

This information sheet is for parents whose children have recently been diagnosed with autism. 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

A couple of years ago we asked parents "If you could go back in time to when your child first received a diagnosis of autism, what would you say to yourself?" Some of their replies are included in this sheet.

"Remember however difficult I'm finding it he is finding it more so. I can't expect or insist he speaks my language: I have to learn his. The journey is long but sometimes the views are fantastic" **Emma**

What is autism?

Autism Spectrum Disorder is a lifelong developmental disorder that affects the way a person:

- **Communicates and interacts with others**
- **Experiences their senses**
- **Thinks and behaves flexibly**

Children with autism share similar difficulties but are affected in different ways and to differing degrees. Their age, gender, intellectual ability and their personality are all important factors in what makes them who they are.

"Take a deep breath and take it all as it comes. Our kids are all different and amazing!" **Ann**

All children grow up and progress. How your child's autism affects them at the point of diagnosis is not how it will be for ever.

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

Coming to terms with 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.

“Don’t give up...the tears of shock and upset when you first get that diagnosis turn into tears of pride and joy when your child takes massive steps that other parents take for granted.” **Sarah**

Everyone’s experience is different; some individuals go through a grieving process, whereas others don’t experience this. Mums and dads and other family members may react in different ways. Again there is no right or wrong way to feel.

Some people take a long time to understand autism, including partners and family members. You can sometimes help this by finding written material you can share with them.

“When you have a child you have lots of dreams for that child. When you find out things aren’t exactly as you thought it’s not the end it’s just different. My son is 14 now. I wouldn’t have him any other way. I’ve learnt a lot as he has grown.” **Jane**

If you are struggling to move on from your initial feelings 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.

At the end of this information sheet there is information about finding support in your area.

“Don’t despair – adjust your views on life – autism makes you appreciate each piece in the puzzle rather than looking at the full picture. Don’t let anyone make you or your child feel less able to succeed in life” **Julie**

Autism and other conditions

For some children autism is their only diagnosis but for others they may have already received a diagnosis of another condition such as:

- Speech and language delay
- Learning disability/difficulty or global delay
- Sensory processing disorder
- Attention deficit hyperactivity disorder (ADHD)
- Development co-ordination disorder (DCD) / dyspraxia

For other children autism is their first diagnosis and other diagnoses may follow. There is a higher incidence of other neurological conditions accompanying autism so many children will have more than one diagnosis.

There are lots of names used to describe autism such as autism spectrum condition (ASC), autism spectrum disorder (ASD), high functioning autism and Asperger syndrome. In recent years the different labels have been brought under the one diagnosis of autism spectrum disorder and children who receive a diagnosis now are usually diagnosed with autism spectrum disorder.

Although all children with autism are unique, they can be viewed as showing one of a number of behavioural profiles. One behaviour profile that is increasingly being identified is the Pathological Demand Avoidance profile (PDA). There are big differences in the recognition of PDA between local areas.

To find out more about PDA download our PDA information sheet or visit:

www.pdasociety.org.uk

“Educate yourself and those around you as much as possible about autism. You know your child best!” **Annette**

Living with autism

“Take a deep breath before reacting! Fight one battle at a time! Work as a team – conflict creates confusion! Find out about how autism affects YOUR child! Find ways to recharge your batteries! Behaviour is ALWAYS communication! Be proud!” **Paula**

Family life with a child with autism can be a challenge. You may have to adjust the way you do things as you learn more about how autism affects your child. This can impact on other family members especially siblings.

Our other information sheets have detailed information on specific difficulties that families often face such as behaviour, sensory, sleep and diet.

Attending training courses alongside other parents who have similar experiences is a great way to understand your child better. See below for information about where Autism West Midlands runs courses but you may find other providers in your local area too.

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.

Your other children may need support too. Some areas run sibling groups or children may be able to access support through their school.

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

“Never give up on what you believe, you know your child. Listen to people’s advice, you don’t always have to take it but people are there for you.” **Alison**

“I have learnt now that there is light at the end of the tunnel. I am coming out on top with my lad. I take the rough with the smooth!” **Jayne**

Services and support

Autism West Midlands offer a number of services to families across the region. Unfortunately due to funding conditions there is variability about what we offer in different areas but some of our services are available to all.

“Find out more, fight for what your child needs and love them whatever! Join support the groups. I did and now my son is 14 and growing into a lovely young man” **Ruth**

Our information helpline is available to anyone across the West Midlands and offers a listening ear, information and signposting to local services.

Our website has a range of information sheets and visual resources to download.

Our Birmingham based team offer advice appointments and support groups in community based venues in Birmingham and the Black Country, training courses for parents in our Birmingham office and activities and trips for families. Although located in Birmingham these activities can be accessed by any family regardless of where they live.

In Shropshire and Sandwell we are commissioned by the local authority to offer services for families who live in these areas only. Our locally based teams offer advice appointments, family outreach, parent training courses, support groups and family activities.

In Solihull we are part of the SOLAR service (Emotional Health and Wellbeing Service for children 0-19). We offer advice appointments, parent training and children's workshops to families known to the SOLAR service.

To find out what is on offer in your area contact the Helpline or visit the events pages on our website:

www.autismwestmidlands.org.uk/events

"Be optimistic and believe they can achieve anything they want to. My son is nearly 20 now and was written off by just about everybody. He now has GCSEs, works full time, has a girl friend and a busy social life" **Lisa**

Information in your area

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. In most areas this is in the form of a website. Search for your local authority and "local offer" using an internet search engine to find yours.

Autism West Midlands Helpline

Our information helpline may be able to signpost you to services and support groups in your local area.

Contact 0121 450 7575 or info@autismwestmidlands.org.uk to speak to a helpline adviser.

GENERAL

Contact

Contact (previously called Contact a Family) 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 child care:

www.contact.org.uk

Their national parent helpline can be contacted on 0808 808 3555 or helpline@contact.org.uk

Their local West Midlands office offers local information and runs a programme of training workshops across the region.

Contact 0121 274 0437 or westmids.office@contact.org.uk

Cerebra

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

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).

Prior to 2014 they were called Parent Partnership Services; however since the change to IASS, 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

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)

The AET offers support and training to schools but also has information on their website for parents and a kidzone with information aimed at young people.

www.autismeducationtrust.org.uk

FINANCIAL SUPPORT

Benefits

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

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

"Be very proud of yourself, for all the hard work and dedication you put in to raise your child. If something works for you go with it, believe in yourself. Special children have special parents" **Denise**