

# The Autism Spectrum Information Booklet

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A GUIDE FOR VICTORIAN FAMILIES



Shaping the future  
for Autism.



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This booklet has been compiled by Amaze to provide basic information about autism from a number of perspectives.

It is a starting point for people with a recent diagnosis, parents/carers of a newly diagnosed child or adult, agencies, professionals and students learning about the autism spectrum for the first time.

Once you have read this information package, contact Amaze if you have any other questions or you require more information.

# What is Autism?

Autism is a neurodevelopmental condition that causes substantial impairments in social interaction and communication and is characterised by restrictive and repetitive behaviours and interests.

People on the autism spectrum may be affected in the following ways:

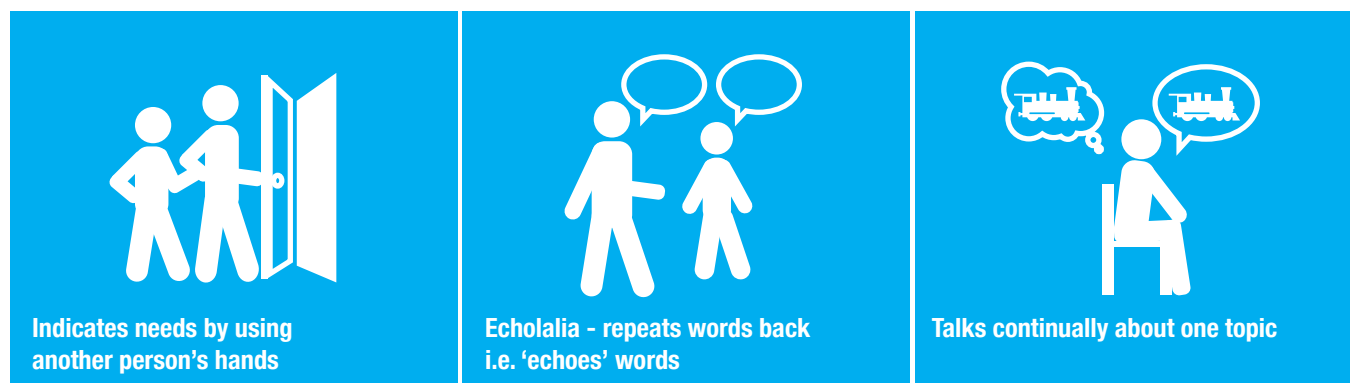
## Social Interaction



People on the autism spectrum may not appear to be interested in joining in with others, or they may want to join in but not know how. Their attempts to respond to social contact may appear repetitive or odd. Alternatively, they may be 'too social', such as showing affection to strangers.

In general, people on the autism spectrum often have poor social skills and difficulty understanding unwritten social rules. They often lack understanding of acceptable social behaviour.

## Social Communication



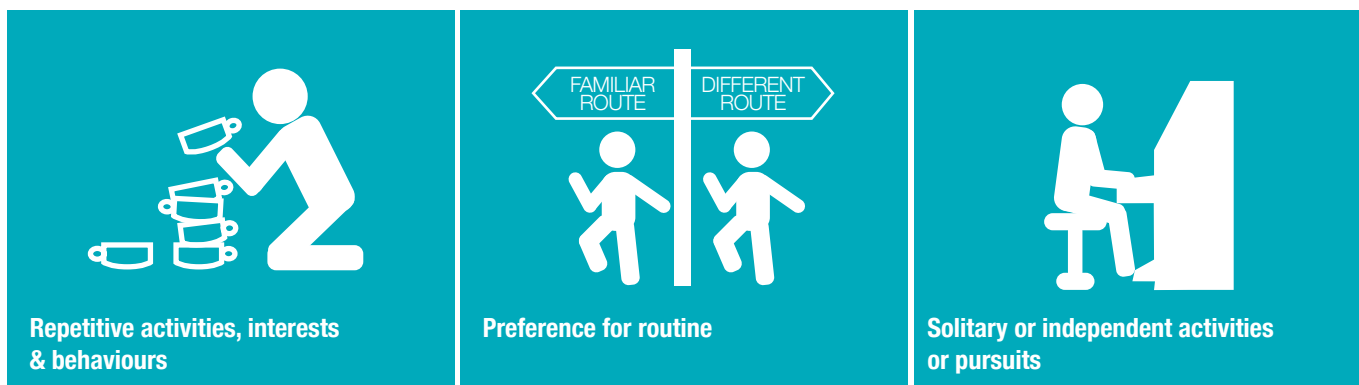
Many people on the autism spectrum have difficulties with verbal and non-verbal communication: some may not speak at all, some have limited speech, some have echolalia (where they repeat what others say).

Others may have a large vocabulary, but struggle with the social use of language. They might have difficulty understanding jokes or satire, may take things literally, or have difficulty taking turns in conversation.

People on the autism spectrum may also have difficulties with non-verbal communication and using and understanding body language, gesture, facial expression and tone of voice to communicate.

Some people have difficulty understanding the feelings of others or that others have different feelings and thoughts to their own. This is known as 'Theory of Mind'.

## Behaviour, Interests and Activities

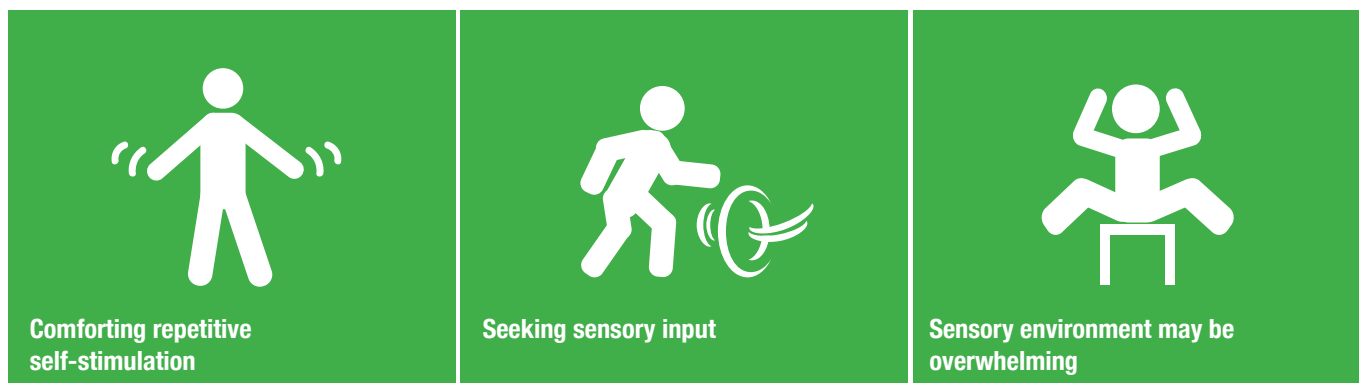


People on the autism spectrum may be preoccupied with detail and may enjoy lining up or colour-coding items such as blocks and toys.

They will often prefer a predictable environment with expected events and routines. Changes in routines can be very difficult for people on the autism spectrum and can cause high levels of anxiety.

A person on the autism spectrum may make repetitive movements such as rocking, twirling, flicking and arm flapping. This is called “stimming” and it can help them to express their feelings, to soothe themselves, and regulate sensory experiences.

## Sensory Processing



People on the autism spectrum often have marked differences in their sensory processing and can be over-responsive, under-responsive or have difficulty in processing sensory information.

Those who are over-responsive may find sound, light, smell, touch and taste overwhelming: they are sensory avoiders.

Those who are under-responsive may seek sensory stimulation from their environment: they are sensory-seekers.

## Every person on the autism spectrum is different

The one thing that people on the autism spectrum have in common is that every single one is unique.

# How is Autism Diagnosed?

If you are concerned that you, your child, or other family member, may have autism often the first step is to speak to your General Practitioner (GP). GPs do not make the diagnosis themselves, but they can refer you to specialists who will carry out an assessment and make the diagnosis.

Specialists that may be involved in the diagnosis:

## Paediatricians/Psychiatrists

A specialist doctor may be involved in the assessment. For adults, this will usually be a psychiatrist. For children up to the age of 18 this may be a paediatrician or a child and adolescent psychiatrist.

There are other conditions that have symptoms in common with autism so it is important to have an accurate diagnosis. Some of these conditions may be treatable. There are also some medical conditions that can occur at the same time as autism and it is important to diagnose and treat these as well.

Paediatricians and psychiatrists will ask detailed questions about the history of the person and the family. This information can give important clues to the diagnosis and possible causes. Paediatricians or psychiatrists may order blood tests, including genetic or chromosomal tests. There are currently no genetic tests for autism, but it can occur along with genetic or chromosomal conditions, such as Fragile X Syndrome. Doctors may also order blood tests for levels of nutrients such as iron. Low levels of these nutrients do not cause autism, but people on the autism spectrum can be fussy eaters and may be missing out on some nutrients. If this is the case, the doctor may recommend supplements to make up for anything that is missing from the person's diet. These supplements will not treat autism, but they may help with the person's general health and well-being.

Sometimes paediatricians will conduct tests that give an estimate of children's developmental levels. They will look at whether children have met developmental 'milestones', such as crawling, walking or talking at the same age most children start to do these things. Psychologists (see below) will conduct more detailed developmental tests.

## Psychologists

Psychologists will often conduct tests that assess a person's developmental or cognitive abilities. These tests are important to determine someone's strengths and difficulties, as well as how they compare to other people their age. These tests may give a summary score, often known as an IQ, and a number of subtest or scale scores. This information is important in making the diagnosis.

People on the autism spectrum often have an uneven pattern of abilities: for example they may be relatively good at visual problem-solving, such as jigsaw puzzles, but relatively poor at social understanding and communication.

This information is also important for planning the best way to help the person. For example, they may learn better if they are given visual information, such as pictures or visual timetables, than they would if they were given verbal instructions or explanations.

It is not always possible to get a reliable score for people on the autism spectrum, especially young children, often due to difficulties in getting them to pay attention and understand and follow instructions. However, psychologists with experience in autism will use their observations of the person's behaviour – not just the test scores – to help make the diagnosis and to judge whether the score is likely to be reliable. In some cases someone's pattern of abilities may be so uneven that the IQ score is not a good summary of their abilities, so it is more important to look at the subtest and scale scores. Some people on the autism spectrum also have an Intellectual Disability (ID). If it is possible to get a reliable IQ score it can help make this diagnosis.

In addition to the observations psychologists make during the cognitive tests, they may also use standardised observation assessments, such as the Autism Diagnostic Observation Schedule (ADOS).

They may observe people at home, school or work. If this is not possible, psychologists will interview the parents, carers or teachers about the behaviour of people they are assessing. They may use a combination of standardised interviews or checklists and informal questioning. If psychologists are assessing adults or adolescents, they will interview the person as well.

## Speech Pathologists

Speech pathologists assess the communication skills of people who may be on the autism spectrum. They are usually involved in the assessment of young children and more rarely involved in the assessment of adolescents or adults. Communication does not just involve speech, but also non-verbal aspects of communication, such as gestures, body language and facial expressions. Speech assessments may involve standardised tests of the person's receptive and expressive language. These tests assess how well the person understands language and how they express their needs, wants, thoughts and feelings, compared to other people the same age.

Another important aspect of communication that speech pathologists assess is 'pragmatics', or the social use of language, including conversation skills and the non-verbal aspects of communication.

Some people on the autism spectrum know a lot of words and talk a lot about their own interests, but may not be able to take turns and carry on a conversation. Speech pathologists may use informal interactions and observations of the individuals, and interviews with their parents, carers or teachers, to gain more information about their everyday communication skills.

As with the psychologists' tests, it is not always possible to get a reliable score from formal tests, especially with young children who may not be able to sit still and follow instructions.

In these cases, information from the parents or carers is especially important. Speech pathologists often interview parents or carers to get background information, such as when the person started talking.

## Occupational Therapists

Occupational therapists (OTs) are not always involved in the assessment of people who may be on the autism spectrum, but they may provide input. OTs assess motor skills, everyday living skills, and sensory processing.

Motor skills include fine-motor skills, such as using pens or pencils and scissors, and gross-motor skills, such as balance, walking, running and coordination. Everyday living skills include self-care, such as dressing and washing.

Sensory processing is the way that a person process information from their senses: sight, smell, touch, hearing, taste and awareness of their own bodies.

People on the autism spectrum may be over-sensitive or under-sensitive to this information, or have a combination of both over-sensitivity and under-sensitivity. For example, they may scream or block their ears when they hear everyday sounds, but not appear to notice when someone calls their name. They may become very distressed by a light touch, but not react to a heavy fall that would be expected to cause pain.

## OTHER PROFESSIONALS

### Neurologists

Neurologists are generally not involved in an autism diagnosis, but paediatricians or psychiatrists may refer individuals for assessments by neurologists to test for other conditions or underlying causes that may be associated with autism. Neurologists conduct tests of brain activity, such as electroencephalograms (EEGs), or brain imaging, such as magnetic resonance imaging (MRIs). EEGs can be used to diagnose epilepsy which is more common in people with autism than in the general population. EEGs can also detect more subtle differences in brain activity, so if a doctor refers an individual for an EEG, it does not necessarily mean that the doctor thinks that the individual has epilepsy. MRIs give a 'picture' of the brain.

Autism is thought to be caused by differences in the brains of affected individuals, but the technology that is available currently may not show the subtle differences that result in autism.

### Audiologists

Audiologists test hearing. They are not usually involved in diagnosing autism, but paediatricians, psychiatrists or GPs will often refer individuals, especially young children, for hearing tests to make sure their communication difficulties are not caused by hearing impairments. Some children on the autism spectrum may appear to be deaf because they do not respond when people call their name.

Some people on the autism spectrum also have a hearing impairment. If they do, then hearing aids, cochlear implants, or sign language may help with their communication. However, due to their autism they will still have difficulties with communication beyond what people with hearing impairments usually have.

# Acronyms and Glossary

## Asperger's Disorder

A type of autism described in an earlier edition of the DSM. Now captured under the diagnosis of Autism Spectrum Disorder in the current DSM-5.

## Autistic Disorder

A type of autism described in an earlier edition of the DSM. Now captured under the diagnosis of Autism Spectrum Disorder in the current DSM-5.

## Autism Spectrum Disorder (ASD)

A condition affecting social communication, social interaction, behaviour and interests; previously classified under separate categories of Autistic Disorder, Asperger's Syndrome, Pervasive Development Disorder - Not Otherwise Specified (PDD-NOS) and now combined under the one name.

## DSM-5

The Diagnostic and Statistical Manual of Mental Disorders, 5th edition, released May 2013 by the American Psychiatric Association to replace the fourth edition (DSM-IV).

## Fragile X Syndrome

An inherited disorder caused by a defective gene on the X-chromosome causing intellectual disability and facial abnormalities in males, and with mild or no effects in females. Between half and a third of people with Fragile X also have autism. For most people on the autism spectrum, the cause of their autism is unknown; for people with Fragile X Syndrome, the cause of their autism is most likely the Fragile X gene mutation.

## Global Developmental Delay (GDD)

A diagnosis given to a child under 5 who fails to meet a number of developmental milestones. Diagnosis of GDD may be given when there are physical barriers to assessment, the child is very young or when clinical severity cannot be assessed.

## ID

A person is said to have an intellectual disability (ID) if they have an IQ (intelligence quotient) below 70 and significant difficulty with daily living skills, including looking after themselves, communicating and taking part in activities with others.

## IQ

Intelligence Quotient - a score derived from one of several different tests designed to assess intelligence. An average IQ is 100, and a score between 90 - 110 is considered to be in the average range.

## Neurodevelopmental

Relating to the development of the brain.

## Neurotypical (NT)

A term which describes people who meet neurological and cognitive milestones and are therefore typically developing.

## NDIS

The National Disability Insurance Scheme, being implemented by the National Disability Insurance Agency (NDIA). A trial site is currently operating in the Barwon region of Victoria.

## Pervasive Developmental Disorder

Not Otherwise specified (PDD-NOS): A type of pervasive developmental disorder that does not meet diagnostic criteria for Asperger's Syndrome or Autistic Disorder under DSM-IV, and now removed in DSM-5. Some people with PDD-NOS may meet the criteria for ASD or Social Communication Disorder under DSM-5.

## Social Communication Disorder (SCD)

A new diagnosis in DSM-5 for those people with deficits in communication and social communication skills but not satisfying criteria for ASD.

## Social Reciprocity

Playing an equal role in a social exchange; both initiating and responding to another, e.g. taking turns in a conversation.

## Social Skills

The ability to interpret and respond to social cues and fit in to social environments.

## Theory of Mind

The ability to understand that other people have beliefs, desires and intentions that are different from one's own. Our *theory* about what the content of other people's *minds* might be.



# Common Questions & Answers

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## Is there a cure for autism?

There is no cure for autism and it is not considered to be reversible. It is a lifelong condition.

Individualised therapy and effective supports will help to overcome the difficulties presented by autism, manage characteristics and help ensure that people on the autism spectrum lead a happy and fulfilling life.

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## What causes autism?

The cause is not clear. Autism can run in families, which suggests genes play an important role in its cause. Multiple genes seem to be involved. However, specific genes for autism have not been conclusively identified and currently there is no medical or genetic screening or diagnostic laboratory test for it. Diagnosis is based solely on the presence of particular behavioural patterns.

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## Is autism caused by something parents did or didn't do?

No. Autism is not caused by a particular parenting style or by the actions of parents. While we don't know exactly what does cause autism, we know that these theories and others like 'cold parenting' are completely false.

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## How common is autism?

Autism is being diagnosed in around 1 in 100 school-age children in Australia. More males than females are diagnosed with autism.

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## Does autism co-exist with other conditions?

Autism can occur by itself or in association with other disorders such as intellectual disability, anxiety disorders, ADHD, learning disability, epilepsy, Tuberous Sclerosis, mood disorders, sleep disorders, eating disorders, and others.

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## Will my child always be the same?

Many parents whose child has just been diagnosed with autism worry that this means that their child will not progress. Although autism is a life-long condition, children with a diagnosis will grow, learn, and develop as they get older. Their characteristics and behaviours will change throughout their life. Life circumstances and life stages, as well as therapy and support, can make a big difference. With the right therapy and ongoing support, people on the autism spectrum can learn to work to their strengths, get around their difficulties, and use their interests and abilities productively.

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## Can children on the autism spectrum go to a mainstream school?

Yes, all children on the autism spectrum are legally entitled to go to a mainstream school. Some may qualify for some extra funding, which the school can use to help the children, for example, by employing an integration aide or acquiring help from a psychologist, speech pathologist or other professional.

Some may qualify to go to an autism-specific school in their region. Those who also have an intellectual disability may qualify for a Special School or Special Developmental School.

If you are a parent, choosing a school for your child is a very personal decision. You may seek advice from other people, but ultimately you will need to decide what is best for your child.

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**Can medication be useful with people on the autism spectrum?**

Medication has no specific role in treating autism itself. However, some people on the spectrum exhibit severe behaviour patterns, experience high levels of anxiety or depression, have difficulty sleeping, or may develop epilepsy. In such cases, medication may have a role in the treatment of these specific conditions and should be prescribed by a practitioner familiar with autism.

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**Is autism cause by vaccinations given to children when they are 18-24 months old?**

No. There has been a debate over the role of vaccines in causing autism, particularly around the Measles/Mumps/Rubella (MMR) vaccine. There are many people on both sides of this debate, and numerous internet blogs, groups and forums supporting either side.

Scientific research has been unable to find any link between receiving the MMR vaccine and consequently developing autism.

The research study that originally suggested a link between the two has since been retracted by the journal that published the study as the researcher's methods were found to be flawed.

Large studies have indicated the same rates of autism amongst vaccinated and non-vaccinated populations indicating no connection between vaccination and autism.

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**Do all people on the autism spectrum also have an intellectual disability?**

No. An Intellectual Disability (ID) is diagnosed when a person scores well below the average in several areas of cognitive ability and adaptive behaviour. People with an ID show impairments across a number of areas, including their verbal skills, non-verbal skills, processing speed, working memory, and adaptive behaviour or life skills. Some people on the autism spectrum have a co-occurring ID (thought to be around 50%), but many are of average or above average intelligence.

People on the autism spectrum often display an uneven pattern of abilities. They may score below average in some areas of cognitive ability, such as verbal skills or adaptive behaviour skills, but score in the average range or above average in others, for example rote memory or non-verbal skills.

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**Are people on the autism spectrum always gifted?**

Sometimes. Portrayals of the autism in movies make it seem as if all people on the spectrum have extraordinary, almost magical, skills!

In reality, some people on the autism spectrum are gifted in a particular area, such as music, maths or drawing. When this talent co-occurs with a low IQ, it is called "savantism". Some people on the autism spectrum have exceptionally high IQs and fit the criteria for being "gifted" as well as meeting criteria for autism.

People on the autism spectrum tend to have an uneven profile of abilities with peaks and troughs, unlike neurotypical people who tend to have an even profile of ability. This is important to remember when thinking about giftedness, as even someone with extraordinary abilities may still experience enormous challenges because of their autism.

Many people on the autism spectrum have abilities such as an excellent memory, keen observation skills, an aptitude for numbers, and a depth of knowledge around subjects in which they are interested. However, they may also find other things, like communicating their feelings, understanding body language, or taking turns in a conversation, very difficult.

It is important to work to the strengths of each person and, as with neurotypical people, encourage them to focus on the areas they enjoy.

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### **Can people on the autism spectrum be taught to communicate?**

People on the autism spectrum vary in their communication skills. Some may never develop language. Others might acquire some functional language, whilst others will develop meaningful, fluent, and effective language.

Communication skills can be taught using alternative methods:

- low-tech options include signing, symbols, printed word, photos, picture exchange systems or any combination of these;
- high-tech supports include voice-generating systems and computer-based products.

For many people, these supports will aid the development of language. As the autism spectrum is very broad, there are some people who may not develop speech, but will develop the ability to communicate through these alternative communication methods.

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### **Is it true that people on the autism spectrum don't want to make friends and don't like interacting with others?**

Sometimes people on the autism spectrum may have a strong desire to interact with people and have meaningful relationships, but may be unsure how to approach others or develop an appropriate friendship. Unlike neurotypical people, they may not intuitively learn the social skills required for interacting with others. They may benefit from explicit instruction to help them develop an understanding of appropriate social interaction and different kinds of relationships.

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### **Do people on the autism spectrum lack empathy?**

No. People on the autism spectrum can have empathy. Someone on the autism spectrum may struggle to understand other people's thoughts, feelings, and intentions. That can make empathy difficult because they won't "get the message" about what the other person is feeling. For example, if someone's mouth corners are turned down, their shoulders slumped, their eyes watery, a person with autism may notice all of these things, but not understand that they mean "someone is sad".

Some people on the autism spectrum will interpret these signs and will feel empathy, but their autism may make it difficult for them to express it.

If you think about it, the rules around what we call "empathy" are very complicated. You need to identify the emotion correctly (from very subtle gestures and expressions), then figure out what to do. What you decide to do depends a great deal on the context (for example, how you react to your friend being upset is very different from how to handle your boss feeling the same way).

Because people on the autism spectrum struggle with the kinds of "social intuition" neurotypical people use, they may need to be taught

explicitly what a facial expression means or what to do when they see a person feeling a certain way.

To make things easier for someone on the spectrum, it can be helpful if you tell them what you are feeling and what you would like them to do about it.

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**I am an adult and I think I might be on the autism spectrum - should I get a diagnosis?**

With more awareness and understanding in the community around the autism spectrum, adults may also wonder whether they have the condition. For many, the diagnosis of their child prompts them to reflect on their own lives and seek further information about a diagnosis for themselves.

Some may struggle with secondary issues such as depression, anxiety and social isolation. In these cases, a diagnosis may be beneficial to have an understanding of the best way to approach therapy and further support, as well as understanding themselves.

Additionally, a diagnosis may also provide someone with access to other services, resources, employment support and financial support within the community. It may be expensive for adults to obtain a diagnosis and if they are well supported and happy, a diagnosis may not be necessary.

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**How can I help someone on the autism spectrum?**

We can all help people on the autism spectrum. It begins with patience, knowledge and understanding about autism. An important fact to remember is that every person on the spectrum is unique. People on the autism spectrum will have unique strengths and challenges. To help a person on the autism spectrum, it is fundamental to identify the person's likes and dislikes as well as their key motivators. Simplifying communication and instructions may also help. Other ways to help include taking the time to listen and communicate with the person, minimising stressful scenarios, and reading books on the subject to obtain a better understanding.

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**What does the future look like for a person on the autism spectrum?**

Many people on the autism spectrum will require support throughout their lives. (And many will not.)

With or without a structured support programs, people on the autism spectrum can live wonderful, meaningful, and fulfilling lives.

# What does Amaze do?

Amaze is the peak body for people on the autism spectrum and their supporters in Victoria. Amaze raises awareness and influences positive change for people on the autism spectrum and their families/supporters and provides independent, credible information and resources to individuals, families, professionals, government and the wider community.

## Early Days Workshops

The Early Days program is a series of free workshops for families with children on the autism spectrum (or those undergoing diagnosis) aged 0-6. They are for parents, grandparents, and family members. Topics include:

- My Child and Autism (Introductory Workshop)
- Understanding Behaviour
- Tips for Everyday Skills
- Progression to School

Early Days also offers a workshop tailored to the needs of non-custodial parents, as well as webinars you can participate in from your home computer.

[www.amaze.org.au/earlydays](http://www.amaze.org.au/earlydays)

## Helping Children with Autism

Our Autism Advisor Service provides information, support and registration for the Helping Children With Autism (HCWA) funding package. The package is available to Victorian parents with children newly diagnosed with autism. The HCWA package is an initiative providing support for children aged 0 – 6 years with Autism Spectrum Disorder (ASD), their families and carers. The package covers a range of initiatives and services, including funding for therapies.

## Capacity Building

Amaze Knowledge is providing training courses and tailored professional development to organisations and interested individuals.

## Amaze Website

The Amaze website has information on autism across the lifespan. It has information about diagnosis, professional supports, and about Amaze. It also includes information about the latest

news and events in the Victorian community.

There are also a number of information sheets on important topics such as transition to school and educational options, strategies to manage day-to-day challenges like sleep, behaviours, friendships and relationships.

[www.amaze.org.au/resources](http://www.amaze.org.au/resources)

## Amaze InfoLine

The InfoLine is an information and referral service for people on the autism spectrum, parents, families and the general public. Our Autism Information Advisors are available to answer your questions about autism and to help you find out who to go to for further assistance.

The Autism Information Team is made up of people with a broad range of experience and their role is to give you information and point you in the right direction for further assistance. Advisors are often on the phone answering queries: if you don't get an answer straight away, please leave a message and an Autism Information Advisor will return your call.

[info@amaze.org.au](mailto:info@amaze.org.au) - 1300 308 699

**\*Please note that we do not provide a Crisis Service or Help Line.**

**If you need urgent assistance, call:**

**Lifeline 13 11 14**

**Suiceline 1300 651 251**

**Parentline 13 22 89**

## Amaze Membership

Membership of Amaze provides a range of benefits: by joining, you are showing your support for the organisation, joining our autism community, and providing strength in numbers to enable us to lobby at government level for improved supports and services for the entire autism community.

In addition, there are a number of additional benefits as a member of Amaze. These change from time to time, but at time of publication include:

- Member discount on attending conferences and events run by Amaze
- The Spectrum magazine
- Regular member offers
- Member discounts on products
- Voting rights at the Annual General Meeting

[www.amaze.org.au/membership](http://www.amaze.org.au/membership)

[member@amaze.org.au](mailto:member@amaze.org.au)

1300 308 699 | (03) 9657 1600

# Funding and Service Options

There are a number of funding options for people on the autism spectrum: a person must meet specific criteria to be eligible and this information differs across organisations and federal/state bodies.

The table below provides a guide to funding and service options available to people on the autism spectrum. Please refer to the contact details for further information.

Note: with the arrival of the NDIS and its roll out across Australia by 2019, there are likely to be changes to funding options. Contact the NDIA on 1800 800 110 to find out about the arrangements for your area.

Organisation	Contact	What do they provide?	Pre-school	School Age	16+ yrs
Helping Children With Autism Package (HCWA) – Autism Advisors (DSS)	1300 424 499	Federal funding package for Early Intervention services and therapies	✓	<input type="checkbox"/> Apply before age 6, funding until 7th birthday	<input type="checkbox"/>
Early Childhood Intervention Services (ECIS) (Department of Education & Training - DET)	03 9637 2000	State funded Early Intervention	✓	<input type="checkbox"/>	<input type="checkbox"/>
	03 9637 2000	Flexible Support Package (FSP)	✓	<input type="checkbox"/>	<input type="checkbox"/>
Federal Department of Health and Human Services (DHHS)	1300 363 079	Child care rebate	✓	<input type="checkbox"/>	<input type="checkbox"/>
Department of Education and Training (DET)	1800 809 834	Program for students with a disability (PSD) in government schools	<input type="checkbox"/>	✓	✓ <input type="checkbox"/> Funding available whilst enrolled at school
Association of Independent Schools of Victoria (AISV)	03 9825 7200	Funding for students with a disability in independent schools	<input type="checkbox"/>	✓	✓
Catholic Education Commission of Victoria	03 9267 0228	Funding for students with a disability in Victorian Catholic schools	<input type="checkbox"/>	✓	✓

Organisation	Contact	What do they provide?	Child 0-6 yrs	School Age	16+ yrs
Centrelink:	132 717				
Carer Allowance		Federal fortnightly allowance for primary carers of people with a disability	✓	✓	✓
Carer Payment		Federal fortnightly payment for primary carers of people with a disability (means tested)	✓	✓	✓
Disability Support Pension (DSP)		A pension for people with a disability who are unable to work full-time	☒	☒	✓
Victorian Department of Health & Human Services (DHHS) - Intake & Response	1800 783 783	Individual Support Package (ISP)	☒	✓	✓
		Futures for Young Adults (FFYA)	☒	✓ Talk to your school's careers advisor	✓ Call 1800 783 783
Medicare Benefits (factsheet available from Amaze)	132 011	Subsidised medical costs	✓	✓	✓
Commonwealth Respite & Carelink Services	1800 052 222	Respite options in your area (including emergency respite - call 1800 059 059 for out of hours emergency respite)	✓	✓	✓
Victorian Government	1800 901 958	Victorian Carer Card	✓	✓	✓
Local Council	Call your local council	Disability Parking Permits; respite options, sport and recreation options etc.	✓	✓	✓
Victorian Taxation Commissioner/ Taxation Services Commission	1800 638 802	Taxi fare subsidies	✓	✓	✓

# Helpful Websites

## **Amaze - [www.amaze.org.au](http://www.amaze.org.au)**

The Amaze website - the first place to go to get information about the autism spectrum.

## **TherapyConnect - [www.therapyconnect.amaze.org.au](http://www.therapyconnect.amaze.org.au)**

An online resource to help families understand therapy for young children with an autism diagnosis.

## **Australian State Autism Spectrum Disorder Associations**

**ACT** Autism Asperger ACT [www.autismaspergerat.com.au](http://www.autismaspergerat.com.au)

**NSW** Autism Spectrum Australia (Aspect) [www.aspect.org.au](http://www.aspect.org.au)

**NT** Autism Northern Territory [www.autismnt.org.au](http://www.autismnt.org.au)

**QLD** Autism Queensland [www.autismqld.com.au](http://www.autismqld.com.au)

**SA** Autism South Australia [www.autismsa.org.au](http://www.autismsa.org.au)

**TAS** Autism Tasmania [www.autismtas.org.au](http://www.autismtas.org.au)

**WA** Autism Association of Western Australia [www.autism.org.au](http://www.autism.org.au)

## **Autism Cooperative Research Centre (CRC) - [www.autismcrc.com.au](http://www.autismcrc.com.au)**

The Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC) is the world's first national, cooperative research effort focussed on autism. The CRC takes a "whole-of-life" approach to autism focussing on diagnosis, education and adult life.

## **National Disability Insurance Scheme (NDIS) - [www.ndis.gov.au](http://www.ndis.gov.au)**

The National Disability Insurance Scheme (NDIS) is a new way of providing community linkages and individualised support for people with permanent and significant disability, their families and carers.

## **Department of Education and Training (Victoria) - [www.education.vic.gov.au/autism](http://www.education.vic.gov.au/autism)**

Brings together a range of autism-friendly learning and development services for Victorian children, young people and adults. This website includes information, resources and policy on learning, development, education and training in Victoria.

## **Raising Children Network - [www.raisingchildren.net.au](http://www.raisingchildren.net.au)**

The national Australian parenting website - click on the autism tab. The autism section of the site provides information and fact sheets on various aspects of autism for parents of children and adolescents on the spectrum. There is a useful guide to therapies, and a service pathfinder to assist parents to make informed decisions about interventions. There are also parent forums on numerous topics.

## **Better Health Channel - [www.betterhealth.vic.gov.au](http://www.betterhealth.vic.gov.au)**

Provides health and medical information to help individuals and their communities improve their health and wellbeing. The information provided is quality assured and reliable, up-to-date and easy to understand.

## **Olga Tennison Autism Research Centre (OTARC) - [www.latrobe.edu.au/otarc](http://www.latrobe.edu.au/otarc)**

OTARC is Australia's first centre dedicated to research into autism.



## **ACT NOW**

**<http://www.med.monash.edu.au/scs/psychiatry/developmental/clinical-research/act-now/fact-sheets.html>**

Aims to build skills and capacity across each region in Victoria in the area of Early Childhood (0-6 years) to enable each network of regional service providers to identify autism spectrum disorder and provide a range of evidence-based interventions for young children on the autism spectrum and their families.

ACT NOW promotes understanding of autism in the wider community and improves linkages and strengthens partnership. There are a number of useful resources and fact sheets available on the website.

### **Autism Help - [www.autismhelp.info](http://www.autismhelp.info)**

An initiative of Gateways Support Services (based in Geelong, Victoria). The site provides practical strategies, information and resources to parents, teachers, child care workers and professionals in the field.

### **PlayConnect Playgroups - [www.playgroup.org.au/Programs/Playconnet.aspx](http://www.playgroup.org.au/Programs/Playconnet.aspx)**

Autism-specific playgroups for preschool children on the autism spectrum or who have autism-like symptoms. They are also very welcoming of young siblings.

### **Early Days Workshops - [www.amaze.org.au/earlydays](http://www.amaze.org.au/earlydays)**

Free workshops for parents of preschool children on the autism spectrum, including an introductory workshop to help newly-diagnosed families navigate the system, as well as skills-based workshops focusing on specific strategies for parenting children on the autism spectrum.

### **My Time Support Groups - [www.mytime.net.au](http://www.mytime.net.au)**

Groups for parents and carers of children up to age 16 with a disability (not specific to the autism spectrum), developmental delay or chronic medical condition.

### **Positive Partnerships - [www.autismtraining.com.au](http://www.autismtraining.com.au)**

A series of online learning modules for parents and carers of school aged children.

### **Asperger's Victoria (previously Asperger Syndrome Support Network - ASSN) [www.aspergersvic.org.au](http://www.aspergersvic.org.au)**

A volunteer group of parents, carers, partners, professionals and people with a diagnosis of Asperger Syndrome, who run a range of support groups and seminars, as well as providing resources such as their quarterly newsletter, fact sheets and library.

### **Parent Support Groups in Victoria - [www.amaze.org.au/support](http://www.amaze.org.au/support)**

A list of Victorian support groups either focussed on autism or on general disability.

### **DiVine - [www.disability.vic.gov.au](http://www.disability.vic.gov.au)**

An online community for and by people with a disability covering a wide range of topics. The website is published by the Victorian Government. Send them your own articles or leave comments. DiVine has been designed to meet the highest standards in accessibility.

### **Carers Victoria - [www.carersvictoria.org.au](http://www.carersvictoria.org.au)**

Provides care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged. Carers Victoria work closely with government and other support organisations to improve the lives of caring families throughout Victoria.

### **Association for Children with a Disability - [www.acd.org.au](http://www.acd.org.au)**

An information, support and advocacy organisation for children with a disability and their families, in Victoria; a non-profit organisation run by parents of children with all types of disability so they know what it means to have a child with a disability.

# The National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is a fundamental overhaul of the way disability services are delivered in Australia.

It will provide people with disability support to live life their way, achieve their goals, and participate in community life.

The NDIS is a social insurance scheme that covers all Australians in the event of disability, and that all Australians contribute to through the Medicare levy.

## How does the NDIS work?

The NDIS takes an individualised and flexible whole-of-life approach to working with people with disability, their families and carers, to develop plans addressing their specific care and support needs.

The NDIS provides people with disability and their families with more choice and control over how, when and where their supports and therapies are provided. It also provides certainty that they will receive the support they need over their lifetime – not just up until a certain age.

The NDIS also focuses on early intervention whereby receiving early supports and therapies can reduce the lifetime impact of disability for you or your child.

## When will the NDIS be available?

The NDIS is a big change from the current system so it is being rolled out in stages across Victoria.

In Victoria, the NDIS is already operating in the Barwon region and will continue being rolled out across three years, with all regions covered by the NDIS by 1 July 2019.

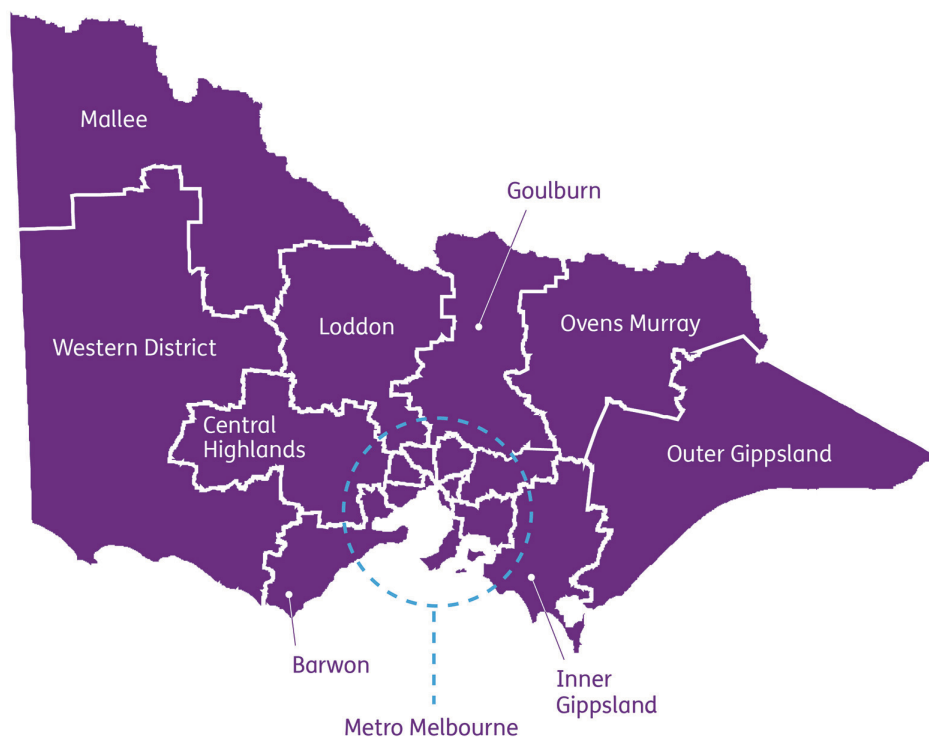
Here is a summary of the roll out by region:

From July 2016, the NDIS will progressively roll out across Victoria in this order:

- North Eastern Melbourne from 1 July 2016
- Central Highlands region from 1 January 2017
- Loddon region from 1 May 2017
- Ovens Murray, Inner Gippsland, and Western Districts from 1 October 2017
- Inner Eastern and Outer Eastern Melbourne from 1 November 2017
- Hume Moreland from 1 March 2018
- Bayside Peninsula from 1 April 2018
- Southern Melbourne from 1 September 2018
- Brimbank Melton and Western Melbourne from 1 October 2018
- Outer Gippsland, Mallee, and Goulburn regions from 1 January 2019

The City of Greater Geelong, the Borough of Queenscliff and Shires of Colac-Otway and Surf Coast already have the NDIS.

For more details on the regions, visit: [www.ndis.gov.au/about-us/our-sites/vic](http://www.ndis.gov.au/about-us/our-sites/vic)



## Will I/my child be eligible?

The NDIS will help people who have a significant and permanent disability and who need assistance with every day activities. This includes people whose disability is attributed to intellectual, cognitive, neurological, sensory, or physical impairment, or a psychiatric condition.

To receive supports from the NDIS you must meet certain eligibility criteria:

- you have a significant and permanent disability;
- you are an Australian citizen, a permanent resident or a New Zealand citizen who holds a Protected Special Category Visa;
- you are younger than 65 when you make a formal request to join the scheme.

An accessible online list of questions will tell you if you are likely to be eligible for support under the NDIS:

[www.ndis.gov.au/ndis-access-checklist](http://www.ndis.gov.au/ndis-access-checklist)

It checks information about you, your age, where you live and any supports you may need to live your life. It is a needs-based assessment, rather than ruling in or out a specific type of disability or diagnosis.

## AUTISM ELIGIBILITY

### Under 7 years old

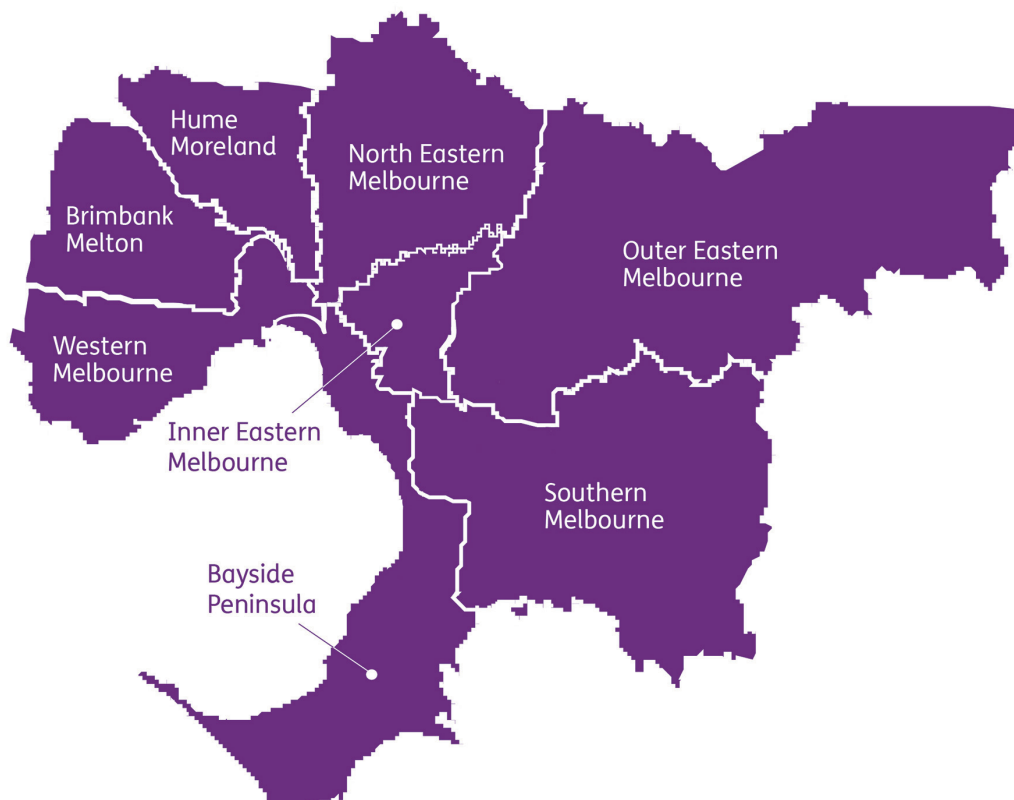
If a child is under 7 and has a diagnosis (diagnosed by a specialist multi-disciplinary team, paediatrician, psychiatrist or clinical psychologist) either of Autism Spectrum Disorder (including Autism, Asperger's disorder, Childhood disintegrative disorder or Pervasive developmental disorder - not otherwise specified /Atypical autism), Global Developmental Delay or Intellectual disability it is highly likely they will be eligible for the NDIS under the Early Intervention requirements.

### Over 7 years old

If you or your child is over 7 years and has a diagnosis of Autism Spectrum Disorder (including Autism, Asperger's disorder, Childhood disintegrative disorder or Pervasive developmental disorder - not otherwise specified /Atypical autism) you may be required to provide additional information on how you or your child's autism impacts on your life or theirs - before being eligible for the NDIS.

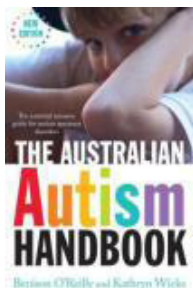
### What next?

Sometimes, information about the NDIS can be confusing and not clear – Amaze will be keeping members informed with the latest information as it comes to us.



# Suggested Reading

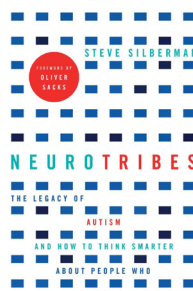
Here are some books and videos that have been helpful to others wanting to find out more about autism.



## THE AUSTRALIAN AUTISM HANDBOOK

*By Bension O'Reilly and Kathryn Wicks (2nd edition)*

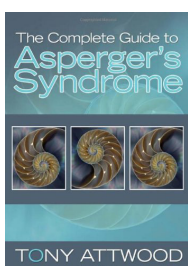
The 'only complete guide to every aspect of raising a child with an autism spectrum disorder in Australia' with chapters covering initial diagnosis, self-help, processing grief, early intervention, schooling, puberty and high school, funding and service providers, it is a valuable resource.



## NEUROTRIBES

*By Steve Silberman*

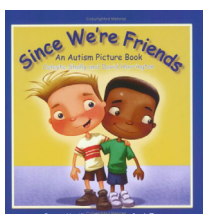
Winner of the 2015 Samuel Johnson Prize for Non-Fiction. This book shines a light on the dark history of autism giving the reader its historical context, the better to illuminate the way forward (and remind the world what must never happen again). Beautifully written and very moving.



## THE COMPLETE GUIDE TO ASPERGER'S SYNDROME

*By Tony Attwood*

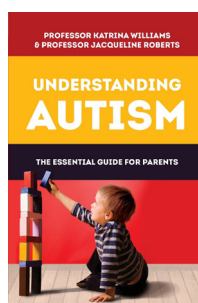
Essential reading for those living or working with a child or adult with a diagnosis of Asperger's Syndrome. It is written in a clear and concise manner, with plenty of examples, practical suggestions and resource lists. It provides a good overview of Asperger's Syndrome.



## SINCE WE'RE FRIENDS - AN AUTISM PICTURE BOOK

*By Celeste Shally*

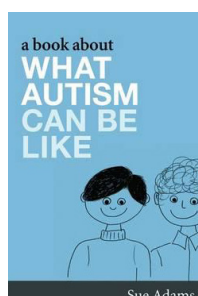
A beautiful picture book explaining autism to children in an easy and accessible way, showing how they can look after and support their friends when they are struggling.



## UNDERSTANDING AUTISM: THE ESSENTIAL GUIDE FOR PARENTS

*By Professor Katrina Williams & Professor Jacqueline Roberts*

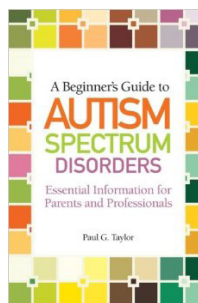
This book addresses the most common questions parents have about the autism spectrum. The book is family-centred and a useful resource in helping you become the kind of parent you want to be for your child on the spectrum, without forgetting the importance of self-care or support for siblings as well.



## A BOOK ABOUT WHAT AUTISM CAN BE LIKE

*By Sue Adams*

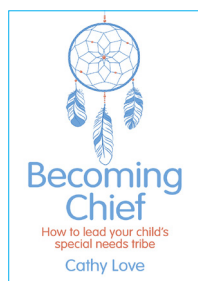
A picture book aimed at children, trying to provide understanding and appreciation of autism. It is an excellent introduction to the subject and a good conversation starter, dealing with being different, but also about acceptance.



## A BEGINNER'S GUIDE TO AUTISM SPECTRUM DISORDERS: ESSENTIAL INFORMATION FOR PARENTS AND PROFESSIONALS

*By Paul G Taylor*

A well-written 100 page guide gently introducing Autism Spectrum Disorder - a great start for anybody who has just encountered autism for the very first time or has a recently diagnosed child. Discusses what autism is, what a diagnosis might mean to you and your family, what to make of certain behaviours exhibited, as well as strategies that might assist the child.

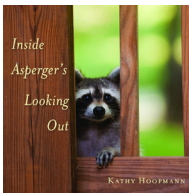


## BECOMING CHIEF: HOW TO LEAD YOUR CHILD'S SPECIAL NEEDS TRIBE

*By Cathy Love*

This short, accessible book is a great starting point for any parent of a child with a disability. This book focuses on the importance of taking charge of your child's needs by building a "tribe" of supporters around them as well as the family as a whole.

This is a very practical guide which encourages you to feel confident and be assertive as you navigate the world of diagnosis, therapy, all while caring for yourself as well. Highly recommended.



## INSIDE ASPERGER'S LOOKING OUT

By Kathy Hoopmann

From the author of "All Cats Have Aspergers" comes this wonderful and beautifully illustrated book which provides us with inside information on what it can be like to have autism. Using the picture book format, Kathy illustrates the day-to-day life and the issues someone on the spectrum might encounter via vivid and sometimes hilarious imagery. This is a useful and funny book to share within the family, but also to explain to others what living on the spectrum means.

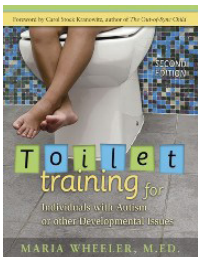
## COMMON ISSUES



## THE INCREDIBLE 5-POINT SCALE

By Kari Dunn Buron & Mitzi Curtis

This book utilises a 1–5 point scale as a tool when encountering problems of social understanding to break down concepts, such as voice volume, the scale starts with 1 being 'No talking at all' and 5 being 'Screaming/Emergency Only'. Gives a visual understanding of specific behaviours and puts them into a social context.



## TOILET TRAINING FOR INDIVIDUALS WITH AUTISM OR OTHER DEVELOPMENTAL ISSUES: A COMPREHENSIVE GUIDE FOR PARENTS & TEACHERS (2nd edition)

By Maria Wheeler

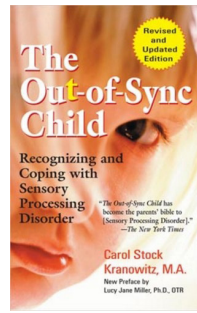
Accessible yet comprehensive, a great place to start if you are looking to toilet train a child on the spectrum. Step by step guide from realisation of readiness, via teaching continence, through to night-time training.



## THE SOCIAL SKILLS PICTURE BOOK: TEACHING PLAY, EMOTION, AND COMMUNICATION TO CHILDREN WITH AUTISM

By Jed Baker

Teaches appropriate social behaviour using photos of students engaging in real-life social situations. A good resource for parents and professionals/teachers, with illustrations for the 'wrong way' and 'right way' to enter a conversation, take turns etc.



## THE OUT-OF-SYNC CHILD

By Carol Stock Kranowitz

Many people on the spectrum have sensory sensitivities: this book explains the term 'sensory processing disorder' to parents in a very accessible way and seeks to provide strategies to help families who have children struggling with sensory input.

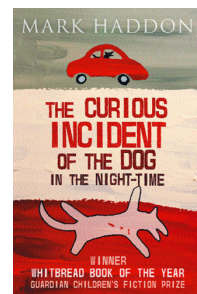
## FICTION



## THE ROSE PROJECT

By Graeme Simsion

This funny book tells the story of Don Tillman, a successful Genetics Professor who is socially awkward. He believes the solution to all his problems is a wife and his 'Wife Project' is a carefully designed questionnaire to find his perfect match. Into his life comes Rosie, not a match, who needs his help to find her real father...

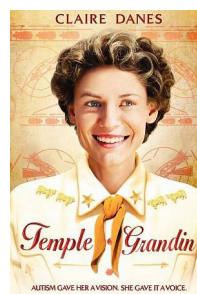


## THE CURIOUS INCIDENT OF THE DOG IN THE NIGHT TIME

By Mark Haddon

Winner of the Whitbread Book of the Year 2003 and the Commonwealth Writer's Prize 2004 for the Best First Book, this story is written from the point of view of Christopher, a 15-year-old boy, and although it is not stated that he has autism, the cover tells us that he has Asperger's Syndrome. A book that will appeal to teenagers but is equally readable by adults and others on the autism spectrum.

## FILMS



## TEMPLE GRANDIN

Directed by Mick Jackson

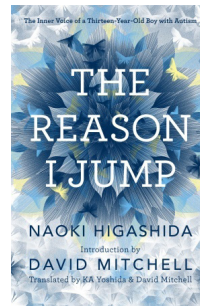
The 2010 movie telling the story of Temple Grandin's life from her diagnosis, through school and university years, tapping into her incredible understanding of animals, all with the support of mum and aunt, struggles with misconceptions of peers, anxiety and sensory sensitivities.



## MARY AND MAX

*Directed by Adam Elliot 2009*

The both sad and warm story of the lonely Mary Dinkle, an 8-year-old living in Melbourne, and her most unlikely pen pal, 44-year-old Max, who is a Jewish man in New York living with Asperger's.

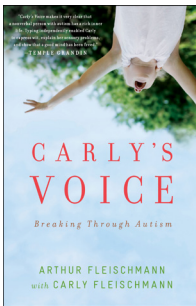


## THE REASON I JUMP

*By Naoki Higashida*

(Translated from Japanese) Written by a 13 year old Japanese boy with severe Autism Spectrum Disorder and who is completely non-verbal, this book is written as questions and answers, with each one making up a very short 'chapter'. Naoki's explanations enable neurotypical people to be more understanding and sympathetic to people on the spectrum. Naoki is a great advocate for people on the autism spectrum. A great book.

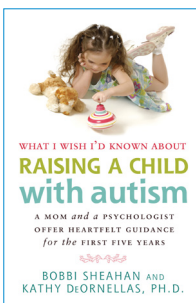
## PERSONAL EXPERIENCES



### CARLY'S VOICE: BREAKING THROUGH AUTISM

*By Arthur Fleischmann with Carly Fleischmann*

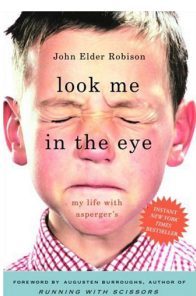
This is the amazing story of Carly as told by her father mixed in with her own words. Carly, who had no spoken language, was diagnosed at the age of 2 with autism. With support from her family and therapists, she found her voice and started to communicate via typing at the age of 10.



### WHAT I WISH I'D KNOWN ABOUT RAISING A CHILD WITH AUTISM: A MOM AND A PSYCHOLOGIST OFFER HEARTFELT GUIDANCE FOR THE FIRST FIVE YEARS

*By Bobbie Sheahan & Kathy DeOrnellas*

Beautiful and funny account of a mother's journey with her daughter and her diagnosis, together with the psychologist that supports the family.



### LOOK ME IN THE EYE: MY LIFE WITH ASPERGER'S

*By John Elder Robison*

Provides a memoir that recounts a life that has been heartbreaking, inspiring and funny in equal measure. After touring with rock band Kiss at the height of their fame, producing special effects for them whilst shunning their company, he finally received a diagnosis at 39.

Provides useful insights which will be helpful to others with autism as well as neurotypical people who have contact with people on the autism spectrum.

## Stay in Touch

There are a number of ways you can receive updates and stay informed of news relevant to the autism community.

### eSpectrum

eSpectrum is the official electronic newsletter of Amaze. It goes out about fortnightly to over 12,000 subscribers. eSpectrum provides information about Amaze, upcoming events, research projects recruiting participants and other important topics of interest to the autism community.

[www.amaze.org.au/espectrum](http://www.amaze.org.au/espectrum)

### Facebook

We have over 12,000 people following us on Facebook! Our Facebook page is a great place to find out about the latest autism news both locally and globally. You can also hear about what others think about specific topics, raise issues or ask a question. [www.facebook.com/autismvictoria](http://www.facebook.com/autismvictoria)

### Twitter

We are on Twitter too! Our followers are growing, and we'd love for you to follow us. [@autismvictoria](https://twitter.com/autismvictoria)

### LinkedIn

Are you a LinkedIn member? Search for Amaze (Autism Victoria) and link in with us!

## Contact Us

### General Enquiries

03 9657 1600 | [reception@amaze.org.au](mailto:reception@amaze.org.au)

### Amaze Membership

03 9657 1673 | [membership@amaze.org.au](mailto:membership@amaze.org.au)

### InfoLine

*Questions About Autism*

1300 308 699 | [info@amaze.org.au](mailto:info@amaze.org.au)

### Autism Advisor Line

*Funding for children 0-6*

1300 424 499 | [hcwa@amaze.org.au](mailto:hcwa@amaze.org.au)

### Early Days Program

*Workshops for parents/carers  
of children 0-6*

1300 307 909 | [earlydays@amaze.org.au](mailto:earlydays@amaze.org.au)

### Amaze Knowledge

*Training enquiries*

1300 262 935 | [learning@amaze.org.au](mailto:learning@amaze.org.au)

## Where to Find Us

### Street Address

**24 Drummond St, Carlton VIC 3053**

*Melways Map 43 J6*

*(Near the corner of Drummond & Victoria Streets)*

### Postal Address

**PO Box 374, Carlton South VIC 3053**



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[www.amaze.org.au](http://www.amaze.org.au)