

Autism Information Sheets (1 of 2) – to be included in the Personal Health Records of people who have been diagnosed as having an Autism Spectrum Disorder (Pervasive Developmental Disorder)

The material in this sheet has been adapted from the Therapeutic Guidelines book 'Management Guidelines for People with Developmental and Intellectual Disabilities' and updated from the 2005 version, Management Guidelines – Developmental Disability' which can be consulted for more detailed information.

Autism spectrum disorders are life-long neurodevelopmental disabilities with onset before the age of 36 months and characterised by:

- impairments in reciprocal social interactions
- impairments in verbal and non-verbal communication skills
- stereotyped behaviour, interests and activities

All people with autism have some degree of difficulty in these three main areas (the diagnostic criteria).

AETIOLOGY (CAUSE)

Autism spectrum disorders represent an abnormality of brain development and function, appearing within the first three years of life. Although the detailed causal mechanism(s) are not known, autism is likely to have multiple aetiologies including genetic factors. Family and twin studies indicate the most common cause is likely to be genetic. A range of studies has found that there may be an associated medical condition (e.g. tuberous sclerosis, epilepsy) in 10-37%.

The **incidence** of autism spectrum disorders varies between studies but is approximately 2-4/1000. Both autism and Asperger syndrome are more commonly diagnosed in males than females. There has been an apparent increase in prevalence, probably due to better recognition of the condition.

PRESENTATION

Although the clinical picture varies from person to person depending on such factors such as severity, age, sex, IQ and personality and there is a wide range of overlapping presentations, the three most commonly diagnosed **types of autism** spectrum disorders are:

- Autistic disorder
- Asperger's disorder
- Atypical autism

1. Autistic Disorder

This is the best known disorder, sometimes designated as classical or childhood autism. It involves the following three core diagnostic areas.

Impairments of Social Interaction

These impairments can present in a variety of quite different ways, including:

- aloofness and failure to develop friendships
- seeking people's company but lacking ability to engage in two-way social interactions
- stilted, one-sided or repetitive social interactions
- being socially passive while tolerating social approaches
- awkward, avoidant or indifferent eye contact (unless eye-contact has been taught)
- not being able to understand social rules e.g. make socially embarrassing comments unintentionally
- impaired understanding of other people's motivations, perspectives or feelings
- markedly impaired use of non-verbal behaviours to regulate social interaction e.g. gestures and facial expression
- lack of spontaneously seeking to share enjoyment with others

Impairments of Communication and Play

Impairments are in the development and use of communication and include:

- a delay in or lack of development of speech without any compensatory forms of communication e.g. gesture or mime
- significant difficulty in initiating and sustaining a conversation (in those with speech)
- stereotyped or idiosyncratic use of language
- lack of imitation of others

In children, play lacks the varied or make-believe qualities appropriate to the developmental level.

Restricted or Repetitive Interests and Activities

Interests and activities are often restricted, repetitive and stereotyped. These characteristics may include:

- interests that are excessively narrow, intense or unusual
- adherence to rigid routines
- intolerance of change
- stereotyped and repetitive motor mannerisms e.g. hand flapping
- persistent preoccupation with parts of objects

Other Commonly Associated Features

Intellectual disability occurs in 70% of people with autistic disorder. The remaining 30% who have normal range intelligence are sometimes called “high functioning”, yet frequently experience major difficulties in functioning independently. On intelligence testing, the profile may be uneven with advanced visuo-motor skills and delayed verbal performance.

Autistic disorder is more common in **males** than females (3:1). **Epilepsy** is common (up to 30%) and can develop at any age. Many individuals with an autistic disorder demonstrate unusual sensory responses such as sensitivity or aversion to particular sounds or tactile sensations, intolerance of particular foods, or fascination with spinning objects or lights.

Autistic children and adults form affectionate attachments to those they know well, and experience sadness and grief after loss or bereavement. They may develop **behaviour disorders** e.g. angry outbursts, self-injurious behaviour, feeding difficulties/fads, sleep problems, and overactivity (particularly as children). **Anxiety** due to poor communication skills, over-stimulation and the lack of predictability in the environment may underlie many behavioural problems.

2. Asperger's Disorder

Asperger's disorder is diagnosed by the presence of social interaction impairments and repetitive and restricted interests as described in Autistic Disorder above. There is usually **no significant language delay**. However, subtle impairments in the social use of language are present and often disabling, e.g. by leading to teasing and social isolation.

Typical characteristics of Asperger's disorder are:

- normal or borderline intellectual ability
- clumsiness
- concrete, pedantic speech
- lack of common sense
- normal or even precocious speech development
- better verbal than non-verbal skills on psychological assessments
- intolerance of change
- anxiety

People with Asperger's disorder often want friendships but lack the skills to make and maintain them. This disorder is more common in males (13:1), but may be underdiagnosed in females.

3. Atypical Autism

This diagnostic grouping is used when core autistic behaviours are present but the criteria for autistic disorder are not fully met. Management follows the same principles as for Autistic Disorder.

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MAKING A DIAGNOSIS

The accurate diagnosis of autism spectrum disorder is important for a number of reasons:

- Parents often suspect that their child is "different". Through assessment, they can understand their child's needs and strengths better.
- Early intervention and appropriate educational programs can be planned.
- Access to specialist and other support services can be facilitated.
- Undiagnosed adults without significant intellectual disability often find a diagnostic assessment is helpful in explaining their experience and enabling access to supports.

Note: Diagnosis requires specialist skills. There are no medical or psychological tests that clearly differentiate people with autism spectrum disorders from the general population. The diagnosis depends on a **clinical assessment** by an experienced clinician using a variety of tools to assess the presence of the three diagnostic criteria and the age of onset. Diagnosis in adulthood can be challenging.

HEALTH ISSUES

Physical and mental health problems may easily be missed in a person who has limited ability to communicate about symptoms and feelings or who has a reduced pain threshold.

Be Aware

Deterioration in behaviour may be due to causes other than the person's autism, such as a physical problem (e.g. middle ear infection), epilepsy, mental illness, family or school stress or changes in routine.

BEHAVIOURAL ISSUES

Common difficulties encountered by parents include the management of:

- difficult behaviour e.g. obsessions, tantrums and aggression.
- communication problems e.g. repetitive speech, echolalia.
- disturbed sleep and fussy eating.
- socially inappropriate behaviour or social isolation or experiencing teasing and bullying.

Referral to appropriate services may be necessary. Experience has shown that early, intensive intervention produces the better outcomes for children with autism.

USE OF MEDICATIONS

No medications currently available treat the core symptoms of autism spectrum disorders. However, medication can occasionally be used for symptomatic control if behavioural treatment and environmental modification have failed, and if the benefits of medicating outweigh the costs.

The use of psychotropic drugs***** in this population requires specialist psychiatric consultation. Some examples of medications used are presented here. (revise this section)

- Anxiety states are best prevented or reduced by environmental modification or behavioural and communication strategies. However, buspirone may be used in highly anxious adults. Benzodiazepines should be avoided.
- Haloperidol at low doses e.g. 0.25 - 6.0 mg per day in children and 1.0 - 10.0mg per day for older adolescents and adults can improve stereotypies, hyperactivity, aggression and discriminant learning. However, the rate of haloperidol related dyskinesias is 30%. Short-term use only is advised.
- Stimulant medication may be helpful for young people with autism who have clear-cut comorbid Attention Deficit Hyperactivity Disorder.
- The antidepressants fluoxetine and clomipramine have been used in adolescents and adults with repetitive behaviours. Their effect is unpredictable.
- Psychotropic treatment for co-morbid psychiatric disorders requires psychiatric consultation. A trial of antidepressant medication may be helpful if a clear-cut depressive disorder is present.

PSYCHIATRIC DISORDERS

Emotional and behavioural problems are common in people with autism spectrum disorders, but the exact prevalence is not known. Depression, anxiety disorders and psychosis may emerge during adolescence and continue into adulthood, requiring psychotropic medication and psychological treatment.

LONG TERM OUTCOMES

Children with autism do not grow out of the disorder, although symptoms change and often improve with age. The onset of epilepsy can compromise progress in adolescence. Outcome is partly dependent on overall intelligence and the development of language abilities and social skills. The best outcomes are seen in individuals with normal range IQs and spoken language by age 5 years. The majority of adults remain heavily dependent on their families or support workers throughout life although some do achieve social independence.

REFERRALS, SERVICES AND RESOURCES

The following services can be helpful for individuals with an autism spectrum disorder and their families.

- Early intervention services (children 0 to 6 years).
- School age children may access school psychological services, specialist autism services, government Disability Services, and relevant medical services such as paediatrician or psychiatrist.
- Adults may access autism specific services. When an intellectual disability is also present, Disability Services can be accessed.
- Other useful services include respite care, home help, and social skills and work-preparation courses for adolescents and young adults. Information about these services may be obtained from the local government disability services and local Autism or Asperger's Disorder organisations.

Useful advice and support can be obtained from the State autism associations.

State Autism Associations - details correct as of May 2005	Telephone numbers	Web addresses
Autistic Children's Association of Queensland	(07) 3273 2222	http://www.autismqld.asn.au
Autistic Association of NSW	(02) 8977 8300	http://www.autismnsw.com.au
Autism Association of the ACT	(02) 6286 8887	http://www.autism.anu.edu.au
Autism Victoria	(03) 9885 0533	http://www.autismvictoria.org.au/home/
Autism Tasmania	(03) 6423 1086	http://www.autismtas.org.au
Autism Association of Western Australia	(08) 9489 8900	http://www.autism.org.au
Autism Association of South Australia	(08) 8379 6976	http://www.autismsa.org.au

Australian and overseas Autism-related internet web sites provide a wealth of up to date information.