **Enthusiasm**
- **Boundless energy when doing something they love**
- **Optimism**
- **Problem-solving**
- **Hyperfocus**
- **Thinking outside the box**

ADHD and girls/women

As with autism, ADHD has historically been seen as a male condition, leaving many girls (more likely to have inattentive type), overlooked, unsupported and dismissed as shy or daydreamers. Even those with a more hyperactive profile might seek movement in less obvious ways, such as twiddling hair or doodling.

As with autism, girls with ADHD aren't all the same, but those who experience some of the below on a regular basis may have ADHD:

- Daydreaming and seeming to be in a world of her own regularly
- Highly sensitive and struggles with emotional regulation - may get upset or cry easily
- Gets distracted and finds it hard to focus on tasks that she's not interested in or change focus
- Can seem disorganised and messy
- Finds it hard to plan and manage time (often late)
- Can seem forgetful
- Hyper-talkative (always has lots to say, but is likely to interrupt and not always listen)
- Has problem completing tasks
- Takes time to process information and directions; seems like she doesn't hear you.

Diagnosis and support for ADHD

In the UK, diagnosis, and treatment by referral in the NHS, starting with your GP and ideally with support from your daughter's school. Waiting lists are very long, and some people go private. Diagnosis is done by a specialist psychiatrist, paediatrician, or other appropriately qualified healthcare professional and involves input from the parents, observation of the child and sometimes information from the school environment.

ADHD is manageable with the right support. This is primarily via medication but also with therapy, parent/carer advice and individualised support. There are a variety of medications, see NICE guidelines: Attention Deficit Hyperactivity Disorder: Diagnosis and Management https://www.nice.org.uk/guidance/NG87). Medication is effective in 90% of people with ADHD.*

* Not all medications work for everyone, and some may not be appropriate at all so always consult your GP.

ADHD support/information services

ADHD Foundation - https://adhdfoundation.org.uk/ Integrated, strengths-based health and education service for people with ADHD, Autism, Dyslexia, Dyspraxia, Dyscalculia and Tourette's syndrome.

ADHD UK - https://adhduk.co.uk/

Aims to help people navigate their life with ADHD, reduce stigma, build awareness, and undertake research that will have a meaningful positive impact on those with ADHD.

ADDitude - https://www.additudemag.com/

Media resource offering expert advice and support on a range of topics related to ADHD.

UK ADHD Partnership - https://ukadhd.com

Aims to support clinicians and allied professionals to identify and meet the needs of children and young people with ADHD.

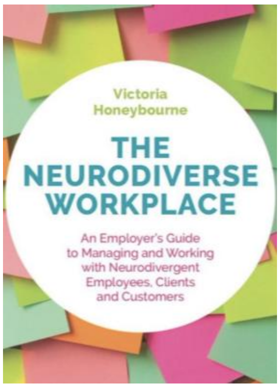
Voices of girls and women with ADHD

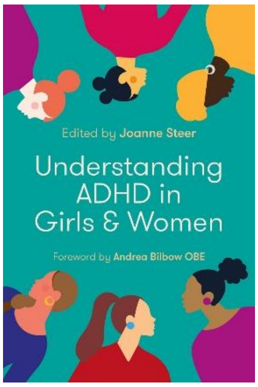
Jessica McCabe's TED Talk about self-discovery, as a young ADHD advocate and educator

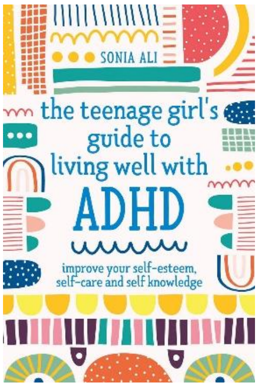
Jessica McCabe's YouTube video channel, "How to ADHD", supporting ADHD life.

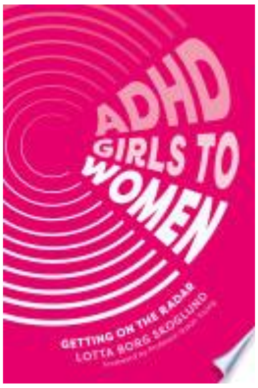
ADHD advocate Stephanie Camilleri's talk with Gloria Yu

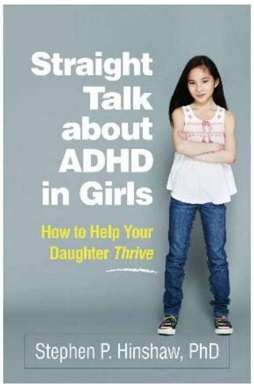
Book Recommendations for girls and women with ADHD











Rejection Sensitive Dysphoria (RSD)

RSD is not a medical diagnosis, but a way of describing a type of emotional dysregulation. It's often experienced by those with ADHD, Autism, social anxiety or forms of trauma.

It's more than being "oversensitive", and the person can be left feeling very intense feelings of failure and distress at situations others may deem to be completely normal and fine. The feelings are very real and genuine, and can lead to feelings of despair and uncertainty, leading some to avoid particular environments and situations altogether; for fear of being rejected.

This may extend into adulthood, and exacerbate feelings of further social isolation in friendship groups or work colleagues.

This involves intense emotional sensitivity to perceived criticisms or rejections, including often seeing neutral or vague reactions as rejection or silent criticisms. This may mean that your daughter may have difficulty starting tasks, projects or goals if there is a chance of failure and may experience severe anxiety and thus avoid situations where they feel there may be a rejection.

Commonly, with our girls, they overcompensate and become people pleasers to avoid any potential rejection. They may be called "over sensitive" when they express their genuine feelings and have difficulty responding logically in these situations. This may reinforce "masking" behaviours they already exhibit.

Read more about this on our website in the Resources section under Wellbeing Bulletins.

appeer.org.uk

Pathological Demand Avoidance (PDA)

PDA is increasingly acknowledged as a presentation of autism, where perceived demands cause overwhelming anxiety and trigger a fight/flight or freeze response.

Demand avoidance is when someone strongly resists doing things that are asked or expected of them. While everyone experiences this sometimes, some people (particularly those who are autistic) have a persistent and intense resistance to everyday demands. This can include basic needs like eating and sleeping, or regular activities like going to school or work. While we don't fully understand the fundamental causes of PDA yet, research suggests it's related to:

- An intense need for control
- High anxiety levels
- Difficulty dealing with uncertainty
- Some people think anxiety might be caused by feeling their control is threatened, rather than being the cause of demand avoidance.

Rather than having its own medical diagnosis PDA is recognised as a part of a person's specific autism or ADHD profile. There are three main types of demands someone with PDA may resist

1. Direct demands - Clear instructions like *"brush your teeth"* or *"put your coat on"*
2. Internal demands - Things coming from within, like feeling hungry or needing to use the bathroom
3. Indirect demands - Implied expectations, like feeling a need to reply or answer a text message

Upsettingly, people with strong demand avoidance may resist activities they genuinely enjoy or want to do, simply because it has become a "demand." For example, they might refuse to eat their favourite food or participate in an activity they were looking forward to, just because it was suggested or expected (even by themselves). Their form of resistance may present in a range of ways, some including:

- Making excuses (sometimes creative ones like "I can't because I'm a tractor")
- Trying to distract or change the subject
- Simply saying *"no"* and refusing to negotiate
- Withdrawing or becoming passive (like walking away or not responding)
- Showing aggressive behaviour (usually as a last resort)

When someone realises they can't avoid a demand, or when their usual resistance strategies don't work, they might experience overwhelming anxiety. This can lead to:

- Meltdowns
- Panic responses
- Potentially aggressive behaviour.

These reactions are usually beyond the person's control. If your daughter has a demand avoidant profile, it's important to understand that these responses are not an active choice she may be making, despite how difficult it may feel in the moment. Demand avoidance can impact a multitude of areas of a person's daily life, including:

- Sleep (both falling asleep and waking up)
- Self-care tasks like hygiene and eating
- Emotional regulation
- Friendships and relationships
- Ability to attend school or work
- Mental health (including anxiety and panic attacks)

For parents and carers, it can be extremely distressing watching your daughter struggle, particularly when doing things you know they want, and genuinely enjoy, doing. Some strategies Appeer parents have shared with us that have been successful include:

- Reducing or removing demands when possible
- Working together collaboratively rather than giving direct orders
- Using indirect communication styles
- Avoiding things that might cause stress (like direct eye contact)
- Providing quiet spaces during difficult situations

- Creating a coordinated support plan involving family and professionals

Further resources:

- **Clare Truman** – Autism specialist with expertise in PDA and offering practical advice.
- **Sally Cat** – A blog with visuals about adult PDA
- **The PDA Society** have excellent resources and support on impactful ways to manage PDA.

PDA SOCIETY
Part of the Autism Spectrum

Selective Mutism (SM)

Lucy Nathanson, a child therapist and founder of confidentchildren.co.uk, specialises working with children with Selective Mutism (SM) and discussed with our community some of her insights on this. Selective Mutism is predominantly an anxiety disorder. The child wants to speak but physically cannot - their throat muscles contract and prevent speech. While children might say they don't want to talk, they actually do want to speak but are too scared. This might be particularly confusing for children, particularly when they might have difficulties naming or understanding what feelings they may be experiencing at a particular moment; which is often the case for many of our autistic girls. Without having the understanding, and language to express what they may be experiencing, it may be easier for them to simply say that they don’t want to talk – as that is what their body is telling them through it’s anxiety response in a particular situation.

Shyness or Selective Mutism?

Selective Mutism can wrongly be mistaken or likened to being, or feeling shy. This is not the case at all.

Shyness occurs in all situations, and children typically warm up as they become familiar with people or situations. In contrast, SM usually occurs only in specific situations or with specific people, and the child never warms up.

Other factors which may influence a child’s anxiety response, resulting in Selective Mutism, include:

Identity

Sometimes the child fulfils the role or identity as the child who doesn't speak at school/rainbows/at Aunty Jean’s etc. Sometimes they keep this alive because they are terrified of the reactions of others if they do speak in a situation where they haven’t spoken previously. So, it's best to brief those around your child that if they do speak to just react normally rather than make a big deal of it.

Feeling Scared

Many times the child says that they don't want to talk. The reality is that they do want to talk, they are just too scared.

Hypervigilance

Sometimes SM children are hypervigilant - might tell parents to keep their voices down in the supermarket etc. They don't want to draw attention to themselves.

Ways to help with Selective Mutism

Lower Anxiety Levels

The best way to begin treatment for SM is to lower anxiety. – As our anxiety increases, our brain's ability to think and reason decreases and vice versa. For example, if a child always worries they will be asked to speak in class, then they may be so anxious that they can't listen to the lesson; which is why SM may present to some as a learning difficulty, when it may not be the case. A child with SM is more likely to talk in a pressure free environment. If for example they are in a small side room at school with their mum playing a board game like Guess Who and do this every week then perhaps you will be able to "slide in" a child that they know from class or that they speak to outside of school, then potentially a liked teacher could play the game. List all the people that the child does not speak to and start with the easiest.

Ask closed Questions

Try asking questions with one-word answers and move on quickly whether or not you get an answer.

Examples include, *"Would you like a lemonade or a coke"* instead of *"What would you like to drink"*. A one word answer, where you have already given them the words, is an easier and less daunting response, than having to engage the brain to think of the answer, particularly during times of perceived stress.

Zoom/Texting

Selective Mutism can be seen in text talk too. Sometimes it helps if the answer is already typed out, i.e., ask the teacher before the lesson what the question will be. Type out the answer for your child and then all they have to do is press send. The same could work for social texting with friends. You could role model this by texting your daughter.

SMIRA - www.selectivemutism.org.uk

Lucy Nathanson - www.confidentchildren.co.uk

Hypermobility

Hypermobility is a condition where joints are more flexible than normal, allowing for a greater range of motion. Generalised joint hypermobility stems from issues with collagen formation, which provides strength and supports joints, skin and other issues. Hypermobility is very common in children and usually decreases with age, impacting around 1 in 10 people.

There is a high correlation between hypermobility and autism, which isn’t fully understood yet. For most people, it doesn't cause problems, but for others, it can have a real impact upon their daily life. Understanding the different ways hypermobility can impact someone, can empower us to adequately advocate for our daughters, in order for them to get the help they may need.

Physical impacts

Motor Skills

Hypermobility may affect both fine and gross motor skills through joint instability and muscle weakness. Overly flexible joints lack the stability needed for precise movements, making fine motor tasks like writing or buttoning clothes difficult. Due to social issues, it may be those with these issues are excellent at avoiding writing, typing, doing their laces or buttons – as a way of masking their difficulties. There are many aids available that can help those with these difficulties, including cutlery, making it easier to complete daily tasks.

Proprioception

People with hypermobility may experience poor proprioception (body awareness in space), causing coordination challenges during both detailed and broad movements.

Chronic Pain

It can take a lot more time and energy for those with hypermobility to engage their joints to complete tasks that, for others, may feel effortless. This can lead to chronic pain and fatigue that directly impede motor skill development and execution.

Chronic Fatigue

When joints hurt during movement, people naturally limit their activities, reducing opportunities to build motor strength and coordination. Persistent fatigue depletes the energy needed to maintain proper form and control during physical tasks. The combination of chronic pain and fatigue particularly impacts a person's ability to engage in activities that bring joy or fulfilment which can impact significantly on their mental health.

Poor posture

Poor posture resulting from joint laxity creates improper body alignment that interferes with motor planning and execution. The increased risk of injuries like sprains and dislocations creates hesitancy to engage in physical activities that would otherwise strengthen motor skills. People may develop compensatory movement patterns to avoid pain, further compromising proper motor skill development.

A difficult cycle

Over time, these factors create a cycle where limited movement leads to further weakness, continuing to impact both fine motor skills (like handwriting or using utensils) and gross motor skills (such as walking, running, or climbing stairs).

Bladder and Bowel Problems

Some with hypomobility also may suffer with bladder and/or bowel problems, as the collagen in these structures are also impacted. It may be that your daughter is still not dry through the night at an older age to her peers, in which case talking to your GP about this and your suspicions of how hypermobility may be impacting this could help. Bowel problems could be equally helped with medical intervention, and by also reviewing your daughter’s diet to support the issues she may experience.

Brusing Easily

Other indicators of hypermobility include soft, stretchy skin which can bruise more easily than other skin types

Light headedness

This can link to chronic fatigue, dizziness and fainting. Seek medical help if this is seen to be impacting your daily life and impacting you in daily life.

Mental Health impacts of hypermobility

In addition to the physical difficulties, often many in our community report how the lack of understanding, kindness and belief from others in their symptoms, often cause them more distress than often the actual symptoms themselves to. By nature, many of these issues are chronic, and can vary day to day depending on many factors – how much activity the person has taken part in the day before, whether they really enjoy an activity and feel it is “worth the pain” one day, and not on another.

In being an invisible illness, that can vary in intensity day by day, it can be difficult for teachers, peers and families to fully understand or believe to be true. This can lead to hypermobility issues resulting in the individual feeling further ostracisation from their peers; the more vocal they are about their symptoms. This can result in many withdrawing from social situations, trying new activities, or feeling voicing their pain will invoke negative responses from others.

It’s important to remember, that just because someone feels pain doing an activity, does not mean that they do not enjoy, or want to do an activity. Often they are just frustrated, if not more frustrated, in being unable to do certain activities. This is part of managing an invisible illness.

Ways to help

Validate

Often, the first and one of most important steps is letting your daughter know that you believe what they is going through is real, and they are not being “lazy” or making things up.

Research her symptoms

There are hypermobile adjacent conditions, including Ehlers-Danlos Syndom, that a person with hypermobility may also have. The Ehlers-Danlos society offer a lot of information and resources on their websites on how to deal with hypermobility, and seek help from professionals with various issues someone may have as a result of their hypermobility.

Seek medical advice

Your first port of call may be your GP, who can then go on to make referrals to various other professionals; including Physiotherapists, Gastroenterologists, Rheumatologists etc depending on the symptoms experienced.

Physical Aids

Cutlery, kitchen aids, dressing aids can help remove many of the barriers hypermobile people may face in daily tasks and create a pathway towards being more independent (including using knives in the kitchen etc). Essentialaids.com may be a good starting point looking for resources, and an occupational therapist can help advise what may work for your daughter.

Transport Aids

Walking Aids, including scooters or wheelchairs, may increase your daughter's ability to participate in daily activities.

The **Ehlers-Danlos** Society

HYPERMOBILITY
SYNDROMES ASSOCIATION

Daily Challenges
And Support

- **Relationships with Food**
- **Mental Health and Wellbeing**
- **Self-Harm**
- **Sleep**
- **Periods**

Relationships with Food

Dr Louise Connor, a chartered consulting clinical psychologist, met with members of the Appeer community to discuss some of the different reasons that autistic people may have difficult relationships with food, which result in them restricting their food intake.

It's important to remember whilst the symptoms may be the same, i.e. your daughter is not eating, the underlying causes of this may be very different to another person's.

Why is my daughter restricting her food?

- **Social Language Challenges** She may struggle to express or understand her food-related issues due to difficulties with social language, leading to food restriction.
- **Intense/Repetitive Interests** Calorie counting and nutritional knowledge might become an obsession or special interest, resulting in restricted eating patterns.
- **Weight Control and Social Fitting** She may restrict food to maintain a certain weight to appear "normal" and fit in with peers who discuss diets and weight management.
- **Anxiety** High anxiety levels can make swallowing difficult. Like all animals, humans only eat when they feel safe. If she doesn't feel safe due to anxiety, she may restrict her food intake.
- **Sensory Issues** The sounds of cutlery, chewing, or general noise in eating environments (like school canteens or family dinner tables) might be overwhelming, leading to food restriction to avoid these experiences.
- **Control** Food and weight management might be used as a way to gain some control over her life when other aspects feel uncontrollable.
- **Success and Achievement** If she struggles in other areas (school, relationships, home life), controlling her weight might provide a sense of achievement and positive feedback that's lacking elsewhere.
- **Social Relationships** Knowledge about calories might be used as a way to connect with peer groups or to make friends. Being the one who always knows the calories in any particular food puts her in the centre of a peer group. She might participate in group dieting to fit in with neurotypical peers.

How can I help my daughter?

Reassurance

Dr Connor reminds us that our brains do not fully develop until we are 24. Perhaps your daughter can only take responsibility for her choices for the next half an hour. If they are struggling with feeling overloaded and with decision making, it might be best to remind our girls that we as parents and caregivers know what they need, and not to worry – we've got this for them. It can be helpful to remind them that we've managed to feed them correct healthy amounts for years so they don't need to worry, as we can take this responsibility on for them.

Replacing Belief Systems

For some girls, we may need to think imaginatively about replacing belief systems they may have built up around food with other things that may help her feel safe and in control. In these situations, it can be useful to see what impact such interventions have on her eating and repeat the process in a trial and error way.

Experimenting and generating "evidence"

Our girls often respond to evidence, and setting up "experiments" may help give her more of a perception of control.

- Perhaps eating with ear defenders on – does that make it easier?
- What about playing with sensory toys while eating, does the sensory feedback make a difference?
- What about getting her involved in cooking, or with watching you cook?

PEACE Pathway

PEACE is a Pathway for Eating Disorders and Autism developed from Clinical experience. It has been set up to support autistic people who may be suffering with eating disorders, their loved ones and their clinicians. Peacepathway.org

PEACE ●

BEAT eating disorders

A UK charity set up to end the pain and suffering caused by eating disorders.

Beat
Eating disorders

Mental Health and Wellbeing

It is often thought that the challenges faced by autistic girls and women are often internalised rather than externalised. For example, a teacher may describe an autistic female student as quiet and no trouble at all but a male one she can see his difficulties because he often has meltdowns in class or throws things (*lived experience generalisations).

This internalisation can lead to increased anxiety, depression and self-harm as detailed below. Many of the young people who access Appeer experience mental health and wellbeing challenges and we hope to support them to understand their feelings and sensory needs in our sessions.

Self-Harm

Deliberately injuring oneself, for any reason, qualifies as self-harm. This can happen for a multitude of reasons and be extremely upsetting and difficult for everyone involved. Here we have shared some of our understanding of potential reasons behind why our community may self-harm, and ways you can help them cope.

Alexithymia refers to having difficultly recognising, naming, managing and expressing emotions – something very common among autistic people. This can lead to feelings of frustration, anxiety and depression, resulting in difficulties with coping and expressing such complex emotions and feelings. For some, this is a sensory coping mechanism when they are feeling overwhelmed. For others, the depression caused from alexithymia leads to feeling of desperation and despair.

Understanding the reasons behind potential causes of self-harm, may lead to identifying better ways to help. For example, if the cause is seeking sensory input, then strategies like wearing an elastic band around the wrist that is “ping’d” when input is needed could help.

Create a “Safety Plan”

Samaritans say this is a tool for helping someone navigate suicidal feelings and urges, should they arise in the future. It can be a way for your daughter, and yourself to plan how to communicate and check in with each other going forwards. Please see the Samaritans website for more information, including templates you can use.

Help and Support

- **Emergency - 999**
  If someone's life is at imminent risk, call the emergency services on 999
- **For urgent mental health support,**
  Call the NHS 111 and select Option 2.

HARMLESS
the centre of excellence for
self harm & suicide prevention

Offer resources online for young people and information for families and friends. See their website for more information and referrals into their service.

Effects on the family

It can be very distressing for parents and carers to watch their daughter's feeling low. *"You are only as happy as your most miserable child",* right?!

We don't have a magic answer unfortunately, but you will find talking to other parents and carers in the same position extremely helpful; perhaps access face to face support groups or online communities.

appeer.org.uk

Mental Health Help and Support

If reaching out to friends or support groups feels overwhelming or you are in **a crisis situation** contact the organisations below or your GP. Remember also that **your mental health and wellbeing is important too and you should also access support for yourself.**

- **Emergency - 999**

  If someone's life is at imminent risk, call the emergency services on 999

- **For urgent mental health support,**

  Call the NHS 111 and select Option 2.

shout 85258

A free, confidential 24/7 text support service for anyone in the UK who is struggling to cope. To start a conversation text *"Shout"* to **85258**.

PAPYRUS
PREVENTION OF YOUNG SUICIDE
HOPELINE247
0800 068 41 41

(Text 88247) For anyone having thoughts of suicide or for those concerned for a young person who might be, confidential support and practical advice.

childline
ONLINE, ON THE PHONE, ANYTIME

https://www.childline.org.uk/get-support/1-2-1-counsellor-chatCall 0800 1111 for 24/7 support

SAMARITANS

Call 116 123 to speak to someone, 24/7, for free

mind

Support line 0300 102 1234
Infoline 0300 123 3393

appeer.org.uk

- **Appeer Resource Section on our website.**

  We have a variety of useful resource sheets, up to date signposting and Wellbeing Bulletins written by our Safeguarding Lead.

Sleep

Research estimates that between 40-80% of autistic children and young adults experience sleep problems, impacting Irritability, Depression, Hyperactivity and Poor learning and cognitive performances. The Sleep Charity have a wealth of information and support on their website. This is their advice to parents of children with SEND.

How can I help my child with Sleep?

Explore reasons for sleep issues.

Underlying reasons may include sensory processing difficulties, lack of understanding about night and day, or medical issues; and

Record what is happening at night using a sleep diary

These are useful to establish any unusual patterns and identify factors affecting sleep. This information can also be shared with professionals to develop appropriate strategies to try and improve sleep.

Use visual aids

These help to support understanding of sleep. Visual timetables can help to show what is going to happen next during the bedtime routine. This can make the evening calmer and easier to deal with.

Avoid screens at least an hour before bed

Screens, like mobile phones, iPads, TVs etc can impact melatonin production – the hormone that helps us to fall asleep. Research suggests that some people with additional needs may not produce enough melatonin or may release it later in the evening. Replacing screens with calm activities like puzzles, reading or drawing may help.

Review Diet

Check to make sure you or your child are not eating or drinking anything sugar loaded before bedtime.

Regular bedtime routine

Ensure your child is in a reassuring routine and put them to bed at the same time each night. It is also important to wake them at the same time each morning.

Review the bedroom

Assess if there are ways to make it as good an environment as possible to promote sleep. Ideally it should be cool, quiet and dark. Consider how their bed feels and if it meets sensory needs

Ask health practitioners

Sleep problems can be complex and it is important to try to identify possible causes. These can includes anxiety issues as well as medical factors. Ask your health practitioner for guidance and make sure to tell them about any unusual night time behaviours including snoring, teeth grinding and night terrors.

Find out more at thesleepcharity.org.uk or call the National Sleep Helpline on 03303 530 541

Sleep strategies from the Appeer team

In addition to this advice, the Appeer team have also found sleep issues can be aided with;

Weighted Blankets

Make your own or buy from somewhere like Amazon

Melatonin

This can be prescribed by CAMHS – Child and Adolescent Mental Health Services (NHS) if sleep issues are significant. *

Side Lights

Either in the same room, or a landing light can provide comfort.

Listening to Music or Stories

Audible or BBC sounds have audio books and podcasts; sometimes following a story or narrative can help take someone’s mind away from their own anxieties.

Background Noise

White Noise machines, fans and other background devices can really help. BBC Sounds also has white/ pink/ brown noise and other options like rainfall, waves crashing etc, which some find very helpful.

* Not all medications work for everyone, and some may not be appropriate at all so always consult your GP.

Periods

Managing periods can be difficult for any young person, let alone those with increased sensory sensitives, who may struggle with change and the internal demands they come with managing the practicalities of periods.

Managing Change

Unlike other aspects of puberty, which one can choose to ignore, periods present a monthly “change” that our girls have no choice but to deal with and confront.

Helping them understand what is happening to their bodies and explicitly showing them how to handle the hygiene aspects of periods is really important.

Some choose to talk to their girls about periods from a younger age, so they understand that it is something that is going to happen to them at some stage and that it cannot be bypassed or avoided.

When her periods do start, you may wish to help her record what day they start on, how long they typically last and the time between periods, to ultimately help her understand if her body follows a certain timing rhythm that may help her predict when she might expect to start her period each month. This could either be on a wall calendar, on shared online calendars or through the use of period tracking Apps. It may be helpful to explain that initially, periods may not follow a uniform cycle, and it may take a few months before their regularity becomes more noticeable.

Sensory Sensitivities

Technology is improving all the time to try and can make life easier. In addition to the conventional sanitary products, there has been a rise in the awareness of period proof clothes our young people can wear, increasing comfort and removing the barriers periods can sometimes present for those wanting to partake in activities like swimming and gymnastics whilst menstruating.

ModiBodi is a very well known brand of period wear, that also makes swimming costumes, leotards and other products that can be worn, cleaned and reused for periods. Online, searching “Period pants” will bring up a multitude of brands that provide like products.

There are also reusable sanitary towels, that are fabric and do not present the same sensory challenges that conventional sanitary towels might.

It’s important to note, that whilst these products are pricey, if looked after correctly, as explained by the manufacturer, they can last for a significant amount of time. Many are also available in an array of styles and colours, particularly for teens, hopefully making them feel more appealing to wear.

Managing the demand

For some, accepting and understanding the demand periods present, both in terms of hygiene and on our bodies, can be extremely difficult to process. Reducing sensory sensitivities and cataloguing the new “routine” your body may be following with a menstrual cycle, can help your child have a sense of control and autonomy over a situation they, in reality, may not feel able to control at all.

Some parents make “period hampers”, and put some treats and products in them, for their child to use when their time of the month arrives. These can include stationery, bath bombs, and other items that help them feel calm and special.

Such tactics can be helpful in trying to internally re-frame the process; that this is part of growing up and a time where she can pay more attention to her body, and give it things to help it feel better.

There is also a rise in monthly subscription boxes online, both period themed and otherwise (make-up, sweets, stationery etc), for parents who like the idea, but would rather outsource the cognitive burden of collating items! Once periods are established and normalised, many report the need for these boxes reduces.

Other ways to help

Sadly, most of us will know the pain that can come with periods. This can be made worse for those that are particularly sensory and experience pain more intensely than others. Sometimes a hot water bottle, paracetamol and a warm bath are enough to provide comfort, but sometimes the issues we face go beyond this. In these cases, it is important to seek medical advice and ask for help with your specific situation.

Below are some commonly shared interventions GPs may recommend for those who experience more issues with their periods than others:

Medications

Sometimes, if appropriate GPs, or Gynaecologists may prescribe medications such as Mefenamic Acid, which can help with intense period pain or Tranexamic Acid which can help reduce flow significantly. *

The "Pill"

Some GP or Gynaecologists may feel that someone would benefit from going on a contraceptive pill to help them regulate their monthly cycle. This may be for a multitude of reasons and have the bonus of being able to "run packs together", reducing the number of periods your daughter may need to experience in a year. (E.g. once a quarter instead of once a month). This avenue would need to be discussed with you daughter and appropriate medical professionals to ensure this would be to your daughter's benefit. *

PMS vs PMDD (Premenstrual Syndrome vs Premenstrual Dysphoric Disorder)

It can be common to experience mood-swings before periods. PMS, is a result of the hormonal fluctuations that occur during our cycles. PMDD is considered a more severe form of PMS that causes more intense emotional and physical symptoms. It is currently thought to impact autistic girls more than their non-autistic counterparts, potentially, due to increased sensitivity to hormonal fluctuations.

Beyond PMS symptoms, PMDD can include intense depression, anxiety, anger, difficulties concentrating, and suicidal ideation, specifically at a certain time in a girl's menstrual cycle, before they start their period. These symptoms will be significantly less prevalent, if at all, at other times. If you suspect you, or your daughter, may have PMDD, you should seek medical advice. It may be helpful to share a diary of your daughter's symptoms, and how they relate in timings to her period.

* Not all medications work for everyone, and some may not be appropriate at all so always consult your GP.

Dysregulated Behaviour

Sometimes, despite all the planning and interventions in the world, particularly before a diagnosis of autism, our girls can suffer from extreme dysregulation. Often, it can be this extreme end of this behaviour that is the indicator to us as parents and carers, that maybe something else is going on with them that we need to address so we can help them.

The most common forms of dysregulated behaviour families tell us about are **Meltdowns** and **Shutdowns**, both of which present very differently, but stem from the same feeling of the overwhelming anxiety an autistic person may feel when they are not emotionally regulated. Both can be tremendously upsetting to witness, particularly if and when we still assume our children are “neurotypical” like their peers, and thus have a level of control over their behaviour under duress.

You might find some of the insights our parents have shared with us over the years may help you process what is going on, and find the best ways to support your young person.

Shutdowns

An autistic shutdown is an involuntary and intense reaction to overwhelming stress or sensory overload, essentially a “freeze” response. During a shutdown, the person may be largely unaware of their surroundings, or experience difficulty communicating due to feelings of overwhelm. Often it can be difficult to spot a shutdown, as they can manifest as quiet withdrawal, reduced responsiveness and difficulty engaging with others. Some report feeling completely unable to move.

Meltdowns vs Tantrums

Meltdowns are the other side of the scale, where feelings of overwhelming stress or sensory overload ignite a “fight or flight” response. Often, particularly by outsiders, meltdowns can be confused with tantrums. Both can be very loud, aggressive and at times physical responses – but the causes and potential ways to resolve them can be entirely different.

All too often parents in our community talk about pressures they feel from well-meaning family and friends (and sometimes professionals) seem to conflate the two. This is particularly common when autistic traits are missed or miscategorised, as often happens with girls. Meltdowns and tantrums can both present in distressed verbal and/or physical aggression at a particular situation, or environment they may be in and want to get out of.

The difference, largely, between the two, can be the level of control a child or young person exerts during a meltdown.
If you're unsure if it's a meltdown or tantrum, maybe a good starting point is to look at the level of control your child is exerting in their dysregulated state. Ask yourself:

- **If they were given a particular item, ignored, or comforted, would this resolve and de-escalate the situation pretty quickly?**
- **Do you understand what it is they are trying to achieve, and is there something they want out of a situation?**

If the answer is "yes" then perhaps the behaviour is a tantrum….Meltdowns can be very different. Often, once a meltdown starts, autistic individuals can lose all sense of control and exhibit extreme and upsetting behaviours, which are upsetting to them and sometimes also their dignity. Often, post meltdown, they can experience extreme shame and upset at what has happened, and don't really understand why or how they could do some of the things they did.

The **Ambitious about Autism YouTube** channel has lots of videos and online materials where young people talk about how they feel about meltdowns; in particular, we'd recommend their video titled **"Young People explain meltdowns"**. We'd really recommend any parent with an autistic loved one watch this to understand, as awful as these situations are for us to see, how it must feel to be at the centre of a meltdown.

Parental Understanding

What is so upsetting and confusing for so many parents is how, despite their child typically being so naturally kind, intelligent and insightful, extreme dysregulated behaviour can feel the exact opposite. It can be very difficult to understand, and even harder not to take personally. Many parents turn inward, blame themselves and then decide (or are told by ill-informed family or professionals) they need to create firmer boundaries or put consequences in place for their young person, to help them understand that this behaviour is not acceptable. Often, this is what society encourages us to do, as that is often seen as "good parenting". The reality of this is that it frequently doesn't work and can actively escalate situations that otherwise could be easily avoided. This can result in further dysregulation, fractures to your relationship, and set your child up for situations they are not equipped to deal with. It can also contribute to traumatic situations, that may take years for your child to work through and process.

Here are some tips we recommend for dealing with meltdowns:

Avoid triggers and let go of others' judgements

This is probably one of the most important, and equally often most infuriating piece of advice parents are given. Often what parents want to hear us is *"how do I stop my child from having a meltdown and instead get them to do X",* whether X is to go on that dog walk, sit at the table for dinner, etc etc. It can be easy to think that just because other children, maybe even siblings, can do certain things, your autistic young person has to be able to – it' just a matter of how to "get them" to do it. As tempting as this logic may be, it doesn't help or result in regulated behaviour. It's important to understand that meltdowns result from complete sensory overwhelm, and it's not that someone is consciously choosing not to do something, but there are various reasons leading them to feel totally unable to do it. It may be that something has happened in their day which has narrowed their window of tolerance, and there are activities they feel they "need" to calm down, and the absence of these result in dysregulated behaviour. It may be doing a certain activity, or going a certain place is just too much for them, and part of understanding them as a person is making these concessions for them with kindness and understanding.

Often it comes down to your personal relationship with your young person, to know and understand when it is something they genuinely cannot do or feel that they just don't want to do. Supporting them in being able to advocate for themselves, and what they may need to do in order to stay regulated is really important, particularly as they make their way into becoming more independent.

Remain Calm and Speak Less

By nature of having a meltdown, your young person is beyond the ability to reason – else they would be behaving in the way they usually do. As the adult, you are there to de-escalate the situation (where possible), or to try and keep them in an environment where they, and those around them, are safe.   Appealing to their usual reasonable nature may actually be counter-productive in these situations and can actively add to sensory overwhelm.

Call for help if needed

The local CAMHS crisis line, in addition to many of the helplines mentioned throughout this Toolkit is there for those going through mental health crisis, and their family members.

Siblings

It may be that there are other people in your lives who you care for, and need to protect, as well as your autistic loved one. In this case, it might be worth having "back up plans" in place, whereby if a meltdown does happen, your other children know where they can go in the house, or who they can call (family, friends) who may be able to come over and remove them from the situation. If this is a situation that sounds familiar, it may be worth also registering your child as a **young carer**, as their life and roles in the family may hit the criteria where their school could benefit from knowing the additional responsibilities they have in the home.

Reconciling post meltdown

We are all human, and sometimes the aftermath of meltdowns, be they verbal, physical, or a combination of the two can exert a huge toll on everyone involved. Often, post meltdown, your young person may remain in a heightened state of anxiety for a prolonged period of time, and be more susceptible to successive meltdowns as a result of this. Be mindful and aware of this.

As much as we may want unpick a meltdown, its causes, how we could have avoided it etc, it might be that your young person needs longer in order to be able to reflect on the situation without becoming dysregulated again. Thinking of your child as a "hot kettle" post meltdown, that may need a long time to completely cool down, might be a helpful analogy in this situation.

However, you and other loved ones may be able to reflect on the situation and whether there were triggers some may have noticed, after the fact, that might be mitigated for and planned for in the future. Reflecting and making a note of these, may mean that when your loved one is ready to go through what might have triggered a particular meltdown, you can help them process what happened and perhaps suggest things that you may have noticed.

Plan for success in the future

Based on what triggered the meltdown, ask yourself if this could be side-stepped and mitigated for in the future. Does it really matter, if your loved one is really stressed out, if they game on the switch for an extra hour, or watch some YouTube to calm down? **Perspective** is the key – what is the best outcome we can reasonably expect in a situation, and what stakes or goodwill are we happy to sacrifice to get it?

Modelling Behaviour

Post meltdown, often our young people feel immense shame which can spiral into feelings of poor self-esteem and poor mental health. What can help, is you modelling or "showing a route" for your daughter for how she can come back from meltdowns, once regulated. You may choose, when you're feeling a bit stressed out, to say to your daughter *"I am feeling stressed out or a bit dysregulated, so I am going to do X, Y or Z to calm myself down".* Normalising the language, role modelling how one may choose to regulate themselves can also be helpful for our young people to see.

Keep Professionals Involved with what's going on

It can be worth talking to your GP, or if your child is registered with CAMHS, bringing up (in a way not to shame your child), the additional issues you are dealing with.

There are courses, like that of Non-Violent Resistant Training, that are run by people who understand the challenges in living with someone who can be violent during meltdowns, where you can talk candidly about what strategies may work. We have found that courses run by, and with a cohort of people, with lived experience is much more effective than those of well-meaning professionals who may lack understanding of the daily challenges, and pressures, living in this situation may bring.

It is also worth letting school know if your child is experiencing meltdowns at home, so they are aware of the bigger picture, and can offer advice and support to your daughter and the family.

Denial of what's happening, doesn't help, and can lead to situations escalating needlessly. Being open, and receptive to help, is the quickest way to getting effective support.

Child to Parent Violence

There are organisations specifically set up to support parents in the strategies they use with their children, to prevent child to parent violence. These are set up specifically to work with parents, and create a safe and non-judgmental spaces where they can talk openly about what is going on, without ever knowing who your children are.

It can also be worth reaching out to Carer's charities who may be able to put you in touch with face-to-face support groups, should you prefer that to online.

Newbold Hope
Newboldhope.com

PEGS – Parental education growth support
pegsupport.co.uk

Challengingbehaviour.org.uk

Information in this section compiled by a lived experience Appeer Parent Carer Facilitator.

Supporting your daughter through education

- School and reasonable adjustments
- EHCPS
- Attendance Issues
- Autistic Burnout
- Further Education and University
- Journeying into Adulthood

Supporting Autistic Girls in School

Many autistic girls find mainstream state school difficult, with large class sizes, noisy canteen, and the complex peer group socialising, but specialist schools aren't always the answer either.

The key is to find the right environment for your daughter and her needs. Do your own research into schools, visit them, talk to parents. If she has an EHCP you can lobby for a specialist school or even a small, private mainstream, which can sometimes cost the LA less than specialist schools or full-time 1:1 support. For more see our section Supporting Autistic girls in School later in the Toolkit.

Remember, you are her advocate

Make an appointment with the SENCo and explain what your daughter needs to make school successful - for example, someone to meet her at the gate in the morning, somewhere quiet for lunch, not having to wear socks…? There are many accommodations a school can easily make to support your daughter. If you are in the EHCP process or have an EHCP then call the case worker and make your wishes known. Use the phrase *"My parental preference is…".*

Reasonable Adjustments

You can ask for **reasonable adjustments** or **accommodations** to help ease or overcome challenges which are having a negative impact on your daughter's school experience. Here, we have collated accommodations that have supported autistic girls in school within our community.

Involve your daughter

She knows best about what is challenging in school, and whether certain adjustments may or may not help her. As their parent or carer, involving your daughter helps you advocate as effectively as possible on her behalf. It may be helpful to start by sitting down with your daughter and make a list of things she finds tricky. Based on this, you can then try to think of solutions. Perhaps some of our suggestions below might help.

What type of Sensory Accommodations can we ask for?

Seating

During our workshops our teens told us that where they sit in the classroom can have a big effect on their anxiety levels. Often teachers know that sitting near to the board or away from sources of noise can their help some pupils. But this isn't always the case – some of our girls feel being singled out in this way makes them more anxious. It's worth highlighting to school that changes to seating plans can be overwhelming. Teachers often want to split up chatty pupils and so change the whole room around. They need to consider that it might work best for your daughter to remain in the same place.

Consider if the chair itself is causing sensory issues. Would a seating pad on a normal chair, or a different kind of chair work better for your daughter. (Or a standing desk, yoga ball, chairs with a built-in kick pads or high backed chairs). Some of our girls like firm pressure and so having a weighted cushion on their lap really helps.

Time Management

It might help (or not if she doesn't like to be singled out) for your daughter to leave or arrive five minutes ahead of the rest of the class. This can relieve sensory (and/or social) overwhelm if busy, noisy corridors cause her distress.

Fidget Toys

"Stimming" or self-soothing behaviour is often our girls' way of dealing with sensory input. Stimming can relieve anxiety and enable your daughter to concentrate when working or listening to the teacher. Our girls tell us that often teachers take these items away because they think they are a distraction, but the reality is that without them listening or concentrating can often become unsustainable for autistic pupils. Fidget or sensory "toys" should be allowed if they are not overly disrupting the lesson.

Uniform

Wearing school uniform can be particularly challenging. Our girls often report that the only thing they can think about is being able to "feel" their clothes which can make everything else really difficult and overwhelming. Ask if the school would allow alternatives to uniform or allow changes such as soft rather than stiff shirts? Take a look at M&S for sensory friendly uniform options or Sensory Smart Clothing online for sensory friendly clothing.

Distractions

Our girls' senses can be very sensitive and are especially heightened when they feel more anxious. They tell us that when in a lesson, they're also hearing, seeing and feeling all the other things around them: the chair they sit on, the clock ticking, their classmates' conversations or even noise from another classroom, bright lights, outdoor noise, the school bell, etc. Think about how to reduce this input for your daughter. Noise-cancelling headphones are very popular – either worn like ear defenders or the more modern Flare style (flareaudio.com) or just normal in earphones (but not connected!).

Visual Presentation

Some autistic girls will have visual sensory difficulties and may need lesson content presented in a different or larger typeface, colour print, or on coloured paper.

Breaks

Often called a Sensory Diet, breaks are an important part of self-regulation. Having a chance to move and release nervous energy can be enough to enable your daughter to continue her lesson or school day. Having an 'exit card' (to leave the classroom) to use when needed will validate her needs, show trust and give her a feeling of control over her environment, which helps reduce anxiety. Many schools are happy to implement this.

Safe spaces

Having a separate area which is quiet and calm where your daughter can go to de-stress and relax is essential, but schools often find this difficult to provide as space is a premium. Ideally these areas would contain sensory toys, cushions, blankets, soft lights and fidget toys. It should feel safe and comfortable and be accessible during sensory breaks, break and lunchtime. This might also be somewhere your daughter might meet other autistic pupils and make much needed connections.

What type of Communication Accommodations can we ask for?

Literal language

Our girls can often have a difficulty with non-literal language. Sarcastic comments can be especially challenging because they are often reacted to “seriously” by others and so can be perceived as very hurtful by our girls. Explaining metaphors or figures of speech can be useful – maybe write them down in a book for her to refer to.

Checking understanding

The teacher may need to check in with your daughter to ensure she has understood what is being asked of her. Asking her to explain the task back to the teacher in her own words is a way of checking understanding. If she has a learning support assistant it can be very useful for them to “translate” what the teacher has said or re-frame it in a way which your daughter can better access.

Presenting work

Handing in work using methods other than pen and paper might help. Does she find using PowerPoint or a laptop for written tasks more engaging or easier to use? Perhaps the teacher could allow spoken answers on tests or essay questions. In some circumstances a scribe or voice-to-text software, word processors or laptops can be allowed in both lessons and exams.

Spoken vs Written

Our girls can take longer processing the spoken word. Information presented verbally not only takes longer to process it may never make it into long-term memory. Because of this your daughter may find remembering instructions or deadlines difficult. Sometimes just a short, written synopsis of a lesson or homework instruction is all that is needed; sometimes full notes and step by step, written processes are needed. Perhaps a teacher would allow your daughter to take a photograph of the board.

Processing Time

It may take our girls longer to understand a question and find the words to answer it. Remind teachers that they may need to allow a little more time for your daughter to answer, and ask them to avoid adding pressure by highlighting slow processing. Saying “Hello? Did you hear me?” is not helpful!

What type of Social Accommodations can we ask for?

Support with relationships

Knowing a teacher or other member of staff is taking an interest in her wellbeing can help your daughter feel safer at school. Our parents and carers tell us that schools often tell them, “She seems fine at school”. Teachers need to be reminded that your daughter may be **masking**. A regular check in with a key adult can make a big difference to her and enable teachers to start to see when she needs a little more support. Scaffolding peer relationships with girls from other year groups can be of benefit. Often this works well if your daughter is introduced to younger girls (starting with helping listen to them read perhaps).

Signals and Cards

Prompt cards are useful to help your daughter ask for support. For example, the teacher might discretely show a yellow card to your daughter when it is her turn to answer a question. Or your daughter could place a blue card on the front of her desk to signal to the teacher that she needs the instructions repeated or that she needs to leave the room, etc.

Unstructured times

Lunch and break time can cause anxiety for our girls because they are unpredictable, and some may not have a friendship group to spend them with. Having plans in place for these times will allow your daughter to know what to expect and thus ease her anxiety. Discuss what activities she could do each break, e.g., Monday break – knitting club or Wednesday lunchtime go to library/lunch club/meet Jane etc. Often creating a printed, visual timetable can help.

Special days

Often schools have mufti day or days where they are completely off timetable for sports day, swimming gala, World Book Day etc. Ensure your daughter is given a full plan of the day well in advance. If she thinks she will find it too challenging because it’s an unpredictable day, allow her to stay at home.

Plans when things go awry

Think about whether there are any advance warning signs your daughter exhibits before a meltdown or panic attack. Give the school a list of these so they can be pre-prepared with a plan of how to de-escalate the situation, e.g., if talking loudly or running around are precursors to a meltdown perhaps the plan could be to suggest time in the quiet space, or a walk around the school, allow use of a fidget toy etc. Your daughter will be reassured knowing these plans are in place.

Praise

Neurodivergent people often have what is known as ‘rejection sensitive dysphoria’ and can find criticism challenging. This often leads to low self-esteem, which is very difficult to build back up. Remind teachers to give lots of positive encouragement and praise - often more than five positive comments are needed to counteract a negative one.

What Executive Functioning Accommodations can we ask for?

Chunking

It can help to have work broken down into smaller chunks, for example, “Now we are planning our story, next we will write the title.” Deadlines can also be broken up, i.e., paragraph one is due on Monday, paragraph two Tuesday, etc. Teachers can help your daughter plan a piece of work by creating a visual timetable.

Stick to timetables

A timetable can help significantly because it makes the school day/week predictable. Changes can be distressing for our girls, so ask the school to give as much notice as possible if there is a change to the normal timetable. If your daughter is in primary school the teacher will still have a plan of the week – ask them to share it with you and your daughter.

Note taking

Our girls might find the pressure of handwriting notes difficult. A lot of them are very fast typists and find this more comfortable. If it will work better for your daughter, you can ask the school if she can work on a laptop or tablet. Note taking this way might feel much easier for her.

Exams and tests

Language processing, both reading and listening, can take longer for our girls. Extra time in exams and internal school tests can be requested and often is granted. Tests often mean that the school day is off timetable and coupled with exam pressure this can cause lots of anxiety. Anxiety can be reduced if the person administering the test or exam invigilator is a familiar teacher or TA. Ask if this is possible.

Go small!

Having a lesson in a small group or taking exams in a smaller room, either with one or two peers or on her own, could help. Our girls tell us that working in pairs or doing 'group work' can be challenging. This is because it adds social demands on top of the academic task. This can be resolved by asking if in these situations your daughter could work alone or with a TA. Sometimes in group work our girls respond well by having a clear role or job to do, for example filming a skit in a drama lesson or setting up equipment in science.

Requesting reasonable adjustments or accommodations

As Parents and Carers, you can request to meet with the SENCo or Head of your daughter's school to discuss which accommodations may suit your daughter best.

You have the right to ask for these accommodations. Teachers need you to advocate for your daughter by highlighting potential issues and providing ideas for solutions to support your daughter learn.

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Education, Health and Care Plans (EHCPs)

An education, health and care plan (EHCP) is for children and young people aged up to 25 who need more support than is available through special educational needs support usually delivered at their school or other educational setting. EHCPs identify educational, health and social needs and set out the additional support they are entitled to receive to meet those needs.

The EHCP is issued by the local authority. The process is long (up to 20 weeks) but clear:

0 to 6 weeks

The Local Authority make a decision on whether to assess a child for an EHCP.

6-20 weeks

If the Local Authority decide to carry out an assessment to see if a child requires an EHCP (known as an EHC Needs Assessment), they will seek advice and assessments of your child from appropriate professionals. This will usually include an Educational Psychologist, and other professionals (e.g. Speech and Language Therapists, or Occupational Therapists) advice may be sought. A decision on whether to issue a plan should be made by 16 weeks. If an agreement has been made to issue a plan, this should be finalised by 20 weeks. There are opportunities to appeal the Local Authority's decisions on whether to assess for an EHCP, or to issue a EHCP plan.

Applying for an EHCP

Often schools write and manage EHCP applications (usually through the SENCo), but many parents successfully do it themselves, with or without help, as it is not uncommon for a school to disagree about the child's needs. Some parents feel confident and able to engage in the EHCP process, particularly if they feel pressures on the school may be impacting a school's capacity to apply themselves.

For those who do decide to apply without help from the school, there are many organisations and websites that can help. Whilst we can't endorse any particular EHCP or legal advocates, we are aware from our community that the following organisations offer helpful resources on their websites and have helplines you can call for more personalised advice.

SOS!SEN

A UK charity that aims to empower parents of young people with SEND to secure the right educational provision.

IPSEA

A charity that provides free and independent legal advice and support to families of young people with SEND.

EHCP Experiences Pages on Social Media

You may find a local private Facebook group of veteran ECHPers for mutual support and information. Search **EHCP Experiences** groups on Facebook or on other social media platforms.

As part of the EHCP process, the LA will reach out to your daughter's school for their view on the level of support needed to support your child. Before applying, it is worth a substantive discussion with your daughter's school about what support you feel they need and whether/how this can be provided by the school.

The best advice we can offer from our own and from the experiences of many in our community is:

- **Follow your instincts**
- **Don't worry about being a "pushy" parent**
- **Keep notes of every exchange and meeting**
- **Collect information about your child's experience at school and their difficulties**
- **Never give up!**

Attendance Issues

Sometimes referred to as Emotional Based School Non Attendance (EBSNA), the number of children persistently absent from school has increased dramatically in recent years, particularly since the end of the COVID pandemic.

As parents, it can be really hard to understand and advocate for our children when they show extreme dysregulating behaviour towards attending school. Often, our own frustration at the situation, and the pressures involved from potentially well-meaning but ineffective interventions, may lead to us turning inward, feeling intense feelings of distress and shame at the situation.

It can feel particularly overwhelming when school or others express confusion at the causes for the situation, sometimes citing that a child or young person "is fine" when they are at school, and are otherwise sociable and often high attaining students.

It's really important in these types of situations that you understand that you are not alone in facing these difficulties and struggles, and there are many people out there facing the similar situations.

Under Pressure

These situations can be extremely complex, and so hopefully some of our advice and thoughts on these issues below may be helpful in discussions with your child's school, or with other agencies who may be working with you to try and support attendance into school. Often these issues arise at a time of "burnout" or extreme distress for our child, which can put further pressures on us and our family life.

Sometimes finances are affected, for those of us who may not be able to balance the caring commitments to our children and working. For others, our financial circumstances may leave us feeling we have no choice but to work, and so non-attendance can put further pressures on support networks we may, or may not, have in place to support our family.

Perspective of many families

The overwhelm, and shame, many feel when handling these difficult situations can be immense. Particularly when there is a disconnect between what the family may be seeing at home, with regard to school, and what school are seeing, when a child is present, this can lead to extreme pressures on the school and family relationship, where each feel that the other is not doing enough to support their child access education.

Yes, building resilience in children is important, but sadly "resilience" for many has become a synonym for many parents of putting children into situations that do not meet their needs, and they are destined to fail in. This is particular evident in situations where children do not present difficulties or dysregulated behaviour at school, but it is only evidenced at home, as parents witness the extreme distress children may be in as a result of interventions (or lack of interventions) that they feel the school could make, to make extremely distressing and avoidable situations less intense, or not happen altogether.

For most families, attendance issues do not come out of "nowhere" but can be a culmination of issues they have seen, and communicated with the school, over years. All too often, by the time attendance breaks down, sadly the relationship between parents and the education provider is worse than ever. Pressures on the school to increase attendance, and parents who cannot get their children to attend school, can sadly lead to combative behaviour, with each blaming the other, or feeling blamed, for the situation they find themselves in.

Keep Your Child on Roll at a School

The pressure to off roll your child, particularly when fines and sanctions are being threatened by schools, can feel immense. Many of our parents in the short term, feel great relief when they initially off-roll their child, as the threat of fines, and often reported combative correspondence from schools and other agencies, stops immediately. You may even think that your child will get the support they need from the LA if you off roll them. Often this isn't the case as in **some counties Local Authorities prefer to manage EOTAS (Education other than at school) provisions through the school – even if a pupil is unable to attend that particular school. It is the SEND department in that school who commission and fund any Alternative Provision that the child may need.**

It is important to remember that every child has a right to access education.

Those that have "off rolled" their child at a school, may sometimes choose to enrol them in another school, if their previous school does not allow them to re-enrol. Being on roll, even if your child is unable to attend, means they are "in the system" and the financial burden, and legal requirement, of their education does not solely fall onto parents.

Consider underlying issues

Particularly for our girls, who may be very intelligent and academic, processing events and understanding their feelings, can be extremely difficult and complex. If you child is saying "I just don't like it" or "I don't know" then perhaps help her to break down a typical, or specific day at school, maybe by going through her timetable with her. You can take notes, or maybe if your child consents, she may let you record her voice as she talks through her day and the issues she may have in each particular lesson. Whilst, individually, an issue may seem small or insignificant on its own, these might accumulate throughout her day combined with similar issues, that become a bigger deal for her. Understanding these issues will be the key for effectively advocating for her. Having your child's voice, or thoughts, are far more powerful than you may think, and keeps all meetings and correspondence focussed on their views and experience, rather than how different parties view surrounding issues.

Speak to the SENCO and Pastoral Leads

The SENCO is your first port of call for getting your child support within school. It may be that your child has an EHCP, but this needs to be updated, or it may be that they are currently not even flagged for any additional support at all (this could be being on SEND Support, or on the SEND register).

The SENCO can also, through their relationships in the school, contact other members of staff to see if they have any concerns or particular strategies for working with your child, that work well and put them at ease. Conversely, there may be staff members whose testimony could help you evidence that additional support is needed, should you choose to pursue changes to, or apply for an Educational Healthcare Plan (EHCP)

Keep an open mind

Seeing our children in such distress, it is easy to become focussed on a particular outcome we may feel would "fix" or get rid of all of the issues. However, it is really important to keep your daughter involved in discussions and what is being said, so she can judge whether she feels able to give something a try, or if something you may be sceptical of, might work.

This is not to say that if she changes her mind on something she agreed to try, or if it stops working, you hold her to her word – but rather, at that point you can help advocate her voice in why, these things she may have agreed to try, are no longer possible for her etc.

Having a voice note that she sends to you, that you could then pass on, might be an example of how you can facilitate her voice being heard in these situations, removing all the onus, and pressure, being solely on you.

Communicate and record issues for non-attendance

For a situation that feels so deeply personal, and often very distressing, it can be very tempting to close down communication with the school, or other involved parties. The quiet can feel liberating, as many parents report feeling they are "battling" with school. In these situations, it can be useful to reframe your role as a parent, in the way you may frame being in a work or office environment. Your role as a parent is to provide suitable advocacy for your child, with the goal of evidencing their struggles, in order for adequate help to be provided for them to access education.

If phone calls or perhaps chats at the school gate feel too overwhelming, email the school. Many find this is an easier way, allowing them to be more objective and clearer in the issues they want professionals to understand. Any day your child is having attendance issues, we recommend you email the school stating the underlying reasons they are unable to attend. This, at a later date, may allow the school, yourselves or potentially other professionals to understand any underlying barriers or causes for your child's EBSNA and put measures in place or enable them to be in an environment, which can meet their needs.

If relationships with certain members of staff have fractured or broken down, email the school office. Ideally look to inform or cc in the school SENCO, Pastoral Leads, or any key members of staff that you think may be helpful.

Even if your child doesn't go back into that school environment, this communication is also evidence that your child's non-attendance is not through lack of care or support, but for real reasons that, if addressed, may have prevented it.

Fines

Sadly, many families have reported the threat of fines, in situations where they feel their child cannot access education, instead of simply not wanting to go to school, and not having a support network to facilitate them returning. This is where communicating with the school, and evidencing reasons behind non-attendance, can be particularly helpful.

If you are feeling under pressure with fines, when your child has needs relating to their special educational needs in being unable to access education, we recommend emailing the school, including the inclusion and welfare officer, with the overall picture.

IPSEA and **SOS!SEN**, are also very helpful organisations to contact, who can provide free independent advice on how to manage these situations. If the issue persists, we have found the involvement of local councillors, or MPs, can help resolve the situation.

Review EHCP

EHCPs provide schools with additional funding for children who have, or may have, special educational needs and need additional measures to access education beyond what a school is able to provide through OAPs (Ordinary Available Provisions) – reasonable adjustments and accommodations like those listed previously in this Toolkit. For information on how to apply for an EHCP, see the EHCP section. These can stay with a child until they are 25, so it definitely is worth pursuing this route for children with send who need more support than is currently being offered. If your child has an EHCP, but is struggling to attend school, you may choose to call an “Emergency Annual Review”, which brings together all professionals involved, and can help review what isn’t working for your child, and what can be put in place to support them.

Alternative Provision

Schools may elect, unprompted, to arrange alternative provision for any children they feel would benefit from a different environment either for part or all of the school week.

Others may be more reluctant to see how Alternative Provision can support your child reintegrate into school life or reduce their social isolation. To this, there is a wide array of Alternative Provisions out there, who may have entirely different offers and aim to support a child in very different ways, with entirely different skills. There are many forms of different Alternative Provisions, which you can find by searching online based on your area. Searching EOTAS (Education other than at school), or Alternative Provision on social media, particularly Facebook, may also be helpful to see what is in your local area. These may be academic education APs, sports, therapeutic, life skills or employment-based provisions.

As an organisation, in Surrey, Appeer runs Alternative Provision Weekday Groups, with different age ranges, to try and connect girls and young women who have been out of school, or struggling to attend school, for a significant period of time and we try to facilitate a peer group that improves their mental health and has them engaging in a community, where they otherwise would be isolated. We have girls partially in school, homeschooled, or who have a package of different Alternative Provisions throughout the week, and work with them to build the life and employment skills they will need to thrive in the future.

Alternative Provisions tend to be funded by schools, or sometimes by parents themselves. Once an EHCP is issued, any Alternative Provision agreed is paid for by the Local Authority, although it may continue to be managed by the school your child is registered to.

Take care of yourself

Being the bridge between what your child is telling you behind closed doors, and what they may say in public to please others, is exhausting. Often, you may logically agree with everything the school or outside professional says but in reality know that your child’s experience is very real to them.

Having a child with EBSNA can be an extremely pressurised experience, that puts emotional or financial strain on the family. It is really important that you look after yourself, as without keeping yourself well, you cannot give your daughter your best advocacy and support. If things feel too much, talk to your GP. Seek out carers’ organisations and support groups; just being around people who “get it" can help reframe everything.

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Autistic Burnout

Autistic burnout happens when autistic people just can't cope anymore. On top of a normal school (or work) day they are managing sensory, social and executive functioning obstacles all the time. They may also be masking while dealing with these challenges. When this gets too much, **autistic burnout** can occur.

Autistic burnout can feel like fatigue, worsened anxiety, depression and feelings of physical illness; manifesting in the need to stay in bed and avoid school or leaving the house.
These symptoms are a reaction to total **overwhelm**. The normal response (from school, the GP or CAMHS) to these types of symptoms might be to suggest talking therapy like CBT or to encourage more social activities. This type of treatment works well for neurotypical people who are suffering from depression or anxiety, **but autistic people may need the total opposite in order to recover - more communication or forced socialising will make them feel worse.**

Allow your daughter to rest or stay at home if she needs to.

It's perfectly ok to stay in bed all day in order to feel better – give her and yourself permission to allow this to happen. If she were recovering from a serious physical illness, you would not force her to go to school or out on a nature walk… Once she has re-calibrated and feels better then perhaps engaging some of the accommodations above will help when or if she returns to school. The suggestions below are particularly successful after this type of burnout and if you ask for them early enough, they may prevent it happening in the first place:

Reducing the timetable to the subjects your daughter is confident in.

This is often called **RAG**ing the timetable, i.e. **R**ed, **A**mber, **G**reen. Core subjects like maths, English and science are red, amber might be history, and green a subject your daughter loves. She might only take 5 or 6 GCSEs. This is ok; **often to get onto A levels at a 6th form or college 5 GCSEs at level 5 is all you need; or 4 GCSEs at level 4 for a BTEC.**

Taking this stress away can really be effective and avoid potential school avoidance down the line – think **"some rather than none".**

Permanent sign-off from PE or other arrangement

Being allowed to do something on their own, like yoga, or to join only those activities she's confident about. Changing for PE is often a challenge. Could she join in PE in what she is already wearing (where practical)? Could she walk around the field with a friend instead of play hockey?

Allow for flexible study

Completion of some work at home may prevent overwhelm.

Remove demands including potential participation in 'enrichment' activities (e.g., DofE, choir).

Appeer Community Advice

We often advise parents and carers to try to re-frame the burnout. E.g. If your child was recovering from a kidney transplant you wouldn't be trying to get them to go to school, apply for a job or go out of the house before they were ready. You would give them lots of opportunities to rest in bed and spend time sleeping if they needed it. Apply this type of reaction and support to your child in burnout.

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Further Education and University

There are different organisations that can offer support with navigating the post 16 stages of your daughter's life. These may be with continuing in higher education, entering the work force, or gaining experience volunteering.

The topics below have been sourced by AS Mentoring (ASM), an organisation that aims to partner and empower neurodivergent people in employment and in finding work. ASM met with some of our young people who were considering going to university and provided the following information to us.

In addition to the academic side of university, it is understandable that our young people may be particularly apprehensive about what university life may look like, particularly if they are considering leaving home for the first time.

Some universities offer summer schools to year 11 and older autistic students, designed to give them an insight into university life, and equip them with some of the skills to ease their transition to the next stage in their life – whatever that may be. Examples of these include;

University of Bath

Offers a residential summer school for autistic students who have completed their GCSEs.

Cardiff University

Offers a summer school for students over 16, where participants can stay overnight on campus.

Birmingham City University

Offers a three-day summer school for autistic students.

Additional Support for University that may be available includes:

Grants or Enhanced/Contextualised Offers

When considering the costs involved with university, it may also be worth investigating whether any particular universities provide Enhanced Offers, or additional grants to neurodivergent students. These will be specific to each university, and this information will usually be available on their websites. These offers are made in recognition of the additional barriers autistic young people may have had to overcome when pursuing their qualifications.

Disability Students' Allowance (DSA)

This is additional financial support that can be applied for from Student Finance and is not a loan and no money is needed to be paid back. Funding received from DSA is intended to cover the study related costs a person may have because of any mental health issues, long-term illnesses or any other disabilities that may impact them and their studies whilst at university. It can include funding a laptop, taxis to campus if public transport is a barrier, priority accommodation, learning assistants, specialist software and other academic support.

Accommodation

Some universities can help identify suitable accommodation on campus and may be able to facilitate students staying in halls of residence for more than one year.

Clubs and societies

These are great ways to help students meet new people, based on mutual interests to facilitate authentic connections. Most universities now have ND societies.

Early arrival induction programme:

Some universities offer an early arrival induction programme.

One-to-one support

Some universities offer one-to-one support from a study assistant. Get in touch with Student Services to check what support may be available at any specific university.

It's important to remember that college and university is just one path available to your young person. Fulfilment comes in many forms. You may have a high IQ and be academic but may only cope volunteering part time. This is just as valuable and just as worthwhile for those individuals.

Journeying into Adulthood

Pathways to Employment for autistic young people.

Apprenticeships

Apprenticeships combine real work with training and study. Unlike college or university, young people apply what they learn directly on the job, gaining hands-on experience and skills. You can find an apprenticeship in many different fields including childcare, hospitality, construction, gardening, office work. Young people spend at least 20% of their time studying for a qualification directly linked to the job role. You can find out more here: https://www.apprenticeships.gov.uk/apprentices/

Work Experience

The Civil Service Autism Exchange Programme (16+)

This is an eight-week work experience programme for autistic young people aged 16-25, where applicants are placed in department depending on one's skills and availability. Tailored careers advice and support is offered before, during and after each placement.

Supported Internships

Some of our girls with EHCPs feel they want to enter the world of employment before 25, but need additional support to develop the skills, knowledge and confidence needed to transition effectively into a working environment.

Most Local Authorities will have a service to support those with EHCPs into work with supported internships and jobs. Even without an EHCP Social Services will be able to offer support and advice for those who need a little help to get started in work or volunteering.

DFN Project SEARCH, Supported Internship

Organisations, including **DFN Project SEARCH**, run one-year transition programmes for young adults aged 16 to 25 who have an EHCPs. These programmes combine businesses, education providers, and adult supported employment providers to provide a transition programme to support young people into paid internships within various organisations. Partner organisations include the NHS, GSK, DPD, Aviva and many more. This is not the same as paid employment but is a way of supporting young people into gaining the knowledge, experience and skillset to go on to paid employment. See dfnprojectsearch.org/our-programme/ for more information.

Paid Internships

Employ Autism Civil Service Internship Programme (18+)

This is an eight-week paid employment opportunity in the civil service for around 200 young autistic people. The scheme starts at the end of July, and the application deadline is usually mid-January earlier that year.

The DfE Supported Internships (Civil Service)
https://www.civil-service-careers.gov.uk/gfie-schemes/

Autism Employment Schemes

The Going Forward into Employment (GFiE) Scheme for Autistic People

Offers temporary fixed term appointments for autistic people for up to 24 months. Currently, this is only open to those that have completed the Civil Service Autism Exchange Internship Programme but may be extended in the future.

MoD Autism Hiring Programme is specifically designed to help autistic people into employment

Cabinet Office GFiFE Scheme for Autistic People

Additional Support

For many young people, transitioning from education to the workplace can be a daunting experience. Some may benefit from specialist mentoring to support them with this process.

Organisations like **AutismForward.org.uk** can provide grants for such specialist mentoring for young people that have been accepted and mentees by any of their approved list of mentoring organisations.

See the autismforward.org.uk/mentoring/find-a-mentor to find out more.

- Those needing support who are in employment can apply for the **DWP Access to Work** grant: gov.uk/access-to-work

Useful Acronyms

ABA Applied behavioural analysis (ABA)

ADD Attention deficit disorder (ADD)

ADHD Attention deficit hyperactivity disorder (ADHD)

ADOS Autism Diagnostic Observation Schedule (ADOS)

APD Auditory processing disorder (APD)

AR Annual Review (AR)

ARP Additional Resource(d) Provision (ARP)

ASD Autistic spectrum disorder (ASD) or ASC Autistic spectrum condition (ASC).

BAS British Ability Scales (BAS)

BSP Behaviour Support Plan (BSP)

CARS Childhood Autism Rating Scale (CARS)

CCG Clinical Commissioning Groups (CCG)

CFA Children and Families Act 2014 (CFA)

CBRS Conners Comprehensive Behaviour Rating Scales (Conners CBRS)

CAMHS Child and Adolescent Mental Health Service (CAMHS)

COIN Communication and interactions needs (COIN)

CSCN Complex social and communication needs (CSCN)

DLA Disability Living Allowance (DLA)

DSA Disabled Student's Allowance (DSA)

EBSNA – Emotionally Based School Non-Attendance

EHCP Education, Health and Care Plan (EHCP)

EOTAS - Education other than at school

EP Educational psychologist (EP)

EWO Education Welfare Officer (EWO)

FTT First Tier Tribunal (FTT)

GDD Global developmental delay (GDD)

IASS Information, Advice and Support Service (IASS)

IBP Individual Behaviour Plan (IBP) IEP Individual Education Plan (IEP)

LA Local authority (LA) LAN Learning and additional needs (LAN)

LGO Local Government Ombudsman (LGO) MLD Moderate learning difficulties (MLD)

OCD Obsessive Compulsive Disorder (OCD)

ODD Oppositional defiant disorder (ODD)

OT Occupational Therapist (OT)

PECS Picture Exchange Communication System (PECS)

PEP Personal Education Plan (PEP)

PDA Pathological demand avoidance (PDA)

PDD Pervasive developmental disorder (PDD)

PMLD Profound and multiple learning disability (PMLD)

PRU Pupil Referral Units (PRU)

SALT or SLT Speech and Language Therapists (SALT or SLT)

SEMH Social, emotional, and mental health needs (SEMH)

SEN Special educational needs (SEN)

SENCO Special Educational Needs Coordinator (SENCO)

SENDIST Special Educational Needs and Disability Tribunal (SEND or SENDIST)

SLCN Speech, language and communication needs (SLCN)

SLDD- Severe learning difficulty and disability (SLDD).

SpLD Specific learning disability (SpLD)

WISC Wechsler Intelligence Scale for Children (WISC)

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We hope this Tool Kit was helpful

For more information contact hello@appeer.org.uk

or visit our website appeer.org.uk

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