HG Mind Works

West Suffolk
NHS Foundation Trust

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AUTISM DIAGNOSTIC
ASSESSMENT SERVICE

# Post Assessment Day

## Information & support for families

*Delivered by HG Mind Works on behalf of West Suffolk NHS Foundation Trust*

**This pack is for you to keep.**

Take your time reading it — there is no rush. Not everything in it will be relevant right now.
It is here as a reference for the days, weeks, and months ahead.
If you have questions about anything in it, please get in touch with us or speak to your child's clinician.

## 1. How are you feeling?

Receiving the outcome of an assessment — whatever it is — can bring up a lot of emotions. Relief. Sadness. Confusion. Numbness. Sometimes all of those at once, or none of them. There is no right or wrong way to feel.

Many parents describe the journey to a diagnosis as long and exhausting. Some feel an enormous sense of relief when a diagnosis finally puts words to something they have known for a long time. Others feel grief — for the future they had imagined, or for challenges they hadn't fully anticipated. Some feel shocked even when they expected the outcome. Some feel all of these things on different days.

Whatever is coming up for you is valid. You do not need to have it together right now.

> ***"A diagnosis doesn't change who your child is. It gives you a better map for understanding them."***

Give yourself time. Be kind to yourself. Lean on the people around you. And if you are struggling, please reach out — to your GP, to one of the organisations in this pack, or to us.

# Part A: If your child has received a diagnosis of autism

Sections 2 to 6 are for you

## 2. What the diagnosis means

A diagnosis of autism means that the clinical team found clear evidence of autism in both key areas — how your child communicates and connects with people, and the patterns and routines that are part of how they experience the world. The evidence met the internationally agreed criteria (DSM-5 or ICD-11) for a diagnosis.

The diagnosis is not a sentence and it is not a ceiling. It is a description of how your child's brain is wired. It explains why certain things are harder for them — and often why certain things come more easily too.

### Autism is a spectrum

The word 'spectrum' means that autism looks different in every person. There is no single 'type' of autistic person. Some autistic people need significant support in daily life; others are largely independent. Most are somewhere in between, and needs can change at different life stages.

Your child's report describes their individual profile — their specific strengths, the areas they find harder, and any recommendations for support. That profile is unique to them.

### Strengths

Although it is natural to focus on the challenges that come with a diagnosis, autistic children often have real strengths too. These are individual, but commonly include:

- A strong sense of honesty and fairness
- Deep focus and commitment when something captures their interest
- Excellent memory and attention to detail
- Creative and original thinking
- Loyalty and sincerity in relationships
- A unique and often refreshing way of seeing the world

Your child's strengths matter just as much as the challenges. Understanding them helps you help your child build confidence and find environments where they can thrive.

### What about causes?

Many parents wonder whether they caused their child's autism, or whether something could have prevented it. The honest answer is that autism is not caused by anything a parent did or didn't do. It is not caused by vaccines. It arises from a complex combination of genetic and developmental factors — many of which we still don't fully understand. It is also worth knowing that autism traits often run in families, so you may recognise some in yourself or other relatives.

## 3. Things that are not true about autism

There is a lot of misinformation about autism online and in wider culture. Here are some of the most common myths — and the reality.

| Common myth | The reality |
|---|---|
| **Autism is caused by bad parenting or vaccines.** | Neither is true. Autism is a neurodevelopmental difference — it has nothing to do with how you have parented your child. The vaccine claim has been thoroughly debunked by decades of research. |
| **Autism is something to be cured or fixed.** | Autism is not an illness. It is a different way the brain develops and works. Support aims to help autistic people thrive — not to erase who they are. |
| **All autistic people are the same.** | Autism is a spectrum. No two autistic people are identical. Your child is an individual — the diagnosis is a starting point for understanding them, not a label that defines them. |
| **Autistic children don't want friendships or connections.** | Most autistic people want meaningful relationships very much. They may connect and communicate differently, but that doesn't mean they don't feel deeply or care about others. |
| **A diagnosis means a difficult life ahead.** | Many autistic people live happy, fulfilling, and successful lives. With the right understanding and support, your child can flourish. |

## 4. Other conditions that sometimes go alongside autism

Autism often occurs alongside other conditions. This doesn't mean something has been missed — it's simply how neurodevelopmental differences tend to cluster. Your child's report will note anything the team identified. Common ones to be aware of include:

| Condition | What it means |
|---|---|
| **ADHD** | Difficulties with attention, concentration, and sometimes hyperactivity or impulsivity. Very common alongside autism. |
| **Anxiety** | Worry or fearfulness that goes beyond typical levels, often triggered by unpredictability, social demands, or sensory overload. |
| **Sensory processing differences** | Being over- or under-sensitive to sounds, light, touch, textures, taste, or smell. Many autistic people experience this strongly. |
| **Sleep difficulties** | Problems falling or staying asleep are very common in autistic children. |
| **Dyspraxia / DCD** | Difficulties with coordination and motor skills — things like handwriting, using cutlery, or physical activities. |
| **OCD** | Intrusive thoughts or compulsive behaviours that go beyond routine-seeking. A separate condition that can be treated effectively. |
| **Learning differences** | Such as dyslexia or dyscalculia — affecting specific areas of learning, not overall intelligence. |

If you have concerns about any of these areas for your child, speak to your GP or your child's SENCO as a first step. Some may benefit from separate assessment or specialist support.

## 5. Talking to your child about their diagnosis

Many parents wonder whether to tell their child, when, and how. The short answer is: most autistic children benefit from knowing. Research and the experience of autistic adults strongly suggests that children who understand their diagnosis tend to have better self-esteem, better mental health, and more self-advocacy as they grow up.

Children often know they are different before the diagnosis — they just don't know why. A diagnosis can be a relief. It gives them language for their own experience and helps them understand that the things they find hard are not their fault.

### How to talk about it

There is no single right way. Some families have an open conversation early; others introduce it gradually over time. What matters most is that the diagnosis is presented positively and honestly.

- Use language your child understands — keep it simple and age-appropriate
- Lead with strengths before challenges
- Explain that their brain works differently — not that something is wrong with them
- Let them ask questions and take their time
- Revisit the conversation as they grow — their understanding will deepen

**Example for younger children (5-8):**

**"Your brain is a bit different from some other people's brains. That means some things are harder for you, like loud places or when plans change. But it also means you notice and remember things other people miss. The doctors have a name for how your brain works — it's called autism."**

**Example for older children (9-11):**

**"The assessment found that you're autistic. That means your brain processes the world differently.**

**It explains why certain things are harder for you, and why you're brilliant at other things.**

**It's not something wrong with you — it's just how you're wired. And now we know, we can get you better support."**

### Telling others

Who you tell is entirely your choice. Many families find it helpful to tell immediate family members, particularly siblings, who may have noticed differences and benefit from understanding. Telling your child's school is usually a good idea — the SENCO can put support in place more effectively with the diagnosis.

You do not have to tell everyone. Your child's diagnosis is private information and you are in control of it.

## 6. Next steps — getting support

You don't need to do everything at once. The most important thing right now is to look after yourself and your family. When you're ready, here is where to start:

| Where to go | What they can help with |
|---|---|
| **WSFT post-diagnosis workshop** | A dedicated session for families following a diagnosis. Covers what the diagnosis means, what support is available, and what to do next. All families we diagnose are referred to this as standard — details will be in your written report. |
| **Your child's school and SENCO** | The Special Educational Needs Coordinator (SENCO) at your child's school is your first port of call for school-based support. Share the report with them. Together you can review what's already in place and think about what else might help. |
| **Education, Health and Care Plan (EHCP)** | If your child has significant needs that the school cannot meet without extra support, you can request an EHCP from your local council. This is a legal document that can provide additional resources up to age 25. Your SENCO or the report can help you make the case. |
| **Your GP** | If you're concerned about your child's mental health, sleep, eating, or physical wellbeing alongside the autism diagnosis, your GP is the right first contact. They can refer you to further support. |
| **Local authority children's services** | If your child needs additional support at home or in the community, your local authority may be able to help. This can include respite care, support for daily living, or help with equipment or home modifications. |

### Looking after yourself

Caring for an autistic child can be deeply rewarding and also genuinely demanding. You need support too. Don't wait until you are struggling to ask for it.

- Talk to people you trust — friends, family, or other parents in similar situations
- Connect with local or online support groups — other parents who understand can be invaluable
- Use respite care if it is available and you need a break — this is not giving up, it is good sense
- Speak to your GP if you are finding things hard — your wellbeing matters

# Part B: If your child did not receive a diagnosis of autism

Section 7 is for you

## 7. What it means if your child was not diagnosed

Not every child who goes through an autism assessment receives a diagnosis — and this is not a failure, and it does not mean the assessment was a waste of time.

There are several reasons why a child may not receive a diagnosis after assessment:

- The evidence gathered did not meet the full criteria for an autism diagnosis
- The difficulties observed may be better explained by another condition or set of circumstances
- Some children show some autistic traits but not at a level that meets the diagnostic threshold
- The picture may not yet be complete — occasionally further information or a re-assessment at a later stage is recommended

Your child's clinician will have explained the specific findings at your feedback meeting, and the written report will set these out clearly.

### Your child's difficulties are still real

Not having a diagnosis does not mean your child has no difficulties. Whatever has been causing concern — at home, at school, or in daily life — is still real and still worth addressing. The report will include any recommendations the team has for next steps, further assessment, or support.

### What to do next if there is no diagnosis:

Read the report carefully — the clinician's recommendations will point you in the right direction.

Share the report with your child's school. Even without a diagnosis, the observations and recommendations can help the school put appropriate support in place.

Talk to your GP if you have ongoing concerns about your child's development, mental health, or wellbeing.

Contact us if you have questions about the outcome or what it means.

### If you disagree with the outcome

If you feel the outcome does not reflect your child, you are entitled to ask questions and seek a second opinion. Please speak to us in the first instance — we can explain the reasoning behind the conclusion. You can also ask your GP to explore other routes.

# 8. Useful organisations and support

These organisations can offer information, support and community for families. Some are relevant regardless of outcome; others are more specific to families who have received a diagnosis.

| | |
|---|---|
| **National Autistic Society** | **autism.org.uk** \| 0808 800 4104 — information, helpline, local groups and events across the UK |
| **Ambitious About Autism** | ambitiousaboutautism.org.uk — resources for young autistic people and families, including a safe online space for young people |
| **Contact** | **contact.org.uk** — support for families of disabled children, including EHCP guidance and helpline |
| **IPSEA** | **ipsea.org.uk** — free, independent legal advice for families navigating special educational needs and EHCP processes |
| **Suffolk Family Carers** | **suffolkfamilycarers.org** — local support for carers and families across Suffolk |
| **Autism Anglia** | **autism-anglia.org.uk** — local autism support services across East Anglia |
| **NHS** | **nhs.uk/conditions/autism** — plain English information about autism, getting support, and what to do next |

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# Thank you for coming

If you have any questions before your feedback appointment, please don't hesitate to get in touch.

## Get in touch with us ↘

| Address | Email | Call |
|---|---|---|
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