

# Diagnosis - FAQs

## FREQUENTLY ASKED QUESTIONS ABOUT AS DIAGNOSIS

### FOR CHILDREN AND ADOLESCENTS (click here for Adults)

I think my child has Asperger Syndrome. I'm wondering...

#### 1. What are the common traits and characteristics of someone with Aspergers?

The Diagnostic and Statistical Manual (DSM) of the American Psychological Association categorizes Asperger Syndrome as an Autism Spectrum Disorder, which falls under the general category of Pervasive Developmental Disorder (PDD). All PDDs share the following three major characteristics: (1) problems with communication or language, (2) poor social skills, and (3) a restricted range of interest and/or repetitive behaviours.

#### 2. Does Aspergers Syndrome (AS) affect a person's intelligence and/or cognitive functioning?

The DSM-IV criterion for Asperger Syndrome excludes those with a cognitive delay from the diagnosis. Although no cognitive delay will be present, individuals with AS can demonstrate significant differences among skills and intellectual strengths, which can be quite confusing. However, it is not uncommon for someone with AS to have superior abilities in some areas and significant deficits in others.

#### 3. Could other family members also have Aspergers or another related neurological disorder?

Yes! Asperger Syndrome, as well as other Pervasive Developmental Disorders, is believed to have a genetic basis. This means that other family members across generations may present similar symptoms or have a diagnosis within the family of Pervasive Developmental Disorders. If you know or suspect that there is a history of PDD or AS in your family this can be an indicator that your suspicions may be right and it is helpful to mention it to your doctor if you decide to pursue getting your child diagnosed.

I'm considering getting my child diagnosed. I need to know...

#### 4. How do I go about getting a diagnosis?

The first thing to do is visit your family doctor. If you do not have a family doctor you can find one by visiting the link on our website for the College of Physicians and Surgeons of Ontario. You can then ask for a referral from a GP or family doctor to a specialist in the field. You may want to investigate local children's mental health agencies to see if they provide diagnostic assessment for Aspergers. Another option is to visit the list of private practitioners on our website that can perform diagnostic assessment.

#### 5. What can I expect my family doctor to know about Aspergers?

Your family doctor may not have heard of Asperger Syndrome, although they may know about related disorders such as Autism or PDD. You can bring some of the material about Aspergers from our website to your next appointment to help your doctor understand more about your concerns, help you find a diagnosis or any other Aspergers related health issues that may arise.

#### 6. Do I have to pay for a diagnosis?

Getting a diagnosis can be done privately or it can be covered by OHIP. The reason some people choose to get a private diagnosis is that there is a shortage of covered medical professionals who diagnose Aspergers, and as such there is often a significant wait to get diagnosed. Click here to view a list of private practitioners on our website.

#### 7. What are the types of professionals that can diagnose AS?

A formal diagnosis can only be given by medical doctors (i.e. GP's, paediatricians, psychiatrists) and psychologists. Some people choose to have a social worker, speech and language pathologist or another related professional provide a preliminary assessment that will allow them to give their opinion on the likelihood that someone has Aspergers. These opinions cannot substitute a clinical diagnosis but can help determine whether seeking one would be worthwhile. Click here to view a list of private practitioners on our website.

The waiting list for getting a diagnosis is long. In the meantime I want to consider...

#### 8. What can I do while I wait to be seen for a diagnosis?

The easiest thing to access while waiting for a diagnosis is literature on Aspergers. There are a growing number of books and workbooks that focus on many issues related to AS. They cover topics from the broad to the specific and some also include activities to try with your child. Another option is to try and find organizations or programs that will not require you to have a formal diagnosis to receive services. Attending workshops about AS is another great way to learn more about how you can support your child, both pre and post diagnosis. You can begin your search for agencies, programs and readings on our website.

9. What is the potential for future consequences my child will face if they have a diagnosis of Asperger Syndrome?  
Getting a diagnosis for your child is understandably a difficult decision. Many parents fear the effects that labelling their child will have, both now and in the future. However it is also important to remember that getting the correct diagnosis will help your ability to advocate for your child to get the treatment and services they need, including educational accommodations. With this in mind, getting a diagnosis can help ensure your child's success today and increase the likelihood of their future wellbeing.

10. How will an AS diagnosis affect other previous diagnoses my child has received?  
If a different diagnosis is given prior to the one of Asperger Syndrome it may not account for all the behavioural, learning and emotional characteristics of AS. Sometimes these diagnoses serve to address some of the challenges your child experiences, however an AS diagnosis will hopefully be more inclusive to all symptoms and rule out the need for the previous diagnosis. Other diagnoses may not be covered by the AS diagnosis and may be maintained along with the Aspergers diagnosis.

11. What can I expect from the assessment process?  
The assessment process can vary and will depend on the person performing it as well as the individual being assessed. Depending on their year of experience with Asperger Syndrome, some doctors may feel less confident than others to make a diagnosis immediately, while others will feel very confident to identify and diagnose AS much sooner. Parents will often be part of the assessment process if the individual is a minor child. The assessment process can involve interview(s) and questionnaire(s). The assessor will want to know about developmental milestones and the concerning traits or characteristics being presented. Questionnaires or standardized tests can be given to assess things like intelligence or language abilities.

12. What do I need to do prior to my child's assessment?  
Any previous assessments your child has had that you can bring or mail in beforehand should be shared with the doctor performing the assessment. It's also useful to begin collecting records and thinking about your child's developmental milestones. You can make a chronological list of events, paying careful attention to moments that triggered any concern or led you to suspect something may be unique about your child. You can also make a list of the current characteristics, behaviours or other problems that are concerning you. Finally, write down any questions you want to ask the doctor. If you don't know what to ask, try doing a bit of reading on Asperger Syndrome. Some of the things you read may trigger questions as they relate to your child.

I'm getting my child assessed. While I'm there I want to know...

13. What can I do if my child does not do well in testing situations?  
There are many reasons children and adults with Asperger Syndrome do not handle testing situations well. These include: (1) sensory distractions, (2) heightened anxiety, (3) inability to focus, and (4) difficulty processing what they are being asked to do. Be sure to tell the person doing the assessment of any problems and share any strategies that you may have that help in such situations. A well done assessment should contain the opinion of the diagnostician regarding the congruency between the results and your child's abilities.

14. How important is it to have a diagnosis of Aspergers rather than Autism Spectrum Disorder (ASD) or Pervasive Developmental Disorder (PDD)?  
This really depends on the age of your child. Although it's possible, it can be difficult to determine how the symptoms they are presenting are specific to Aspergers before the age of 5. What's important at this stage is the identification that there is some form of PDD. Narrowing in on the correct diagnosis can take place in later years and will help secure the best and most appropriate care and services for your child.

My child was assessed and has been diagnosed with Asperger Syndrome. The first things I want to know are...

15. Should I tell my child that they have Aspergers?  
The decision to tell your child of their diagnosis can be a hard one that most parents struggle with, especially if their children are very young. When thinking about whether or not to tell your child it is important to consider what they may already know, who else in their life knows and how it may benefit them to know about their diagnosis. Generally it is better for children to know about their diagnosis as soon as their level of maturity allows them to comprehend it, though when this is will differ for each child. Ultimately each child is unique and it is up to the individual's parents to determine if they are ready emotionally and cognitively to understand what having AS means.

16. What should I do if I don't agree with the doctor's diagnosis?  
Getting a second opinion is your right. Most doctors will encourage you to do so if that is what you wish to do.

17. Should I have other assessments done after the diagnosis?  
It really depends on the benefit it would have for your child. Extra assessments can sometimes be beneficial for gathering more specific information about your child; however they can also be overwhelming for both parent(s) and child. Getting further assessments can also delay the commencement of active treatment for your child. When considering additional

assessments it is important to consider what purpose they have and how they could benefit the treatment plan for your child.

#### 18. Do I need to tell others about my child's diagnosis? Who?

It is not necessary for you to tell anyone about your child's diagnosis, however it is strongly recommended that you disclose it to all professionals involved in your child's life. This includes teachers, doctors, social workers, therapists, speech and language pathologists, occupational therapists and any other professional working with your child. If your child is mildly affected you may not have to tell other individuals involved in their life (babysitters, camp counsellors, extended family, etc.) however knowing about the diagnosis can help them have a better understanding of your child and improve upon their interactions with them.

#### 19. What can I do to support my child with Asperger Syndrome?

The first thing you need to do once your child has been diagnosed is figuring out what AS means to your child. Aspergers presents differently in each individual so it is important to know how it affects your child. Identifying the most pressing issues relevant to your child (i.e. sensory, anxiety, emotional management) will go a long way in alleviating frustration or feeling overwhelmed with information when developing and starting a plan for intervention and support. You can also research and learn the methods of intervention used with children with AS that target the issues you identify. Share these with any professionals involved in your child's life and apply them to all interactions with your child. You can find much of this information on the internet and in books, many of which are available through links posted on our website. It is also a good idea to seek parent support groups to connect with other parents who have children with AS, gain insight into the disorder and learn from the experiences of others. Click here to see the complete list of community resources on our website.

FOR ADULTS (click here for children & adolescents)

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The process of finding a diagnosis is long and hard. While I'm waiting I want to consider...

## 8. I've already come this far? Why would a diagnosis of AS be important for me as an adult?

It is not always necessary for an adult to seek a diagnosis of Aspergers. Some of the reasons one should seek a diagnosis for AS in adulthood include: (1) access to new and more appropriate services, (2) previous diagnoses that may be less useful or inclusive can be discarded, and (3) getting a diagnosis can provide relief, comfort and clarity for someone who has been trying to find the answer to what they've always felt has been different about them.

## 9. What can I do while I wait to be seen for a diagnosis?

The easiest thing to access while waiting for a diagnosis is literature on Aspergers. There are a growing number of books and workbooks that focus on many issues related to AS. They cover topics from the broad to the specific and some also include activities for gaining insight into yourself and how AS affects you. Another option is to try and find organizations or programs that will not require you to have a formal diagnosis to receive services. Attending workshops about AS is another great way to learn more about how you can find support, both pre and post diagnosis. You can begin your search for agencies, programs and readings on our website.

## 10. What can I expect from the assessment process?

The assessment process can vary and will depend on the person performing it as well as the individual being assessed. Depending on their year of experience with Asperger Syndrome, some doctors may feel less confident than others to make a diagnosis immediately, while others will feel very confident to identify and diagnose AS much sooner. The assessment process can involve interview(s) and questionnaire(s). The assessor will want to know about developmental milestones and the concerning traits or characteristics being presented. Questionnaires or standardized tests can be given to assess things like intelligence or language abilities. Although there are limited professionals who perform Aspergers assessment for adults, they can be easier to diagnose as their developmental challenges have been present for much longer, making them more evident.

## 11. What do I need to do prior to my assessment?

Any previous assessments that you've had that you can bring or mail in beforehand should be shared with the doctor performing the assessment. It's also useful to begin collecting records and thinking about the challenges you've had at various stages of your life. You can make a chronological list of events, paying careful attention to moments that triggered any concern or were particularly troubling for you. You can also make a list of the current characteristics, behaviours, challenges or other problems that are concerning you. Finally, write down any questions you want to ask the doctor. If you don't know what to ask, try doing a bit of reading on Asperger Syndrome. Some of the things you read may trigger questions as they relate to your experiences.

I'm getting myself assessed. While I'm there I want to know&hellip;

## 12. What do I need to do to access this information for other professionals who work with me or may work with me in the future?

The more information you can provide to professionals who work with you in your treatment, the better equipped they will be to help meet your specific needs. However, due to privacy laws it is required that you provide consent when two professionals who work with you discuss any aspect of your diagnosis or treatment. Special consent forms must be signed that will specify who is allowed to speak to whom and what information they are allowed to share. If you have any workers at the time of your assessment that you want to share the assessment results with let the diagnostician know and ask for the proper consent forms.

## 20. What can I do if I do not do well in testing situations?

There are many reasons individuals with Asperger Syndrome do not handle testing situations well. These include: (1) sensory distractions, (2) heightened anxiety, (3) inability to focus, and (4) difficulty processing what they are being asked to do. Be sure to tell the person doing the assessment of any problems and share any strategies that you may have that help in such situations. A well done assessment should contain the opinion of the diagnostician regarding the congruency between the results and your abilities.

I've been assessed and have now been diagnosed with Asperger Syndrome. The first things I want to know are&hellip;

## 13. What should I do if I don't agree with the doctor's diagnosis?

Getting a second opinion is your right. Most doctors will encourage you to do so if that is what you wish to do.

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