Information and supports for parents of neurodivergent children

Please note this resource sheet provides signposting to resources or helpful services for families who are awaiting a Neurodevelopmental appointment. It includes links to helpful websites, as well as some brief strategies and techniques which may be useful. However, as your young person does not have a diagnosis currently, this is general advice. You may need to look through this sheet to find and pick what resources or advice specifically suit your needs.

In the case of urgent concerns about your child's mental health or wellbeing, please contact NHS24 or attend Accident and Emergency.



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General information and support

- An extensive range of resources can be found using this link https://services.nhslothian.scot/camhs/online-resources/
- A guide from National Institute for Clinical Excellence (NICE) to help to understand what to
 expect from the autism assessment process and what should happen if an autism diagnosis is
 confirmed
 - https://www.nice.org.uk/Media/Default/About/NICE-Communities/Social-care/quick-guides/Autism-in-U19s-quick-guide.pdf
- Edinburgh Psychoeducation Intervention for Children (EPIC) provide leaflets on the typical strengths and challenges of neurodivergent children aimed at both parents and teachers. They also offer a more detailed booklet covering some practical strategy ideas.
 https://www.ed.ac.uk/clinical-brain-sciences/research/epic-edinburgh-psychoeducation-intervention/epic-resources
- The National Autism Implementation Team (NAIT) are a practitioner researcher partnership who are based at Queen Margaret University. They have parent information sheets to support children's communication, eating and drinking, autistic masking, and anxiety related attendance. Education | ThirdSpace https://www.thirdspace.scot/nait/education-resources/
- NHS website 'Every Mind Matters' provides various resources to improve mental wellbeing as well as resources for carers https://www.nhs.uk/every-mind-matters/
- 'TASSK' (Tools and Strategies to Support Kids) is a pre-recorded online workshop which covers emotional regulation, attention, transitions, sensory difficulties, relationships, structure and routine
 - https://sites.google.com/edubuzz.org/mhwb-information-point/parents-carers/further-learning/occupational-therapy-webinars?authuser=0
- Solihull provides access to free online courses for parents and young people using the access code 'TARTAN' https://inourplace.co.uk/
- Edinburgh Council offers a range of parenting programmes which are self-referral based and free for parents and carers with children living or attending school in Edinburgh
 https://www.joininedinburgh.org/parenting-programmes/
- The Salvesen Mindroom Centre has resource guides, real life stories and lived experiences, and advocacy support for young people. The charity also works closely with work research partners at the University of Edinburgh to ensure support is evidenced based and up to date https://www.mindroom.org/
- Cambridgeshire community services NHS trust have developed a Diagnosis Support Pack (DSP),
 while this is designed for those with a diagnosis it does have a variety of helpful information for
 while you wait for assessment and can be translated online into different languages as well as

easy-read formats

https://www.cambscommunityservices.nhs.uk/beds-luton-community-paediatrics/diagnosis-support-pack

- Young Minds Charity provides information about emotional wellbeing, and can provide guidance about finding support https://www.youngminds.org.uk/
- Royal College of Psychiatrists has information about parenting, young people's mental health, and includes weblinks, book references and advice
 - https://www.rcpsych.ac.uk/mental-health/parents-and-young-people
- Family Lives is a charity providing advice, web links, helplines and videos for parents: http://www.familylives.org.uk/how-we-can-help/
- National Autistic Society provides a variety of advice and guidance https://www.autism.org.uk/advice-and-guidance
- <u>Branch Out Together</u> -https://www.branchouttogether.org was formerly the Lothian Autistic
 Society and provides social activities and events.
- Embrace Autism is a place to find research & experience-based autism content for personal elucidation & empowerment. By autistic people, for autistic people.
 - https://embrace-autism.com
- Ambitious about Autism is the national charity for autistic children and young people. We stand
 with autistic children, young people and their families to champion rights, campaign for
 change and create opportunities. www.ambitiousaboutautism.org.uk
- MIND provides information and tips about living with ADHD
 https://www.mind.org.uk/information-support/tips-for-everyday-living/adhd-and-mental-health/
- There are various positive video clips on YouTube which may help young people who are
 interested in learning about their own potential neurodiversity to explore this further:
 http://amazingthingshappen.tv/
- Being autistic in mainstream education | Becky Cox | TEDxYouth@StPeterPort
 https://www.youtube.com/watch?v=nFfWMzUoKbA
- The world needs all kinds of minds | Temple Grandin
 https://www.youtube.com/watch?v=fn 9f5x0f1Q
- Neurodiversity the key that unlocked my world | Elisabeth Wiklander | TEDxGöteborg
 https://www.youtube.com/watch?v=Qvvrme5WlwA
- How autism freed me to be myself | Rosie King
 https://www.ted.com/talks/rosie king how autism freed me to be myself/up-next
- Autism: A Quick Trip To My Home Planet | Monique Botha | TEDxSurreyUniversity
 https://www.youtube.com/watch?v=NCAErePScO0

Sleep

- Sleep Scotland: Scotland -based Charity promoting sleep hygiene https://sleepscotland.org
- NHS Every Mind Matters NHS Health Information Website with info about sleep: https://www.nhs.uk/every-mind-matters/mental-health-issues/sleep/
- Sleep Charity provides advice for parents for ensuring children and teenagers get a good night's sleep https://thesleepcharity.org.uk/

School

- Enquire provides information about accessing support through education https://enquire.org.uk/parents/
- Information about different behaviours between school and home
 https://www.calderdale.gov.uk/v2/sites/default/files/Different-behaviour-between-school-and-bome.pdf
- Learning About Neurodiversity at School (LEANS) https://salvesen-research.ed.ac.uk/leans
- Autism education trust includes information for parents/carers and all educational settings from early years https://www.autismeducationtrust.org.uk/
- Autism information about education
 https://www.autism.org.uk/advice-and-guidance/topics/education

Anxiety & Mental Health

- Advice on various mental health topics
 https://www.autism.org.uk/advice-and-quidance/topics/mental-health
- Thrive helps you prevent and manage stress, anxiety and related conditions. The game-based app can be used to relax before a stressful situation or on a more regular basis to help you live a happier, more stress-free life. This app is provided free by the NHS
 https://thrive.uk.com/thrive-app
- Free online courses covering low mood, stress and resilience https://llttf.com/resources/llttf-yp-resources/
- Open Minds information sheet about anxiety with some tips and strategies https://www.calderdale.gov.uk/v2/sites/default/files/Anxiety.pdf
- These are NHS Lothian videos for parent information on anxiety:
 - o Understanding Anxiety Workshop https://vimeo.com/637899585/a4a632bd0c
 - o Supporting Children with Anxiety Workshop
 - https://vimeo.com/637889751/e2d94cf5d5
 - o Supporting your child with fears and worries information for parents/carers https://learn.nes.nhs.scot/66800

o CAMHS Anxiety Management- Relaxation - https://learn.nes.nhs.scot/66801 (this one is designed for young people)

Behaviour

- Parenting Across Scotland: Information, weblinks and helplines for difficult behaviour of different age groups http://www.parentingacrossscotland.org/info-for-families/
- Children 1st has downloadable information, links to local services and helplines for parents and
 YP over 10 http://www.children1st.org.uk/help-advice/
- Autism information about various behaviours:
 https://www.autism.org.uk/advice-and-quidance/topics/behaviour
- Open Minds information sheet about behaviour difficulties with some tips and strategies https://www.calderdale.gov.uk/v2/sites/default/files/Behaviour.pdf
- Information sheet and tips on how to manage meltdowns
 https://www.calderdale.gov.uk/v2/sites/default/files/Meltdowns.pdf
- Information on challenging behaviour, positive behaviour support and person-centred support
 Homepage for the Challenging Behaviour Foundation
 https://www.challengingbehaviour.org.uk/

Sensory needs

- Information about sensory integration:
 https://www.sensoryintegrationeducation.com/pages/what-is-si
- Information about sensory differences and how to help
 https://www.calderdale.gov.uk/v2/sites/default/files/Sensory-differences.pdf
- NHS GGC offer a range of online resources to help families support children's independent living skills, this includes information about sensory processing differences and strategies to try. Parents may like to access this information, available

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

Change, uncertainty, and transitions

- Autism information about dealing with change
 https://www.autism.org.uk/advice-and-guidance/topics/behaviour/dealing-with-change/all-audiences
- Tips for coping with change
 https://www.calderdale.gov.uk/v2/sites/default/files/Preparina-for-Change.pdf

Repetitive behaviours and routines

- Information about obsessions & repetitive behaviour
 https://www.autism.org.uk/advice-and-guidance/topics/behaviour/obsessions
- Information sheet and tips on Obsessions, repetitive behaviour and routines
 https://www.calderdale.gov.uk/v2/sites/default/files/Obsessions.pdf

Mentoring & Skills development

- Canongate Youth have a variety of groups which one can access without a referral, they
 provide support for children and young people who face barriers and challenges
 https://canongateyouth.org.uk/startup-about/
- Move on match volunteer mentors to vulnerable young people aged 14-25 to support them to achieve goals and reach their full potential https://moveon.org.uk/mentoring-service/
- Skills Development Scotland (SDS) support pupils, parents and teachers with a comprehensive range of career information advice and guidance (CIAG) services.
 https://www.skillsdevelopmentscotland.co.uk/

Parenting Support

- Russ Harris is a Psychiatrist who has the personal experience of a child receiving a diagnosis of
 autism. He has written about his own experience and the skills that helped him to cope with it in
 his book "The Reality Slap" which shares ideas from Acceptance and Commitment Therapy
 applied to the challenges of parenting an autistic child.
- Ross Greene's book "The explosive child" offers a helpful guide to collaborative problem solving as a family to understand what might lead to meltdowns, which are common for neurodivergent children, and how to use that insight to reduce the frequency and intensity of these.
- Vocal https://www.vocal.org.uk/ are a carer's organisation based in Edinburgh who can offer emotional and practical support to parents whose caring responsibilities are above and beyond those of typically developing children this is likely to be true if you are parenting a neurodivergent child.
- **Kindred** -www.kindred-scotland.org/ provides support to parents of children with complex needs and this includes individual support, groups and events.
- Enable www.enable.org.uk supports people who have a learning disability, including their friends, family and anyone else who cares for them.
- TASSK was originally run by the OT Group Service as an online group for parents of children on
 the ND waitlist. Following feedback about parents struggling to attend a live group, we
 decided to record the sessions and make the videos and resources available online for families
 to access at their convenience.

There are 3 sessions that focus on supporting parents to learn strategies to support their children with everyday activities and the videos and resources can be found on the CAMHS website "Online Resources" page under the "Parenting" heading: Online Resources – Child and Adolescent Mental Health Services (nhslothian.scot)

Helplines

• NHS24: call 111 for urgent care advice and support

ParentLine Scotland: 08000 28 22 33

Family Lives UK: 0808 800 2222Young Minds UK: 0808 802 5544