## ADULT ASPERGER'S

# A user manual for friends

How we function, how to interact with us and practical tips

Have you become acquainted with an Aspie, or suddenly found out that one of the (slightly strange) friends you have known for a while, is an Aspie?

### Congratulations!

Being friends with a person with Asperger's (Aspie) does not have to be very different from being friends with anyone else, but people with Asperger's are in many ways quite different from average people. Therefore, it may be helpful to you to know a little about how we are so we can communicate better and you can understand why we do strange things that you do not understand.

There is little information available about what it is like to be an adult with Asperger's Syndrome, that's why we've created this booklet to help you. Aspies are different from each other (despite the stereotypical image that is often given in the media and in professional descriptions). In this booklet, there are only general tips that can guide you in the right direction.

[?] The most important thing is always to ask (try not to assume how you would have liked that yourself - we are too different in the way we work for such assumptions to be valid).

It goes both ways. Also tell us how you perceive things yourself. [!]

## ASPERGER'S - A QUICK INTRODUCTION

Asperger's syndrome is a condition within the autistic spectrum. In practice, there is no difference between Asperger's syndrome and so-called high functioning autism. It is a diagnosis, which is much debated, and many different theories as to its cause exist, none of which will get any attention here. Diagnostic Criteria, causes, epidemiology or therapies will also not be mentioned here. Such information is relatively easy to find in the library or on the internet.

Aspies are structured neurologically in a different way than most other people - who are hereafter referred to as "neurotypicals", people who are neurologically typical. It's the way we work which is different. The problems arise in the interaction between people who are so different. Some Aspies cope very well and never need to be diagnosed. Others experience the condition as a great handicap.

It is not possible to cure Asperger's syndrome. One can change (or be forced to change) your behaviour and how you appear to others, but it will not change how the person works. Sometimes it will be useful to adapt to others, sometimes the price is too high for it to be useful.

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One of the worst features of Asperger's Syndrome is that we can "pull ourselves together". We can seem perfectly normal and at ease at work, at the doctor's or on a visit to someone and then fall apart completely we come home. Moreover, it is not possible look at us and to see that there is something different. It can make people think that our real difficulties are just habit, laziness or disrespect.

### FIRST A LITTLE ABOUT BEING A FRIEND

The pain of getting a "slap in the face" is great for somebody with these difficulties. When the person is in a difficult situation, it may be that they cannot manage to seek support or find solutions. The risk of getting frustrated or looking for the wrong solutions is big if you don't have anyone is genuinely interested in what you are struggling with.

Psychologist Synnve Schølberg, interview published 02.03.02

http://helsenytt.no/artikler/aspergers\_syndrom.htm

Some things are extra challenging for us. It is good to have someone who can be

- ... the one that we can safely ask about things things you feel you really should know, things which it feels stupid to ask, get a neurotypical view on things that happened to you (because we don't get it without working out stuff like that you understand instinctively)
- ...the one who believes in the difficulties we face (because they are real but often ignored or dismissed as exaggerations)
- ...the one who can help in social situations, give advice and lead in the right direction (because we don't understand all the expectations and messages between the lines and need someone who can interpret for us)
- ...the one who can point to positive things and contribute to increase self-confidence (because self confidence can be pretty low for perfectionists with an invisible handicap)

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In translating, I have focused on an idiomatic translation rather than a literal, which reflects the style of the original. As an Aspie I have used the term Aspie rather than "people with Asperger's".

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For a quick read, focus on Preface with a quick introduction - unless you read something else, read this A summary in the end - lazy individuals can jump here

## COMMUNICATION

Communication between Aspies and neurotypicals can be hard because of the very different ways that they work. They have different needs, interests, etc. It can be difficult for both sides to get the other side to understand and accept this.

Aspies can understand social rules and how neurotypicals theoretically think, though we may not be able to put this into practice because normal interaction goes too fast.

Aspies perceive what is being said very literally. Although we have learned what different pictorial expressions mean, we still think many of them are strange. Besides, it can be difficult to recognise irony and sarcasm. It's helpful to keep this in mind so you avoid phraseology that can be easily misunderstood.

When you ask a question, you will most likely get answers to exactly what you asked. Additional info that would really be quite relevant is not necessarily included. You should also try to avoid including unspoken information. For example, you ask an Aspie if he tends to have pasta for dinner and he replies that he almost never does. It would be a wrong conclusion to draw that that he does not *like* pasta. He didn't say anything about it.

Communicate clearly and concretely. Say what you mean and mean what you say. Do not wrap the meaning in lots of words and politeness.

It is typical for Aspies to be fairly direct. We do not manage, or more often do not want to pretend to think something we do not think. If you ask an Aspie about something be prepared to get an honest answer! Communicating with neurotypicals can be frustrating in that regard - that is confusing when someone does not do what they have said they will do or hide what they really feel, but expect it to be understood anyway. We may also tend to be a bit naive. We appreciate honesty and sincerity and do not necessarily have an automatic scepticism towards others.

Although we are very sensitive to criticism ourselves, we can often correct others in a somewhat brutal way. Aspies have a perfectionist mind-set. It can be extremely important to correct a mistake, combined with the fact that we often do not know how to say it in the most considerate way.

Aspies will easily to focus on details, but find it difficult to see the full picture. That's why you either get the full story of the holiday trip, or nothing at all.

#### ABOUT UNDERSTANDING OTHERS

Aspies may have trouble realising that others do not have the same way of thinking as they do. We may be surprised when others say that they would do something different in a situation, which we would never have thought of doing. It can also be difficult to adapt what you say to the person you are talking to because it is difficult to assess what the other person knows or does not know, and what is relevant to them.

Some talk the same way no matter who they talk to. They do not understand (or care) that there are different rules for different contexts, talking to the boss, an acquaintance or a close friend. It is in

our nature to treat people the same. For example, social status is not something we are concerned about. We have a strong sense of justice.

Because it is difficult to know what is going on in the minds of others, it is difficult to interpret their intentions. It can lead to a bit of paranoia. The effect is enhanced by the fact that Aspies are more prone to teasing and bullying and thus may have a history of negative experiences.

#### ABOUT BEING SOCIAL

Socializing wears us out. We need to recharge our batteries with a lot of time for ourselves. We need to be alone on our own little cave, doing things we like in an environment that has been protected from unpleasant sounds and other disturbing stimuli without having to worry about being interrupted all the time.

Social situations we are not used to and do not feel safe in, cause a lot of anxiety. The more stressed an Aspie is, the worse their social abilities (funny problem, right?). Some of us just hardly talk when we are with people we don't meet often. Others talk too much or interrupt constantly. Most people work much better when they get to be with other folk, a little at a time. Fewer people are easier to relate to.

Many Aspies do not have much need to socialise, and then there is no point in themselves in trying to force them into it. Others have a greater need for social contact, but still get very tired of it and need to relax afterwards. Maybe they can't be together with people if they have participated in something the day before, and they have not had time to recover.

One of the most demanding aspects of an Asperger's encounter with neurotypicals is small talk. Small talk has been compared to the bureaucracy of socialization. We just don't see the point of wasting time and energy talking without exchanging any relevant information. It is difficult to maintain a conversation you don't understand the point of, and which takes a lot of energy. Small talk can be confusing because one does not understand what the other really *wants*.

Unwritten rules are difficult to understand. You may need to explain in detail how one is expected to behave; tell what fits in one setting, but not in another. If an Aspie has said something that seems disrespectful and rude, for example, it is not necessary that they understood that what was said was an inappropriate remark in that situation.

### ABOUT EYE CONTACT

Many of us have problems with eye contact. Shall I look at you now? Have I looked at you too long now? Should I look away now, should I not? When should I look at you and when should I look away? If I do not look you in the eye, where then should I focus my eyes? This means that you may not get that response you want - the one you are talking to may seem evasive or disinterested. Some children with Asperger's have experienced not being believed even when they speak the truth, because they avoid looking the adult in the eyes.

Not having eye contact is not the same as not following the conversation. It may well be that the Aspie follows the conversation much better if they doesn't have to look you in the eye. Some just can't follow the conversation if they are forced to make eye contact. Just talking directly to someone can be an overwhelming experience in some situations. You should therefore not judge the person who turns away as rude, it's just a way of dealing with the situation.

Having a conversation with someone who hardly looks at you at all can seem very unnatural you, but feeling free to avoid having to look directly at you can be very refreshing for those who have Asperger's. It may make it easier for them to communicate with you. To maintain eye contact can require a lot of energy because it must be controlled consciously all the time, it does not come naturally, and it can be very intense, it feels like the invasion of their personal space.

#### ABOUT TALKING TOGETHER

Aspies and neurotypicals have different ways of talking. An Aspie can easily go back to a topic you discussed ten minutes ago because he has come up with something more about it, but this can be confusing for a neurotypical conversation partner. Normal people move quickly from topic to topic without giving it anything more than superficial attention, while this is frustrating to an Aspie. For many, it may be important to express yourself accurately and to be sure the other person understands exactly what you think (which can make it all a bit pedantic).

One of the biggest problems is the speed normal conversation goes at. An Aspie spends a lot of time interpreting and understanding what is being said and then finding, formulating and expressing their answers. Much of what neurotypical people do completely automatically requires conscious thought by the Aspie. We also miss some information that is provided through facial expressions, body language and what lies between the lines of what is being said, because we cannot interpret it. A conversation requires a lot of concentration. We are easily distracted. It can be difficult to stay focused on the conversation rather than the thoughts and feelings that come up, or sensory inputs.

Many people find that they can think of different theories about what takes place in a social situation (he means what he says, or he doesn't mean it, he wants me to understand that he means something completely different instead, or doesn't he mean it, he is trying to trick me or maybe he thinks it just a little etc.) but can't find out which interpretation is the right one. Neurotypicals seem to be doing such analyses much faster and have an instinctive sense of which theory to bet on.

Be patient when asking questions. Allow the person time to understand and provide an answer. For example you push the person to respond faster, you increase the stress with the result is that it takes longer. It can also be difficult to answer questions that are vague - such as explain how you feel, what you think about a case, what did you do this weekend? You don't want to a complete and comprehensive report, but what should I start with? What should I include and what exclude? What details are relevant to you? It can help be more concrete.

Knowing how to initiate or end a conversation is difficult. If an Aspie ends the conversation by simply walking, it probably is not to be rude. He just does not know not how it is usual to end. It can be so frustrating that he just gives up having the conversation.

Maintaining a conversation is also difficult. It is generally difficult to know what to say, when, what is enough, how much is too much. You may be afraid to say something stupid or not manage to convey what you have to say. You may feel that the person is not listening unless you are receiving confirmation in the form of hmm sounds and occasional yes and ok. It doesn't come naturally to us. Many also have trouble adjusting the volume and tone of voice according to the situation.

If the Aspie does not understand a what you are saying, he may not ask to clarify it. Maybe he spends a long time responding or switching to a completely different topic. We often are afraid to do something wrong and are very susceptible to criticism and it makes such things as asking for a clarification or asking for help difficult in general.

#### ABOUT TALKING (IN GENERAL )

Some think it is physically, mentally or emotionally tiring to talk. It is therefore natural that they content themselves with talking when they have something meaningful to say. It can be very irritating to have to talk when you don't want to. Sometimes it can be completely impossible, even if you try.

Many Aspies prefer writing as a form of communication rather than talking and can, for example, have a lot of fun talking to others via the internet or sending text messages. It provides the opportunity to communicate without having to think about eye contact, body language and other tedious things. One just needs to focus on what is actually being said (written) and it gives a better opportunity to think through things before answering. Writing makes it easier to convey sensitive things one had not managed to say face to face.

Many - very many Aspies - hate phones. For the most part, they avoid having to talk on the phone or avoid it totally. Many of the problems are the same as in a regular conversation, but to a greater extent because it's even harder to know, for example, when to talk and not.

#### ON GREETING PEOPLE

There may be many reasons why an Aspie may find it difficult or unnecessary to greet people.

- It can be a strain to have to make sound with your voice, especially if you are in a situation that is already tiring.
- You can simply forget it. If it's obvious that you see him and he sees you, it's not necessary to tell each other that you do.
- If you already said 'Hi' to each other earlier in the day, there is no need to repeat it (especially if one is of the opinion that greeting is unnecessary).
- Shaking hands can be perceived as an invasion of one's personal space. It is however, an extremely unhygienic and irrational custom since nobody carries swords any longer. Unfortunately, this is usually difficult to avoid when meeting new people.
- Maybe he just didn't see you. It happens to us all, and even more often Aspies in environments with a lot of noise and many distractions (shops and town centres for example) or generally high stress areas. Also, some of us have trouble recognising faces.
- Some perceive greeting people just as unnecessary hassle.

If someone with Asperger's drops the standard 'hello' one when you pass by, then it is not too rude. It's just so unnatural for him, or too strenuous. Maybe he needs you to greet first, to be

reminded of it. Moreover, many have never been part of the community at the school they attended, or even were bullied, and thus quite accustomed to people not greeting them. They become surprised because it was not expected, and thus does not get a response until it is too late.

You may need to accept that your greeting is answered with a small nod. Look at it as a polite compromise.

It may also be that the person tends to leave without saying goodbye. It's probably because they have no need for this themselves, and will not think that it could be important for you. Or he doesn't know how to say it, maybe afraid to interrupt, or he doesn't want to get any attention (a farewell greeting could trigger a goodbye-hug or time-consuming small talk on the way out).

## **FEELINGS**

Many Aspies are very sensitive people. We are very sensitive to impressions like that come via the senses, and can respond strongly to emotional stress.

How sensitive a person is varies greatly. Sensitivity increases with stress or when one is sick, when exposed to pain or other stress. Aspies need more time to get over it and should be given this. They may need more "nurture" than others in the same situation. Sensitivity can also be affected by mood, diet, hormones and many other things.

This means that even if you are fully capable of something one day (or moment), that doesn't mean it has to be that way the next day. People who are not so sensitive themselves can easily believe that this is due to stubbornness. Anyone with Asperger's can also feel guilty and believe this. This can really drag you down. If an Aspie feels that if they cannot manage a certain thing one day, it may be possible to make the challenge easier, for example accepting that he does not talk that day to you about this (even if he is with you).

Very many people have problems with recognising and describing feelings or what goes on inside them. This probably also has something to do with that language itself is based on neurotypical's experience of the world (as a case in point, it was difficult to find suitable words for the section on overload reactions).

It seems that Aspies become emotionally mature later than neurotypicals. Although we often lie ahead of peers intellectually at school, it often takes longer to "grow up". Many people believe that we have a different range of emotions compared with neurotypicals, especially the more complex emotions. The feelings are lacking - for example, some have never felt envy. There can also be less variation in the intensity of some emotions, with a short distance from zero to maximum reaction. It seems like the brain doesn't perceive the intermediate stages. Of course, this is confusing for those around us. It also can be difficult to understand other people. Maybe the difference between being irritated and anger is not detected.

Some have trouble coping with anger, they may have exaggerated reactions to small things or explosive reactions (either with others or alone) or go and brood on it. The anger can be directed against themselves or others. Although triggered by a small issue, often many things lie behind this reaction and it will have built up. It may be related to very high levels of stress in general life, hopefully one can find things to change that can make life easier. It is probably also connected with the difficulty of expressing feelings and needs, and not being able to explain things you want to ADULT ASPERGERS - A user manual for friends

convey, even if you do not necessarily see this yourself there and then. Be aware that some people express anger although though they are really upset, for example with themselves.

Many people find that Aspies have unusual reactions to things. For example, a person might smile constantly when something tragic has happened or he is experiencing something painful. Many Aspies smile or grin automatically when stressed. They may have difficulty being believed when they say how they are doing.

Aspies do not forget. They can ponder on things that have been said for days, even months afterwards and wonder what you meant by this or that, can what I said have been misinterpreted, do you think I was stupid, etc. etc? This is tiring. It is also not very healthy if you go and carry grudges for things that happened a long time ago. Hurtful things that have been said can plague us for years.

You may want to keep this in mind, maybe they are still thinking about something yourself didn't even notice.

#### DO ASPIES HAVE EMPATHY?

Empathy is the ability to understand what other people think and feel. Aspies are generally quite bad at this. But empathy is not the same as the ability to have compassion (empathy can defined as "the ability to know exactly how to ruin the day for another"). We can have great empathy for others, if we find out how they feel. The easiest way to get to know this is being told. If you try to tell something with nonverbal hints, you will most likely be misunderstood. However, many times we are unable to understand the feelings of others unless they are like something we experienced themselves. Most people find it easy to feel compassion for someone who is exposed to something that has an obvious physical cause and causes physical harm, but struggle to understand complex emotions such as occur in interpersonal relationships.

It may also be that we would really like to express compassion but does not know how. To avoid making a mistake, they say nothing. Many find it very difficult to expressing compassion, or giving a compliment etc. It is also common to express oneself by doing something practical instead of using words.

Aspies tend to respond to the pain of others by feeling hurt themselves (for example instead of trying to comfort). For oversensitive people it may mean that you need to protect yourself, thus closing down emotionally. Aspies will also naturally try to help by giving a person what they themselves would have needed in that situation. For people who are very different this can be completely the wrong thing (a well-known problem for marriage counsellors).

Many of us are very fond of animals; we have the opportunity to show care, without worrying about making mistakes that could easily have made with humans. Animals are easier to understand.

## SENSORY HYPERSENSITIVITY

Aspies perceive the world differently from neurotypicals. The brain interprets signals from the senses differently, so that ordinary impressions can feel overwhelming or are not felt at all.

We lack filters that can help us sort out and deal with unpleasant sensory impressions. It seems as if the hypersensitivity decreases somewhat as you grow into adulthood, but there are large variations from day to day (or during the day) and it is very individual what you find tolerable or troublesome.

Many, especially if they have not been diagnosed until relatively late, have constantly heard from childhood that what they experience is not possible, cannot exist. You can't feel pain, because I don't expect you to feel pain. Of course, this is extremely frustrating. You should take it seriously if a person tells you about an impression he thinks is really hard to take in —what they experience is probably very differently from how you would.

It is common for Aspies to be less sensitive to heat, cold and pain / discomfort than others. We may prefer to wear a t-shirt when others wrap up in warm jackets in the winter (but also refuse to take off the same warm jacket in summer). Some, on the other hand, are hypersensitive to these things.

Tactile hypersensitivity can mean that one cannot wear clothes of certain materials. Maybe you wash clothes very reluctantly because then they feel different, and you limit your wardrobe to garments of the same safe kind. Some surfaces can feel very nasty to touch.

Some Aspies have great reluctance to be touched, especially if it is unexpected. A light touch can feel like an electric shock or as if you were burning. Often, more powerful pressure is not as unpleasant as a gentle touch. This reluctance does not just have a purely sensory side, we often need safe personal space. Don't touch an Aspies unless you are sure it's okay.

Hypersensitivity to sound makes you quickly tired of being in noisy places, or situations with a lot of people for example. This can limit what kind of social things one can participate in. It can be challenging to be with children. In addition to being exhausted over time by general noise, one can also react very strongly to some sounds. Many people react violently sudden unexpected or loud noises. It can be unbearable to listen to vacuum cleaners, motorcycles roaring past, dogs barking, whistling or smacking lips to name a few examples.

Many people have trouble separating sounds from background noise. That makes it difficult to understand what you say when there are other people around you or if the TV is on. I'm not sure that it helps to raise your voice, because the problem doesn't necessarily lie in actually hearing what you say, but more in that the brain fails to interpret it with too many other sounds around.

Hypersensitivity to light can make a sunny day seem painful, as can being in places with many things to look at, constant switching and moving things can wear you out in the same way as with sounds. Some people respond to fluorescent lamps and can't be in rooms with such lighting or they get dizzy or get a headache from PC screens with too low refresh rate.

Some are hypersensitive to tastes and smells. It can make food which seems inviting to others seem repulsive to them because they can perceive aromas that others don't. Some have big problems with the perfume or deodorants of others, or may respond to some detergents with nausea.

## **OVERLOAD**

When an Aspie is subjected to an overwhelming amount of stress (meeting conflicting demands, unexpected things happening or many people talking at once) or too many sensory impressions at once, it will overload their systems. This can show up in different ways. Some just stop working and withdraw completely into themselves. Noticing this is not always easy. Others react excessively aggressively because they do not cope with the situation. The first one will probably be more easily accepted by the folk around, but both are equally destructive for those who experience it.

It is futile to try to reason or talk the person "round". They might hear you, but the ability to communicate is greatly reduced. It is impossible to make choices or think through things (if this happens in a conflict situation, then be aware that you *just can't* win the discussion. Wait until it is over and you can talk quietly afterwards). In fact, the person is out of it and cannot "pull themselves together".

What helps is reducing the stress. Accept that the person is unable to talk with you right now. If possible, get the person out of the situation, into a quiet place without lots of sounds, lights and people and let her have the time she needs to recover. It's fine if there is somewhere available to be alone a bit in demanding situations. For example, it may be possible to be able to retreat to a quiet room for periods during a party.

Talk to the person before such a situation arises, so that you know what they need and how you can help. Many of us have great difficulty figuring out what we feel, defining it and expressing it especially in such a situation. To ask what's wrong in the middle of an overload situation can increase frustration because one cannot express it. The best, of course, is to be aware of such situations so you can prevent many of them from arising if possible.

Maybe you, seeing it from the outside, can identify the different factors that trigger overload situations. It can be difficult to identify this ourselves, because if you do not take note of it, we do not notice it until suddenly it can no longer be ignored.

Remember that although it seems like a small thing that triggers a very strong reaction, there is more to the situation than you see there and then. Things may have built up and inflicted such a heavy burden that it is the straw breaks the camel's back.

## **ROUTINES**

We need to be in charge. Aspies can be very flexible as long as we can control changes, but totally inflexible when faced with changes from outside. What we really want is to control the amount of unpleasant things we face. We don't really want to be selfish or difficult.

Our routines may seem completely pointless to you, but sudden changes can cause a lot of concern and perhaps more stress than we can handle. Changes are easier to accept if you show understanding for our challenges. If you get the most necessary needs met, you can often relax so that we manage to meet the demands of others regarding things that are important to them.

Aspies need to know what is going to happen. Give clear messages well in advance of what will happen when something is planned. If you promise something, be sure you can keep it. Try to

avoid unnecessary changes of plan at short notice. If something unexpected happens, give the person time to get over this and get used to the situation.

Surprises are not a good idea; even with the best of intentions. Sorry.

## ABILITY TO FOCUS INTENTLY

Many Aspies have interests that they pursue with great enthusiasm. Some people have one thing they always have has been interested in, others are constantly replacing or adding new interests. Some Aspies, especially women, do not have specially pronounced interests, but still have one they tend to go into deeply. Examples of interests may be IT, trains, nature, TV series, manga, writing, World War II or collecting. Often they are very specialized within a very narrow area.

A person with such intense interests can often talk about it for a long time; a very long time; preferably without interruption. Most people have realized that this is not very popular (and therefore may not want to talk about it at all) and censor themselves. But if you feel that the topic is getting tedious the best thing you can do, is just to say so.

Aspies can be difficult to get started, but once we get started, it can be equally hard to stop. It is good to have various personal projects to keep you going. But it can be good that someone around you points out that there are other things that are worthy of your interest too (for example remember to eat). It is incredibly annoying to be interrupted while we are concentrating deeply - try to avoid it, or do it carefully.

Although we have great concentration when it comes to something we care about, we have an equal inability to concentrate when it comes to things we are not interested in.

## **FOOD**

Aspies can be incredibly strange when it comes to food. It can come from hypersensitivity to taste, smell, or how the food feels in the mouth. Many people prefer to eat the same things every day or have a few types of food to choose from, others love trying new things.

When someone refuses to eat a type of food, it should be respected - they may perceive it as disgusting, and the thought of eating it can make you want to vomit (and some do if they forced to eat it). Many people prefer "pure" foods, i.e. foods that are not mixed together. One can, for example, prefer to eat a hamburger in its individual components. Some people find that eating in the presence of others is very unpleasant.

This can make eating when visiting a problem. Perhaps it's easiest to avoid it. If you can accept that the person eats what he or she wants (even if it means that he is satisfied with only potatoes) it is a good solution. Maybe you can offer him a simple slice of bread or whatever he fancies, even if you are eating something else for dinner. Such solutions require those present are inclusive people and can accept different ways of seeing the world. This is definitely not an attention seeking ploy.

Socializing tends to require that something is eaten - but it is not necessarily the case. Even if you feel like a bad host unless you have something to offer, that is not how you are perceived by an Aspie. We're pretty easy going that way.

If you try to learn the rules an Aspie has for what he wants to eat or not, and in which situations, you will probably find that it is too complicated for you to manage.

## **STIMMING**

(Stimming - self-stimulatory behaviour)

All people stim to some extent. Aspies have a greater need for it and often do so in more conspicuous ways.

Stimming are repetitive movements or things one does to focus on certain sensory impressions (so other things can be sorted out, compared to what was said about missing filters below "sensory hypersensitivity"). You may not even notice it.

There are endless ways to stim. For example: tapping your foot, chewing on pens, talking to yourself out loud or in your mind, drumming your fingers, rocking back and forth, jumping up and down, biting you nails, focusing on small details, touching different things, pen-clicking, humming, walking around.

This is a way to relieve stress and calm down. Many people feel that it helps to concentrate and think better. It's comforting. Stimming in some situations is the way out of an overload reaction. To stop an Aspie from stimming would be devastating: we need it.

If someone's stimming annoys you, ask them to stop. If they don't, then don't get on at them. Some become very grumpy if they are interrupted while they are stimming. Particularly if they don't even notice that they are doing it (many do not know the term and are unaware that they need to stim). If there is one type of stimming that causes the person to get unwanted attention and they are not aware of it, it may be okay for you make them aware of it. Be aware that when a stim is stopped, it usually surfaces somewhere else instead - often completely unconsciously.

## ABOUT GETTING THE DIAGNOSIS

Anyone who is diagnosed as an adolescent or adult may experience this as a relief. Finally get they acknowledgement from others that the difficulties they have been trying to tell people about, and that the limitations he has felt all the time really do exist. Presumably, he has always been told that he must buck up. Stop exaggerating. Try a little harder.

Now that he learns that his problems are real, he can be more confident in telling others when he cannot cope; about situations that can lead to being overloaded. What he really thinks about things that he never understood the point of, but which everyone said were right and normal. He may feel safe enough to stop trying to act like everyone else, or stop pushing himself as hard as he did.

To you, it may seem like he's changing. You may think he's become "sicker" than he has been and this worries you. That's not it. Although he changes how the outside world looks at him, the inside is just the way it has always been. Instead of being concerned, you can enjoy that he dares to be himself and that you get the opportunity to get even closer to the person he really is.

If you are still concerned, you can try to find out a bit more about what autism and autistic culture are in practice and talk to him about what's troubling you. Then you can think about whether it really is such a big deal or if it doesn't matter so much that he doesn't behave like everyone else, *really*.

## IN ADDITION TO THE THINGS MENTIONED, MANY ALSO HAVE PROBLEMS WITH

- Getting to sleep.
- Motor skills. Many can be clumsy, constantly bumping into things, being a bit slow.
- Tics.
- Disturbing thoughts which can border on obsessive thoughts (kind of thought or emotional tics?).
- The sense of balance, including car sickness.
- Assessing distances, speeds, etc.
- Recognising faces (parapognosia).
- Remembering right / left.
- Short-term memory.
- Work. Most people manage the academic aspect well, but do not cope with the social side of things. Job interviews can be difficult.

People with Asperger's Syndrome may also have other neurological conditions such as dyslexia, dyscalculia, ADD, ADHD and Tourette syndrome. Because we experience a lot of stress and other difficulties we are more prone to depression and anxiety than the average.

## LITERATURE AND WEBSITES

Note: Most of the research is done on boys/men with Asperger's. Literature therefore revolves largely about how the syndrome is expressed in them. Women often feel that they do not recognise themselves in the descriptions.

### Website about autism by autistics

www.creative-minds.info/Lorelei/Home.htm
www.aspergerinformation.net/ (English)
thiswayoflife.org/index.html
http://www.elmindreda.org/reflections/ (English

## **Asperger Discussion Forum**

www.bokstavbarna.no (Norwegian) www.autismesiden.no (Norwegian) www.wrongplanet.net

#### Various

/ Swedish)

www.hu.sll.se/gn/opencms/web/AF/index.html
Swedish website with some well-grounded articles on autism and Asperger syndrome.

#### www.autisme.dk/default.asp

Danish Autism Knowledge Centre (pay special attention to *Attwood and Gray's criteria for discovery of Aspergers* which describes Asperger's syndrome from a positive point of view, see articles about diagnosis).

#### isnt.autistics.org/

Institute for the Study of the Neurologically Typical. English language satirical page on what is called "sick" and "challenging."

http://www.autistics.org/library/more-autistic.html

English article that addresses various reasons why one may seem more autistic than before.

http://www-users.cs.york.ac.uk/%7Ealistair/survival/

English language Survival Guide for People with Asperger's, written by Marc Segar who has Asperger's himself.

### **Books**

Tony Attwood: Asperger's Syndrome: A Guide for Parents and Professionals A good book that deals with children with Asperger's.

There is very little literature (especially in Norwegian) that addresses adults with Asperger's and the problems we face, but some autobiographies can be listed:

Donna Williams: Nobody Nowhere: The Remarkable Autobiography of an Autistic Girl

Gunilla Gerland: A Real Person: Life on the Outside (original Swedish title: En Riktig Människa)

Temple Grandin: Jeg er autist En usædvanlig kvindes usædvanlige historie (I am autistic: an unusual woman's unusual story)

ADULT ASPERGERS - A user manual for friends

Malin Nordgren: Jag avskyr ordet normal: vuxna med Asperger's syndrome (I detest the word normal: adults with Asperger's syndrome.



## SUMMARY OF PRACTICAL TIPS

- Ask! Because you need to find out how exactly he works, because he needs to find it out for himself, and because he probably has a hard time finding words for the things he experiences and needs to get better at it.
- Be honest. Say what you mean, don't hide messages between the lines. Prioritize being concrete and obvious over being polite.
- Remember that what you say is perceived very literally. Avoid formulations that invite misunderstanding (e.g. asking if he wants coke, but really mean asking if he wants to have something to drink. Alternatively you say you will come over just at eight when you really mean you will be coming closer to half past nine, and if you say he "can call you anytime" you have to accept that he calls you five in the morning the next day).
- Beware of irony and joking that can be misunderstood.
- Be careful when making constructive criticism.
- Don't be offended quickly. If you are offended, make sure it is not a misunderstanding, don't assume he knows how you understood what he said.
- Avoid general, comprehensive questions that are difficult to answer (what are you thinking about? my suggestion, how is your new job, how are you). Try to be more concrete so that it is easier to find out which piece to draw out (do you agree my suggestion why not? are the people nice at your new job? you look tired has something special happened?)
- Accept the need to be alone. It's not personal.
- Don't force him into something because "it just is like that". If you can't give good reasons then it doesn't have to be like that.
- Help in social situations. If you are chatting and he is next to you but doesn't know whether he can take part in the conversation, make it clear by bringing him into it, e.g. give him the time he needs. If he tends to say something rude inadvertently, you can agree on some kind of advance sign that you can use to warn him of a dangerous situation.
- That thing about eye contact and not always being able to talk; it's not personal either.
- Accept that sometimes he will not manage things he can manage at other times. You might get him to realize this himself.
- Be careful interpreting what he is saying, or his body language. It does not mean necessarily what is natural for you naturally assume.
- He has feelings even though it may not seem that way to you. He only has other ways of expressing them.

- Remember that sudden anger, despair or reluctance to do anything can come from an overload. Although he cannot express it. Give him the opportunity to rest and time to recover. Talk about things like that before they occur.
- Regarding perceiving sensory impressions differently: look around and think about it what can easily be made more autistic-friendly turn off the TV instead of having it on standby, when you are not charging your mobile phone you do not need to leave it plugged in, leave off the perfume etc. (depending on what they react to of course).
- Prepare him for things which are going to happen. Provide as much info as possible. Don't talk about something which might not happen without warning him about this possibility. Give him time to adjust if something unexpected happens.
- Do not give empty praise, but help him to keep his confidence up.

