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Introduction

Autism spectrum disorder, which is often referred to as ASD, is the term used to describe a group of disorders that includes **autism**, **Asperger's syndrome** and **pervasive developmental disorder** (also known as atypical autism). Autism is the most commonly occurring form of ASD.

The symptoms associated with ASD appear early in a child's development and this is why it is considered to be a 'developmental disorder'. The term 'spectrum' is used because it describes the wide variety and differing levels of severity of symptoms found in children with ASD. For example, two children could be diagnosed with ASD, yet one may have an intellectual disability, no spoken language and be considered low functioning; whereas the other may have average or even above average intelligence, appear to have normal speech and be considered high functioning.

Some experts think that Asperger's syndrome is a high-functioning form of autism. Others believe there is no difference because these disorders share the same characteristics and similar difficulties. What is important is that the general approach to treatment for both these disorders is the same, with specific treatment being tailored to the needs of the individual.

Recent research suggests that on average, one in 160 children will be diagnosed with ASD, with boys outnumbering girls four to one. Approximately 75 per cent of children with a diagnosis of ASD are of low intelligence, while around 10 per cent may demonstrate high intelligence in specific areas such as mathematics or computer studies. A very small number have a remarkable ability in a specific area, for example musical skills or memory.

This Tip Sheet provides information for families and carers about ASD and tips for managing the difficulties individuals with ASD often experience.

What difficulties do individuals with ASD experience?



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Children and adults with ASD have difficulties that are usually grouped into three areas.

1. Verbal and non-verbal communication

Communication skills vary depending on the intellectual and social development of the individual child or adult. Some people with ASD have little, if any, speechand others appear to have normal speech. However, those that do have speech often find it difficult to communicate effectively.

For example, a person with ASD may say odd and inappropriate things, repeat verbal statements made by another person (called 'echolalia'), talk about one specific topic for long periods of time with no awareness that others have lost interest, or say things that are not relevant to the current conversation. The unusual communication style of those with ASD can sometimes lead to children and adults with ASD being the victims of bullying.

In addition, those with ASD may find it difficult to keep eye contact with others and understand non-verbal communication such as facial expressions and hand gestures including pointing. They often do not respond when others are talking to them and in some instances may not react to their own name.

2. Social awareness and interaction

Children and adults with ASD often have difficulty following social rules, which may make them appear unfriendly. For example, they tend to avoid looking at the person talking and do not appear to be listening. When interacting with others, those with ASD may not follow common social behaviours. For example, they may touch and even lick others, or make blunt and impolite comments.

3. Activities and interests

Children with ASD rarely play games or engage in imaginative play (e.g., playing make believe). Instead, they may use toys and other objects in unusual ways (e.g., lining up objects, spinning and flicking objects). They can become obsessed with an item such as a piece of string or a pencil and carry it around constantly, and may collect objects (e.g., stones, sticks, batteries). Both children and adults with ASD may also be more sensitive to touch and the taste or texture of some foods. Examples of this include rejecting a family member trying to give them a cuddle or insisting that all labels are cut off their clothes because the touch of them on their skin is unbearable. Some people with ASD may also act as if they are insensitive to pain or changes in temperature so they may put their hand directly into a flame. They also dislike change and being in new situations. They may also show odd behaviour such as acting as if other people don't exist, or doing things that cause them injury. Examples include repetitive hand-flapping, spinning, rocking, walking on their toes and biting themselves. Behavioural problems including temper tantrums and aggression are also common.

The severity of difficulties in these three areas varies across individuals. For example, a high functioning person with ASD may have milder difficulties such as a fixation with certain topics of conversation and difficulty understanding facial expressions or gestures. In comparison, a low functioning person may have no verbal language, engage in self-injuring behaviour such as repeatedly banging his or her head against the wall, and need constant support in everyday activities such as dressing and preparing a meal.

People with ASD are also more likely to develop mental health problems. Both children and adults with ASD often experience stress and anxiety caused by their difficulty in dealing with change and unpredictable situations. They are also at risk of developing depression, especially in late adolescence and early adulthood. Because people with ASD often have difficulty understanding and communicating their own feelings (including anxiety or distress), these problems

might not be picked up.

Children and adults with ASD may also experience sleep problems. Children in particular may have difficulty going to sleep, continue to be active through the night, wake frequently and sleep much less than expected for their age.

What causes ASD?

There is no clear explanation about what causes ASD. However, family studies have shown that genes play a role. For example, if one identical twin has autism then the other has around a 75 per cent chance of also having autism. In nonidentical twins, there is a five to eight per cent chance that both twins will have autism. ASD also tends to occur more often than expected among people with certain medical conditions. Researchers are investigating the link between children whose mothers had problems during pregnancy or delivery, as well as the contribution of viral infections, dietary imbalances, and exposure to environmental chemicals.

What signs might suggest someone has an ASD?

Typically, ASD is identified before a child starts school and many children are now diagnosed from a very young age. Usually parents, a health professional or a childcare worker will have noticed something unusual in the child's development. Examples include failure to respond with appropriate social behaviours such as smiles or other facial expressions, poor language development, and a lack of other forms of communication such as pointing and waving. Some children are not diagnosed until they are at school, with concern often raised by teachers. Less commonly, a diagnosis may occur in late adolescence or adulthood. Those diagnosed at an older age are generally higher functioning and have less severe symptoms. However, they still experience social, communication and behaviour difficulties.

Assessment for ASD diagnosis and treatment

Because many of the behaviours associated with ASD are also present in other disorders, a medical assessment is important so that other possible causes of these difficulties (such as a hearing problem) can be ruled out. A diagnosis of ASD in children generally occurs after a thorough assessment by a team of health professionals. An assessment team is usually made up of a psychologist, a speech pathologist, and a paediatrician or child psychiatrist, and can provide information needed to make decisions about approaches to treatment. A diagnosis in adults can be made by either a psychologist or psychiatrist experienced with ASD.

The information that health professionals will need in order to make a diagnosis and to plan treatment will come from a range of sources. This will include from relevant medical tests such as hearing and eye tests, interviews with parents and other caregivers to gain information about development and significant life events, and assessment of intellectual ability, communication and motor skills. Assessment of communication will include looking at how language is developing as well as how the person uses language to communicate. Assessment of motor skills will include looking at both fine motor skills such as holding a pencil and picking up small objects as well as at gross motor skills such as jumping and running. In assessment of children in particular, observations of behaviour in a range of settings such as at home and school typically occur.

Possible outcomes for individuals with ASD

With appropriate treatment it is possible for people with ASD to become active

members of the community. However, some will require high levels of support and lifelong care and supervision. Research shows that children with ASD can greatly improve when treatment is provided early on in the disorder. With early intervention all children will improve and up to one third make very good progress.

Because ASD is a lifelong disorder, individuals with ASD may need further treatment and assistance as they face new challenges during adulthood. Adults with ASD who are low functioning need constant care. They generally live at home with their parents or in residential facilities where their needs can be met. Adults with high functioning ASD often lead relatively normal lives including working to support themselves and living on their own. The ability of an adult with ASD to manage a job, home duties, and finances is determined by the severity of their symptoms, their level of education and training. An understanding of the difficulties these adults experience by those around them can make a big difference to their ability to cope in different situations.

How is ASD treated?

No single treatment program has been found to be successful in treating all individuals with ASD. Health professionals plan treatment to match the person's particular needs, their strengths and difficulties. In treating ASD in children it is important to begin the treatment early on in the disorder, plan a treatment program to meet the child's needs, treat both behaviour and communication problems, and involve parents and other primary caregivers. Early intervention focuses on teaching social skills, developing motor and communication skills, reducing problem behaviours (e.g., emotional outbursts, head-banging, interrupting) and promoting positive behaviours (e.g., turn-taking in social situations).

Medication is sometimes used to improve attention span or reduce unwanted behaviours, such as hand-flapping. However it is important to explore other ways of reducing these behaviours because some medications have harmful side effects, especially if taken over a long period of time. Psychological treatment, including behavioural interventions has been shown to improve the functioning of people with ASD. Mineral and vitamin supplements and special diets might also be used but there is no scientific evidence to support their effectiveness in treating ASD.

When seeking treatment it is important to consider treatments that have scientific evidence supporting them. There is a long list of possible treatments for ASD, some of which have no evidence to show that they work. Effective treatment programs for ASD should include psychological treatment to address difficulties in behaviour and attention and promote the development of language and communication and social skills.

Tips for helping individuals with ASD

It is important to seek professional advice about suitable treatment strategies for people with ASD. The age of the person, and the severity of their difficulties are both important factors to consider when deciding on what can help. Listed below are some strategies that can be put in place to assist parents and other carers of people with ASD.

Provide a reasonable level of daily structure through the use of a daily or weekly diary and prepare the person for any changes to their routine. When a significant change is going to happen, spend time prior to the event talking to the child or adult about what is going to happen and ensure that they have support to manage any anxiety. This may help them cope with change more easily.

Give a step-by-step list of instructions for completing everyday activities,

such as getting ready for school or taking a shower. A wall chart with pictures illustrating each step can be a good way to present this information. This can be helpful for higher functioning children and adults.

Develop a regular routine for the day including set times for meals, activities and sleep. Once a routine is in place, avoid changing it if possible. Children and adults with ASD can become extremely upset if their routine is changed.

Provide instructions in simple language allowing time for the individual to absorb the information and respond. Try not to use phrases such as "pull your socks up" or "it's raining cats and dogs" because people with ASD often take things literally. If an appropriate response is not given it is helpful to check that the person has understood.

Provide visual cues such as pictures or a story outline to support communication. For example, when giving instructions or setting up a daily diary use pictures to demonstrate tasks and to help understanding.

Teach and practise social 'rules' such as turn-taking and how to greet people, and provide opportunities for the individual to interact with others. Strategies such as role-plays can be a useful way of helping the person to learn new social skills.

Seek help when family issues arise. Raising a child or supporting an adult with ASD can be difficult and stressful. Family assistance and treatment can improve outcomes for both the person with ASD and those around them.

Other resources

Helping Children with Autism initiative

In 2008 the Australian Government Department of Health and Ageing announced a number of initiatives to support the assessment of and early intervention for children with ASD. More information on these initiatives, who is eligible and how they can access the various services, can be found at www.health.gov.au/internet/main/publishing.nsf/Content/mental-autismfactpar.

Autism associations

Australian Capital Territory	New South Wales
Autism Asperger ACT	Autism Spectrum Australia (ASPECT)
Phone: 02 6290 1984	Phone: 02 8977 8300
<u>www.autismaspergeract.com.au</u>	<u>www.autismspectrum.org.au</u>
Northern Territory	Queensland
Autism NT	Autism Queensland
Phone: 08 8948 4424	Phone: 07 3273 0000
www.autismnt.com.au	www.autismqld.com.au
South Australia	Tasmania
Autism SA	Autism Tasmania Inc.
Phone: 1300 288 476	Phone: 03 6278 9985
www.autismsa.org.au	www.autismtas.org.au

Victoria	Western Australia
Autism Victoria	Autism Association of WA
Phone: 1300 308 699	Phone: 08 9489 8900
<u>www.autismvictoria.org.au</u>	www.autism.org.au

Seeking professional assistance

If you feel that you, or someone you know, would benefit from professional assistance to address problems associated with ASD, you can contact an APS psychologist. An APS psychologist trained in developmental psychology and assessment has expert knowledge in the assessment and treatment of ASD. They can also help individuals manage other problems that may be associated with a diagnosis of ASD such as anxiety, depression, behaviour problems, relationships and workplace issues.

The Australian Psychological Society Autism and PDD Provider List

This list identifies psychologists across Australia who have expertise in the assessment and intervention of ASD: www.psychology.org.au/medicare/autism.

To talk to an APS psychologist, speak to your GP or medical specialist about a referral or phone the APS Find a Psychologist Service on 1800 333 497. Alternatively, you can locate a psychologist in your area by visiting the APS Find a Psychologist Service website -<u>www.findapsychologist.org.au</u>.

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