

Before and After a Diagnosis Information Booklet



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About Autism

Autism is a lifelong developmental disability that affects the way a person communicates with other people and relates to the world around them. It is a completely different computer system with different programmes inbuilt. It is a different way of thinking and is often incredibly logical and rigid. (You might hear this referred to as black/white thinking).

It is a spectrum condition which means it affects people in different ways. There is no such thing as 'normal' therefore those who don't have Autism are often referred to as 'neurotypical' – this relates to the fact that Autism doesn't mean you are not normal it just means you act differently.

Our world is a neurotypical social world, not an autistic one. Neurotypicals often act irrationally and illogically. We often fail to have common sense and often let our emotions rule our decision-making process.

All Autistic individuals find it harder to manage the world the way it is. They approach the world differently from other people and have difficulty with the following:-

- Social communication and interaction.
- Restricted, repetitive patterns of behaviour, interests or activities. (including sensory behaviours)

Child Diagnosis

It is important to get advice on where to begin. Many people fall at very basic hurdles i.e. being told by their GP that the child is too young for a diagnosis.

There are a few tips to ensure you get the best possible start along the pathway to a diagnosis.

1st Tip – Consult your child or young person’s educational placement i.e. Nursey, primary, infant, junior, middle, high school etc – the reason is part of the diagnosis hinges on your child or young person presenting with similar traits in two or more differing environments.

It is important that you consult with the SENCO as it might be that although your child or young person doesn’t have a meltdown every day, there might be smaller signs of processing delay or inattentiveness that are going unnoticed.

2nd tip – Contact your GP and explain your concerns.

Ask to be referred to community pediatricians

3rd Tip – Keep a diary; keep a record of behaviors, patterns, traits

Trying to get a referral for a diagnosis can be difficult and once you have been referred the waiting times can be long. During this period, yours or your child's difficulties do not go away. This is often the most difficult time when you are waiting for answers and not sure where to turn.

Seek support from other parents

The best type of support comes through those who have been through the process or those who have similar difficulties. You may want to access support groups or find a social media platform where you can talk to others share your experiences, listen and get advice from those in a similar position.

Research and learn

Use this time to learn and educate yourself on Autism, what it means and the typical difficulties that those on the spectrum face on a daily basis. there are many websites and books available that help you do this. Just make sure that the resources you are using are credible and from a reliable source. We recommend either the National Autistic Society or the NHS website.

Try some Autism Strategies

Just because you haven't received a diagnosis of Autism doesn't mean you can't try some of the approach used for those with Autism. Look into sensory strategies and behaviour strategies as well as mindfulness exercises to help manage Mental health Issues.

Ask your Educational/Work setting for support

Ask your employer or headteachers for support. let them know what you struggle with, how you can help and if they can put this into place for you this is known as a Reasonable Adjustment.

Ask your Local Authority for support

Your Local Authority should be able to provide support, normally in the form of a Family Support Worker. Check your Local Authorities Local Offer to see what they offer and how to access this.



Adult Diagnosis 18+

Many people are not diagnosed as Autistic in their childhood years, this can be for a number of reasons but a diagnosis during Adulthood can create a sense of relief and an ability to accept yourself and explain the reasons for your difficulties in your life so far.

There are many reasons Autistic Adults seek a diagnosis:

- Acceptance
- Explanation and understanding
- a way to seek extra support at work or University
- to be able to fully understand themselves
- and many others

Within Norfolk, the Adult diagnostic service is known as Autism Service Norfolk.

Autism Service Norfolk is an NHS-employed service funded by Norfolk County Council. It provides a gateway for the diagnosis of adults 18+ with suspected autism without a learning disability. It is also able to provide some pre and post-diagnostic support around the diagnosis. Autism Service Norfolk does not provide any mental health or social care support or management. This service provides a diagnostic pathway for adults over the age of 18 without a learning disability.

Referrals can be from the individual or by a health care professional. However, your GP must be made aware of the referral for it to be accepted.

Contact details

Norwich Community Hospital, Bowthorpe Road, Norwich NR2 3TU

T: 01603 272257

E: asnreferralsandenquiries@nchc.nhs.uk

Managing The Diagnosis

Feelings and reactions

The emotional effect of a diagnosis can be overwhelming and even heart-breaking, at first. In some cases, people have compared the reaction and feelings similar to that of the grief process. It can feel like a lot to deal with and a lot to take in. It is a whole completely a new set of rules, systems and things to understand which are alien to us in the beginning.

Often when you have a new diagnosis you find yourself isolated and often people report that family members become distant and uninterested still believing your child or young person to be in control of their behaviours, or worse feel your child has developed 'learnt behaviour'.

Feelings and reactions will differ with mums and dads reacting the most differently. You will experience emotions such as worry, sadness, grief, guilt or anger – or quite possibly a combination of the above. – This is natural and is a result of you being a neurotypical person being faced with an 'autistic' world.

A diagnosis often however can lead to more specialist support including medication, school support and extra funding. A diagnosis can also reaffirm previous feelings and thoughts. It can confirm that your child does have a neurological disorder and isn't simply choosing to behave the way they are. It is often good to have a 'concrete' name for it, something you can use to explain things to other parents or family members, and something that people can read up on and gain understanding about.

Expectations and Beliefs

Often people who are going through the diagnostic process or who are pre-diagnosed turn to the internet for advice and guidance. Unfortunately, the majority of the results on Google searches are heavily Americanised and therefore do not reflect how we manage diagnoses in the UK. You may have even started comparing your child or young person to those on message boards and online forums seeking those all-important confirmations that there is something to be concerned about.

Coping with others

Dealing with people, including professionals, who don't yet know your child or your family can be a challenge. It is really difficult for some autistic individuals to meet new people and be able to converse verbally with them without further build up.

Often this produces difficulties when people are trying to assess your situation or make judgments of the wishes and feelings of Autistic individuals. It is important that you try and keep adult involvement in your family consistent (although not possible always due to sickness and typically social care involvement).

Professionals will need to build up a rapport and have a working understanding of Autism or you might be left feeling like your parenting is being questioned or being faced with questions around attachment disorders. Always keep a record of anything said by a professional, ask them to email you a record of any meeting (even if informal). Get a list of all professionals involved and outline which ones relate to health, social care and education.

Request the same GP handle the care of the Autistic individual – although this does not work for emergencies for the day-to-day care it is vital you do not have to repeat your history to every GP in the practice particularly, if you have to bring the Autistic individual to see the GP. The appointment needs to be quick and to the point to avoid meltdowns.

You are on a journey of discovery. Your tour guide is the autistic person

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Some important misconceptions about Autism Explained

Autistic people cannot make eye contact

Some autistic people will indeed struggle to use eye contact as they find social interaction more generally quite difficult – on the flip side lots of autistic people overuse eye contact

Autistic people prefer to be alone

Misunderstanding social expectations and the social world can mean that an individual withdraws in order to reduce negative experiences and discomfort, not necessarily because they do not want to interact with others (some isolate themselves due to sensory processing issues)

Autistic people do not show affection

Affection is very often expressed by autistic people, this just might not be as neurotypicals would expect.

Autistic individuals have often been said to have no empathy. In reality, however, people with autism are often highly concerned with the feelings of the people around them, sometimes to a nearly paralysing degree. But they struggle to make sense of the social signals – the subtle shifts in facial expression, body language, and tone of voice – which “neurotypicals” rely on to broadcast their emotional states to one another.



Some important misconceptions about Autism Explained

Autism is caused by bad parenting

Autism is a neurological disorder it is a disability related to the way the brain works, although it should be stressed that some inconsistent parenting strategies can affect the ability an autistic individual has to cope in the neurotypical social world

Autism is caused by the MMR vaccination

There is no proof of this, they are exploring many different theories on the exact cause of Autism. There is also no concrete proof that Autism is genetic although it has been shown multiple times to be genetic throughout families.

Autism used to be rare but now it is more common

There is more awareness of how the brain works and subsequently more awareness of the neurological difficulties and differences across people, this has caused a higher number of people to be diagnosed. Previously, all you needed to do was look at your eccentric uncle's scenario some of these individuals would likely be diagnosed Autistic in today's world. There is also clearer guidance on how to diagnose and it has only been since the 1980s that we have been able to diagnose Autism.

Seeking Support

Education

- Speak to your child's school Special Educational Needs Coordinator (SENCO).
- Review the SEND (special educational need and/or disability) Local Offer information.
- Look at the advice pack developed for schools and professionals.
- The Education Triage Scheme in Norfolk enables your child's school SENCO to seek telephone advice directly from a psychologist if there is concern that your child's skills or behaviours may be suggestive of a neurodevelopmental difference such as autism or ADHD.

Please speak to the school SENCO if you have concerns.

Mental Health Support

- Just One Norfolk mental health support. All referrals for mild to moderate mental health support for 0-25-year-olds are processed by Just One Number. Self-referral is available. The team will then allocate to the most appropriate service and update you.
- Discovery College offers free educational online courses and webinars on mental health topics for 16 - 25 year olds.
- This May Help - advice for supporting your child's mental health.
- Childline - call 0800 1111.
- Papyrus - prevention of young suicide - call 0800 068 4141 or text 07860 039967.
- Samaritans - call 116 123 or email jo@samaritans.org.

Family Support

- [Norfolk SENDIASS](#) offer free impartial advice about SEND
- [Positive Behaviour Support \(PBS\)](#) online course offers some practical strategies to help you positively support your child.
- [Family Voice Norfolk](#) parent carer forum.
- [Norfolk and Suffolk SEND association \(Nansa\)](#) provides support and activities for children, young people, adults and families.
- [Recovery College](#) provides free online training about autism for adults.
- [ASD Helping Hands](#) provides workshops, activity days and residential breaks for children, young people and their families
- [Autism Anglia Norfolk Support Groups](#) provides links to support and activity groups for children and young people
- [Carers Matter Norfolk](#) specialises in supporting young carers and their families.
- [Autism Central](#) provides resources, online drop-ins and support for families.
- [ADHD Foundation](#) resources for families
- [PDA Society](#) pathological demand avoidance resources for families

The Benefit System

Here are some of the benefits you or your child might be entitled to claim. Some of these are non-means tested i.e. they are available regardless of income or employment status.

- Disability Living Allowance for anyone below the age of 16
- Personal Independent Payment (DLA for anyone above the age 16)

Disability Living Allowance

DLA has the following rates:

Care Component	Weekly Rate
Low	£26.90
Middle	£68.10
High	£101.75

Mobility Component	Weekly Rate
Lower	£26.90
Higher	£71.00

To make a claim for DLA you will need to call : 0800 121 4600

For more information on DLA please visit :

<https://www.gov.uk/disability-living-allowance-children>



CEREBRA DLA Guide

CEREBRA has developed a guide to completing the DLA form. You can download it by [clicking here](#)

Personal Independence Payment

PIP has the following rates:

Daily Living	Weekly Rate
Lower	£68.10
Higher	£101.75

Mobility	Weekly Rate
Lower	£26.90
Higher	£71.00

To make a claim for PIP you will need to call : 0800 917 2222

For more information on DLA please visit : <https://www.gov.uk/pip>



Disability Rights PIP Guide

Disability Rights has developed a guide to completing the PIP form. You can download it by [clicking here](#).



If you receive DLA or PIP you might be able to claim carer's allowance for looking after you. For this, they must:

- You must be over 16 to claim a carer's allowance.
- You must spend 35 hours + caring for someone
- You must have been in England, Scotland or Wales for at least 2 of the last 3 years
- You normally live in England, Scotland or Wales, or you live abroad as a member of the armed forces
- You're not in full-time education
- You're not studying for 21 hours a week or more
- You earn no more than £139 a week after tax, National Insurance and expenses

For information on carers allowance please visit:

<https://www.gov.uk/carers-allowance>

You might also be able to claim

- Housing Benefit or Council Tax Reductions
- Universal Credit

The Autism Information and Advice Service

Our Autism Advisors can offer bespoke advice and guidance based on your or your family's needs. This could range from Benefit advice and Educational Issues to support and advice around behavioural issues.

To access the service please first read what we can and can't support with then complete our [referral form](#).

Once this has been submitted you can either book a Zoom or phone appointment with us or we will contact you directly.

We can offer Information and Advice on:

- SEN Support and Educational, Health, and Care Plans
- The autism diagnosis pathway for both Adults and Children in Norfolk, Great Yarmouth, and Waveney
- The welfare system and guidance on how to complete and apply for disability benefits, as well as information on appealing decisions
- Challenging behaviors relating to an autism spectrum disorder
- Short breaks applications and Young Carers Groups
- Adult Social Care and Budgets
- Suitable Training, Events, and Social groups

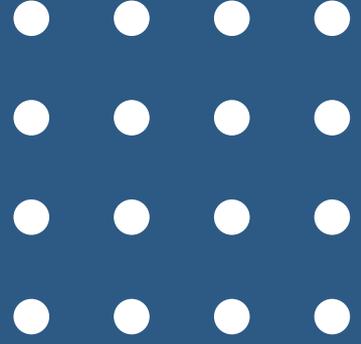
We may also signpost you to other organisations if their support would be more appropriate.

This service cannot provide:

- advice and information to those who have high levels of ill mental health
- diagnosis of any neurological divergent condition or offer an opinion on whether we think someone may or may not be neurodivergent
- a guarantee of a positive outcome at any appeal or tribunal
- offer in-house or hands-on support in any environment
- support an adult (18+) without their direct consent although we can advise Parents/Carers on possible ways to support them

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