



AWAITING ASSESSMENT: SUPPORT AND INFORMATION

WHAT IS THIS BOOKLET?

This booklet was made by Aishling Dempsey, Senior Assistant Psychologist at Community Paediatrics East Sussex Healthcare Trust, with input from the Allied Health Professionals, Nurse Teams and Clinical Psychologist Anita Marsden. It is to support you and your family as you wait to be seen by our team.

We are sorry that the wait is long, our service is overwhelmed. Please know we are dedicated to supporting each young person who is under our service. This booklet contains:



Information about the assessment process



Things you can do while you wait to be seen



Tools to support wellbeing and behaviour



Support you can access without a diagnosis

Waiting for an assessment can be a challenging time. Parents and caregivers want their children to understand themselves, and access support so that they can grow and thrive.

It is important to acknowledge that you are already supporting and accommodating your child. Hold a space of compassion for you and your family on this journey.



While assessments and potential diagnoses may be an important part of your journey, we hope that this booklet can validate your experiences, and empower you and your child to better understand and support themselves *before, during and after* the assessment.



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RISK

Please note that **we are not an emergency service**. Please use the contact numbers below if you have concerns about your child's wellbeing, safety or that of members of your household:

Concerns:

If you have concerns about your child's wellbeing, please contact your GP in the first instance. You may also wish to seek advice via:

- Your Health Visitor (pre-school aged children) or the East Sussex School Health Service (school aged children): School Health One Point (SHOP) 0300 1234062 or kentchft.esschoolhealthservice@nhs.net
- ISEND CLASS+ advice line 01273336887

Escalating Concerns:

If mental health issues or behaviour are escalating and becoming unmanageable or putting safety at risk, please contact:

- CAMHS/Children's Service's Single Point of Access (SPOA) 01323 464 222 or 0-19SPOA@eastsussex.gov.uk. Out of hours (Monday-Thursday 5pm-8.30am, after 4.30pm on Fridays, weekends and bank holidays) with serious concerns that can't wait until the next working day, contact their Emergency Duty Service 01273 335906 or 01273 335905.
- Sussex Mental Healthline 0800 0309 500 for a 24/7 telephone service offering listening support, advice, information and signposting to anyone experiencing mental health difficulties or are concerned about the mental health of a relative or friend including carers and healthcare professionals. You do not need an appointment.
- Childline 0800 1111 or www.childline.org.uk/get-support/
- Samaritans 116 23 or www.samaritans.org/how-we-can-help/contact-samaritan/
- NHS 111 is the non-emergency number to call when you need medical help fast, but it is not a 99 emergency. Mental health call handlers may be available
- If your child is open to a local CAMHS team, you can call the local office and request the Duty and Liaison team.

Urgent Concerns:

If you or a member of your household are in immediate danger CALL 999 or attend your nearest Emergency Department if necessary.

THE ASSESSMENT PROCESS

Our team supports young people across East Sussex who have been referred for a neurodevelopmental assessment. Our team is made up of:

- Paediatricians
- Occupational Therapists (OTs)
- Speech and Language Therapists (SLTs)
- Neurodevelopmental Nurses
- Neurodevelopmental Associate Practitioners
- ADHD Nurses
- Clinical Psychologists
- Neurodevelopmental Clinic Supervisors

Together, we work with parents, caregivers and young people to explore and identify a young person's unique neurodevelopmental profile or 'neurotype'.



This means we are exploring *how their brain works*: how they learn, their strengths and challenges, their preferences, needs, how they understand and relate to the world.

The assessments we use to understand young people's neurotype help us to answer the question of whether they might be **neurodivergent**.

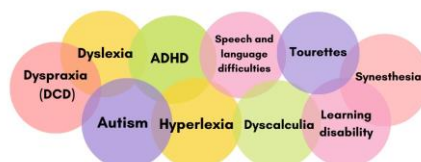


We live in a neurodiverse world. This means that there are different brain types. In the same way we all have different eye-colour and height, we all have different 'neurotypes'.

Some brain functioning styles are more common than others. Being neurodivergent means that your brain works in a way that is different from what is seen as the 'norm' in society.

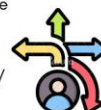


There are a number of ways of being neurodivergent. They often overlap, meaning many people experience more than one type of neurodivergence. Here are some examples of neurodivergence:



In our service, we mostly focus on autism assessments. Sometimes, additional assessments are needed to differentiate between diagnoses. Often, this is a cognitive assessment which identifies whether a young person has a learning disability.

There are different routes within our service. Some families have one appointment where they meet multiple professionals and reach a conclusion. This is called a 'One Stop' clinic where a young person is assessed, and history is discussed with parents/caregivers. For some families, a conclusion or decision may be reached after an 'Initial Assessment' with a paediatrician.



Many families will meet with multiple professionals before a conclusion is reached. This can mean having an Initial Assessment with a therapist of paediatrician, having an assessment and review appointments.

The types of assessments/pathway through our service will depend on what best meets your child's needs.

You might like to watch this video, explaining what neurodivergence is. Scan the QR code or type the following video title into YouTube: Neurodiversity Explained by Kickstart Learning.



During your visits, you will be asked to provide a family and developmental history of your child, as well as discussing your current concerns.

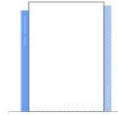


Our team will also work closely with those around your child, including school to gain a shared understanding of your child's strengths, challenges and preferences.

Remember, you and your child are the experts of your own experiences, it is important to feel that your child has been seen and understood.

After the assessments our team will discuss potential diagnoses, support and recommendations with you and your child.

A report of the assessment and conclusion will be written up and shared with you, the referrer, your child's GP and social care (if the child is known to social services).



If it is in the child's best interest the report may also be shared with other relevant professionals at your request such as school or housing officers.

We hope that you and your child feel appreciated and understood throughout this process. However, the assessment process can be quite problem focused as we explore your child's difficulties and support they might need. This can feel difficult.

It can also be difficult for young people's self-esteem to take part in assessments which are tricky for them.

It is important for your child to know that there is nothing wrong with them, and that the purpose of these assessments is to understand how their brain works, so that they can learn about themselves and get the support they need to thrive.

PREPARING FOR THE ASSESSMENT

There are some things that you can do to help you and your child practically prepare for the assessment process:

1. Think about your child's development and questions that might be asked during the assessment (examples on the next page)
2. Think about your child's current strengths and difficulties
3. It is helpful for young people to know why they are being assessed. There is a section on how to explain neurodiversity to your child, and how to talk to them about the assessment in the following few pages
4. Talk with your child about the assessment and explore what they think about their sense of self, and how their brain works.



In making these preparations, we hope that you can:

1. Feel prepared to provide information so that we can best understand your child
2. Advocate for your child



And that *your child* can:

1. Feel a sense of safety, inclusion and autonomy in the assessment process
2. Understand how their brain works and think about their sense of identity



The following pages provide information, prompts and suggestions surrounding areas you might like to think about before the assessment. We hope that they can help you prepare and organise your thoughts.

Attitude Toward Structure, Routine, Repetition and Sameness:



- Do they thrive with routine and structure?
- Any needs for sameness?
- Anxiety and reaction to uncertainty or change
- Do they have particular ways they like to move their body repetitively?

Sensory Experiences and Preferences:



- What is their experience of the sensory world?
- Do they notice smells, textures or noises that others don't?
- Sensory experiences that are upsetting
- Sensory seeking behaviours (e.g. stimming- jumping, listening to the same song over and over, tapping, rocking)

Co-ordination and Motor Skills:



- What are their gross motor skills like? (e.g. balance, riding a bike, are they clumsy)
- What are their fine motor skills like? (e.g. writing, buttoning up clothes, tying shoes)

Areas of Passion or Expertise:



- Special interests
- Ability to hyper-focus for a long time on one thing
- Excellent memory and knowledge of a particular subject
- Difficulty engaging in other subjects or topics

Behaviour:



- Do you have any major concerns/worries in this area?
- How do they express their distress or anxiety?
- Do they have meltdowns/shutdowns?
- How are you currently managing behaviour?

Strengths and Appreciation:



- What do you appreciate about them?
- What are their strengths?

Developmental History:



- Pregnancy and birth
- Major developmental milestones (e.g. walking)
- Developmental delays? (e.g. speech and language)
- Family history of neurodivergence (e.g. autism, learning disability) or significant mental health problems

Home:



- Who is at home?
- Self-care skills (washing, dressing, eating)
- Safety skills (road, kitchen)
- Support needs and any difficulties

School:



- What is school like for them generally?
- Grades, progress and learning abilities
- Reading and writing
- Additional support (TA, EHCP) or ability to ask for help
- Favourite/least favourite subjects
- Attention levels

Relationships:



- How are things going socially?
- Friends and nature of friendships
- Other relationships (e.g. pets, family)
- Play style (e.g. creativity, repetitive play like lining toys up)

Mental and Physical Health:



- How is their physical health?
- How is their mental health?
- Any anxiety, low mood, meltdowns?
- What behaviours do they use to communicate distress?

Social Communication Preferences:



- What is their eye-contact preference?
- What is their communication style like (e.g. answering direct questions, info-dumping, do they enjoy back and forth conversations)

TALKING TO YOUR CHILD ABOUT ASSESSMENTS

Often, young people do not know why they are being assessed. They can feel scared or think that there is something wrong with them. It is important that they know that this is not the case. It is helpful for your child's self-esteem, anxiety and sense of autonomy to know about the assessment process before they take part.

Starting the conversation:

Introducing the idea of an assessment to your child might sound something like:

I've noticed you are working really hard at school this year, but it seems like things might be tricky sometimes....I'm thinking that if we know more about how your brain works, your teachers and I could do a better job at helping you. We are going to go meet someone who is going to help us learn all about how your brain works so that:

- Teachers know how to teach you
- Parents know how to support you
- You can understand yourself better
- You know how to advocate for yourself
- You can learn about all of the things you are great at

Describing the process:

Your child might like to know what the process will be like. Although each young person's journey will be different, most will have multiple meetings with some doctors and other professionals that will learn about who they are and how their brain works.

These appointments might involve:

- Talking about their feelings, preferences and challenges at home, with friends or at school
- Playing some games and puzzles (let them know that some will be easy and some will be hard)



It would be useful to have a chat with your child about autism and neurodiversity. While some young people might know a little about autism, sometimes this can be a negative understanding or they might not see how it relates to them as each autistic person is different.

Having open, positive and affirming conversations about autism is an important part of helping young people understand being autistic in a way that is not negative, harmful or scary. Being autistic is not a bad thing, there are lots of autistic people in the world with different strengths, needs and challenges.

Scan the QR code of type 'Amazing Things Happen' into YouTube for a great video to help you explain what it means to be neurodivergent to your child:



Getting their input:

It is important for young people to have their voices heard in the assessment process. Your child may be encouraged to let us know what is tricky for them, what things they like doing and to ask questions if they like. This not only helps us know what is important to them, but it also gets them more invested in the process.

Often, young people we see have a sense that they are 'different'. Autistic adults often speak about always knowing that they are different, and having the language to explain this difference is a helpful, wonderful thing.

Starting this conversation might look like this:

There are things the people we are meeting might like to know to help support you better, I'm wondering what you know about how your brain works, or what would like to know?



*Adapted from Dr. Liz Angoff's material for explaining assessments

WHY ARE ASSESSMENTS USEFUL?

It is likely that your child has been referred to our team for an assessment as they have preferences and differences that are causing challenges for them, e.g. *in school, sleeping, communicating, regulating emotions, speech, friendships or sensory experiences.*

Neurodevelopmental assessments are useful for young people (and their families) to understand themselves and to learn how best to support themselves to reduce challenges. They do this by:

- Improving self-esteem, wellbeing and identity development
- Providing a shared language to understand and explain differences and preferences
- Validating the experiences of young people and their families and providing professional clarification (especially if you are not sure how best to support your child)
- Identifying specific support needs and priorities (e.g. speech and language therapy, learning disability)
- Providing direction for learning, reading and recommendations
- Supporting access to appropriate support
- Opening up doors to new communities of like-minded people (e.g. the autistic community)
- Helping people to understand how to change the environment around a young person to suit their needs, preferences and strengths



HOWEVER...

Assessments and diagnoses are just one part of you and your child's journey. Assessments and diagnoses do not:

- Change who your child is
- Immediately change their challenging experiences of the world
- Change their ability to learn, develop and grow

They provide clarification, and new words to explain and understand your child's experience of the world.

SO WHAT CAN WE DO NOW?

Waiting for an assessment can be frustrating and stressful. The next few pages will provide you with information to help you and your child to understand how they experience the world and reduce challenges in the meantime.

With this, you can explore ways to embrace who they are, adapt and accommodate their environment to suit their needs, and come up with strategies to support their emotional wellbeing, learning and development. The next few pages will talk about:



How a neurodiversity-affirming mindset can support your child's wellbeing and behaviour



Tools to help you and your child map out their needs so you can best accommodate them to reduce challenges



Wellbeing tools that are useful for supporting emotional regulation, no matter what neurotype



Sign-post resources and support services that you can access without a diagnosis

NEURODIVERSITY-AFFIRMING MINDSET



Being neurodiversity-affirming means valuing all neurotypes and brain functioning styles. This means re-framing neurodivergent ways of being (e.g. preferring to be alone or not to make eye-contact, rocking and jumping or preferring routine) which are often seen as problems or deficits, as something to value and celebrate.

In adopting this mindset, you can validate your child's way of being and encourage others to do this same. You can provide support and accommodations to make the world more comfortable so that they can thrive.



You do not need an assessment or diagnosis to practice a neurodiversity-affirming mindset. It is beneficial for *everybody* to understand how their brain works (their strengths, preferences, support needs and difficulties).

Taking a neurodiversity-affirmative approach to parenting promotes a peaceful and accepting way of being. It will benefit your child's development and wellbeing, as well as the wellbeing of everyone else in your home.

Purple Ella, an autistic advocate speaks about how using neurodiversity-affirming strategies to parenting are helpful for all children. Learning from autistic advocates is a great way to understand neurodiversity-affirming approaches to parenting.

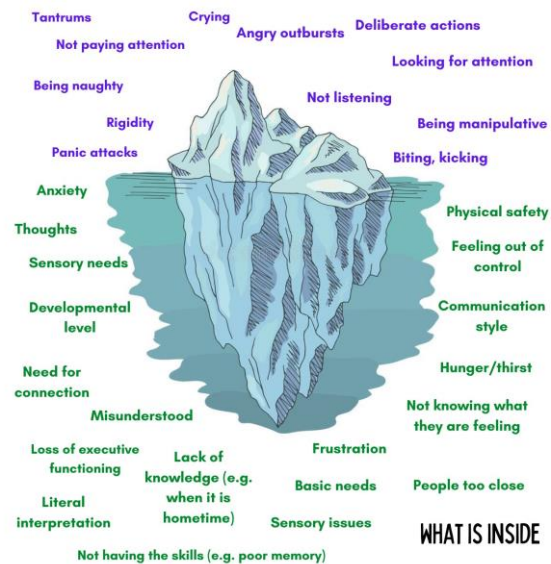


Purple Ella : What do do when waiting for autism assessment

BEHAVIOUR IS COMMUNICATION

Understanding that behaviour is often how children communicate their needs and big feelings will support you help your child when they are feeling dysregulated. It will support you to identify the stressors that might be leading to dysregulation and behaviour that challenges. This will also help you to recognise the behaviours your child uses to communicate their needs and feelings.

WHAT WE SEE/THINK WE SEE



To understand what might be underpinning your child's distress or behaviour that challenges (e.g. what triggers their threat response), it might be useful to map out their support needs and preferences. This can help you and your child start to think about how their brain works.

Think about some of the following areas, and if your child experiences differences or challenges in these areas which impact their quality of life:

- Language and speaking
- Information processing
- Paying attention
- Starting tasks
- Understanding spoken instructions
- Sensory processing
- Need for sameness and routine
- Motor skills
- Communication differences
- Anxiety



Think about the impact of the environment, sensory inputs, societal expectations, skill development and the types of supports that might be needed in these areas.

For example, supporting executive functioning with to do lists or pictures, reducing sensory input, providing safe quiet spaces, reducing expectations to communicate in a neurotypical way.



THE WINDOW OF TOLERANCE

HYPER-AROUSAL: EMOTIONAL DYSREGULATION: RED ZONE

When you are in the red-zone, you are in 'fight or flight' mode. Your reactions take over and **you lose control**. You feel anxious and overwhelmed. **This can look like a 'meltdown'**.

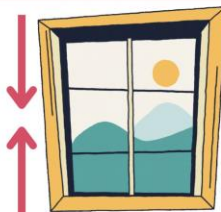
Signs you are here:

- Tension, shaking
- Emotionally reactive
- Defensive
- Racing and intrusive thoughts
- Feeling overwhelmed and unsafe
- Impulsivity
- Anger and rage

SHRINK YOUR WINDOW OF TOLERANCE

Stress, trauma, anxiety, sensory overwhelm, routine disruption, demands, executive functioning challenges

When your window of tolerance is shrunk, it doesn't take much to make you 'lose it' and feel really distressed



EXPAND YOUR WINDOW OF TOLERANCE

Meditating, stimming, listening to music, engaging in hobbies, resting, breathing, exercise, reducing demands, supporting executive functioning

When your window of tolerance is expanded, you are more able to cope with challenges

OPTIMAL ZONE: EMOTIONAL REGULATION: GREEN ZONE

When you are in your window of tolerance, you feel like you can deal with the stress and pressures of life. This is the ideal place to be. We should aim to be here as often as possible.

Signs you are here:

- Feel and think simultaneously
- Awareness of boundaries
- Feelings are tolerable
- Reactions are appropriate to the situation
- Feel open and curious

HYPO-AROUSAL: EMOTIONAL DYSREGULATION: BLUE ZONE

When you are in the blue-zone, you are in 'freeze' mode. Your body might start to shut down. You may feel numb, exhausted and depressed. **This can look like a 'shutdown'**.

Signs you are here:

- Feeling 'dead' or flat
- No energy
- Passive and disconnected
- Can't think

HAND BREATHING

Taking deep breaths is one thing you can do to calm your mind, your body and bring you into the present to reduce any anxiety or big feelings.

Lots of children struggle to see the point of taking breaths, it is useful to explain to them why taking breaths helps. Taking breaths stimulates the vagus nerve. This is in charge of turning off your 'fight or flight' survival mechanism. This will reduce anxiety and bring you back more control.

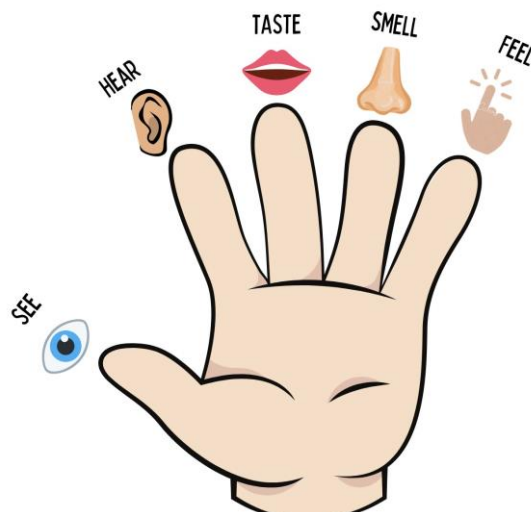
It is best to practice this as often as possible, not just when you are feeling overwhelmed and dysregulated. Taking deep breaths is something that is always accessible. Many people benefit from having something tactile to focus on to help them take breaths. This is what hand breathing is for. Simply run one finger along your thumb and fingers on the other hand. Breath in while your finger runs up the outside, and breath out as it runs down the inside.



SENSORY GROUNDING

Similarly to hand breathing, grounding techniques take you away from the anxiety or big emotions you are feeling, and bring you into the present moment. By focusing on what your body is feeling and where you are in the physical environment, you can move out of 'fight or flight mode' and feel calmer.

This exercise involves touching each finger and naming one thing you can sense with each of the senses. Practicing this often when feeling calm or for fun and noting how it feels will increase its benefit when feeling anxious or sad.



DAN SIEGAL'S HAND MODEL OF THE BRAIN AND FLIPPING YOUR LID

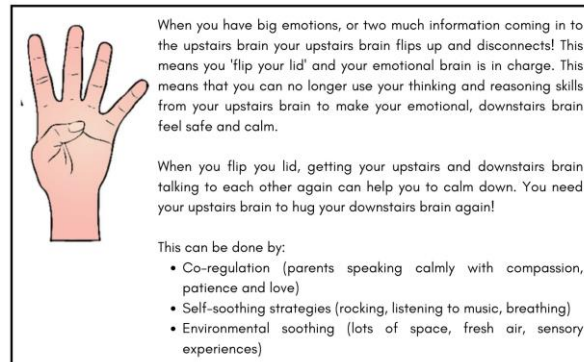
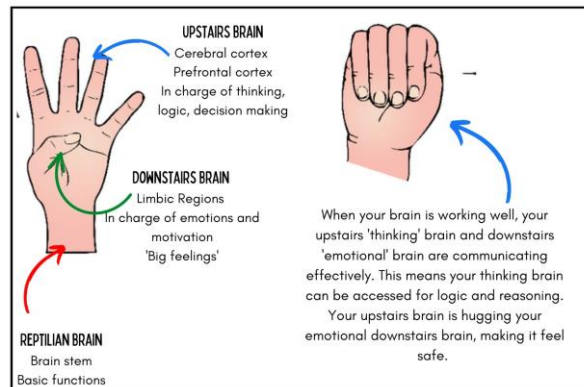


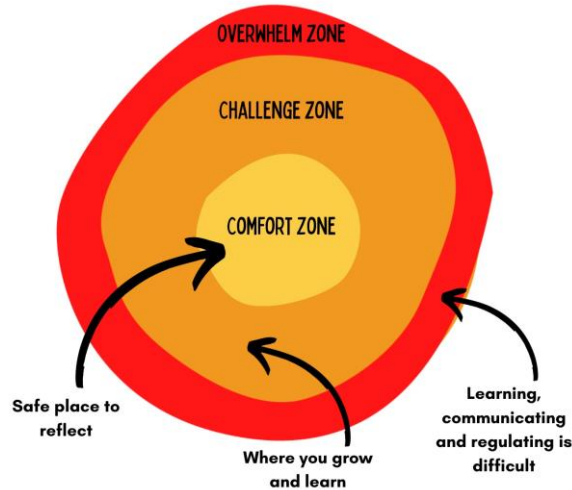
Photo credit: Healthy Minds, Sheffield Children's NHS Foundation Trust

COMFORT ZONE, CHALLENGE ZONE

The 'Comfort Zone, Challenge Zone' is a similar idea to The Window of Tolerance, presented in a different visual.

Having this visual drawn or printed out might support your child to identify when they are feeling calm and regulated (comfort zone), if they are in a place to learn, do tasks, practice wellbeing (challenge zone) or if they are feeling too overwhelmed.

It can also support them to understand that working on their wellbeing and mental health is not always comfortable, but that they have the agency to let others know when they are feeling too overwhelmed.



GROWTH MINDSET & SELF-REGULATION



INSTEAD OF THINKING...
(FIXED MINDSET)

- HE NEEDS TO LEARN SOME SELF-CONTROL.
- SHE KEEPS GIVING ME A HARD TIME.
- MY CLASSROOM WORKS FINE FOR ALL THE OTHER STUDENTS.
- HIS BEHAVIOUR COMES OUT OF THE BLUE.
- NOTHING WORKS FOR THIS CHILD.
- SHE JUST NEEDS TO CALM DOWN.
- HE WON'T EVER LEARN SELF-REGULATION.



TRY THINKING...
(GROWTH MINDSET)

- HE NEEDS HELP WITH SELF-REGULATION.
- SHE IS HAVING A HARD TIME. HOW CAN I HELP?
- EVERY STUDENT IS UNIQUE. WHAT CHANGES CAN I MAKE TO SUPPORT THIS STUDENT?
- LET'S LOOK DEEPER FOR PATTERNS AND SETTING EVENTS.
- WHAT ELSE CAN I TRY?
- DOES SHE EVEN KNOW WHAT CALM FEELS LIKE?
- HOW CAN I HELP HIM LEARN SELF-REGULATION?

GROWTH MINDSET AND SELF-REGULATION
DECREASE JUDGEMENT AND INCREASE CURIOSITY



Credit: northstarpaths.com



REFRAME THE BEHAVIOUR

"KIDS DO WELL IF THEY CAN"

—ROSS GREENE



Credit: northstarpaths.com

BOOKS

Books for your child to understand themselves and support their wellbeing:

- The Neurodivergent Friendly Workbook of DBT Skills by Sonny Jane Wise*** This book is *highly* recommended by the psychology team for older children
- The Brain Forest by Sandhya Menon
- Me and my PDA: A Guide to Pathological Demand Avoidance for Young People by Glòria Durà-Vilà and Tamar Levi
- The Reason I Jump by Naoki Higashida
- The Secret Life of Rosie by Rose Smitten
- Libby Scott fiction book series

Parenting books to support emotional regulation:

- The Whole-Brain Child: 12 Proven Strategies to Nurture Your Child's Developing Mind by Daniel J. Siegal
- No-Drama Discipline: The bestselling parenting guide to nurturing your child's developing mind by Daniel J. Siegal
- Yes Brain: How to Cultivate Resilience, Encourage Curiosity, and Inspire Passion and Purpose in Your Child's Life by Daniel J. Siegal
- Avoiding Anxiety in Autistic Children: A Guide for Autistic Wellbeing by Luke Bearden



VIDEOS

Here are some QR codes to Youtube videos which might help you and your child to understand their emotions, de-stress and manage behaviour that challenges. To open use your phone camera or a QR scanning app.



The Size of Feelings



Why Do We Lose Control of our Emotions?



Practical Tips for Dealing with Anxiety



Upstairs Downstairs Brain



PDA (demand avoidance)



Hand Model of the Brain



Using Your Senses to Calm Down



Body Scan! Mindfulness for Children




Negative Thoughts

WEBSITES FOR INFORMATION AND RESOURCES

Here are some brilliant websites that are full of resources, including ones used in this booklet.

- **northstarpaths.com**- visuals designed by a psychologist with inclusive classrooms and parenting in mind
- **brightandquirky.com**- webinars, videos and information for parents
- **kentcht.nhs.uk**- check out the sensory processing online workshop
- **pdasociety.org.uk**- Pathological Demand Avoidance Society website with information and strategies for parenting a PDA kid
- **understood.org**- 'Through Your Child's Eyes' series looking at how experiencing various challenges feels for children with additional needs
- **differentminds.scot**- lots of information on autism

SERVICES YOU CAN ACCESS WITHOUT A DIAGNOSIS

 <p>For families with disabled children and young people in Sussex Amaze is a charity that offers information, advice and support to parents and carers of children and...</p>	amazesussex.org.uk Information, advice and support to families of children and young people with special educational needs
 <p>National Autistic Society We are the UK's leading charity for autistic people and their families. Since 1962, we have been providing support, guidance and advice, as well as...</p>	autism.org.uk A wealth of information, resources for parents and young people.
	CLASS+ Support and information for parents. https://czone.eastsussex.gov.uk/inclusion-and-send/isend-services/communication-learning-and-autism-support-service-class/classplus/