

# Asperger Syndrome Information for Families



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## Where to Get This Handout

This handout can be downloaded from <http://www.drcheng.ca> in the Mental Health Information section. Your comments are encouraged as they will help ensure this handout is helpful!

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## Purpose of This Handout

This handout provides basic information for parents about Asperger's Syndrome.

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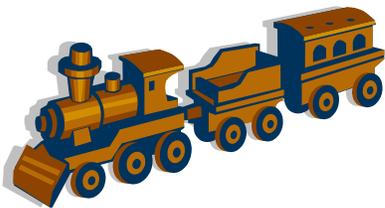
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## “Thomas the Train Lover...”

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*Thomas is a 10-year-old boy who has always been really interested in trains. He knows so much about trains that he can go on and on with his vast, encyclopedic knowledge. If you wanted to know the train schedule at the local train station, he could tell you. Schoolwork has never been a concern and he has always done well academically with little effort.*

*Unfortunately, when it comes to anything involving people, he has a lot more difficulties. He just can't seem to relate to others, and has no friends. He doesn't seem to get social cues. He'll talk endlessly about trains without realizing that others are getting bored, and conversations are a monologue not a true dialogue. He tends to come off as being selfish and self-centered, because he just can't seem to see things from other people's point of view. As he gets older, it's becoming apparent that he really is quite different from his peers. One day after school, frustrated he was excluded by other peers at lunch again, he says, 'Sometimes I just wish I could fit in like the others...'*

## What is Asperger Syndrome?

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Asperger's Disorder (commonly known as Asperger Syndrome or AS) is an autism spectrum disorder (ASD) characterized by social impairment and restrictive, repetitive behaviors and interests. Individuals with AS have normal intelligence and language development. Despite this, they often have difficulties “reading” facial expressions and body language, seeing other people's viewpoints, and understanding social relationships.

The term “Asperger's Disorder” first appeared in a 1981 medical paper by Dr. Lorna Wing and is named after Dr. Hans Asperger, an Austrian psychiatrist and pediatrician who described the condition in the 1940's.

Symptoms include:

- Difficulty understanding and using communication cues such as facial expressions, gestures, eye contact, and tone of voice
- Trouble with “social reciprocity”—the back and forth two-way conversational exchange; instead, an individual with Asperger's may talk excessively about their own interests, without being aware that others are not interested



- Difficulty making friends or getting along with their non-Asperger's peers, which may lead to social isolation or teasing/bullying by others
- Difficulty seeing things from other people's perspective, so that they may come across as self-centered and selfish
- Resistance to change; they prefer sameness and regular routines

Individuals with Asperger's may also have other conditions as well such as:

- Regulatory and sensory processing disorders (aka sensory integration problems), such as a sensitivity to being touched, or to loud noises
- Clumsiness or coordination problems that may affect handwriting (aka dysgraphia) or the ability to play team sports (they often shy away from physical activities at school or in the community.)
- Attention-deficit disorder (ADD) or attention-deficit hyperactivity disorder (ADHD) which may cause distractibility, impulsivity (acting before thinking things through) and hyperactivity (excessive need for movement).
- Anxiety, depression, or obsessive compulsive disorder characterized by persistent thoughts or repetitive actions.

### **What are the Strengths of Asperger's and Autism Spectrum Disorders?**

One theory for the increased incidence of Asperger Syndrome is that perhaps these Autism Spectrum traits are in fact adaptive, and helpful in our technological society...

These individuals tend to:

- Be object rather than people focused
- Be able to focus their attention for long periods of time
- Be able to retain objectivity, rather than being easily influenced by others
- Notice and recall things that others may not
- Bring a unique perspective to a problem and a willingness to explore unusual or unconventional solutions
- Have strong visualization skills that are an asset in engineering and design applications
- Show great depth of knowledge in areas of interest

Thus, some do very well in technological careers (like science, engineering or computers). However, individuals with AS, just like the rest of us, have interests across a broad range of fields that also include arts, music, drama, and social sciences, to name just a few.

### **How Does One Help Someone With Asperger Syndrome?**

Individuals with Asperger Syndrome have a unique way of perceiving the world which can be an asset. However, their social difficulties can limit their future opportunities for employment, leisure activities, or relationships. Social skills intervention at home or school can improve their quality of life as an adult.

As children with AS grow into adulthood, more than a third develop mental health issues such as depression and anxiety. Stress at school due to bullying or lack of accommodation to sensory issues (to sound, light, noise, smell, etc.) can trigger mental illness. It is critical that family, teachers, and all those in regular contact with the child be educated about Asperger Syndrome and the child's individual needs.

In most cases a four-prong approach is required:

1. Changing the environment—School and home accommodations that take into account the child’s difficulties; e.g., giving lots of warning before transitions, incorporating regular routines, educating classmates about Asperger Syndrome, providing the child with a “safe” place to go to if they are being overwhelmed by sensory stimulation.
2. Helping the child cope—Teaching the child to self-regulate themselves; e.g., to identify and express his feelings appropriately and how to recognize and deal with stress.
3. Helping the child learn social skills—Teaching the child how to identify and respond to other people’s emotions, practise turn taking, appropriate conversational skills, etc.
4. Treating associated conditions such as Sensory Processing Disorders, Attention-Deficit Hyperactivity Disorder (ADHD), Learning Disabilities and Mental Health Disorders.

### **School Accommodations and Interventions for Asperger Syndrome**

#### General principles

- Parents should familiarize themselves with these recommendations because they may also be helpful for home situations as well.
- Parents should ensure that the school has all available documentation; i.e., diagnostic, educational, speech, occupational therapy, physiotherapy, etc.
- Parents should familiarize themselves with the IPRC (Identification and Placement Review Committee) and IEP (Individual Education Plan) process. (Consult your school board website for more information.)
- Close communication between parents and teachers (and ideally with any other involved health care professionals) is essential.
- For many of the issues mentioned here such as ADHD, anxiety, or sensory processing, there is additional information available at <http://www.drcheng.ca>.
- There are different approaches to supporting students with AS that may vary by school and school board. Some school boards have specific classes designated for students with autism, or high functioning autism (such as Asperger’s).



For more information about school interventions and accommodations, there is excellent information available from the Ottawa chapter of Autism Ontario as well as the Ottawa Asperger’s Parent Support Group. In addition, Autism Ontario has a manual called Navigating the Special Education System in Ontario. See the ‘Local Resources in Ottawa’ section at the end of this handout for more details.

**The following table lists some general recommendations for students with AS, but note that every child is unique so accommodations need to be tailored for the individual child.**

<b>Feature of Asperger Syndrome</b>	<b>Recommended Strategies for Asperger Syndrome (AS) student</b>
<b>Resistance to change:</b> the need to have the same routine every day,	<ul style="list-style-type: none"> <li>• As much as possible, ensure a consistent, predictable environment with routines.</li> </ul>

<p>and the tendency to become distressed if routines are changed even in the slightest way.</p>	<ul style="list-style-type: none"> <li>• Provide a written schedule for the day's events; for some AS students, it is enough to have it on the board; others may need it written on a sheet that they can keep at their desk.</li> <li>• Anticipate future events that will cause changes in routines; e.g., the teacher can tell the child that s/he will probably be away several times during the year and that there will be a supply teacher.</li> <li>• Give transition warnings; i.e., instead of simply switching from one activity to another, tell the child ahead of time that there will be a change.</li> <li>• Give choice whenever possible; e.g., "You can finish up now, or you can have another minute..."</li> <li>• With major changes like going to a new school, the child should be orientated ahead of time, by visiting the new school (several times if necessary), walking the route if appropriate, meeting teachers ahead of time, etc.</li> </ul>
<p><b>Social skills difficulties:</b> unlike other students, the AS student does not automatically learn the subtle social rules required to get along with other children, and thus may appear self-centered; talking at rather than with others; saying inappropriate things even if they are true; e.g., calling someone 'fat', saying their clothes are ugly, etc.</p>	<ul style="list-style-type: none"> <li>• Explicitly teach social skills to the student, either one-on-one (ideally in a subtle way so the child doesn't feel singled out), or as part of the teaching to the entire class.</li> <li>• In direct interactions with the student be prepared to gently cue the child to more positive behaviors.</li> <li>• Create and rehearse "social scripts" (dialogues for different social situations) and "social stories" (short stories that explicitly explain what to do in a social situation and why).</li> <li>• Praise and positively reinforce the child for showing positive social skills, even if they seem obvious.</li> <li>• Keep an eye on the child's interactions with peers, and intervene if the child's behaviors are causing other peers to take notice and start teasing – kids with AS are at high risk of social ostracism, teasing and bullying from others. Improve the child's self-esteem and at the same time help the child to connect with peers by letting the AS student use their academic strengths to help others; e.g., an AS student who is a good reader could be given an opportunity to read to peers with difficulties in reading. Find one or two empathetic peers who can be a guide and protector for the AS student.</li> <li>• No matter how frustrated you may be with the student, avoid any teasing, ridicule or shaming.</li> </ul>
<p><b>Poor eye contact</b></p>	<ul style="list-style-type: none"> <li>• Many students with AS find eye contact overwhelming, so <b>do not</b> insist on eye contact when speaking to the student. In fact, forcing eye contact will make it even harder for the child to pay attention.</li> </ul>
<p><b>Difficulty interpreting and modulating volume and tone of voice</b></p>	<ul style="list-style-type: none"> <li>• Students with AS may not be able to tell the difference between your "happy" voice and "angry" voice so use words to explain your emotion; e.g., if you are frustrated, say you are frustrated and don't just rely on your tone or volume to convey your emotion.</li> <li>• Similarly, a child with AS may smile or laugh when anxious or look bored when happy so be careful how you interpret their moods. Teaching them to practice appropriate facial expressions in a mirror may help.</li> </ul>

<p><b>Non-verbal communication difficulties:</b> much of our communication is non-verbal, relying on gestures, or body language.</p>	<ul style="list-style-type: none"> <li>• Do not rely exclusively on body language. Check in to see if the AS student understands the message you are trying to send; ask him to explain what you said in his own words</li> <li>• Practise non-verbal cues, e.g., watch TV with the sound off or observe a social interaction from a distance in the playground and ask the child to describe the action and how people might be feeling.</li> </ul>
<p><b>Tendency to be concrete and take things literally. This tendency also may cause student to misinterpret sarcasm or humor.</b></p>	<ul style="list-style-type: none"> <li>• Limit the use of metaphors (or explain them the first time you use them); e.g., instead of: "I'm worried about how you're doing in math—you've got to pull up your socks!" say "I'm worried about how you're doing in math—you need to ask questions if you don't understand, and make sure you regularly do your homework."</li> <li>• Be aware of how much non-literal or metaphorical communication you are using; e.g., your tone of voice, sarcasm, expressions, rhetorical questions, etc.</li> <li>• Note that many children with AS enjoy humor and expressions of speech so rather than avoiding them completely explain them the first time you use them.</li> <li>• Because thinking tends to be concrete, simplify abstract concepts. Presenting visual images that represent abstract concepts may help (Temple Grandin, well-known author, speaker, and individual with AS, found the image of a dove, peace pipe, or the signing of a peace agreement helped her understand the concept of peace.)</li> </ul>
<p><b>Comprehension tends to be weak</b></p>	<ul style="list-style-type: none"> <li>• Do not assume that a child who reads fluently or parrots back what you say perfectly comprehends at the same level. Ask followup questions to be sure they've understood.</li> </ul>
<p><b>Concentration and organization difficulties:</b> the student with AS may have difficulties with distractibility, inattentiveness, and organization skills. In addition, many students with AS also have co-occurring Attention Deficit Disorder (ADD) or Attention-Deficit Hyperactivity Disorder.</p>	<ul style="list-style-type: none"> <li>• All the usual ADD/ADHD accommodations that help a child pay attention or focus better may be helpful for example, seating the child near the front of the classroom</li> <li>• Limit visual distractions where the child sits</li> <li>• If the student is taking a long time to answer a question, try not to interrupt as this may derail the child's concentration and s/he will have to start over again to get his/her train of thought back</li> <li>• If a child is under stimulated, then offer healthy ways of stimulation (e.g., if he/she fidgets, allow the child to go for a walk, sit on an exercise ball, etc.)</li> <li>• Break homework tasks into small steps, setting deadlines for the completion of each.</li> <li>• Older students may find it helpful to keep all their subject notes in one binder; younger students may benefit from colour-coded binders or duotangs matched with textbooks marked with matching dots.</li> <li>• Constant communication to and from school is essential to keeping student organized.</li> </ul>
<p><b>Restricted range of interests:</b> e.g., coins, dinosaurs, etc. They may lecture and bore other students</p>	<ul style="list-style-type: none"> <li>• Set limits on how much the student can talk or occupy him or herself with that topic. For example, let the student ask only THREE questions about that topic, at a certain time</li> </ul>

<p>about their area of interest, and try to spend all their mental energies pursuing that area.</p>	<p>each day.</p> <ul style="list-style-type: none"> <li>• While setting limits, realize that the interest area can be used to connect the child with peers with similar interests, or to help teach academics. For example, a child interested in trains may be motivated to solve math questions involving train scenarios. A story or article about trains could be used for a reading assignment. Use the special interest as a bridge to other interests, e.g., the study of trains might lead to comparisons to other modes of transportation.</li> </ul>
<p><b>Motor difficulties:</b> which includes fine motor problems (such as difficulties with handwriting, and being able to copy and understand what they are copying), as well as gross motor problems (clumsiness that makes it difficult for the child to play team sports in the gym or school yard.</p>	<ul style="list-style-type: none"> <li>• Some school boards provide Occupational Therapy support to AS students for fine motor, and sometimes gross motor difficulties</li> <li>• Gross motor: make accommodations for gym class so that the child isn't pushed into competitive situations with other peers. Do not have students choose teams because the child with AS will inevitably be the last child picked.</li> <li>• Fine motor: typical accommodations include: <ul style="list-style-type: none"> <li>• Special pen/pencil grip to make it easier to hold pens/pencils</li> <li>• Allowing the child to write on graph paper which makes it easier for him/her to plan visual-spatially</li> <li>• For older students, allowing the use of keyboard for taking notes or written assignments or tests</li> <li>• Providing photocopies of teacher's notes and more time to copy off the board.</li> </ul> </li> </ul>
<p><b>Sensory processing issues:</b> children with AS may be overwhelmed by seemingly harmless sensory stimuli such as sound, or touch.</p>	<ul style="list-style-type: none"> <li>• Be aware that the child may become easily over stimulated by noises, lights, strong tastes or textures, and that if s/he can't recognize that s/he is over stimulated, then teachers will need to recognize the cues and teach the child to also recognize them.</li> <li>• For touch hypersensitivity, make accommodations so the child is less likely to be touched unexpectedly; for example: <ul style="list-style-type: none"> <li>• Allow the child to have more personal space in 'Circle Time'</li> <li>• Allow the child to be at the front, or the back of a line up, but try to avoid the middle of a line up due to jostling</li> <li>• Assign the student a locker at the end of a hallway so they only have to deal with one student beside them.</li> <li>• Use firm touch rather than light touch</li> <li>• Tell the student if you are about to touch him/her</li> </ul> </li> <li>• For troubles with auditory processing: <ul style="list-style-type: none"> <li>• Some kids may benefit from FM systems (the child wears a headset that broadcasts the teacher's voice directly into the child's ears, thus reducing the amount of other noises that could interfere)</li> <li>• Seat the child near the teacher, yet away from distractions (e.g., away from the hallway door)</li> <li>• Speak slowly, in small phrases</li> <li>• Use visual cues, or written instructions to reinforce verbal messages</li> </ul> </li> </ul>
<p>Heightened emotions may lead to</p>	<ul style="list-style-type: none"> <li>• Allow a safe, quiet spot where a child can cool down.</li> </ul>

frustration, fear, withdrawal, and anger	<ul style="list-style-type: none"> <li>• Help the child learn a vocabulary for identifying and describing his/her emotions, so that teachers can act appropriately</li> <li>• Work with the child to come up with a list of strategies to deal with being overwhelmed, such as: <ul style="list-style-type: none"> <li>• Deep breathing (in through the nose and out through the mouth)</li> <li>• Telling the teacher so that other strategies might be tried such as <ul style="list-style-type: none"> <li>• Having a 'time out'</li> <li>• Using soothing stimulation (e.g., squeezing a ball, going for a walk, listening to relaxing music)</li> </ul> </li> </ul> </li> <li>• Be alert to signs of depression such as increased disorganization, withdrawal, tiredness, decreased threshold for stress, crying, suicidal talk, etc. (children with AS are at higher risk for depression.)</li> </ul>
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### **Disclosing the Diagnosis to Your Loved One**

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How does one go about sharing the diagnosis of Asperger Syndrome with a loved one? Do you tell them? Or not?

Here's an example of things you might say:

Parent: "I want to talk to you about something..."

"You've probably noticed that there are things that are really easy for you to do, like \_\_\_\_\_."

"You've probably also noticed that there things that are really hard for you to do, like \_\_\_\_\_"

"I want you to know that the reason this is hard for you, is because you have a condition known as Autism Spectrum."

"In this condition, its easy for people to do things like \_\_\_\_\_, but harder to do things like \_\_\_\_\_, such as things that have to do with other people."

"The good news, is that we can help you with this, and make things easier for you."

"I want to tell you about some very famous people who are felt to be on the spectrum... People like Albert Einstein, Sir Isaac Newton, Bill Gates and most engineers."

"How's that sound?"

### **"Thomas still loves trains..."**

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*After the diagnosis of Asperger's, Thomas' parents were able to see his behaviors in a new light, and find new ways to help him cope with things.*

*His parents did a lot of reading, and joined the local Autism and Asperger's parent support group.*

*They were able to see that much of his difficulty getting along with others wasn't due to him intentionally trying to be difficult, but to his Asperger's.*

*They saw that he often didn't 'get it' in social interactions with others, and they were able to provide more help so that he could understand social relationships.*

*His parents used 'Social Stories' to help Thomas, and they also enrolled him in a special social skills course for children with Asperger's.*

*At school, when the teachers became aware of Asperger's, they were able to come up with an Individualized Education Plan (IEP) to take into account his needs.*

*Thomas is still obsessed with trains, but he has started to develop other interests such as computers. Through that interest, he has more to talk about with some of the other classmates, and he is slowly starting to make a new friend.*

*Thomas still has a lot of struggles and challenges ahead, but at least now he and his parents know that they aren't alone, and that there is at least some support out there...*

## **Getting Support in the Ottawa Area for Asperger's and Autism Spectrum Conditions**

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For the most up-to-date list of resources, visit <http://www.eMentalHealth.ca>.

**Seeing a physician** is an important first step in getting help if you suspect Asperger's or Autism Spectrum conditions, as they can help identify what type of problem there may be, and refer you to more specialized services if required.

### **Service Providers**

**The Ottawa Children's Treatment Centre** (<http://www.octc.ca>) and the **Children's Hospital of Eastern Ontario** (<http://www.cheo.on.ca>) provide some service for Asperger's – call for further details.

**Children at Risk:** Provides services to families of children diagnosed with autism spectrum disorders to develop their child's behavioral, communication, and social skills, and to advocate for their ongoing needs. 235 Donald Street, Suite 212, Ottawa, Ontario, K1K 1N1, Phone: (613) 741-8255 Web: <http://www.childrenatrisk.ca>

### **Support Groups for Autism Spectrum Conditions**

- Asperger Syndrome Parent Support Group: The Asperger Syndrome Parent Support Group is an excellent support for parents of children with Asperger's Syndrome. Services provided include a comprehensive resource guide. Phone: (613) 230-6305. Web: <http://www.autismottawa.com>
- Aspirations: Aspirations is a support group for mature teens and adults with Asperger Syndrome. Family members, friends, and professionals are also welcome. Phone: (613) 725-0459. Web: <http://aspirations.topcities.com/>

### **Internet Resources about Asperger's**

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- Online Asperger Syndrome Information and Support, <http://www.aspergersyndrome.org/>
- For school accommodations
  - "Understanding the Student with Asperger Syndrome: Guidelines for Teachers" by Karen Williams, 1995, *FOCUS ON AUTISTIC BEHAVIOR*, Vol. 10, No. 2. [http://www.udel.edu/bkirby/asperger/karen\\_williams\\_guidelines.html](http://www.udel.edu/bkirby/asperger/karen_williams_guidelines.html)
  - Autism Ontario has a detailed list of educational resources at [www.autismontario.com](http://www.autismontario.com).

## Useful Books about Asperger's

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Visit or call the CHEO Family Resource Centre for a large selection of books about Asperger's and autism spectrum conditions. Address: 401 Smyth Road, Children's Hospital of Eastern Ontario, K1H 8L1, (613) 738-3942, <http://www.cheo.on.ca>

Other places with libraries include:

- Children's Integration Support Services (CISS), 613-736-1913.
- Autism Society Ontario (ASO), Ottawa Chapter, 613-230-6305.

Useful Books include:

- The OASIS Guide to Asperger Syndrome: Completely Revised and Updated : Advice, Support, Insight, and Inspiration by Patricia Romanowski Bashe
- More Than a Mom: Living a Full and Balanced Life When Your Child Has Special Needs, by Amy Baskin and Heather Fawcett
- Asperger's Syndrome: A Guide for Parents and Professionals by Tony Atwood
- Navigating the Social World: A Curriculum for Individuals with Asperger's Syndrome, High Functioning Autism and Related Disorders, by Jeanette McAfee M.D.
- Helping the Child Who Doesn't Fit In, by Stephen Nowicki, Marshall P. Duke
- Asperger Syndrome and Adolescence: Practical Solutions for School Success by Brenda Smith Myles and Diane Adreon
- Teaching Your Child the Language of Social Success, by Marshall P. Duke, Elisabeth A. Martin (Contributor), Holifield, Stephen, Jr. Nowicki
- Good Friends Are Hard to Find : Help Your Child Find, Make and Keep Friends, by Fred H. Frankel, Barry Wetmore (Illustrator)
- Social Skills Training for Children and Adolescents with Asperger Syndrome and Social-Communications Problems by Jed E., Ph.D. Baker
- Teach Me Language: A Language Manual for children with autism, Asperger's syndrome and related developmental disorders, by Sabrina Freeman, PhD and Lorelei Dake. Not just for non-verbal children; helpful for teaching concepts from friendship to grammar to letter to word problems and more.
- Teaching Children with Autism to Mind-Read: A Practical Guide, Patricia Howlin, Simon Baron-Cohen, Julie Hadwin
- Comic Strip Conversations, by Carol Gray, which uses 'social stories' to help teach kids social skills
- Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence by Luke Jackson
- The Social Skills Picture Book by Jed Baker
- Taming the Recess Jungle, by Carol Gray

