

# Autism and the autistic spectrum disorders

**Most children with an autistic disorder will need lifelong support and assistance, as will their families. Although there is no treatment that will 'cure' the underlying disability, much can be done to assist the child and the family.**



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The autistic spectrum disorders are a group of developmental disorders characterised by marked impairment in three areas of development. These areas of development are crucial for functioning in human society:

- social understanding and interaction
- language and communication
- the ability to develop functional play, interests and activities.

These disorders, once thought to be rare, are now relatively common, but with marked individual variation.

In the last decade or so, numerous theories on the causation and treatment of these conditions have arisen and been widely propagated so that many parents are confused about the most effective way to help their child. This article reviews the current knowledge of this puzzling and frustrating group of disorders, and aims to assist the family

doctor in supporting affected children and their families.

## Definition and concept of an autistic spectrum

The term 'infantile autism' was coined by Kanner in 1943 to describe a group of 11 children with absent or poor speech, marked social withdrawal, and repetitive play and motor mannerisms. Over the next decade or so, the disorder became increasingly recognised, and Kanner and others (especially Rutter) developed a set of diagnostic criteria.

At almost the same time (1944) Hans Asperger, in Germany, published a case series of older children with markedly poor social interaction, speech used mainly in 'monologues', and intense preoccupation with specific nonfunctional routines or interests. To this disorder he gave the name 'autistic

## IN SUMMARY

- The autistic spectrum disorders are characterised by marked impairment in social understanding and interaction, language and communication, and the ability to develop functional play, interests and activities.
- The main distinctions between autism and Asperger's syndrome are that in the latter there is no major delay in early speech development and intellectual ability is within the normal range.
- There is little evidence to support gastrointestinal disturbance as a major contributing factor to autism.
- Doctors can reassure parents that there is no credible evidence linking childhood immunisations to autism.
- The treatment of the child with autism is essentially educational and behavioural, starting as soon as the diagnosis is made.
- Even with some effective language and IQ within the average range, most autistic children will require lifelong support.

psychopathy'; however, not surprisingly, his work was not widely recognised at the time.

In 1981, Uta Frith translated and republished Asperger's work, drawing attention to this group of children who had problems suggestive of autism, but with better speech development and general ability than was then accepted as diagnostic of autism. Lorna Wing further elaborated on these findings, suggesting the idea of a 'spectrum' of clinical presentations, from the child with severe classical autism – mute, isolated, with repetitive motor mannerisms – to the child or adolescent with good speech but no reciprocal social interactions and odd, persistent preoccupations and interests. Moreover, there may be variation in the same child over time, so that a child may present early in life with typical autism, but in later school years have characteristics closer to those of Asperger's syndrome. Such children are often referred to as having 'high-functioning autism'.

*The Diagnostic and Statistical Manual, 4th Edition* (DSM-IV) gives criteria for three disorders:

- Autistic Disorder
- Asperger's Disorder
- Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS).

The WHO's *International Classification of Disorders, 10th Addition* (ICD-10) makes a similar distinction under the headings of 'Typical Autism' and 'Atypical Autism'.

The main distinctions between autism and Asperger's syndrome are that, in the latter, there is no major delay in early speech development and intellectual ability is within the normal range.

PDD-NOS is diagnosed when an individual meets many, but not all, of the criteria for autism or Asperger's syndrome, and, thus, is somewhat vaguely delineated.

## Characteristics of autism: 'the triad of impairments'

### Impaired social interaction

The child with autism often appears aloof or detached; avoidance of eye to eye contact is usual, with the gaze often tangential or 'looking through' the adult. The child may appear affectionate with parents and immediate family, but usually ignores other adults and children. Some children, especially the more able ones, may make initial eye contact and even smile at others,



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but when the adult reciprocates, the child drifts away from further engagement.

The child does not bring items to others to show or share, and has trouble with turn-taking. Often the child does not understand that others can help if he or she needs it: simple difficulties (such as a puzzle piece not fitting) can result in a screaming tantrum, the child being unable to seek help even from his or her parents.

### Impaired communication

In children with 'typical' autism, speech development is delayed. There may be no speech, but the child may use strange sounds, hum or sing to him- or herself, or make other noises. When speech does develop, it is seldom used for real communication;

continued



Figure 1. A 14-month-old child pointing to draw attention to an item of interest. Failure of this important gesture may be the first subtle sign of autism.

there may be phrases and words ‘imported’ from television or films, produced out of context and without meaning or put to some other use. One child known to me always used the phrase ‘Negative, Captain’ (from *Star Trek*) to signify ‘No’. Echolalia is very common.

There are some unusual patterns of speech development: some children seem to have a reasonable vocabulary at 18 months but do not develop further speech and cease to use those words they have. Others have a quite impressive vocabulary recorded, but they may have used most of the words, or even phrases, on only one occasion.

A striking aspect of the speech delay in autism is the absence or scarcity of non-verbal communication to compensate for reduced speech. This may be evident well before the concerns about speech delay are felt. Researchers in Cambridge, England, have shown that failure in very young children (younger than 18 months) to develop the gesture of pointing to indicate an



Figure 2. Toys lined up in an outdoor play area, regardless of the function of the toys. A child with autism left this arrangement in our clinic’s play area.

object of interest may be an early indicator of autism (Figure 1).

In children with Asperger’s syndrome, early speech develops normally, but is rarely used conversationally, and is often stilted or contains odd rhythms, syntax or pronunciation.

### Restricted patterns of play, interests and activities

Children with autism show a fixation with particular activities and often cannot be moved on from these. In those with severe autism this may take the form of repetitive motor mannerisms, such as twirling themselves around, flapping hands or posturing their fingers. Other children may be fascinated with a single activity, such as watching the wheels of toy cars or trucks or watching the same video (*Thomas the Tank Engine* is a favourite) repeatedly for hours on end. A child may persist in lining up all toys, regardless of their nature or purpose (Figure 2).

A major characteristic of autism is the lack of development of social role or symbolic play, which becomes obvious from 2 years onwards in typically developing children (Figure 3).

Children with Asperger’s syndrome become obsessed with one topic, such as dinosaurs, which they will talk about to the exclusion of all else.

In both autism and Asperger’s syndrome, children often have a preoccupation with fixed routines and rituals, and with maintaining ‘sameness’ in many aspects of life. Minor changes, such as a different route to preschool, a different cup, or a change in the arrangement of their room, can lead to severe tantrums.

In about 50% of children with autistic spectrum disorders, there is a marked faddiness of diet, with resistance to new foods; a different texture of food or even a change in the packaging of a food can lead to refusal to eat.

### Prevalence

The first studies of the prevalence of autism in the 1960s and 1970s suggested that autism was an uncommon disorder: the prevalence rate in most studies was about 4/10,000 children. However, studies in the last two decades have shown a much higher prevalence. In a recent overview of 32 studies conducted between 1966 and 2001 in 13 countries, Fombonne reported that the ‘base rate’ of prevalence for autism is about 10/10,000 children, while the rate for all ‘pervasive developmental disorders’ is 27.5/10,000, but may be as high as 60/10,000. However, he concluded that this apparent increase in prevalence could be explained by changes in the definition and diagnostic criteria, especially in the widening of criteria since the original observations were made.

A consistent finding in all studies is the striking preponderance of males affected; roughly four boys are affected for every girl.

The increased prevalence documented recently has been greatly publicised in the media and has generated numerous theories of causation, which in turn have had an impact on treatment.

### Causes of autism

For the first two decades or so after autism had been defined, it was widely believed that the disorder represented an extreme emotional reaction to aberrant

parenting, especially an absence of loving attachment by the mother. In the 1960s and 1970s, however, cumulative evidence showed that autism was a neurodevelopmental disorder. Defining precise causes, or, more accurately, causal pathways, has proven more difficult and elusive; nevertheless, current research has shed some light on possible mechanisms.

### Genetic anomalies

In a small proportion of cases there is a recognised genetic anomaly, either a chromosomal abnormality or a single-gene disorder. These anomalies include tuberous sclerosis, fragile X syndrome, phenylketonuria (before treatment was available), and duplications of chromosome 15q11-q13. In most of these disorders, autism is part of a clinical picture that includes moderate to severe intellectual disability, epilepsy or other neurological or physical disabilities.

These recognised disorders account for less than 10% of all cases of autism. Most children and young people with autistic disorders are physically well, handsome and (apart from a degree of intellectual disability in some cases) without other neurological impairment. However, there is substantial evidence that, even in these children, genetic factors underlie the disorder.

The evidence for genetic involvement has come from twin studies, family studies, linkage analysis in families with multiple cases, and some studies using information from the human genome research. Several candidate sites have been suggested on a number of chromosomes. These include 7q, 16p, 18q, and 19p, in addition to the abnormalities of 15q already noted.

Recently, it has been suggested that:

- the autistic phenotype may depend on the inheritance of a number of genes concurrently
- each characteristic of an autistic disorder is the expression of a different gene
- it requires a combination of as many

as 10 or more of such genes to lead to an autistic spectrum disorder, the number and nature of the genes accounting for the wide variability of these disorders.

### Environmental influences

The possibility of gene–environment interaction is certainly plausible and has fuelled a great deal of speculation, especially in view of the apparent increase in prevalence of these disorders. However, to date no specific environmental influences have been found to play a major part in the pathogenesis of autistic disorders. Some of the hypotheses on environmental influences have led to the promotion of certain treatments for autism, so are worth examining for any substantiating evidence.

### The gastrointestinal tract

Several authors have hypothesised a connection between gastrointestinal tract (GIT) disturbance and autism. The broad hypothesis suggests that a primary immune-mediated GIT disturbance results in inflammatory reaction and increased permeability ('leaky gut'). This leads to the absorption of dietary peptides, especially those derived from cow's milk and gluten, which have an effect on the vulnerable developing brain, either directly or through immunological reactions.

Wakefield and colleagues described endoscopic findings suggesting a specific inflammatory disorder with ileal lymphoid hyperplasia, which they named 'autistic enterocolitis', and other workers described GIT disorders in children with autistic disorders. However, these studies lacked age-matched controls and the symptoms were nonspecific, comprising mainly constipation or recurrent diarrhoea, which are not uncommon in young children in the general population. One study, by D'Eufemia and colleagues, did demonstrate possible increased GIT permeability to a sugar challenge in autistic subjects compared with controls, but suggested

that this was nonspecific, as the same finding has been made in other disorders.

A major nested, case-control study by Black and colleagues in 2002 compared 96 young children with autism with 449 matched controls and found the same incidence of GIT disorder (9%) in both groups. They concluded that there is little evidence to support GIT disturbance as a major contributing factor to autism.

### Immunisation

In a now notorious paper in *The Lancet* in 1998, Wakefield and colleagues postulated that the enterocolitis found in children with autism might have resulted from the measles–mumps–rubella (MMR) vaccine. This hypothesis was promptly publicised widely in the nonmedical media (as a result of a press conference to 'launch' the paper), and has been blamed for a decrease in the rate of MMR immunisation in the UK. There have now been many epidemiological studies that have found no connection between MMR immunisation and autism, but many parents still express anxiety about this. A conclusive study from Denmark has shown that the incidence of autism is the



Figure 3. Well-developed, symbolic, social role play by a 2-year-old girl. This pattern of play is delayed or absent in children with autism.

continued

same in children who have and those who have not had MMR immunisation.

Scarcely had the concerns about MMR immunisation subsided than a new alarm was raised about the possible toxic effects of the mercury preservative, thiomersal or thimerosal, found until recently in some vaccines. Again, this was a hypothesis with little supporting evidence; thiomersal has gradually been removed from vaccines in most countries, including Australia. However, a comprehensive study, again from Denmark, has shown that the greatest increase in the prevalence of autistic disorders has occurred since mercury preservative was removed from all vaccines in Denmark in 1992.

Doctors may be confident in reassuring parents that there is no credible evidence linking childhood immunisations to autism. In fact there never was such evidence: the alleged links were entirely speculative. The symptoms of autism are usually first noted between 18 months and 2 years of age, which coincides with the time that children may be receiving standard immunisations.

### Pregnancy and birth complications

Some studies have found a somewhat higher rate of complications in pregnancy with, and birth of, babies with autism compared with controls, but there is no consistent finding of any one complication occurring more often. The likeliest explanation of these findings is an increased vulnerability to such problems, rather than a primary cause of the autistic disorder.

### Prenatal drugs and toxins

The recognition that about 30% of infants affected by thalidomide also developed autism has drawn attention to the possible effects of other drugs or toxins. The evidence is still variable, although there are increasing reports of neurodevelopmental effects, including autism, in the children of mothers who took the antiepileptic drug sodium valproate in pregnancy, even in the absence of physical markers

of the fetal valproate syndrome. However, only about 10% of children of mothers who took valproate in pregnancy are affected at all, and which other factors may be operating, including genetic influences, are unknown.

### How does autism present?

Parents seldom come to their doctor with a direct query about autism; instead, their initial concerns may be about one aspect of development or behaviour.

Because there is wide variation in symptoms, autistic disorders present in different ways. In particular, there is variation according to symptom severity and degree of overall developmental or cognitive disability. The more severely affected children usually present early, but conditions such as Asperger's syndrome may not be diagnosed until the child is well into the school years. There are, however, some classical presenting concerns; these are summarised in the box on page 53.

### How is the diagnosis made?

In the case of the most severely affected child with classical autism the diagnosis may be obvious to most observers. However, such children represent a minority of those referred because of concern. The diagnosis may be quite difficult to make, and controversial in many cases as the diagnosis depends solely on the observation and interpretation of behaviour. There is no confirmatory laboratory test.

The process of diagnosis comprises:

- skilled observations of behaviour (ideally across several settings such as home, preschool, clinic)
- formal assessment of developmental/cognitive performance
- assessment of receptive and expressive language
- assessment of family and social issues
- medical assessment.

This process is best carried out by a multidisciplinary team, the members of which can co-ordinate observations,

develop a comprehensive picture of the child, and, in discussion with the family, plan appropriate interventions.

A formal assessment of a child's developmental and cognitive abilities is important. This will provide information not only on the child's abilities, but also on how well the child responds to a 'demand' situation, and on his or her capacity to learn through imitation, follow directions and concentrate on a task to completion. This often reveals how the child copes with frustration as tasks become more challenging, and the capacity to participate in activities other than his or her own interests.

### Formal instruments

The diagnosis of autism is made if a child meets the DSM-IV or ICD-10 criteria (the latter is used more widely in Europe). However, since these criteria are the 'bare bones' of diagnosis and very subjective, scales have been developed that quantify various characteristics and have reasonable test/retest and interobserver reliability. Those used most often are the Autism Diagnostic Interview-Revised (ADI-R), the Autism Diagnostic Observation Schedules-Revised (ADOS-R) and the Childhood Autism Rating Scale (CARS).

To date, there are no equivalent scales to assess the diagnosis of Asperger's syndrome or PDD-NOS. The diagnosis of these conditions may be variable, and often depends on the perspective and information sources of different examiners. A structured observation of the child at school is often the most revealing investigation for these conditions.

### Medical investigations

Apart from hearing and vision checks, what investigations are needed? Although investigation of possible aetiology yields an answer only in a few cases, it is important to rule out conditions that are highly likely to recur in the family. Moreover, an answer can help to alleviate parental guilt, gives further information on prognosis

and gives parents access to a particular support group.

The basic investigations in a child who has no neurological or other clinical signs apart from the autism itself comprise:

- chromosome karyotype analysis
- DNA screen for fragile X syndrome
- urinary metabolic screen to exclude metabolic disorders.

Generally, neuroimaging is not helpful and requires a general anaesthetic; it may be indicated if other relevant signs are present, such as hypopigmented skin lesions. MRI is preferable to CT scanning, but may be more difficult to obtain.

An EEG is recommended by some researchers to rule out the epilepsy-aphasia syndromes. In practice, however, it is very difficult to obtain a satisfactory EEG on an active and fearful autistic child; thus, this investigation is reserved for those who have a history suggestive of seizures.

Sometimes in our clinic we will carry out tests to allay parents' concerns aroused by the 'alternative' theories of causation mentioned above, and to counteract unscientific testing in (usually overseas) 'specialist' laboratories – e.g. testing of hair samples for 'heavy metals'. Thus, we may look for antigliadin and antiendomysial antibodies to rule out gluten sensitivity, and measure blood lead and blood or urinary mercury levels. However, these are not by any means routine investigations.

### The stability of the diagnosis

In the preschool years the diagnosis of autism is an evolving one; some children who meet all the criteria for autism when first seen, make much better progress in the first one or two years than originally expected. Others, who appear to be quite mildly affected in the beginning, show more serious problems as they progress through school, as language and social relationships become more complex and inferential. It is important, therefore, to review the child's progress periodically.

By late primary school age, the rate of learning and development, together with

## Autistic spectrum disorders: presenting features

### Speech delay

- Children with classical autism most often present at about 24 to 30 months of age with speech delay.
- Often parents have few concerns until the child is aged about 18 months, when they notice that speech is not progressing beyond the first few single words; this may be accompanied by some social withdrawal.
- There is a well-trodden path in which parents express concern that their child is deaf, conductive hearing loss due to glue ears is found, and grommets are placed. After another few months when there has been no significant progress regarding speech (usually when the child is about 21 months to 2 years old) parents seek further help.

### Behaviour problems

- From 3 years of age onwards, there may be concerns about the child's unusually severe and frequent temper tantrums, persisting well beyond the 'terrible 2's' stage.
- Careful enquiry may reveal that these episodes occur when the child cannot express his or her needs or wants, either verbally or nonverbally – e.g. by gestures.
- Temper tantrums may occur when some familiar routine is changed, when the child encounters a new environment, or even if a different route to a familiar place is taken.
- Some young children present with persistent hyperactivity, restlessness and impulsivity, which may disguise the accompanying delay in language development and paucity of meaningful play.

### Impaired play and social interactions

- These days, when many young children spend part of their time in child care or preschool, staff at such centres may be the first to draw attention to a child who is showing unusual difficulty in developing age-appropriate social interactions with other children.
- These staff may also identify children whose play and interests are unusually focused on a particular activity or interest and who actively resist being involved in a variety of games and activities.

### Learning and school difficulties

- In children with the so-called 'milder' versions of autistic disorders, especially Asperger's syndrome and pervasive developmental disorder, early speech development is within the normal range and concerns are seldom raised before they enter school. (In many such cases, a careful history will often reveal that the parents, especially the mother, had worried about the child and felt that there was 'something different' about him or her from an early age.)
- At least 50% of children and young people with Asperger's syndrome have significant learning difficulties despite having of normal intelligence. Many also have problems with concentration on learning tasks, in contrast with their abnormal focus on their own particular interest. Often the first working diagnosis is attention-deficit hyperactivity disorder, until the lack of true conversation, the paucity of meaningful and functional interests, and adherence to narrow routines and play become clear.
- Some children with Asperger's syndrome may present with behavioural problems at school in the form of resistance to expected school routines, very poor social interactions with peers, and even aggressive behaviour if favourite routines and interests are interrupted.

continued

the persistence and severity of autistic symptoms, will provide a firmer foundation to make long term prognostic predictions.

### Referral for diagnostic assessment

Children in whom an autistic spectrum disorder is suspected should be referred to a local paediatrician, who can then arrange a multidisciplinary assessment. Diagnostic assessments can be carried out by:

- the developmental assessment unit of

the children's hospital in all capital cities

- some State and Territory Autism Associations
- diagnostic assessment teams based in major regional centres
- developmental disabilities services, which exist in most States and Territories.

### Treatment

The treatment of autism is essentially educational and behavioural, starting as

soon as the diagnosis is made. The focus of any early intervention program is on promoting communication and social skills, developing meaningful play and interests, and reducing time spent in repetitive nonfunctional activities. The program may comprise a combination of speech therapy, occupational or play therapy and early education, delivered in a mixture of individual and group sessions, at home, in a clinic setting or at preschool. Some programs combine all these elements in a comprehensive way, beginning in individual sessions at home and continuing if the child attends preschool.

How much therapy is needed is unclear. There is some evidence that a highly intensive (40 hours/week) behavioural program results in better progress; however, the original studies suggesting this have not been convincingly replicated. In addition, the wide variation in cognitive abilities and characteristics in children with autism makes assessment of any one approach difficult. Most of these programs are run within the private sector and can be very expensive for the family.

Some recent systematic reviews have pointed to major weaknesses in the current research; however, there is evidence that an individual program delivered for 20 hours/week leads to greater gains in the child's competence than less involved or more sporadic interventions. As yet, there is no evidence to support one specific program over another.

In the USA and Canada critical reviews have led to the provision of State or Province funding for children to attend an individual program for 20 hours/week in the preschool years. In contrast, the sad reality for most families in Australia is that Government-funded programs are few, inadequately resourced and marked by long waiting lists and breaks in treatment. Nongovernment, not-for-profit agencies, such as the Autism Associations, are also not well funded to meet the expanding need, and most have to charge fees.

## Commonly prescribed medications for autism

### Neurostimulants

Neurostimulants may help children to achieve academically. This is especially so for the more able young people with Asperger's syndrome, many of whom have additional problems with concentration. Academic achievement is an important goal for these children. However, use of these medications may exacerbate repetitive activities and obsessions, or increase social withdrawal and moodiness, so close monitoring is important.

### Clonidine

Clonidine (Catapres) is sometimes helpful in the young autistic child who is extremely hyperactive; it can cause drowsiness. It is less useful in the older child.

### Antipsychotics

Antipsychotics, especially haloperidol (Serenace, Haldol Decanoate), have long been used in autism, but the risk of dyskinesias is high. The newer atypical antipsychotic risperidone (Risperdal) has been found in one reasonably large randomised controlled trial to be effective and well-tolerated in reducing severe challenging behaviour, especially aggression and self-injurious behaviour, in children and adolescents with autism. However, risperidone sometimes leads to unacceptable weight gain. Additionally, there are no longer term studies of the newer antipsychotics that assess outcome or risk of adverse effects such as tardive dyskinesia in this population.

### Selective serotonin reuptake inhibitors (SSRIs)

SSRIs have been used mainly for the treatment of repetitive behaviours; however, they may cause increased agitation in children and seem to be more useful in older adolescents and adults. There are no large-scale, randomised controlled trials of their use in autism and related disorders.

### Antiepileptic medications

About 15 to 30% of people with autism develop a seizure disorder over their lifetime, and will need anticonvulsant therapy. Additionally, some antiepileptic agents, especially sodium valproate (Epilim, Valpro), are of help in mood stabilisation in cases of abrupt severe mood swings.

For older children it is important that they have support at school to help in learning and reduce difficult behaviour. Teachers need to be supported in trying to understand the child with an autistic spectrum disorder in the classroom and playground; in some areas support teachers can assist in this understanding, and help may also be found from experienced psychologists from the Autism Associations.

Some techniques that have been found to be very useful include:

- **Visual cues.** Even quite verbal children and young people with an autistic spectrum disorder can benefit from cues such as pictures and symbols to assist in initiating communication, making choices or expressing feelings and needs.
- **Visual timetables.** A picture timetable of the day's activities helps the child to understand the changes from one activity to another and to anticipate new activities, something many autistic children have great difficulty with.
- **Preparation for change.** Changes in routine, or even in activities, should be anticipated and prepared for. Techniques include using pictures (as mentioned above) as well as a timer to warn about the end of one activity, explaining the next activity, and allowing the child to partake in a favourite activity for a time as a reward for compliance.
- **'Social stories'.** Some children, especially those with Asperger's syndrome or high-functioning autism, find the technique of rehearsing potentially challenging social situations in the form of a third-person narrative helpful. This is especially so if the young person has the story to refer to in the appropriate setting.

## Medication

Medication has a very limited role in the treatment of children and adolescents with autism. No medication has an effect

## Alternative treatments for autism

### Diet

A diet free of gluten and dairy foods is very often instituted by parents. The idea is related to the theories of a connection between the gastrointestinal tract and autism. There are studies that show no association between gluten and autism, and no effect of gluten challenge on the behaviours in autism; however, many parents will try the diet at least for a time.

### Vitamin B<sub>6</sub> and magnesium

Supplements of vitamin B<sub>6</sub> and magnesium have been advocated because of a putative role of these substances in catecholamine synthesis. Several controlled trials have shown no benefit, but again many parents will try this for a time. Other vitamin and mineral mixtures have been advocated with even less foundation.

### Omega 3 and 6 fish oil mixtures

Omega 3 and 6 fish oil mixtures are said to be beneficial because of their role in prenatal brain development. There are no convincing studies of their effectiveness in autism.

### Chelation therapy

The relatively new approach of chelation therapy is based on the 'theory' of mercury accumulation from vaccines or environmental sources as a cause of autism. The theory is unfounded, and the therapy, with dimercaptosuccinic acid (DMSA), is potentially harmful. Unfortunately, in spite of the deregistration of some doctors in the USA for carrying out this treatment, some parents (and doctors) in Australia are taking it up because of claims made on various internet sites.

on the core impairments of autism; however, some drugs may provide symptomatic relief in some cases. The most commonly prescribed medications are listed in the box on page 54.

## Other treatments

Several other treatments are advocated by various agencies. Most have no scientific basis, but at some time almost all parents of an autistic child will try some of them because of the promise of progress or even cure held out by a number of associated internet sites. The box on this page lists some of these alternative treatments.

In dealing with parents who are trying or wishing to try the alternative treatments, I have found active disparagement to be counterproductive; it is much better to encourage trust and discussion, express interest, present the scientific evidence,

but acknowledge that many parents will try some of these treatments. However, it is important to point out treatments that are potentially quite hazardous, especially chelation therapy.

## Outcome

Most children with autism will grow up with the disability; 70% continue to need support with most aspects of life – working, accommodation and recreation. However, a consistent finding is that between 10 and 15% of children have a very good outcome, living independently and making their way in the world (although some may have some social eccentricities). What distinguishes these individuals early in life is not entirely clear, although both normal intelligence and the development of communicative language before school entry can contribute to a favourable prognosis. Nevertheless, even if they have some

### Autism and the autistic spectrum disorders: useful resources

#### Websites

- Autism Council of Australia: [www.autismaus.com.au/](http://www.autismaus.com.au/)
- Autism Spectrum Australia (Aspect): [www.autismnsw.com.au/](http://www.autismnsw.com.au/)
- Health Information: [www.healthinsite.gov.au/topics/Autism](http://www.healthinsite.gov.au/topics/Autism)
- Association for Science in Autism Treatment (ASAT): [www.asatonline.org/resources/library/index.html](http://www.asatonline.org/resources/library/index.html)
- Cambridge Center for Behavioral Studies (reviews behavioural treatments and research): [www.behavior.org/autism/](http://www.behavior.org/autism/)
- Different Roads to Learning (resources and information on behavioural–educational programs): [www.difflearn.com](http://www.difflearn.com)
- Siblings Australia Inc: [www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)

#### Books

- Howlin P. Children with autism and Asperger's syndrome: a guide for practitioners and carers. Chichester: John Wiley & Sons; 1998.
- Fitzpatrick M. MMR and autism: what parents need to know. London, New York: Routledge; 2004. (Of interest to doctors and parents; the author is a GP in North London and the father of a child with autism.)

effective language and IQ within the average range, most children with autism will need lifelong support.

For children and young people with Asperger's syndrome, the outlook is not as well-documented, because of the variability and less well-defined diagnostic criteria. Most will need some extra support for learning and completing school, but there is as yet little information on adult outcome.

There appears to be some increased risk of depression in adolescents with Asperger's syndrome; this may be due to an underlying disorder of serotonin in the brain, but the feeling of social isolation is also very important. Young people with Asperger's syndrome often want friends and social relationships like their peers, but have no idea about how to form and sustain friendships. In addition, they are too often the butt of teasing and bullying.

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The outcome in terms of useful occupation, social adaptation and some measure of independence will be the result, not only of the individuals' own characteristics, but also of the opportunities and supports offered by the society in which they live. Early intervention in the preschool years, supported learning in the school years and opportunities for continued learning and skill development after school are all needed to support people with these disabilities.

### **Family support**

Support for the family of an autistic person is an extremely important aspect of management. The family will need emotional, financial and practical support from the time of their child's diagnosis and throughout his or her life.

Some financial resources may be available through Centrelink, including the

Carer Allowance for a child and the Disability Support Benefit for the older adolescent and adult. Some State and Territory Government resources may be appropriate, such as taxi vouchers when a child's behaviour may be too difficult on public transport or even in the family car without an escort. The new Medicare Plus scheme may enable some families to gain access to some private therapy – e.g. speech therapy or psychologist's assistance with behaviour management.

Respite care, within or outside the family home, and after-school and vacation care are likely to be needed. In the long term, supported accommodation will be necessary for most adults with autism.

The siblings of a child or adolescent with autism also need supports of their own; various websites may be of help in this regard. Some useful resource web-

sites and books are given in the box on page 56.

### **Conclusion**

For most of those affected, autism and Asperger's syndrome are major disabilities requiring support and appropriate interventions at most stages of life. Although no medical treatment is available for the disorder, the doctor can play an important part in early diagnosis, supporting the family and co-ordinating care. In addition, the doctor can play a very important role in advocacy for the availability of adequate and soundly based programs to be available to all affected persons, regardless of their capacity to pay. **MT**

*A list of further reading is available on request to the editorial office.*

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**DECLARATION OF INTEREST:** None.

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## Further reading

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