

# Living Well with Autism

A Comprehensive Family Guide

Produced by HG Mind Works | Child & Adolescent Mental Health Service

## This booklet will help you:

- Understand your child's autism diagnosis
- Support your child at home and in school
- Communicate effectively with HG Mind Works
- Access helpful resources, apps and books

### Remember:

Autism is not an illness. It is a different way of experiencing the world. With the right support, autistic children can flourish and lead fulfilling, happy lives.

This Guide Provides:

- ① What Is Autism?
- ② Following Your Child's Diagnosis
- ③ How Parents Can Support Their Child
- ④ School and Education
- ⑤ Working with HG Mind Works
- ⑥ Looking After Yourself
- ⑦ Apps and Books to Help Children Understand Autism
- ⑧ Quick Reference – What to Do and When

Autism Spectrum Condition (ASC), also called Autism Spectrum Disorder (ASD), is a lifelong neurodevelopmental condition that affects how a person communicates, interacts with others, and experiences the world around them. The word 'spectrum' reflects the wide range of ways autism can present – no two autistic people are the same.

Autism is not caused by bad parenting, diet, vaccines, or anything a parent did or did not do. It is a neurological difference present from birth, though it may not be formally diagnosed until later in childhood or even adulthood.

## The Three Core Areas

### 1 Social Communication

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- Difficulty understanding unspoken rules of conversation, facial expressions, sarcasm, and social cues. May prefer direct, literal language.

### 2 Social Interaction

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- May find forming and maintaining friendships challenging. Some autistic children prefer solitary activities; others enjoy socialising but find it exhausting.

### 3 Repetitive Behaviours & Routines

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- Strong need for predictability and routine. May have intense special interests, and may engage in stimming (self-stimulatory behaviours) to regulate emotions.

# What is Autism?

Many autistic children experience the world through their senses very differently from non-autistic people. They may be over- or under-sensitive to:



#### Over-Sensitive (Hypersensitive)

- Sounds (e.g., hand dryers, loud music)
- Bright or flickering lights
- Certain textures of food or clothing
- Strong smells or tastes



#### Under-Sensitive (Hyposensitive)

- Physical touch (e.g., hugs, labels in clothing)
- Temperature changes
- Pain (may have a high pain threshold)
- Movement and balance

#### Why this matters:

Sensory overload – when too many senses are overwhelmed at once – can cause significant distress, meltdowns, or shutdowns. Understanding your child's sensory profile is one of the most powerful tools you have as a parent.

## Meltdowns vs Shutdowns - What Is the Difference?

#### Meltdown

- Explosive or intense emotional response
- May involve crying, shouting, or physical behaviours
- Triggered by overwhelming sensory or emotional input
- Not a 'tantrum' – the child has lost control and cannot stop it

#### Shutdown

- Internal withdrawal; the child goes quiet and 'switches off'
- May become very still, unresponsive, or emotionally flat
- Can look like the child is 'fine' – but they are not
- Needs quiet, calm, and time to recover

# Sensory Differences

# Following Your Child's Diagnosis

Receiving an autism diagnosis for your child can bring a range of emotions – relief, grief, confusion, hope, or a mixture of all of these. There is no right or wrong way to feel. What matters most is what you do next.

## Your Immediate Next Steps:

- 1 Take time to process the diagnosis as a family. You do not need to have all the answers immediately.
- 2 Keep a copy of the diagnostic report in a safe place – you will need to share it with school, your GP, and other services.
- 3 Inform your child's school as soon as possible so they can begin putting support in place.
- 4 Register your child with the HG Mind Works team and attend all follow-up appointments.
- 5 Contact your local authority's Special Educational Needs and Disabilities (SEND) team to explore support options.
- 6 Speak to your GP about any co-occurring conditions such as anxiety, ADHD, or sleep difficulties.

# Telling Your Child About Their Diagnosis

Most children benefit from knowing about their diagnosis in an age-appropriate way. Being open and honest helps your child build a positive identity and understand themselves better.

## Tips:

- Use clear, positive, and factual language (e.g., 'Your brain is wired a bit differently, which means...')
- Avoid framing autism as something that is 'wrong' with them
- Use books and stories written for children about autism (see Section 7)
- Reassure them that they are loved, supported, and not alone
- Follow their lead – answer questions honestly and revisit the conversation over time



## **When to Seek Urgent Support:**

If your child is experiencing a mental health crisis, is in danger of harming themselves, or is in immediate distress, contact HG Mind Works, your GP, or in an emergency dial 999. You can also contact the Samaritans on 116 123 at any time.

You are your child's greatest advocate. Your day-to-day support at home will have a profound impact on their wellbeing, confidence, and development. This section outlines practical strategies for life at home.

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### **Creating a Predictable and Safe Home Environment**

Routine and predictability are the cornerstones of a supportive home for an autistic child. When your child knows what to expect, they feel safe – and when they feel safe, they can learn, connect, and grow.

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#### **Create Predictable Daily Routines**

Establish consistent daily routines for waking, mealtimes, school, and bedtime.

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#### **Use Visual Schedules for Clarity**

Use visual schedules and timetables displayed prominently in the home.

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#### **Provide Advance Transition Warnings**

Give advance warning before transitions: "In 10 minutes we will be leaving the house."

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#### **Prepare for Changes to Routine**

Prepare your child for changes to routine as far in advance as possible.

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#### **Use Timers to Support Time Awareness**

Use countdown timers or visual clocks to help with time management.

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#### **Create a Calm and Safe Space at Home**

Create a dedicated calm or "safe" space in the home your child can retreat to.

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# How Parents Can Support Their Child

# Communication Strategies



## Top Tips for Clear Communication:

- Use simple, direct, and literal language – avoid sarcasm, idioms, or ambiguous phrases
- Allow extra processing time – pause after asking a question before repeating it
- Get down to your child's physical level when speaking to them
- Use visual supports such as pictures, symbols, or written instructions alongside spoken language
- Avoid overloading with multiple instructions – give one clear step at a time
- Acknowledge feelings before trying to solve problems
- Write things down as a reminder if needed

# Managing Meltdowns and Emotional Regulation

## Before a Meltdown — Prevention

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- Learn your child's warning signs (e.g., increased stimming, covering ears, withdrawing)
- Identify and reduce known triggers where possible
- Build in regular 'downtime' each day to decompress from sensory demands
- Teach and model simple emotional regulation strategies (e.g., breathing exercises, movement breaks)

## During a Meltdown — Immediate Response

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- Stay calm – your regulated nervous system helps regulate theirs
- Reduce sensory input: lower lights, reduce noise, create space
- Do not try to reason with your child during a meltdown – their thinking brain is offline
- Ensure safety – remove any immediate hazards
- Offer minimal verbal communication; use a calm, low, steady voice if needed

## After a Meltdown — Recovery

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- Allow time and space to recover fully before addressing what happened
- Be warm, non-judgmental, and reassuring – 'You are safe. I love you.'
- Later (not immediately), gently discuss what happened and what might help next time
- Do not apply consequences for meltdowns – they are not a choice

Many autistic children experience significant sleep difficulties, which can worsen anxiety, behaviour, and overall wellbeing.



### **Practical Strategies Include:**

- **Bedtime Routine:** Maintain a consistent bedtime routine each night.
- **Environment;** Use blackout curtains and white noise if your child is sensitive to light or sound.
- **Professional Support:** Speak to your GP or HG Mind Works if sleep problems are severe – melatonin can be prescribed in some cases.
- **Screen Time:** Reduce screen time at least one hour before bed.
- **Sleep Supports:** Consider weighted blankets, which many autistic children find calming.

### **Sleep and HG Mind Works:**

HG Mind Works can refer your child to specialist sleep services if needed. Do not wait – poor sleep has a significant impact on your child's mental health and your own.

# Sleep Support

# Working with Support Services

Many children and young people receive support from a range of professionals, including schools, HG Mind Works, paediatricians, therapists, GPs and community services.

Understanding how these services work together can help you access the right support and advocate effectively for your child.

## Support Services May Provide

### Assessment & Diagnosis

- Autism assessments
- ADHD assessments
- Cognitive and developmental assessments
- Mental health assessments
- Speech, language and communication assessments

### Therapeutic Support

- Psychological therapies
- Family and parent support
- Occupational Therapy (OT)
- Speech and Language Therapy (SaLT)
- Psychiatry and medication reviews
- Emotional wellbeing support

### Helping Your Child Get the Most from Appointments

- Use clear, direct language when discussing appointments and support plans
- Allow additional processing time where needed
- Share relevant information with professionals before appointments whenever possible
- Encourage your child to express their views, preferences and concerns
- Bring examples of challenges and strengths from home, school and community settings
- Keep copies of reports, letters and recommendations in one place

### Working Effectively with Professionals

- Attend appointments or provide as much notice as possible if you need to rearrange
- Complete questionnaires and forms fully and accurately
- Share updates about changes in behaviour, wellbeing or circumstances
- Ask questions if recommendations are unclear
- Ensure key professionals have the information they need to support your child
- Keep communication open between services where appropriate

**HG Mind Works can work alongside schools, NHS services, local authorities and other professionals to provide additional assessment, therapy and specialist support.**



Our clinicians support children, young people and adults across the lifespan, providing continuity of care as needs change over time.

Whether you are seeking assessment, therapy, post-diagnostic support or guidance through complex care pathways, we can help you understand your options and access the support that is right for you and your family.

**Every child's pathway is different.**

There is rarely a single service that meets every need. Building the right network of support often involves several professionals working together over time. HG Mind Works can help coordinate, complement and strengthen that support, from childhood through to adulthood.

# HG Mind Works

## Support for Every Stage of Life

### Support Beyond Childhood Care That Grows With You

Unlike many services that end when a young person reaches adulthood, HG Mind Works can continue to provide support throughout life.

Whether someone is moving from HG Mind Works, entering further education, starting work, living independently, or navigating challenges later in adulthood, our team can provide ongoing mental health, neurodevelopmental and wellbeing support tailored to their changing needs.

We believe support should adapt as life changes. It should not stop because someone reaches a particular birthday.

Key points:

- Continued support beyond age 18
- Seamless transition from child to adult services
- Mental health, autism and ADHD support across the lifespan
- Consistent clinical oversight and continuity of care
- Support for education, employment, relationships and independent living
- Family guidance and support where appropriate

# Looking After Yourself

## An Important Reminder:

You cannot pour from an empty cup. Looking after your own wellbeing is not selfish – it is essential. Children are deeply attuned to their parents' emotional state. When you are regulated, you help your child regulate too.

## The Emotional Impact on Parents

Parenting an autistic child is deeply rewarding, but it can also be exhausting, isolating, and emotionally complex. Many parents experience:

- Grief – for the future they imagined, or for the struggles their child faces
- Anxiety and hypervigilance – always anticipating the next crisis
- Exhaustion – from the intensity of daily support, advocacy, and appointments
- Isolation – feeling that others do not understand their family's experience
- Guilt – questioning whether they are doing enough or 'causing' difficulties

All of these feelings are valid and normal. You are not alone.

## Practical Strategies for Parent Wellbeing

- Join a local or online parent support group for parents of autistic children
- Access a Carers Assessment through your local authority – you may be entitled to respite support
- Speak to your GP about your own mental health – parent wellbeing is taken seriously
- Use Short Breaks funding (where available) to access regular time away from caring responsibilities
- Build a support network – be clear with family and friends about what kind of support you need
- Try to maintain at least one activity each week that is just for you

# Useful Support Organisations for Parents

Organisation	What They Offer	Contact
National Autistic Society (NAS)	Information, helpline, local groups, advocacy	<a href="http://www.autism.org.uk">www.autism.org.uk</a> / 0808 800 4104
Ambitious About Autism	Education support, campaigns, young person resources	<a href="http://www.ambitiousaboutautism.org.uk">www.ambitiousaboutautism.org.uk</a>
Autism Alliance UK	Network of specialist autism charities	<a href="http://www.autismalliance.org.uk">www.autismalliance.org.uk</a>
Contact (for families of disabled children)	Benefits advice, peer support, helpline	<a href="http://www.contact.org.uk">www.contact.org.uk</a> / 0808 808 3555
Family Lives	Parenting support, helpline, online resources	<a href="http://www.familylives.org.uk">www.familylives.org.uk</a> / 0808 800 2222
Carers UK	Rights, benefits, respite, support for carers	<a href="http://www.carersuk.org">www.carersuk.org</a> / 0808 808 7777

# Apps and Books to Help Children Understand Autism

The right book or app can open up conversations about autism in a way that is accessible, empowering, and even fun. Below is a curated list of resources to help your child understand who they are, manage their emotions, and develop their skills.

## Recommended Apps for Children

These apps have been selected for their effectiveness, accessibility, and positive approach to supporting autistic children.

Name	Type	Age	Description	Cost
Choiceworks	App	3–12	Visual schedule, waiting, and feelings boards. Ideal for routines and emotional regulation.	Paid
Breathe, Think, Do with Sesame	App	2–6	Sesame Street app teaching calming strategies and problem-solving in a fun, accessible way.	Free
Ziji – Be Your Own Hero	App	5–14	Mindfulness and emotional regulation app designed with neurodivergent children in mind.	Free
Autism iHelp	App	2–8	Vocabulary and communication app specifically designed for autistic children.	Paid
Social Stories Creator	App	4–12	Create personalised social stories to help children prepare for new situations.	Paid
Calm	App	7+	Guided meditations, sleep stories, and breathing exercises. Excellent for anxiety management.	Free/Premium
Headspace for Kids	App	3–12	Age-appropriate mindfulness exercises in short, engaging sessions.	Free/Premium
Molehill Mountain	App	8–16	Specifically designed for autistic young people to manage anxiety. Evidence-based.	Free
Model Me Going Places 2	App	5–12	Uses video modelling to prepare children for real-world social situations.	Paid
TalkBoard	App	3–12	AAC (Augmentative and Alternative Communication) app for non-verbal or minimally verbal children.	Free

## Recommended Books – For Younger Children (Ages 4–8)

Name	Type	Age	Description	Cost
The Superhero Brain	Book	4–8	By Anniken Røste. Explains autism as a superpower in a positive, accessible way.	~£8
Different Like Me	Book	5–9	By Jennifer Elder. Stories of famous people who were 'different', including those with autism.	~£10
My Friend Has Autism	Book	4–8	By Amanda Doering Tourville. Introduces autism from a peer's perspective – great for siblings.	~£9
Can I Tell You About Autism?	Book	7–11	By Jude Welton. A child explains their autism to others – brilliant for schools too.	~£9
The Curious Incident of the Dog in the Night-Time	Book	10–14	By Mark Haddon. A novel narrated by an autistic boy – widely loved and hugely empathetic.	~£8
All Cats Have Asperger Syndrome	Book	5–10	By Kathy Hoopmann. Uses photographs of cats to describe autistic traits in a gentle, humorous way.	~£9

## Recommended Books – For Older Children and Teens (Ages 9–18)

Name	Type	Age	Description	Cost
The Reason I Jump	Book	12+	By Naoki Higashida. Written by a non-speaking autistic teenager – profound and deeply moving.	~£9
Odd One Out	Book	13+	By Julian Clary & David Roberts. A coming-of-age story with an autistic protagonist.	~£8
The Spectrum Girl's Survival Guide	Book	13+	By Siena Castellon. Written by an autistic teen for autistic girls – incredibly practical.	~£12
Been There, Done That, Try This!	Book	12+	By Tony Attwood. Real stories and advice from autistic individuals for autistic individuals.	~£14
Autism Spectrum Disorder – The Ultimate Teen Guide	Book	13+	By Blythe Grossberg. Evidence-based guide for autistic teens navigating school and social life.	~£14

## Books for Parents and Families

Name	Type	Age	Description	Cost
The Explosive Child	Book	4–8	By Anniken Røste. Explains autism as a superpower in a positive, accessible way.	~£8
Ten Things Every Child With Autism Wishes You Knew	Book	5–9	By Jennifer Elder. Stories of famous people who were 'different', including those with autism.	~£10
The Complete Guide to Asperger's Syndrome	Book	4–8	By Amanda Doering Tourville. Introduces autism from a peer's perspective – great for siblings.	~£9
Raising Martians – From Crash-Landing to Leaving Home	Book	7–11	By Jude Welton. A child explains their autism to others – brilliant for schools too.	~£9
NurtureShock	Book	10–14	By Mark Haddon. A novel narrated by an autistic boy – widely loved and hugely empathetic.	~£8
The Autistic Brain	Book	5–10	By Kathy Hoopmann. Uses photographs of cats to describe autistic traits in a gentle, humorous way.	~£9

# Quick Reference — What to Do and When

Situation	What to Do
My child is having a meltdown	Stay calm, reduce sensory input, ensure safety, minimal verbal communication. Do not apply consequences.
My child refuses to go to school	Contact school and HG Mind Works promptly. Do not force. Work on gradual reintegration. Identify specific triggers.
I think my child has anxiety	Speak to your GP and HG Mind Works. Keep a diary of triggers. Explore Molehill Mountain app.
My child is not sleeping	Implement a consistent routine, reduce screens before bed. Speak to GP about melatonin if needed.
I feel overwhelmed as a parent	Contact NAS helpline (0808 800 4104), your GP, or Family Lives (0808 800 2222). You deserve support too.
My child is in crisis or danger	Call 999 for immediate danger. Call HG Mind Works crisis line. Contact your GP urgently.
I want to explore support groups	Contact NAS for local groups. Search Facebook for local autism parent groups. Check your local authority website.

# A Final Word

Your child's autism is not a tragedy. It is a different way of being human. With understanding, patience, and the right support, autistic children grow into remarkable adults. Trust your instincts, accept help when it is offered, and never stop advocating for your child – because you know them better than anyone.

## Get in touch with us



Address 

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[hg-mindworks.com/wsft](https://hg-mindworks.com/wsft)

Email 

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[westsuffolk@hg-mindworks.com](mailto:westsuffolk@hg-mindworks.com)

Call 

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02081268767