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Autistic Spectrum Disorders

A Resource for Families in Wales

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This booklet provides an introduction for people who have a family member with autism. A few important things to point out at the start are:

- Autism is no-one’s fault.
- The causes of autism are not yet known.
- It is a life-long condition and as yet there is no known cure.

What are Autism Spectrum Disorders?

Autism is often the short-hand name given to a wide 'spectrum' of disorders, which includes Asperger syndrome and high functioning autism (HFA). Whatever term is used similar approaches are needed. Autism affects around 1 in 100 people in very different ways. Some can live typical and independent lives, form relationships and have children, while others will always need specialist support.

All will, however, have some difficulty in the following three areas:

- social communication;
- social interaction;
- social imagination.

Difficulty with social communication

This includes spoken language and non verbal communication. 80% of the way people communicate with each other is through non verbal means such as gesture, facial expression and body movements. This includes things like pointing, a wave, a smile or frown, turning away, an angry stance and fidgeting. Many people affected by autism can struggle to understand these non verbal signs.

Some will also take spoken words very literally: for example, interpret the phrase 'It's smashing' as meaning something is breaking rather than something is good; or not understand the intended meaning of commonly used phrases or jokes. Some may also have difficulty in interpreting other people's tone of voice.

Many people with autism have limited language and need to use symbols or signs for communication. Some may repeat what's just been said, or talk only about one topic. Even though some people may have excellent language skills, they may still not know when to start or end a conversation or understand the 'give and take' rules in conversation.

Difficulty with social interaction

People with autism often don't understand other people's emotions or feelings and find them too unpredictable.

This can make it hard for them to form friendships or fit in socially, even if they want to and this can cause anxiety. Some people may not understand social rules, such as how close to stand to someone, or what appropriate conversation topics are.

Others may appear insensitive, or prefer to be alone, not seek comfort from others or seem to behave very strangely.

Difficulty with social imagination

Many people with autism are extremely creative, so difficulty with social imagination must not be mistaken for lack of imagination.

Some have difficulty in understanding other people's thoughts and actions, imagining consequences to different situations or predicting what will happen next. Others may have no concept of danger. Although some do have imaginative hobbies or interests, these could be repetitive activities. Many find coping in unfamiliar situations extremely hard and need support to prepare for change or plan for the future.

Other characteristics

- Routines and rules - such as wanting to travel the same route to a place each time, always carrying a specific item, following set rituals.
- Sensory sensitivity - over or under-sensitive sight or sound, or sense of touch, smell or taste.
- Special interests - that can turn into a career or remain a lifelong hobby.
- Learning disabilities - around two-thirds of people with autism also have a learning disability.

Assessment and Diagnosis

You or others may have concerns about your family member's learning, development or behaviour which may seem unusual or different as described earlier.

These concerns can occur at any age and it is important to discuss them with someone who can help. Some families can experience difficulties in getting professionals to accept their concerns and so need to be persistent.

"I knew my son was struggling behaviour-wise at school but I kept getting told he was immature for his age. A diagnosis was given after a lot of pro-active phone calls on my behalf." (Parent).

The first point of contact is often your family doctor but for children can also include the health visitor or teacher. After an initial consultation with your family doctor, it may be decided to refer you on to get an assessment before a formal diagnosis can be made. It is important to note that a diagnosis cannot be made without a detailed assessment by a specialist in autism.

Getting a diagnosis of autism may bring a sense of relief both for the individual and the family, but can also be a very emotional time. It can improve understanding of how to support the person but it can cause conflict within families and with friends. Diagnosis can allow access to some services, support and financial help, although a diagnosis of Asperger syndrome can be a barrier to some services. This is because individuals with Asperger syndrome generally have above average IQ and often may not fit the eligibility criteria to receive services or their issues may not be as easily seen by those without a good understanding of the condition.

Assessment can be done by a psychiatrist, child specialist or a team of specialists. This will usually include a detailed personal history, opinions of others, a structured questionnaire and observation of the person's behaviour. The specialist considering the diagnosis should explain the process clearly and it is important that a recognised assessment method is used.

ADOS, 3di and DISCO are the names of some commonly used assessment tools. Assessment can be completed over several visits spread over some time. This can be a long and drawn out process which may be tiring.

If a diagnosis is made, a number of terms can be used. These include autism, ASD (autism spectrum disorder), Asperger syndrome, high functioning autism, autism spectrum condition and others. It is important that families are given a clear explanation of the diagnostic term used and understand the individual needs that have been identified during the assessment.

Diagnosis is less likely before the age of 2 years but can happen at any age including into adulthood. The earlier a diagnosis of autism can be made, the better the chances of the person receiving the most appropriate help and support.

The effect of having a relative with autism in the family

Parents

The presence of autism is likely to have an effect on the whole family and this will vary according to family circumstance. Mothers tend to be the main carers and may experience more emotional distress and health problems than fathers. This is more likely if the child has behaviour problems and if there is little family support. Mothers often have to give up work or can work only part-time and this has a significant impact on their own career hopes and the family finances.

Fathers tend to be affected more by the stress experienced by the mother than by the autism itself, and this can put pressure on relationships. Fathers often hide their feelings, but may show anger. Mothers often rely on talking to others, especially other mothers of children with autism, to help deal with their emotions. There is some evidence to suggest that a higher rate of lone parenting exists amongst those caring for children with autism, compared to the general population.

“My husband couldn’t accept that there was something wrong and this caused friction in our family, although the grandparents have been great it has been a rollercoaster ride for all of us” (Parent).

However, often parents do become experts on autism and in particular on their child’s traits and difficulties. They can act as an advocate for their child in numerous situations. Don’t underestimate your expertise. Understanding your child’s specific issues can support them as they progress to adulthood.

Siblings (Brothers and sisters)

If there are other children in the family, explaining autism to them may be difficult although siblings are often more accepting than adult family members. Each family will have its own way of approaching this, but the more openly autism can be talked about the easier it should be for the whole family to accept and make any necessary changes to support the individual with autism.

Siblings may pick up from an early age that their brother or sister is different, even if they don’t understand why. Explanations can be short and simple, adding knowledge over time as needed. There are several excellent books which have been written for siblings (See Further resources section).

Common problems, like turn taking and sharing toys, which exist between brothers and sisters can be much more difficult to deal with when autism is a factor. Helping the whole family to understand autism is invaluable. Difficulties should be talked about and not ignored, ground rules set and alternative approaches tried. It is very likely that family life will be “unfair” at times for the other children and acknowledging this, explaining why this is the case can help prevent resentment. Praising the sibling for their support is key to maintaining a healthy sibling relationship.

“My son’s condition had a huge impact on my daughter when she lived at home. Anxiety and frustration caused a volatile relationship between them. Now that my daughter has moved out they have a much better relationship. Most of this could have been avoided by early diagnosis as he was not diagnosed until the age of 14” (Parent).

The effect on siblings can be varied. Some may become protective of their sibling with autism and others may feel resentment or embarrassment.

“... people look at us in funny ways... just because it’s a family with autism. So if he starts swearing or starts kicking, you know, it’s quite embarrassing because people might think, oh, you know, their mother or father taught him to do that, so it’s quite embarrassing to me to think that people sort of disrespecting my family and me and my brother.” (Teenage sibling).

Some siblings may develop better social and caring skills and higher self-esteem. Other siblings can feel pressured by high expectations from parents. As they get older, siblings may worry about the role that they will have to play in their brother or sister’s future.

“When [my mum’s] really old, am I going to have to look after him, which I wouldn’t mind doing, but is he going to be able to look after himself? That’s what worries me about it,” (Teenage sibling).

Siblings may also worry about whether their own children will have autism. These issues may require discussion with a knowledgeable and experienced professional.

Partners

It used to be thought that people with autism cannot have successful relationships because of their social difficulties. This is not true. Many have partners and children. Some manage these relationships very well, whilst others may experience great difficulties.

Partners may find that living with someone with autism can be difficult because of the subtle nature of the condition. There are no physical signs, and it can be hard for families and friends to understand that unusual or different behaviours are not deliberate.

Effects over time

Effects on families can be expected to change over time. Childhood can be difficult due to a lack of understanding about autism within the family, amongst relatives, friends and the general public. Teenage years are difficult for most families. However, autism can delay progress towards independence and cause frustration on all sides. Teenagers with Asperger syndrome can also be more prone to depression and this can be hard for the whole family. As with the general population depression needs to be identified and treated and it can continue or recur from time to time. However, depression is not an inevitable result of Asperger syndrome.

Living with a person with autism

The first step to coping with any condition is knowledge and understanding. The more you know about autism the better.

Some initial strategies for coping may include:

- Understand that apparently hurtful behaviour may not have been meant that way. It could be a result of the inability to read your thoughts and feelings.
- Use clear language and allow time for the person to understand.
- Find the best way to communicate and remember this may include pictures, symbols and notes.
- Try to remember that social situations are often stressful.
- Accept that they may be very interested in things that are very boring to you, and allow them time and space to pursue this interest.
- Give plenty of notice when changes are due to occur. It may be hard for the person with autism to give up routines.

- Agree on a timetable for certain activities, such as mealtimes.
- Staying calm works best! Allow the individual with autism some time out to calm down if anxious or frustrated before trying to discuss an issue.

Public reactions

Autism is an ‘invisible disability.’ Although many people have heard of autism, few people really understand the condition. Behaviour can at times be hard to explain and so the general public may not appreciate that the person has problems with social situations. This means that going out in public can be stressful, tiring and embarrassing.

“Several times when we have parked in a disabled space people have commented that I shouldn’t have parked there as they cannot see anything wrong” (Parent).

Families may be faced with public ignorance and intolerance. It is important to seek support and help if this becomes a problem.

“It’s not bad parenting and this is why...”

“Most professionals support by telling you all theory or recommending more books to read. I am asking for their help because I’ve got the knowledge and read the ideas but am struggling to make it work. When you are shattered, physically and verbally battered, mentally and physically exhausted there is no one to help” (Parent).

Behaviour is an expression of the way a person with autism experiences and makes sense of the world and how they relate to others. It is important that families understand that the behaviours that they see are not driven by parenting style.

A range of behaviours could be observed, such as:

- Refusing to eat, being uncooperative.
- Obsessions and ritualistic patterns.
- Physically harming self or others, lack of sense of danger.

- Inappropriate questions, shouting, swearing, running away.
- Flapping hands, rocking, spinning.
- Inappropriate or unintentional sexual behaviour.

“At the heart of understanding why difficult behaviours occur is the following assumption; all behaviour has a purpose” (Veronica Bliss 1999).

If a person cannot communicate their wants and needs then their feelings may be expressed through their behaviour. Communication difficulties can lead to frustration, anxiety and confusion and create misunderstandings.

A lack of understanding of social rules and the perspectives of others may lead an individual to develop behaviour which could appear inappropriate but helps them to avoid or limit social contact they find uncomfortable.

A need for routine and predictability means that it is often important for people to understand what is happening now, for how long, when it finishes and what happens next. Without clear information some may become distressed.

Sensory considerations

What we see, hear, feel, smell, and taste gives us information about our surroundings and ourselves. As well as an under or over sensitivity, many people with autism find it hard to process a range of sensory stimulation at one time. Some behaviours are an attempt by the person to create a comfortable environment and avoid their senses becoming overloaded.

“There’s a test if you can’t hear enough but there is no test if you hear too much, being over sensitive to noise is like having the radio turned up too loud all of the time, when people shout it hurts my son’s ears” (Parent).

Difficulties with coordination can cause clumsiness or unusual movement, such as odd posture or walking on tip toes, which can be misunderstood as attention seeking behaviour.

Remember, all behaviour has a purpose although sometimes it can take time to understand.

What can be done to make things better?

Does a particular behaviour really need to change? If the behaviour is mild there may be no need for action. If it poses a risk to the person concerned or to others or prevents a person from developing, then steps need to be taken. However, it is important to recognise that all behaviours have a function and that if a behaviour is removed then a suitable alternative will be needed.

It can be useful to keep a 'behaviour diary' to help identify what causes the behaviour. It can then be easier to develop ways to deal with it.

For example, if the person is always upset in a particular place where there are bright lights or a humming background noise, it may help to change or avoid the place if possible. If this is not possible other things may help such as tinted glasses or ear defenders.

If the person is unsure how to respond to different people or social situations it may help to create a 'social story,' a short story (often with pictures) which explains who they will meet or what will happen beforehand, so that they know what to expect and more importantly what to do in response. Role playing a situation beforehand can help the individual practice this response but they may not always wish to do so.

There is a wealth of information available for families in terms of understanding and managing behaviour. See the Further Resources chapter for more information.

What support is there?

Understanding and awareness of autism is increasing, meaning that services and support for people with autism are slowly becoming more widely available. Often, different services are available in different areas.

Help from Social Services

The role of social services is to help people who need support. People with autism and their carers are entitled to have an assessment of their needs carried out by the local social services department. As a result of the assessment, there may be an entitlement to:

- day services, residential services, or housing;
- home help or respite care;
- aids, equipment or grants for housing adaptations;
- services for carers if the carer is judged to need them.

Help from the Local Health Service

Relevant health professionals include doctors, CAMHS (Child and Adolescent Mental Health Services), health visitors, psychologists, occupational therapists, speech and language therapists, psychiatrists and community nurses. They can offer support with:

- counselling;
- psychiatric help;
- speech and language therapy;
- physical and sensory difficulties;
- behaviour management;
- diet, sleep, toileting difficulties.

These services are accessed through the NHS following a referral from a doctor, social worker or school.

Help with education

Children with autism may go to mainstream schools, special schools, autism-specific schools, or mainstream schools which have a specialist teaching base attached to them.

Children with autism who have special educational needs (SEN) are entitled to receive extra help at school. This may be provided by the school or, if the child's needs are more complex, will be funded by the local authority.

The child may already be receiving extra help in school, but if not and the family or teachers think this is needed; a further assessment of their needs may be carried out. SNAP Cymru offers information and support to families of children with special educational needs.

Working closely with your child's school will help raise awareness of autism and you may also be able to signpost staff to additional training or resources.

Help from voluntary organisations

There are a number of charities that may be able to offer help and support. These may be autism specific and non-autism specific charities and families can contact these organisations directly. The internet, local libraries and doctors' surgeries are useful places to find information.

Benefits and other support

A range of benefits are available to families and people affected by autism. They include:

- Disability Living Allowance (DLA).
- Carer's Allowance.
- Child Tax Credit.
- Income Support.
- Housing/Council Tax Benefit.
- Working Tax Credit.
- Employment Support Allowance (ESA).

The benefits and the amount a person is entitled to will depend on the individual circumstances.

There are a range of other schemes which families may be able to access. These include:

- Blue Badge car parking permits - Contact the local social services team.
- Disabled toilet key scheme (RADAR) - Web: www.radar.org.uk
Tel: 020 7250 3222.
- Motability - Web: www.motability.co.uk Tel: 0845 456 4566.
- Cinema Card - Web: www.ceacard.co.uk Tel: 0845 123 1292
- Disabled Persons Railcard -
Web: www.disabledpersons-railcard.co.uk Tel: 0845 605 0525.
- Extra nappies for 3 year olds and upwards -
Ask a health visitor/local authority.
- The Family Fund - Web: www.familyfund.org.uk
Tel: 0845 130 4542.
- Other concessions - In some areas there may be travel/leisure concessions for people who receive DLA. Contact the local social services team.

Complaints

If families are unhappy with any aspect of assessment, service or support including availability, they have the right to complain to the organisation. Families can also ask for help and advice from places like the National Autistic Society, SNAP Cymru and Citizens Advice Bureau.

Useful Links and Further Resources

Links within Wales:

Join a support group

There are many excellent support groups and societies operating across Wales. Joining a local group can help families keep up to date with news and useful local information. It is also a good opportunity to receive information and support from other people

affected by autism. The NAS Autism Helpline (0845 070 4004) or the NAS Autism Services Directory can help families locate their nearest support group.

Keep learning

There are lots of opportunities through a variety of organisations to hear people with autism talk about their experiences, and to attend seminars, workshops and training programmes. Many Local Authorities and Local Health Boards in Wales run local autism training opportunities.

There are also many online resources:

www.awares.org - The All Wales Autism Resource (AWARES) provides details of a wide range of useful resources for people in Wales, including events and learning opportunities. Every autumn this website also hosts the world on-line autism conference which attracts contributions from many of the world's leading 'autism' educators, researchers, clinicians, family members and individuals with an ASD.

www.autism.org.uk - The National Autistic Society website includes a wealth of information about behaviour, communication and play, benefits, diagnosis, and practical tips for parents, as well as training opportunities. There are a wide range of free factsheets available for download and also publications available to purchase from the National Autistic Society by visiting www.autism.org.uk/shop

www.autistica.org.uk - the website of this autism research funding charity includes a range of information on biomedical research to bring benefits to individuals and families affected by autism spectrum disorders.

www.thegraycentre.org - Information and resources relating to social stories and comic strip conversations.

www.do2learn.com - Games, songs, communication cards, print resources and information for special needs.

www.pecs.com - Information about the widely-used Picture Exchange Communication System.

www.contactfamily.org.uk - Contact a Family is a UK wide charity that provides support and information for families with a disabled child.

www.snapcymru.org - SNAP Cymru is a charity in Wales offering information and support to families of children with additional learning needs (ALN).

There are also many good books, booklets and DVDs which will help increase your understanding.

- In April 2008, the Welsh Assembly Government published the world's first government action plan for autism and this strategy has led to a local ASD being identified within every local authority area in Wales. You can find out who your local ASD lead is by contacting your local social services dept or by contacting the Welsh Local Government Association (tel 02920 468600). The WLGA is the home for three ASD regional support officers who will also be able to give you the information you require. Make sure you receive by email regular copies of the WLGA ASD Strategic Action Plan newsletter, which updates autism progress and practice throughout Wales, simply give you email address to the WLGA ASD Regional Support Officers (ASDinfo@wlgaco.uk)
- Also in Wales from 2010 the Wales Autism Research Centre (WARC) located in the School of Psychology, Cardiff University. The Director of the autism research team is Professor Sue Leekam, Chair in Autism. The research centre's website is www.cardiff.ac.uk/psych/home2/warc/

Other Information for parents

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Ives, M. and Munro, N. (2002) *Caring for a child with autism: a practical guide for parents.* London. Jessica Kingsley Publishers.

Richman, S. (2006) *Encouraging appropriate behaviour for children on the autism spectrum: frequently asked questions.* London. Jessica Kingsley Publishers.

Information for siblings

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Information for partners

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Specific resources that were used are:

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- The National Autistic Society web-site resources.
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