



Post-Diagnostic Support Pack for Primary School Aged Children: Autism

Support and signposting for young people and their families following a diagnosis of Autism.







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Introduction

Introduction to the Post Diagnostic Support Pack

Welcome to the **Autism post-diagnostic support pack** for young people and their families! Getting a diagnosis of Autism can be a significant experience. For some people, this could be welcomed or a relief to have this diagnosis confirmed; for other families it might take a while to get used to this news.



It can be difficult to know where to go for support after a diagnosis
- to start you and your child on this journey, we have put together a
pack **signposting resources and support available in Leeds**. This pack aims to help you learn
more about your child's strengths and needs and see examples of how others understand
and advocate their own needs.

Many people come to view Autism as part of their **identity** - we hope this pack helps you on your journey of discovering what Autism might mean to you and your child and help you understand the part it plays in your lives.

A good place to start is the **Neurodiversity Information Hub** which provides information for all children, young people and families in Leeds around understanding neurodiversity and what further support is available in the community. This website has been developed in partnership with the Neurodevelopmental assessment team who would have undertaken your assessment.

Please access the Neurodiversity Information Hub through this link:

https://www.mindmate.org.uk/nd/

or by scanning the following QR code on your phone.



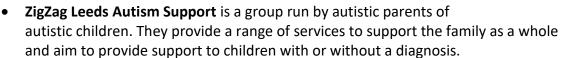


Support

Key websites for young people with Autism and their families

Where to start

- Leeds Local Offer provides information for children and young people with special educational needs and disabilities and their parents or carers. It shows families what they can expect from a range of local agencies including education, health and social care.
 - https://leedslocaloffer.org.uk/#!/directory/suggestions



https://www.zigzagautismservices.co.uk/



Emotional and mental health support

As with neurotypical peers, some autistic young people may experience difficulties with their emotional wellbeing and mental health. There are some specific challenges that autistic young people might face - they could be more likely to experience anxiety and additional stressors with demands of everyday life and aspects of school. Everyone manages these things in different ways and many young people manage this through peer support



from friends and family. If you need to access more support, it may be helpful to start by speaking to school or college. Support and help can come in many forms – being Autistic, you might need help and advice about how to manage day to day demands or there may be changes that school or your family can make in how they support you to help life run more smoothly. You may benefit from a referral to a specific service for support or therapy.

- The **Every Mind Matters** website has some self-care advice videos as well as other information aimed at young people, parents and carers to support them to maintain their mental health.
 - https://www.nhs.uk/every-mind-matters/
- You can also access information regarding emotional wellbeing and mental health on the MindMate website:
 - o https://www.mindmate.org.uk/

Mental Health support will often need to be **adapted to suit the specific needs** and challenges that present in Autistic young people. Below details a list of resources to support better understanding of neurodivergent mental health needs:

- Autism and Meltdowns The Nest Approach
 - https://drive.google.com/file/d/1qWe5TjoLmTwCOAJSpwDeP7xUaXaKxTS9/vi ew
- Understanding Autism and Trauma

- o https://www.barrierstoeducation.co.uk/autism-and-trauma
- Understanding Autism and Anxiety
 - https://www.barrierstoeducation.co.uk/anxiety

Urgent Support

These are services to access if you are in crisis and they are offered to both autistic and non-autistic people. The services and information listed below can offer support with anxiety, depression and other mental health symptoms that are common in autistic young people.



- For immediate advice and support, contact the **CAMHS helpline** on 0800 953 0505 between 8am and 8pm every day.
- West Yorkshire Night OWLS (run by the Leeds Survivor Led Crisis Service) is a
 confidential support line for children, young people, their parents and carers who
 live in Bradford, Leeds, Calderdale, Kirklees and Wakefield. They can be contacted if
 a young person is in crisis and there are concerns regarding their emotional
 wellbeing.
 - O 0800 1488 244
 - O Text: 07984 392700
 - https://www.lslcs.org.uk/services/night-owls-helpline/
- Samaritans offer immediate mental health support and information online for everyone. Their helpline is free, available 24/7 and available to all ages. Call 116 123 or email jo@samaritans.org.
 - o https://www.samaritans.org/
- The **Stem4** website contains information for young people, parents and carers about supporting young peoples' mental health.
 - https://stem4.org.uk/

Local support for families

Parents as well as siblings might need additional support to understand Autism and how to adjust their approach to support their family member who is autistic. Speaking to school is a good place to start as they can facilitate support to you as a family and direct you towards local services. Here are some services below that might be useful for families of neurodivergent children and young people (in addition to the groups listed earlier in this pack).



- STARS is a team that works in education with autistic children and young people.
 They offer some support to families with training sessions and resources on their websites. They aim to build on families' understanding of autism, offer practical strategies that can be implemented at home and facilitate discussion between families to share ideas and empower each other.
 - o http://www.starsteam.org.uk/support-for-parents-of-children-with-autism
- Autism & ADHD Parent Support UK have a Facebook group for parents/carers and autistic children as well as pre-diagnosis workshops for tips from fellow parents whilst you wait for your child's neurodevelopmental assessment.
 - https://www.facebook.com/groups/autismadhdparentsupportuk/
- Carers Leeds offer advice and support online, via telephone and face-to-face for friends and family members who care for someone with any illness, mental health condition or disability, including neurodevelopmental conditions.
 - o https://www.carersleeds.org.uk/
- Leeds Parent Carer Forum (PCF) is an independent parent carer forum run by local parents. Parents in this group aim to improve the quality of life of SEND families in Leeds and encourage better outcomes through engagement and participation. They in partnership with the Local Authority, Education, Health and Social Care.
 - 07423436813
 - info@leedsparentcarerforum.co.uk
 - https://www.leedsparentcarerforum.co.uk/
- Lotus Links Peer Support offers sessions to families who have children with specialised educational needs and/or disability who experience anxiety-led distress behaviours. This fortnightly group provides a space for parents/carers to connect, share their worries and receive support.
 - o https://www.facebook.com/lotuslinkspeersupportleeds
- The Cygnet Programme is offered in West Leeds (Armley, Holbeck, Kirkstall, Headingley, Horsforth, Meanwood, Farsley). It is a parenting support programme for parents and carers of children and young people aged 5-18 with an autistic spectrum condition. To access this service, your child must already have a diagnosis of autism.
 - https://barnardos-parenting.org.uk/cygnet-programme/
- The YoungSibs website provides information and advice for siblings of children with additional needs, through child-friendly articles and the 'ask a sibling advisor' feature.
 - o https://www.sibs.org.uk/youngsibs/
- **Contact** is a charity for families with disabled children. They offer information, workshops, and emotional support for family members.
 - https://contact.org.uk/

- Airedale and Wharfedale Autism Resource offer peer support, supporting zoom sessions, events for parents/carers as well as activities for children and young people.
 - o https://aware-uk.org/
- Home Start offers group and individual support to families with children who are
 going through challenging times. Volunteers who work for Home Start offer support
 including helping people access local services in their area and working with families
 to support parents aid the development of their child's emotional and social
 development.
 - o https://www.home-start.org.uk/
- **SCOPE** has a range of family services including emotional and peer support.
 - o https://www.scope.org.uk/family-services/
- **Little Hiccups** is a Leeds based support group set up by parents who have children under 16 with additional needs and disabilities. They offer activities for children and emotional support and counselling to parents free of charge.
 - o https://www.littlehiccups.co.uk/
- SNAPS Yorkshire offers activities, socialisation and play in Leeds for children with additional needs and their siblings, as well as one-to-one and group parental support.
 - https://www.snapsyorkshire.org/
- The **National Autistic Societ**y website has helplines for various topics including parent-to-parent emotional support, school exclusions, and support for the transition to adulthood. These can be found under 'phone and email services'.
 - o https://www.autism.org.uk/what-we-do/help-and-support

Parenting

This section aims to help parents of autistic young people better understand and support their child with their recent diagnosis.

Books:

- Caring for a Child with Autism: A Practical Guide for Parents
 - Martine Ives and Nell Munro (2001)
 - This guide answers the questions commonly asked by parents and carers following a diagnosis of autism and discusses the challenges that can arise in home life, education and socialising.
- Playing, Laughing and Learning with Children on the Autism Spectrum: A Practical Resource of Play Ideas for Parents and Carers
 - o Julia Moor (2008)



 This resource demonstrates how to break down play activities into manageable stages, and looks at ways to gain a child's attention and motivation and to build on small achievements.

• A Practical Guide to Mental Health Problems in Children with Autistic Spectrum Disorders: It's not just their autism!

- Alvina Ali, Michelle O'Reilly and Khalid Karim (2013)
- This book offers practical guidance to help parents recognise and handle comorbid conditions and dispels the myth that they are just a part of autism. The authors cover a wide range of common mental health problems experienced by autistic children, including Obsessive Compulsive Disorder (OCD), anxiety, eating disorders, psychosis, stress, tics and depression, and illustrate these issues with case studies. They also provide vital advice in an accessible format and suggest strategies to ease the difficulties which arise from these comorbid conditions.

Autism, Identity and Me: A professional and Parent Guide to Support a Positive Understanding of Autistic Identity

- o by Rebecca Duffus
- This informative and engaging guidebook provides parents, school staff and therapists with the tools needed to support children and young people as they develop a positive understanding of their autistic identity. Having a positive understanding of your autistic identity is an indicator of higher selfesteem and wellbeing as an adult. This guidebook supports the development of this and will be valuable for all adults working with autistic children and young people aged 10+.

School

Autistic young people will have **varying levels** of additional academic, social and environmental needs in school. Some young people manage mainstream education with minimal additional support whilst others may need a lot of support in school or even a specialist provision. Schools are responsible for meeting additional needs of all children **regardless of any specific diagnosis**. Some needs can be met universally within the classroom, and some require additional **targeted interventions** or some more **individualised support**. Any concerns regarding school should be raised with your teacher or the Special Educational Needs Co-ordinator (SENCO).



Who can support me?

- **SENCO's** are teachers who have additional responsibility as leaders of SEND (Special Educational Needs and/or Disabilities) in their school. They work with other staff in school, and external professionals as required, to ensure that individual children's needs are met through a graduated approach. This means that additional support is carefully planned, put in place and then regularly reviewed, to ensure that all children can continue to make progress. Please get in contact with your child's SENCO if you have any concerns.
- Geeks Room Education Centre in Leeds offers both online and onsite classes using
 educational based games focusing on core curriculum subjects in an autism-friendly
 environment, for individuals aged 8 years onward. This involves interactive gaming,
 one to ones, weekend clubs, school sessions and home education sessions.
 - o https://www.geeksroom.org.uk/services
- STARS are a team of autism specialists who offer advice and training to mainstream settings. They work in early years settings, primary schools, secondary schools and post 16 provisions.
 - http://www.starsteam.org.uk/
- STARS bite-sized eLearning provides bite-sized practical resources designed for
 parents of school-aged children and young people, covering a range of topics that
 parents have indicated are important to them. Each video will have an associated
 resource pack. Not every child will need this support, but it is available to access if
 necessary.
 - https://www.leedsforlearning.co.uk/Page/28038
- Leeds SENDIASS (Special Educational Needs and Disabilities Information Advice and Support Services) support children and young people with special educational needs and disabilities (SEND) and provide support to their parents and carers. They provide a free, impartial and confidential service through their website and online resources. Self-referrals can be made on their website.



- o https://sendiass.leeds.gov.uk/
- The **Autism Education Trust** has information and advice on working with your child's school, exclusions, and elective home education.
 - https://www.autismeducationtrust.org.uk/parents
- For further information regarding school, please visit the Neurodiversity Hub:
 - o https://www.mindmate.org.uk/nd/education/

Daily Life

Sensory Processing

It can be really common for neurodivergent people to have differences in sensory processing. This can cause great **enjoyment** in some cases but can also be **challenging** at times. It may be harder for neurodivergent people to keep sensory systems in balance, and it may have an impact on how they go about **daily life**.



- The Humber Sensory Processing Hub provides detailed resources and information to educate families about sensory processing in children across different environments.
 - o https://sensoryprocessinghub.humber.nhs.uk/what-is-sensory-processing/
 - o https://sensoryprocessinghub.humber.nhs.uk/resources/
- There is a range of support on the Neurodiversity Hub around strategies and advice on sensory processing that you can access. This includes information about further support from other services:
 - https://www.mindmate.org.uk/nd/what-is-nd/sensory-processing/

Sleep

Getting to sleep and staying asleep can be difficult for neurodivergent children and young people. There are a range of resources and websites that can provide further support and information.

- The **Scope UK** website provides information to help young individuals with their sleep. As a first step, we recommend reading the advice on the link below:
 - o https://www.scope.org.uk/advice-and-support/help-disabled-child-sleep/
- If you require further support, you can contact their Sleep Right Support Services to
 access online or face-to-face sessions in Leeds where you will be linked with a Scope
 practitioner trained to help with sleep.
 - o https://www.scope.org.uk/family-services/sleep-right/
- The Sleep Charity offers a useful sleep diary for younger children.
 https://thesleepcharity.org.uk/wp-content/uploads/The-Sleep-Charity-Childrens-Sleep-Diary.pdf
- <u>Sleepopolis</u> provides information regarding sleep (and sleep tips) for autistic individuals.
 - https://sleepopolis.com/education/sleep-and-autism/

• For further information regarding sleep, please visit the Neurodiversity Hub: https://www.mindmate.org.uk/nd/living-nd/support-with-sleep/

Eating and food

A healthy, balanced diet is important for all young people but there are some specific issues related to diet and food for Autistic children and young people. Neurodivergent young people are also more likely to have issues relating to diet and eating relating to their sensory differences.

- The National Autistic Society has produced this guide on understanding your autistic child's challenges with eating, and how to support them with maintaining a healthy diet.
 - https://www.autism.org.uk/advice-and-quidance/topics/behaviour/eating/all-audiences
- ARFID Awareness UK has helpful information about ARFID and other eating disorders, and their relationship with neurodiversity.
 - o https://www.arfidawarenessuk.org/the-link-with-autism-1
- Sammy's new food week by Charlotte Olsen
 - This book follows the story of Sammy, a child who is trying some new foods.
 It may be helpful as a visual guide for children and young people to consider the benefits of trying new food.

For further information regarding this, please visit the Neurodiversity Hub:

https://www.mindmate.org.uk/nd/living-nd/eating-nd/

There are helpful resources on the **Mindmate website** including general dietary advice for Autistic children and young people.

Neurodivergent friendly activities and days out

Going out for the day or to an activity can be a challenge for neurodivergent children and young people. The Neurodiversity Hub provides information about local activities and days out which may be more accessible to neurodivergent children and young people.



- https://www.mindmate.org.uk/nd/living-nd/activities-nd/
- Leeds local offer provides signposting to SEND friendly activities and days out.
 - o https://leedslocaloffer.org.uk/#!/search/list?query=YPPlacestovisit&exact=1

Some Autistic young people may enjoy engaging in activities with those who have similar interests to them (sometimes referred to as special interests). Engaging in activities of similar interest can support a sense of belonging and community.

- For example: Spectrum Gaming is an online community for autistic young people
 with an interest in video games. This community was created (by Autistic people) to
 help autistic young people build friendships and increase self-acceptance through
 playing online games together and taking part in regular meetups.
 - o https://www.spectrumgaming.net/

Shopping

Neurodivergent children and young people may struggle with sensory overload when going shopping. Some shops now offer quieter shopping sessions where music and announcements are turned down. Visiting at these times may help you to feel less overwhelmed when going shopping.

- AccessAble is a website which provides key and detailed information about different
 places, such as: health centres, shopping centres, tourist attractions, hotels,
 accessible toilets. Each place has an 'Access Guide' with information about how to
 get there, parking, what the building is for, and many pictures both inside and
 outside the building. This can be really useful if you'd like to know how accessible the
 place is for you, to help support you to find your way and reduce the anxiety of going
 to new places.
 - Visit the website here: https://www.accessable.co.uk/
 - Here is an example guide for one of the CAMHS health centres, Parkside Community Health Centre: https://www.accessable.co.uk/community-health-partnerships/access-guides/parkside-community-health-centre
- Leeds Trinity shopping centre has a quiet hour every Tuesday from 9am until 11am.
 In this time the music is turned down, lighting reduced, reduced amount of tannoy announcements, and limiting strong smells. On the first floor there is the Guest Services team which provide free hidden disability (sunflower) lanyards which can be used whilst visiting the store. Here they also have free access to 'sensory backpacks', which include the hidden disability lanyard, along with sensory toys and ear defenders.
 - You can contact the Guest Services team about anything either by email (<u>info@trinityleeds.com</u>) or phone (0113 394 2415).
 - You can email them to ask for specific requests, such as photos of the shops/restaurants to see before you go.
 - Visit the website here: https://trinityleeds.com/accessibility-mobility-services
- Morrisons offer a quieter hour every Saturday 9am until 10am. During this time, they turn the radio and music off, dim the lights, avoid tannoy announcements where possible, reduce movement of trolleys/baskets, and turn other electrical

noises down such as checkout beeps. There is a sign up to show other customers it is a quiet hour.

- Visit the website here for further information:
 https://my.morrisons.com/blog/community/quieter-hour/
- Through the Maze is a service which provides information and signposting for those
 who require information in an accessible format. It was originally made for those
 with a learning disability, but it can be useful for anyone who needs an Easy Read
 format to learn about events or things there are to do in Leeds. The website has
 visuals, text to audio functions, and larger clearer text/information.
 - Visit the website here: https://www.through-the-maze.org.uk/
- For information regarding this, please visit the Neurodiversity Hub:
 - https://www.mindmate.org.uk/nd/living-nd/shopping-nd/

Travel

Travelling can be overwhelming for neurodivergent people, particularly those who have difficulties communicating, struggle with change, or experience sensory overload. Depending on the method of transport, there are a range of resources and information that can help.

Air travel

Most airports offer advice and support ahead of your journey, as well as assistance when you arrive at the terminal. Check with the airport before you travel by looking at their website, where there is often lots of helpful information.

This storybook by Charlotte Olson might help your child prepare for flying for the first time.

o https://www.suziebooks.co.uk/aeroplane.htm

• Rail travel

You may be eligible for a Disabled Persons Railcard. For more information about whether you qualify and how to apply visit:

o https://www.disabledpersons-railcard.co.uk/are-you-eligible/

Bus travel

First Bus and Arriva have both made some communication cards that may be helpful to print off and use when interacting with the bus driver and other passengers:

- o <u>https://www.firstbus.co.uk/uploads/node_images/Extra-Help-To-Travel-journey-assistance-cards-june-20-v2.pdf</u>
- https://cdn1originals.webdamdb.com/13953 123098735?cache=1623151186&responsecontent-

<u>disposition=inline;filename=Journey%2520Assistance%2520Cards%2520A4%2520-%2520UPDATE2021.pdf&response-content-type=application/pdf&Po</u>

What does Autism mean to me?

Understanding neurodiversity

The resources listed below are intended to help you and your child to understand their Autism, through information, advice, and personal experiences and testimonies.



- The CBeebies website have videos to help explain autism to young children.
 - o https://www.bbc.co.uk/cbeebies/joinin/pablo-talking-to-your-child-about-autism
- Explaining Autism Spectrum Disorder Book
 - o Clare Lawrence (2010)
 - Clare Lawrence provides a clear and concise introduction to explaining Autism.
- For information regarding understanding Autism, please visit the Neurodiversity Hub:
 - https://www.mindmate.org.uk/nd/what-is-nd/

Understanding Autism; resources and books

Getting a diagnosis can be a really big thing and it may take time to work out what autism means to you and that's okay. We're all unique individuals so everyone will have different feelings about their diagnosis. It can be helpful to understand how others relate to being autistic. There are a lot of neurodivergent people sharing their stories on social media, websites and books. Here are a few that might help you get started.

- Debunking Autism Stereotypes & Autism Myths
 - o https://www.themix.org.uk/your-body/learning-disabilities-syndromes/debunking-myths-about-autism-45645.html
- Living with "High Functioning" Autism (Connor's Experience) YouTube
 - o https://www.youtube.com/watch?v=WVnSIExQ5WY

Books

Some of the books we recommend include:

- The abilities in me: Autism
 - o Gemma Keir (2019)
 - This picture book explores the day in the life of a young girl and boy with autism through bright, colourful illustrations and text. Perfect for teachers, parents and children alike, this book will bring awareness of the condition and teach children how to be supportive and be kind.

• All Cats Are on the Autistic Spectrum

- Kathy Hoopman (2020)
- This book takes a playful look at the world of autism, and these fun feline friends will strike a chord with all those who are familiar with typical autistic traits, bringing to life common characteristics such as sensory sensitivities, social issues and communication difficulties.

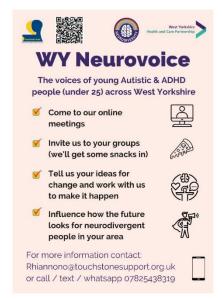
Ways To Be Me

- o By Libby Scott and Rebecca Westcott (Appropriate for age 9+)
- This fictionalised portrayal of a young autistic girl is written by Rebecca
 Westcott, in close collaboration with 12-year-old autistic author Libby Scott,
 making it a truly original and inspirational book that will give readers of all
 ages a deeper understanding of what it's like to be autistic.

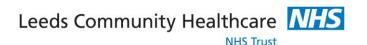
Your voice

Along your Autism journey, you may find you have learnt things about yourself and might continue to do so. You may become interested in advocating for yourself and others using your own experiences and thoughts. Below you can find some groups that support young people in promoting their voice and influence.

- Leeds Youth Council voice and influence for 10- to 18-year-olds
 - As a young person growing up in Leeds it's important that you have the right to say what happens in the city and to be able to let people know when you think things could be improved. From your streets to your schools, parks, youth activities, health and support services and much more - if you think you can help make things better then Leeds Youth Council can support you and give you platforms to do this.
 - https://www.leeds.gov.uk/children-and-families/leeds-youth-voice/youthcouncil
- West Yorkshire Neurovoice work with ADHD and Autistic young people to encourage advocacy and sharing of lived experience. Being collaborative and inclusive in their work, they use their collective expertise and your lived experience to further inform ADHD / Autism services going forward. They have a particular focus on addressing any social inequalities that neurodivergent individuals may face.
 - https://touchstonesupport.org.uk/clinicalservices/west-yorkshire-autism-and-adhd-deep-divecoproduction/



- The **Advonet Group** and **Leeds Autism AIM** provide free accessible self-advocacy resources and tools.
 - https://advonet.org.uk/resources/self-advocacy-resources/ Advonet Group link to resources such as; Self-Advocacy pack, Phone Call Planner, Advocacy factsheets (regarding; council housing, debt, universal credit etc.),
 Speak4Yourself cards,
 - https://leedsautismaim.org.uk/resources/self-advocacy-tools/ Leeds Autism
 AIM link to resources such as: Communication Profiles, Social Profiles, Weekly Planner, Autism Health Passport, and so on.



- National Children's Bureau help young people by working in partnership with organisations and support to improve services and change policies, putting children at the heart of decision making. See their Involving Children and Young People page to find out more: - https://www.ncb.org.uk/what-we-do/involving-children-young-people
 - See their 'Our Turn To Talk' Podcast where young people are advocating for and sharing their differences and needs: https://www.ncb.org.uk/what-we-do/involving-children-young-people/listen-our-turn-talk-podcast
- The Hidden Disabilities Sunflower lanyard is a visual indicator that you can wear to show others that you have additional needs, or a condition that may not be obvious. It signals to other people that you may need a little help, understanding or more time in shops, at work, on transport or in public spaces. You do not need a diagnosis to wear a lanyard.
 - Find out more information and how to get a lanyard here: https://hdsunflower.com/uk/

This is a general guide to Autism resources – please note that these resources contain information that is created and maintained by other public and private organisations.

Inclusion within this pack should not be taken as a recommendation or endorsement of their information, products or services, and be aware that information quickly becomes outdated.

We are always looking to improve these post-diagnostic support packs; therefore, **sharing any feedback is highly welcomed**. Please email **nd.cypmhs@nhs.net** if you wish to do so.

Leeds Community CYPMHS, Neurodevelopmental Team; Dr Jenny Perry (Clinical Psychologist), Amber Wilkins (Assistant Psychologist), Narjes Froozani (Psychology Intern), Abbie Lowe-Smith (CYPMHS Assistant), Katharine Rice (CYPMHS Assistant).

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