

Post Diagnostic Support for Parents & Carers

This information sheet is for parents whose children have recently been diagnosed as autistic. Its aim is to introduce you to autism and where you can get more information and support. It will refer to other more detailed information sheets on specific topics along the way.

All our information sheets can be downloaded at:

www.autismwestmidlands.org.uk/online-resources

What is autism?

Autistic people's brains work differently from non-autistic people's brains. This influences the way an autistic person experiences their senses, how they communicate and interact with others, and how they think and process information. Each autistic person will have unique strengths and challenges in different areas of life.

To find out more about autism download our '**A Guide to Autism information**' sheet.

Processing a diagnosis

Receiving an autism diagnosis for your child can be a shock. Even if you have had to fight for a while, when the diagnosis is made, it can produce mixed emotions. There is no right or wrong way to feel about your child being diagnosed. Feelings may include sadness, anger, relief, denial, guilt, frustration, fear, and grief. These emotions may change each day.

Everyone's experience is different. Parents and other family members may react in different ways. Some people take a long time to understand autism. You can sometimes help this by finding material you can share with them.

If you are struggling with your emotions, you may want to seek professional help. Your GP can refer you to a counsellor. For many parents talking to others who have been through the same mixture of emotions can be helpful.

When your child was diagnosed you may have heard autism explained via a medical model of deficits. The medical model can pathologise and fail to reflect some of the lived experience of autistic people. Autistic individuals do experience difficulties in their lives, but these difficulties are not always directly related to their autistic characteristics. Many of the difficulties that autistic people face are due to living in a world that is designed predominantly to meet the needs of non-autistic people. The courage, character and resourcefulness that is needed to live in an often neuro-hostile world is frequently overlooked. Autistic strengths related to different communication and thinking styles such as critical thinking, attention to detail, a deep focus and integrity are often missed or misunderstood.

For some children autism is their only diagnosis but for others they may have already received a diagnosis of another condition. For other children autism is their first diagnosis and other diagnoses may follow. **Autism can often co-occur with other conditions** so many children will have more than one diagnosis.

Family life can be a challenge, both for the autistic child and for others. You may have to adjust the way you do things as you learn more about your child. This can impact on other family members especially siblings. Your other children may need support too. Some areas run sibling groups or children may be able to access support through their school.

Our other **information sheets** have detailed information on specific difficulties that families often face such as behaviour, education, sensory, sleep and diet. Attending training courses alongside other parents who have similar experiences can be a great way to understand your child better.

Support from other parents can also be beneficial. This can be by attending local support groups or via one of the many social media groups set up by other parents.

You may find you have lots of **meetings with professionals** to attend. Be prepared for these meetings and remember you know your child better than they do.

Services and support

GENERAL

- Our **information helpline** is available to anyone across the West Midlands and offers a listening ear, information and signposting to local services and support. Contact 0121 450 7575 or info@autismwestmidlands.org.uk to speak to a helpline adviser.
- Our website has a range of **information sheets and visual resources** to download.
- Autism West Midlands offers different types of support for autistic people and their families in different areas. Depending on the area there may be possibilities for **advice appointments, support groups, training face to face or via webinars and various trips or activities.**

- **Contact** is a charity that supports families with disabled children by offering guidance and information. Their website has information pages on a range of topics including, medical, education, social care, health, financial, work and childcare. www.contact.org.uk Their national parent helpline can be contacted on 0808 808 3555 or helpline@contact.org.uk
- **Cerebra** offers information, advice and support to families who have children with “brain conditions” who are under 16 years. They have a range of information sheets to download and have a specific service to help with families struggling with sleep disorders. www.cerebra.org.uk / Email: info@cerebra.org.uk
Helpline: 0800 328 1159

EDUCATION

- **The Local Offer.** Under Special Educational Needs and Disability (SEND) Law each local authority must publish and keep under review information about services available for children and young people with SEND aged 0-25. This is called the Local Offer. Search for your local authority and “local offer” using an internet search engine to find yours.
- **Independent Advice and Support Service (IASS).** There should be an IASS in every local authority area. They are free, impartial and confidential services which offer advice and support on issues relating to children with special educational needs and disabilities 0-25 years (SEND). In addition to information and support on special educational needs they also support on health and social care issues. To find your local IASS you can use the following link: www.councilfordisabledchildren.org.uk/information-advice-and-support-services-network

- **IPSEA (the Independent Panel for Special Education Advice)** provides free legal advice and support for parents of children with SEND. Their website has lots of information, legal guides and template letters you can download, and their helpline offers advice and support. www.ipsea.org.uk
- **Autism Education Trust (AET)** offers support and training to schools but also has information on their website for parents. www.autismeducationtrust.org.uk
- **National Autistic Society (NAS)** have some helpful information on reasonable adjustments, exclusion and educational support for autistic children and young people. <https://www.autism.org.uk/advice-and-guidance/topics/education>

FINANCIAL SUPPORT

- You and your child may be entitled to extra financial support. The following link to the government website provides more information about specific **benefits** such as Disability Living Allowance, Personal Independence Payment, Carers Allowance and Universal Credit. The organisations Contact and Cerebra, listed above, offer information and support about benefit applications. www.gov.uk/browse/benefits/disability
- **Family Fund** is the UK's largest charity providing grants for families raising disabled or seriously ill children and young people. www.familyfund.org.uk

Recommended resources

Books

Autism in Childhood by Luke Beardon

Parenting rewired: How to raise a happy autistic child in a neurotypical world by Danielle Punter and Charlotte Chaney

Nurturing your autistic young person by Cathy Wassell

Websites

<https://autismunderstood.co.uk/>

Social media content

<https://www.instagram.com/neurowild/?hl=en>