



Post Diagnostic Pack for Children, Young People and Families Following a Diagnosis of Autism



This post-diagnostic pack contains information about Autism, services available at the practice that may be of interest to you and further external resources.

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1. What is Autism?

Autism is a neurodevelopmental condition, meaning the brain processes information differently. Autistic people see and interact with the world differently. This is sometimes called “neurodivergence”. The key is to accommodate these differences, as there is no right or wrong way to view or engage with the world.

Click on the video below for a useful explanation about Autism:



Autistic people may prefer to communicate and interact with others differently. They may prefer things to be familiar and predictable, tending to engage in the same activities, interests, and behaviours. They may also have different sensory perceptions, meaning they might be more or less sensitive to for example light, sound or touch than others.

Autism is different for everyone. Every autistic person has similarities in how they communicate, interact, and engage with the world around them, but this might be different for each person. Understanding each person’s profile is key to moving forward after a diagnosis. Challenges often arise because a person’s differences are not understood.

Receiving a diagnosis and an affirmation of neurodivergent identity can make a real difference and help people better understand themselves and their experiences. Click the following link to hear from members of the Autistic community about their experiences of being Autistic:

<https://www.autism.org.uk/advice-and-guidance/stories>



Examples of features we see in Autism:

Differences in how language is used: This may include taking things literally, requiring more time to process information, using different words and phrases from others around them or repeating what others say (echolalia).

Differences in body language, self-expression, movement and proximity.

A preference of ‘sameness’ and difficulty with transitions, change or shifting attention to non-preferred activities.

Having strong emotional responses and not being able to communicate their feelings.

Preferring reduced levels of eye contact.

Differences in communication – e.g. a preference to download information than participate in a two-way conversation, may shift topics to their interests, may not enjoy social chit-chat.



**Sensory sensitivities to light, sound,
taste or touch.**

Highly focused interests or hobbies.

Preference to be interact one to one or a small group.

2. Sharing the diagnosis with your child

Parents sometimes wonder how best to share the diagnosis with their child. This depends on the individual, and you know your child best. It can be helpful for parents/carers to learn more about Autism through our recommended websites and books in our 'Resources' section.

When helping children understand Autism you are helping them understand and embrace a meaningful part of their identity in addition to how their brain works, their strengths, challenges, and the experiences they have. This process may be gradual, and your child may need some time to process the information. Dr Liz Angoff has created the following resource called "Explaining Autism to Kids" which can be useful when speaking to your child: <https://explainingbrains.com/autism-handout/>.

3. Understanding their individual profile

a) Masking

'Masking' or camouflaging refers to a strategy which can be conscious or unconscious and refers to individuals hiding or suppressing autistic traits to fit in socially. Research suggests people learn how to mask by observing, analysing and mirroring the behaviours of others – in real life, movies or books (National Autistic Society, 2024a).

Examples of masking:

- Forcing eye contact with others
- Holding back stimming behaviours
- Creating "scripts" for conversations or social situations
- Imitating other people's facial expressions or gestures
- Hiding special interests

For more information about masking, please use this link:

<https://www.autism.org.uk/advice-and-guidance/topics/behaviour/masking>

b) Demand Avoidance (sometimes referred to as Pathological Demand Avoidance)

Pathological demand avoidance (PDA) is the most used term. However, the neurodivergent community is considering using the term '**Pervasive Drive for Autonomy**' (PDA).



Demand Avoidance is associated with Autism but is not part of every individual's profile. Individuals experience an overwhelming reaction to a perceived demand and will respond in a way that means they can avoid the demand/situation. This often happens at transition points, for example, when it is time to get ready for school or go on holiday. PDA can happen even when the situation is motivating and something someone would enjoy. PDA is driven by anxiety and leads to the individual striving for control, which is not always easy to interpret as it can often present itself differently from how we typically see anxiety.

To find out more about PDA, please use the following resource which includes videos and information: <https://www.pdasociety.org.uk/what-is-pda-menu>

4. Strengths

There may have been conversations about your child's challenges as part of the Autism assessment and diagnosis, but it is also important to highlight strengths. Autism brings unique traits and abilities that others do not have, and these should be celebrated!

HYPERFOCUS

**WHEN ENGAGED WITH SOMETHING YOU ENJOY,
YOU CAN EXPERIENCE A 'FLOW' STATE WHERE
EVERYTHING ELSE DISAPPEARS APART FROM THE
TASK YOU ARE FOCUSED ON.**

ATTENTION TO DETAIL

**YOU MAY BE VERY OBSERVANT AND NOTICE
THINGS OTHERS DON'T. THIS CAN BE VERY
HELPFUL IN YOUR DAY TO DAY LIFE.**



STRONG SENSE OF JUSTICE

IT CAN BE A GREAT STRENGTH TO HOLD A STRONG SENSE OF WHAT IS RIGHT AND WRONG.

BEING AN EXPERT

YOU MAY HAVE A FAVOURITE TOPIC OR SPECIAL INTEREST THAT YOU KNOW LOTS ABOUT AND CAN SHARE INTERESTING FACTS WITH OTHERS.

CREATIVE PROBLEM SOLVING

HAVING AUTISM CAN MEAN YOU CAN THINK OF UNIQUE SOLUTIONS TO TRICKY SITUATIONS FROM YOUR STRONG ABILITY TO THINK OUTSIDE THE BOX.

5. Supports

Support should always come from a view of understanding and accepting Autism. It is important to understand the world as autistic people see it and adapt demands, environments, and expectations to best support your child.

There will be local supports in your area and it is always worth looking into them. You could ask your child's school if they have any links to organisations or groups that can provide you with information and support.

The National Guidelines (NICE) recommend various supports including parenting approaches and support for children and young people with for example, problem-solving and regulating emotions.

<https://www.nice.org.uk/guidance/cg128>

The Scottish Intercollegiate Guidelines Network (SIGN) guidelines have booklets for parents/carers and young people based on current medical research and on the opinion of healthcare professionals.

<https://www.sign.ac.uk/patient-and-public-involvement/plain-language-versions-of-guidelines/autism/>

The National Autism Implementation Team provides a programme on Autism training, a map of parent supports and other useful resources available for parent/carers.

<https://www.thirdspace.scot/nait/education-resources/>

Supports can involve:

Parent/Carer Support and Education: We help parents understand Autism, their child's unique profile, including strengths and challenges, how best to support them, and positive strategies to help children thrive.

Support for Children and Young People: For example, using evidence-based psychological therapy to help with anxiety and low mood which may occur alongside neurodiversity.

Environmental Adaptations: Discussing with your child whether and how Autism impacts educationally and liaising with school regarding supports and adaptations such as visual timetables, sensory toys and headphones.

Social Demands: Consider communication differences and what demands are placed on your child to communicate and interact with others. Even when a child may seem to manage, they likely have to work exceptionally hard in each social situation when communicating with non-autistic people. Discussing your child's communication profile and considering whether they are masking could help reduce these demands, and support your child in "unmasking".



Not everyone who is Autistic is the same but there are some general hints and tips that can help:

- Consider how many social events your child has in the week. Even the ones that are motivating can drain someone's energy quickly.
- Build in recharge time – allowing time to be alone, engage in interests and preferred activities or give time for discussing their interests.
- Provide warning, preparation and opportunities to process changes in routines and plans or when introducing new places, situations or people.
- Provide consistency:
 - Keep a sense of routine where possible
 - Give instructions and information in the same way
 - Make sure the adults supporting your child all agree on boundaries, language, and plans
- Match your child's language level – make sure you do not use language that is more complex than your child's.
- Reduce verbal language – consider writing things down and using visuals where you can, especially when discussing emotive topics.
- Use language that is clear and explicit:
 - Only phrase something as a question if it is a question
 - Give instructions in the order you want them completed
 - Try and reduce language of uncertainty e.g. limit use of words like "if," "could" and "should"
 - Reduce the non-literal language and the need for inference or 'reading between the lines'
- Model emotional vocabulary:
 - Label when you are feeling a particular way – don't always focus on the negatives or your child's emotions
 - Link events to emotions and ways of expressing emotions



- When a child is overwhelmed or dysregulated reduce the language load – offer reassurance but don't ask questions or try to solve the problem in that moment.
- Offer validation – when a child shares their perspective on a situation reassure that you can see how they have perceived it in that way rather than correcting their perception.
- Seek out opportunities for your child to have a chance to communicate with other autistic/neurodivergent people – we know that this communication is much easier and more comfortable.
- Provide opportunities for your child to seek out sensory activities that are regulatory, for example, if they like dark, small spaces could you make a small area where they can go if they need to recharge, or have materials they like to touch available.
- Consider sensory overload – noise, clothing and food textures, lights, etc. Where possible reduce the sensory input. For example, allowing them to wear clothes they like to an event or activity you know will be overwhelming.

Remember some triggers cannot be avoided. Preparing, planning and having coping strategies available, such as a comfort object or a favourite activity can help.

6. Resources

Online Resources

a) Websites

For Children and Young People:

This website has been developed by a young person with Autism. It has useful explanations and ways to develop skills:

<https://www.autismunderstood.co.uk>

SWAN is a space created by autistic women, girls and non-binary people for autistic women, girls and non-binary people, where we can be who we are, understand ourselves better, and share their experiences, challenges, interests and joys.

<https://swanscotland.org>



The Curly Hair Project is an organisation that helps people on the autistic spectrum and the people around them. They use animated films, stories, comic strips and diagrams to make their work interesting and easy to understand:

<https://thegirlwiththecurlyhair.co.uk>

'*Understanding The Spectrum*' is a comic strip explanation that can be printed off in multiple languages:

<https://the-art-of-autism.com/understanding-the-spectrum-a-comic-strip-explanation/>

Autism Understood by Spectrum gaming is a website about Autism, for autistic young people.

<https://autismunderstood.co.uk>

Yellow Ladybugs is a non-government organisation, dedicated to the happiness, success and celebration of autistic girls, women and gender diverse individuals.

<https://www.yellowladybugs.com.au>

For Parents:

Scottish Autism is a charity that provides information on Autism and resources for families, adults and children with Autism. Find them here:

<https://www.scottishautism.org/about-autism/about-autism/what-autism>

They also have an online programme which supports parents and carers post-diagnosis:

<https://www.scottishautism.org/services-support/family-support/online-supportright-click>

National Autistic Society (NAS) is a UK wide charity which provides numerous resources, information and training events. There is a separate section that discusses the overlap between Autism and anxiety:

<http://www.autism.org.uk>

The *NHS* provides accessible information on Autism, the diagnostic process and information for after diagnosis:

<https://www.nhs.uk/conditions/autism/>

<https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/autism/autism/>

A Practical Approach at Home for Parent and Carers: Autism Spectrum Disorder is guide containing information about understanding Autism, the importance of creating a supportive environment and advice:

<https://www.falkirk.gov.uk/services/social-care/disabilities/docs/young-people/Autistic%20Spectrum%20Disorder.pdf?v=201906271131>

'Missing the Mark' Facebook Page and Website

(<https://missingthemark.co.uk>) by Eliza Fricker discusses Autism, school anxiety and pathological demand avoidance.

Sensory Differences

Joining in with Sensory Differences contains resources to help understand sensory processing:

<https://www.nhsggc.org.uk/kids/life-skills/joining-in-with-sensory-differences/>

The website and book *'Out of Sync Child'* explains more about sensory processing difficulties and offers advice on how to manage these challenges:

<http://out-of-sync-child.com/>

Making Sense of Sensory Behaviour provides practical approaches for parent and carers looking after young people experiencing sensory differences:

www.falkirk.gov.uk/services/social-care/disabilities/docs/young-people/Making%20Sense%20of%20Sensory%20Behaviour.pdf?v=201906271131

Regulation

This website offers an introduction into understanding behaviour and strategies that may help:

<https://raisingchildren.net.au/autism/behaviour>

'Lives in the Balance' website is run by Clinical Psychologist, Ross Greene. The website includes information and behaviour management resources for parents/ carers:

<https://www.livesinthebalance.org/>

The *'Think Kids'* website outlines an approach called 'Collaborative Problem Solving'. The website is US based and the training programmes might not be available here, but it provides information and videos about the approach:

<https://thinkkids.org/cps-overview>

The *'5 Point Scale'* is an accessible resource for children to convey how they are feeling. This website explains the scale, has videos on its use and free downloadable work sheets:

<https://www.5pointscale.com/>

This is a helpful introduction into emotional regulation and provides some strategies to try, including using an emotions chart:

<https://onlinegrad.pepperdine.edu/blog/emotional-self-regulation-childrenautism/>

Sleep

Sleep Scotland is a charity which promotes healthy sleep for children and young people with a focus on neurodiversity. Resources are limited in the Dundee area, but they can provide telephone-based support (parents can self-refer or refer via GP):

www.sleepscotland.org

Education

Enquire is the Scottish advice service for additional support for learning. They provide practical advice and information about the education and additional support needs system in Scotland through their website and helpline (0345 123 2303):

<http://enquire.org.uk/>

The Salvesen Mindroom is a Scottish charity supporting children with learning differences and their parents. They recognise the common overlap between learning challenges and neurodiversity. Their family advice specialists offer support and can be contacted through their website:

<https://www.mindroom.org/contact-us/>

The Autism Toolbox is a Scottish website that discusses the strengths and challenges of Autism, mainly in the context of learning and schools. They also suggest strategies for easing these difficulties:

<http://www.autismtoolbox.co.uk/>

b) Videos/Podcasts

For Children and Young People:

NAS has made a video called 'Amazing Things Happen' explaining Autism. This may be a useful starting point in introducing Autism to siblings and family members:

<https://www.youtube.com/watch?v=RbwRrVw-CRo>

My Autism and Me by Rosie King:

<https://www.bbc.co.uk/newsround/15655232>

Rosie King reflecting on her diagnosis:

https://www.ted.com/talks/rosie_king_how_autism_freed_me_to_be_myself

This website provides links to Podcasts about Autism:

<https://theautisticadvocate.com/podcasts/>

The '21andsensory' podcast discusses all things about sensory processing and autism, including chatting to neurodivergent people from all walks of life:

<https://21andsensory.wordpress.com/21andsensory-podcast/>

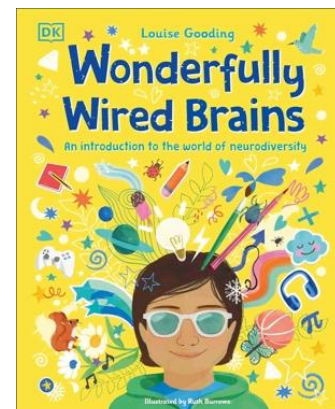
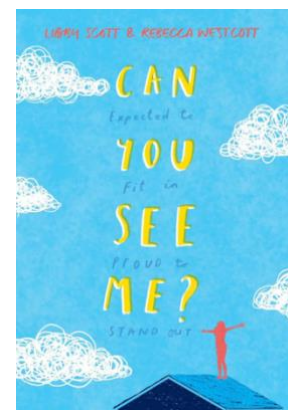
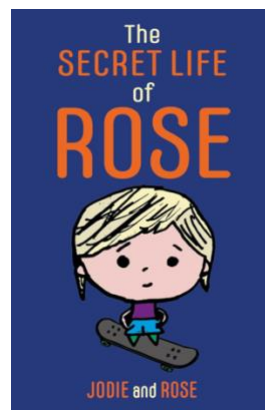
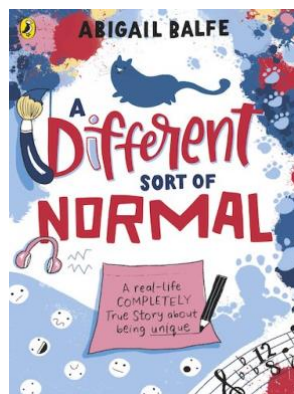
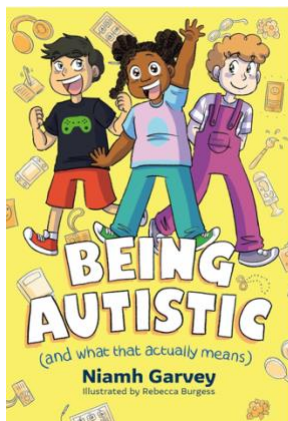
For Parents:

The Occupational Therapy team in NHS Tayside have created some YouTube videos on sensory processing in children and teenagers:

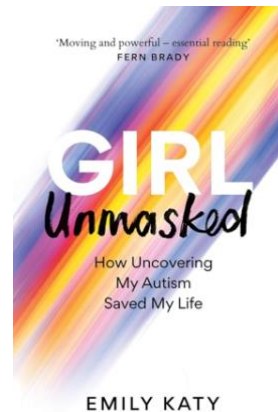
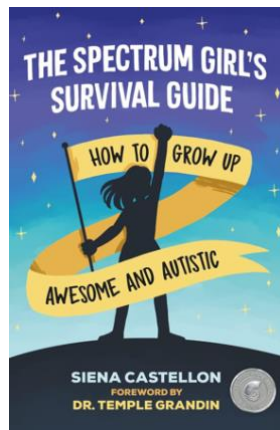
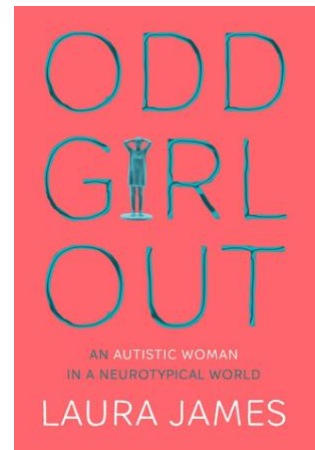
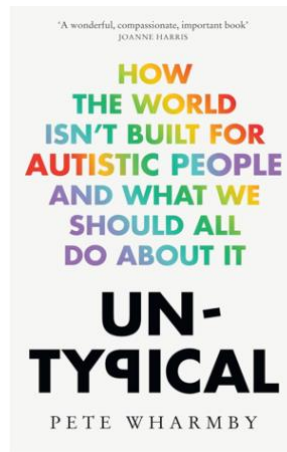
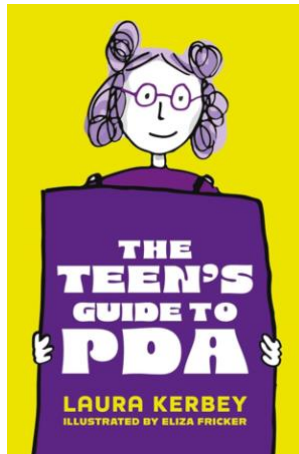
https://www.youtube.com/watch?v=yLxwRf_6DNk

c) Books

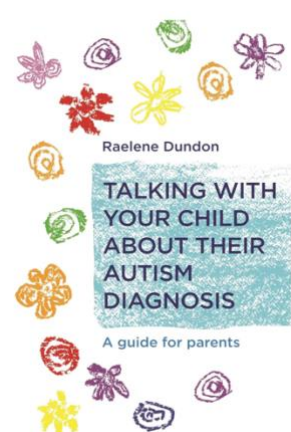
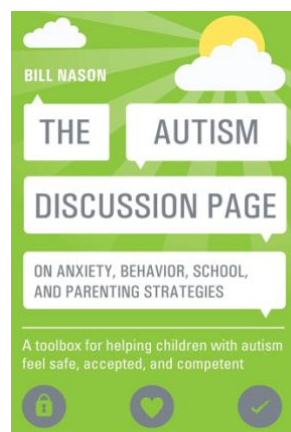
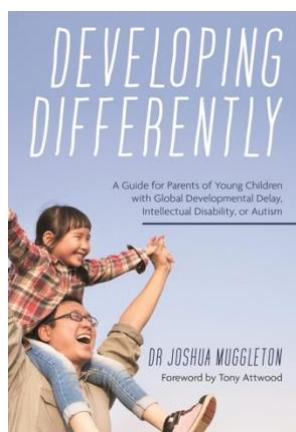
For Children and Young People:

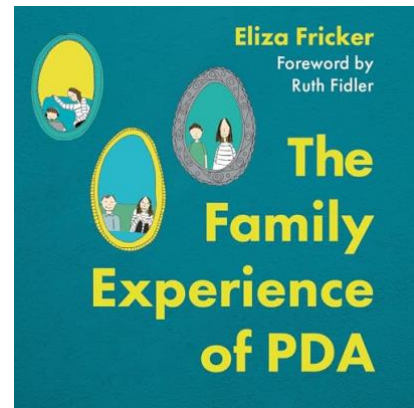
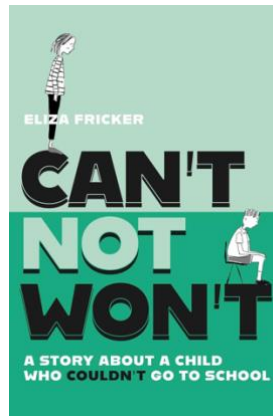
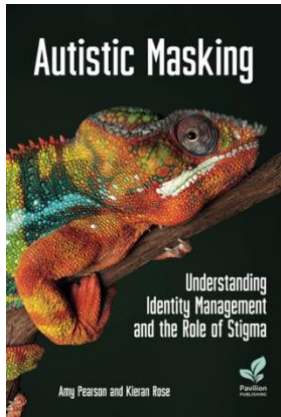


Over 16 years:



For Parents:





d) Local Edinburgh Support Groups/Initiatives

Barnardos Cygnet parenting support programme is for parents and carers of five to eighteen years old. It provides practical solutions to support children:

<https://barnardos-parenting.org.uk/>

Autism Ideas Midlothian is a good signposting page for ideas and resources informed by people connected to Autism:

<https://autismideasinmidlothian.com>

ND:Well is a partnership with established third sector agencies including Tailor Ed, Barnardos and CAMHS to provide services to support young people and families in Edinburgh who are neurodivergent:

<http://tailoredfoundation.co.uk/ndwell>

Edinburgh Disability and Neurodiversity Hub (EDAN) is a partnership to support families with children or young people who are disabled and/or neurodivergent. Information about the services available and how to access them can be found on this site:

<http://theyardscotland.org.uk/edan-hub/>

Number 6 One-Stop Shop is provided by the Autism Initiatives UK for young people (16 years and above) living in Edinburgh. The service provides free social opportunities and one-to-one advice and support on a range of issues.

<https://www.number6.org.uk>

e) Social Media Accounts

These accounts should be viewed by adults in the first instance and accessed with supervision. The Edinburgh Practice cannot be responsible for the content posted.

Instagram accounts to follow:

@neurowild_

@21andsensory

@abigailbalfe

7. Neurodiversity Support at The Edinburgh Practice

The Edinburgh Practice offers a wide range of neurodiversity support services delivered by our highly specialised multidisciplinary team. We work from a strength and rights-based approach that fully embraces neurodevelopmental differences. We offer a range of services for children, young people, adults, parents/carers and families delivered at the practice and/or in educational settings.

Educational Psychology

Educational Psychology is available for children, young people, parents/carers and adults.

Educational Psychologists offer:

Support for Children and Young People

- Supporting children and young people to understand their diagnosis, using age-appropriate resources.
- Consultation with children and young people to help identify their strengths, challenges as well as the supports they find helpful at home and school.

Support for Parents and Carers

Consultation, support and advice to parents/carers regarding:

- Understanding neurodevelopmental conditions including Autism and ADHD.
- Playing and interacting with children.
- Understanding and managing increased anxiety.
- Strategies to support emotional regulation.
- Understanding and supporting sensory needs.
- Awareness of masking.



- Supports for home and school including a safe space, visual timetable, predictable routines and sensory supports.
- The Getting it Right for Every Child (GIRFEC) process including SHANARRI and Child Planning Meetings (CPMs).
- Preparing for Child Planning Meetings. Our Educational Psychologist can attend CPMs, if requested by parents (with school's permission).
- Signposting to resources and supports.

Support for Independent Schools

- Consultation and advice to school staff regarding neurodevelopmental conditions including information regarding neuroaffirming practices. Sessions can be tailored to the schools' needs and requirements.

Clinical Psychology

Clinical Psychology is available for children, young people, parents/carers and adults.

Clinical Psychologists offer:

- Psychoeducation and therapeutic support to develop an increased understanding of the strengths and challenges that can come with neurodiversity (for parents and/or for individuals) and how to best support children and young people to allow them to thrive.
- Evidence-based psychological therapy for mental health difficulties, such as anxiety or low mood, which may occur alongside neurodiversity.
- A space for children and young people to work through some of the challenges that can arise from navigating a neurotypical world.

Speech and Language Therapy

Speech and Language Therapy is available for children and young people.

Speech and Language Therapists offer:

- Support for children, young people and their families to understand autism, with the option to have information adapted to support language and communication differences.
- A neuroaffirming approach which can help an individual understand their communication style as well as building an understanding of communication in autism and develop strategies to support the autistic person.

Occupational Therapy

Occupational Therapy is available for children and young people.

Occupational Therapists offer:

- Support with daily living skills such as self-care, engaging in meaningful activity, and creating routines and structure.
- Thorough assessments, generating collaborative and tailored intervention plans for the home, school, further education, or work environment.
- Sensory assessments and recommendations to help identify any sensory sensitivities clients are experiencing.

Dietetics

Dietetics is available for children, young people, parents/carers and adults.

Dieticians offer:

- Our specialist Dietician provides thorough assessment, and collaborative intervention plans specifically tailored to individual needs if you or your child are experiencing eating or nutrition difficulties believed to be linked to neurodiversity (such as ARFID).

Systemic Family Therapy

Systemic therapy is available for children, young people, parents/carers, adults and families.

Systemic Family Therapists offer:

- An initial meeting with the person who has received the diagnosis along with significant others. For a young person, this might be parents and siblings and for adults, their partners and/or children, if this was felt helpful.
- The systemic family therapy works towards developing a shared understanding of the meaning of the diagnosis for each person and how it influences relationship patterns. For example, does the diagnosis bring more closeness or distance; what does it change; does it change how each person makes sense of patterns of behaviour and responses between them?
- The aim of developing this shared understanding between family members is to identify new possibilities for interaction and to strengthen existing bonds of attachment and resilience in families.

Play Therapy

Play therapy is a non-directive and child-centred therapy where children can express themselves freely. The child leads their play, choosing toys and activities. Children do not need to communicate verbally or explain what they are doing. Clear and appropriate boundaries to support children with self-regulation and safety are provided.

Play therapy includes:

- At initial appointment to meet with parents/caregivers and the child to assess whether play therapy is currently the most suitable intervention.
- During subsequent appointments, the play therapist responds to the child's lead in a non-judgemental and attuned way to help further and deepen their exploration of their inner world through play.
- Meetings with parents continue throughout to discuss the therapeutic process and provide tailored support for family relationships.

Art Therapy

Art Therapy is a type of psychotherapy which uses creative art-making as a tool to support self-understanding, healing, and emotional and mental wellbeing. Art therapy is available for children, young people, parents and carers.

Art therapy includes:

- An initial meeting with the person who has received the diagnosis, along with their parent or carer. The therapist will discuss how art therapy works and answer any questions.
- At follow-up appointments, your art therapist will provide materials and guidance adapted to your needs, supporting you through creative exploration and expression of your thoughts, emotions, and experiences.
- Art therapy can be less challenging and intimidating than talking therapy, fostering self-discovery through increased freedom of expression. It can increase the accessibility and efficacy of therapy for neurodivergent individuals. It can be structured or fluid, depending on your needs.

Psychiatry

Our Consultant Psychiatrists have expertise in Autism and ADHD. Our doctors offer assessment and diagnosis for mental health difficulties which may occur alongside neurodiversity (e.g. anxiety and depression).



Neurodiversity Support Fees (per session)

Educational Psychology: £140

Clinical Psychology – Psychological Therapy: £140

Speech and Therapy: £130 (initial) £110 (follow up)

Occupational Therapy: £130

Dietetics: £130

Systemic Family Therapy 1 hour session: £140

Play therapy: £100

Art therapy: £100

Psychiatry Assessment 1 hour: £370

Psychiatry Review 30 minutes: £210

8. Frequently Asked Questions

How common is Autism?

The government prevalence surveys last estimated that around one in 100 people and approximately 700,000 autistic people live in the UK (National Autistic Society, 2024b).

What causes Autism?

Researchers don't know the primary causes of Autism, but studies suggest a combination of genetic and environmental aspects (National Institute of Health, 2024).

I am worried about getting the appropriate support from my child's school, what can I do about this?

In our experience, most schools are very supportive and want to help their pupils thrive and reach their full potential. Neurodiversity is now more frequently spoken about and understood in schools, with a lot of teachers already using strategies such as visual timetables and providing step-by-step instructions.

Following a diagnosis of Autism at The Edinburgh Practice you can request a school letter from your child's clinician stating their diagnosis, the clinician's recommended strategies and any special circumstances required. We also recommend sharing the report with your child's

teacher or support staff, as this can help staff understand your child's strengths and difficulties.

9. Feedback on our Welcome and Post-diagnostic Packs

We are always trying to improve our services and would really appreciate and value your feedback on our Welcome and Post-diagnostic Packs. Please answer our six-question survey by scanning the QR code or clicking the link below:

<https://www.surveymonkey.com/r/J9WY7L9>



10. References

National Autistic Society. (2024a). *Masking*. National Autistic Society.
<https://www.autism.org.uk/advice-and-guidance/topics/behaviour/masking>

National Autistic Society. (2024b). *What Is Autism?* National Autistic Society.
<https://www.autism.org.uk/advice-and-guidance/what-is-autism>

National Institute of Mental Health (2024). *Autism Spectrum Disorder*. National Institutes of Health. <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd>